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Master Thesis

Digital storytelling as tool for conveying cancer diagnoses to children

Author:
Maiken Beate Fjellanger
Supervisor:
Ankica Babic

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Don't follow
your mind unless it lives
inside your Heart.

~ Mooji ~

UNIVERSITY OF BERGEN

Abstract

Faculty of Social Sciences
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Digital storytelling as tool for conveying cancer diagnoses to children

by Maiken Beate Fjellanger

The experience of receiving a cancer diagnosis might be hard for many, especially for children as they lack knowledge and understanding of what this entails. Receiving information is said to have great effects on the way one handles difficult emotions in difficult situations. It is therefore important that the children receive information about cancer understandable to them. As children seem to enjoy the use of technical devices from a young age, this might be utilized to communicate difficult issues in a child-friendly way.

The goal of this thesis was to get an indication towards how a digital story application could function as a tool for conveying cancer diagnoses to children, as well as how the interaction design in such applications could support intuitive interaction. The focus group are children of five years of age and upwards. To answer these research areas, a prototype was developed on the basis of data gathered from professionals, and evaluated with children who have experienced receiving a cancer diagnosis in early age (4-14 years). The result indicated that digital storytelling could be helpful in the process of conveying cancer diagnoses to children. Valuable feedback according to interaction design suggests improvements such as increased visibility of clickable elements and concrete instructions regarding scroll-navigation in the prototype.

Overall reactions was positive and suggest needs for such tools.

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Chapter 1

Introduction

The experience of receiving a cancer diagnosis might be hard for many, especially for children as they lack knowledge and understanding of what this entails. Children often associate cancer with death (Fottland, 2004). It is therefore very important that children receive information about cancer that is understandable to them once they learn about the diagnosis. To convey this information in best possible way it should be done in a way that captures the children's attention. One solution could be to use technical devices since they have increased during the past years, and one can witness even very small children handling an iPad, totally immersed by it. It is clear that many children today enjoy using technical devices.

The idea is to utilize this contemplation and enjoyment in the context of learning about a serious topics like cancer through a digital storytelling. The main goal of the project is to get an indication to whether informing of cancer diagnoses through a digital story could help children increase their understanding of cancer and thereby reduce difficult emotions (like fear and anxiety) related to the diagnosis. This will be done by developing a functional prototype of a digital story application about cancer and difficult emotions; where the story content should be developed in cooperation with professionals who possess in-depth knowledge about child cancer. The prototype developed will then be evaluated by children who have experienced receiving a cancer diagnosis. This evaluation should present the prototype to the children, and interview them about their experience of using the digital story.

1.1 Research Questions

The project has two focus areas; one practical with focus on facilitation of digital storytelling for child friendly learning, as well as a technical focusing on interaction design. These are the research questions:

- **How will digital storytelling function as a tool to enlighten children about cancer upon receiving a cancer diagnosis?**
- **How can the interaction design in a digital story application be made to optimally support intuitive interaction for children in the selected age group?**

The first research question seeks to find out whether digital storytelling will contribute to children's understanding of cancer when receiving the diagnosis. It also seeks to find out how a tool like this will be welcomed by children. It will also be valuable to see health care professionals' attitude about having a tool like this for the children. This question will be answered through interviews with professionals, as well as via usability testing with children who have experienced receiving a cancer diagnosis; this will include observation of the children when using the prototype, followed by interview.

The second research question seeks to answer which design considerations must be taken in order to optimally customize the application to the target audience. Design will be made by following design principles and requirements established. For discovering critical issues in the interaction design, observing children when using the prototype will be important.

Chapter 2

Theory

This chapter presents theoretical topics relevant for this research: children's reaction to cancer diagnoses, digital storytelling, interaction design, and children and design. Popular tools used in relation to children with cancer will also be mentioned.

2.1 Children's Reactions to Cancer Diagnoses

To get a deeper understanding of how a child friendly tool for informing about cancer and difficult emotions will be relevant a qualitative meeting with children who have had cancer might be helpful. In the article "Kommer jeg til ådø? Kreftsyke barns betraktninger om døden" by Fottland (2004) children in the age of 10-12 presents their experiences of receiving a cancer diagnosis. To get some insight into how a child can experience a situation like this one child's story will be presented. Maria's story was chosen as this was considered to be the story which best shed light on children's need for information in such a situation. In addition, children's experiences will be summarized, as well as the mastering strategy *seek information.*

2.1.1 Maria's (11) Meeting with Cancer Diagnosis

Maria was 11 years old when she learned she had a brain tumor. According to her father, Maria did not receive information from the physician at this time, but was rather sent out of the office while the physician explained the suggested diagnosis to him. She had, however, picked up that cancer was the topic of the conversation, and reacted with crying despairingly. A woman in her neighborhood had recently died of brain cancer and Maria believed she would suffer the same fate. She experienced feeling injustice towards why exactly she had to become sick. She also experienced fear for what they were going to do with her at the hospital. This all led to a inconsolably hysterical outbreak when she believed she cried to the next day. The next day she received the diagnosis - tumor in the cerebellum. It was, however, not known whether it was benign or malignant prior to surgery. The parents were first informed, and then Maria. Maria told that she calmed down during a conversation with the physician, when she learned that the tumor most likely was benign and that her possibility of recovery was great. She also got thorough information about the operation (Fottland, 2004).

2.1.2 Commonalities

Fottland (2004) concludes that all of the four children who participated in the research, to different degrees, experienced the events linked to getting cancer as stressors. This was mostly due to them being forced into a new, unsafe and unpredictable situation. Most of the children also experienced difficult emotions. All experienced the feeling of uncertainty, some of them also felt despair, sorrow and fear of dying. Two felt injustice towards this happening to them and one of them felt guilt, both towards himself and his parents (Fottland, 2004).

2.1.3 Mastering Strategy: Seek Information

Van Dongen-Melman, Pruyn, Van Zanen and Sanders-Woudstra (1986, referenced in Fottland, 2004) have through extensive research found six strategies which are important for making children with cancer experience mastery. These are: seek information, seek support and solace, search for causes, denying and avoiding, accepting the situation and to trying to change the situation.

For this thesis the strategy *seek information* is relevant. Van Dongen-Melman et al. (1986, referenced in Fottland, 2004) refer to a number of studies that have documented that receiving accurate information about own illness has a great significance in relation to sick children's feelings of uncertainty and tendencies for depression.

For all of the four children in Fottland's (2004) study, specific information about the severity of the disease and possibilities to recover, in addition to close support from parents and health professionals in the difficult time of receiving the cancer diagnosis, had a positive effect on the way the children coped with painful emotions. According to Sommerschild (1998, referenced in Fottland, 2004), the requirement for triggering positive mastering strategies in humans is having enough knowledge in relation to the difficult situations they encounter. Hope is also important as children who are given hope for the future within such situations are encouraged to utilize their own mastering strategies for handling painful emotions (Fottland, 2004).

2.2 Digital Storytelling

Storytelling is an important part of the human culture, both in relation to entertainment and education (Zhou, Cheok, Pan, & Li, 2004). Stories have been used in generations to carry on traditions, lessons of life, and cultural values (Cueva, Kuhnley, Lanier, & Dignan, 2011), as well as to help children develop communication skills (Hourcade, 2008). A reason for using stories might be that it is easier to remember facts presented in a story than a simple list of facts (Hourcade, 2008). According to Hourcade (2008), technology can play a positive role in storytelling by, among other things, providing storage and possibilities of sharing.

During the last years digital storytelling has emerged as an engaging tool for education and learning (Robin, 2008). Digital storytelling combines the traditional process of storytelling (selecting a topic, conducting some research, writing a script, and developing an interesting story) with multimedia (Robin, 2008). Multimedia is a combination of different media in an interface, which is connected through various forms of interactivity. The different medias could be text, graphics, sound, animations, and video. The interactivity is what makes multimedia differ from previous forms of combined media such as TV (Chapman & Chapman, 2004, referenced in Rogers, Sharp, and Preece, 2011g). The possibility to interact in ways which are not possible with single media (i.e. books, audio, video) is assumed to have effects like easier learning, better understanding, more engagement, and more pleasure (Scaife & Rogers, 1996, referenced in Rogers et al., 2011g)).

The combination of media also allows new ways of presenting information, not possible with single media. This opens up for possibilities to allow learners to explore ideas and concepts in different ways (Rogers, Sharp, & Preece, 2011a). Digital storytelling can, for example, be utilized to make abstract or conceptual content more understandable

(Robin, 2008), like interactive multimedia simulations for illustrating abstract concepts (e.g. mathematical formula and law of physics) that students find difficult to grasp (Rogers et al., 2011a).

Robin (2008) presents three categories of digital stories: *personal or narrative stories*, *stories that inform or instruct*, and *stories that retell historical events* (Robin, 2008). *Personal or narrative stories* are stories where the author tells a personal story. *Stories that inform or instruct* are primarily used to convey instructional material in different subjects (it could be medical education, science, art, technology etc.). In *stories that retell historical events* digital media is used to recount events from history (Robin, 2008).

2.3 Interaction Design

Interaction design can be defined as "Designing interactive products to support the way people communicate and interact in their everyday and working lives" (Rogers, Sharp, & Preece, 2011i). According to Lowgren and Stolterman (2004, referenced in Rogers et al., 2011i) and Saffer (2010, referenced in Rogers et al., 2011i) the art of interaction design is much concerned with practice, but is not restricted to particular design practices. It is rather extensive and promote a range of techniques, methods, and frameworks. There are, however, four basic activities that should be conducted in the process of interaction design:

- establishing requirements
- designing alternatives that meet the requirements
- prototyping the alternative design for them to be communicated and considered
- evaluating the product and the user experience it offers (Rogers, Sharp, & Preece, 2011h).

These activities should be done iteratively to continuously improve the design. The feedback of an evaluation might, for example, provide information about changes that need to be done to the design, and even establish new requirements (Rogers et al., 2011i).

When designing interactive products it is important to have a good understanding of the user group it is intended for, as well as the objectives of developing an interactive product for them (Rogers et al., 2011i). In order to identify these objectives Rogers et al. (2011i) suggests classifying them in terms of usability and user experience goals.

2.3.1 Usability Goals

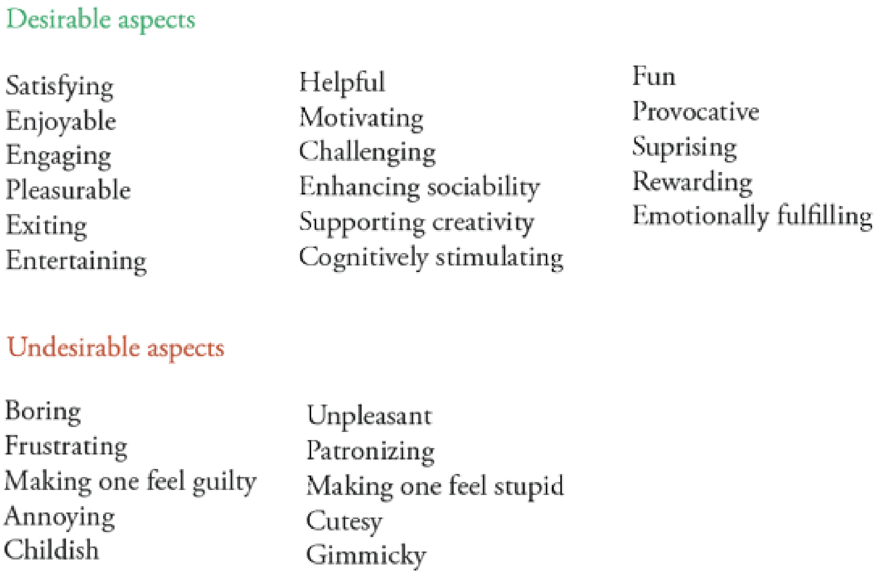
Usability refers to products being easy to learn, as well as effective and enjoyable to use, and is divided into the following goals (Rogers et al., 2011i):

- **Effectiveness** which refers to how good a product is at doing what it is supposed to do.
- **Efficiency** which refers to the way the product supports the users in doing their tasks.
- **Safety** which refers to protecting the users from unwanted situations and dangerous conditions.
- **Utility** which refers to the extent the right kind of functionality is provided by the product - to make sure the user can do what they want or need to do.
- **Learnability** which refers to how easy is to learn to use a product.
- **Memorability** which refers to how easy it is to remember how to use a product, once it is learned (Rogers et al., 2011i).

2.3.2 User Experience Goals

Unlike usability goals, which have an objective perspective (focusing on the product), most user experience goals have a subjective perspective as they evaluate the product from the perspective of the user. User experience goals concern analyzing and developing the experience of the user. There exists a multitude of user experience goals, which cover a wide span of emotions and experiences, both desirable and undesirable (Rogers et al., 2011i). Examples of user experience goals is shown in Figure 2.1.

User experience and usability goals are interdependent. Aspects of the user experience (e.g. how it feels and looks) are effecting the usability. Conversely, good user experience requires good usability (Rogers et al., 2011i). Not all usability and user experience goals will be relevant for every product. It is also useful to keep in mind that not all combinations of usability and user experience goals are achievable. Making a process



Desirable aspects

Satisfying
Enjoyable
Engaging
Pleasurable
Exiting
Entertaining

Helpful
Motivating
Challenging
Enhancing sociability
Supporting creativity
Cognitively stimulating

Fun
Provocative
Suprising
Rewarding
Emotionally fulfilling

Undesirable aspects

Boring
Frustrating
Making one feel guilty
Annoying
Childish

Unpleasant
Patronizing
Making one feel stupid
Cutesy
Gimmicky

Figure 2.1: Desirable and undesirable aspects of user experience. From "What is interaction design?" (Rogers, Sharp, & Preece, 2011i)

control system both fun and safe, for example, might be challenging (Rogers et al., 2011i).

2.3.3 Design Principles

To aid the way designers think when designing for user experience, design principles are used. Rogers et al. (2011i) defines them as "generalizable abstractions intended to orient designers towards thinking about different aspects of their designs (p. 25)". A diversity of design principles has been articulated. The most common ones (according to Rogers et al. (2011i)) are:

- **Visibility** which refers to functions being visible and intuitive.
- **Feedback** which refers to the user receiving information about what has been done.
- **Constraints** which refers to the restriction of certain user interactions, that only can take place at a given time.
- **Consistency** which refers to using similar elements for similar tasks, and using similar operations, in the design.

- **Affordance** which refers to an attribute of an object that makes it intuitive to know how to use it. To afford means 'to give a clue' (Norman, 1988, referenced in Rogers et al., 2011i).

2.3.3.1 Design Principles for Children

Borse, Robles and Schwartz (2006, referenced in Sandhu and Bhardwaj, 2013) do not think that design principles made with adults in mind can be applied when designing for children. They have their own needs when it comes to interface, navigation and usability issues (Sandhu & Bhardwaj, 2013). Different design principles for children have been developed. The principles, validated through empirical data to be the most important, presented in "Interaction Design and Children" by Hourcade (2008) are listed here briefly:

- Visual design
  - **Icons** should represent recognizable actions or objects, which are easily distinguishable from each other and the background (Hanna, Risden, Czerwinski & Alexander, 1998; Shneiderman & Plaisant, 2004; referenced in Hourcade, 2008). They should also be big enough for the children to easily click on them (Hourcade, 2008).
  - **Text** should be minimized, making the design applicable for children who can not read (Druin, Bederson, Hourcade, Sherman, Revelle, Platner & Weng, 2001, referenced in Hourcade, 2008).
  - **Visual complexity** should be avoided. One way of dealing with complexity is by using multilayer strategies (Shneiderman, 2003, referenced in Hourcade, 2008).
- Interaction styles
  - **Direct manipulation** entails rapid, reversible and incremental actions (Shneiderman & Plaisant, 2004, referenced in Hourcade, 2008). Rapid actions is important because children are more impatient than adults. Reversibility is important for encouraging exploration while keeping the children in control. Incremental actions is needed to avoid complex instructions (Hourcade, 2008). Visibility of objects and actions of interest, and a replacement of typed

  commands by pointing actions on objects of interest is also important (Shneiderman & Plaisant, 2004, referenced in Hourcade, 2008)

  - **Menus** should be immediately visible, and not hierarchically organized when designing for children under the age of seven, based on the findings of Browne Hutchinson, Bederson and Druin (2006, referenced in Hourcade, 2008) and Druin et al. (2001, referenced in Hourcade, 2008).
  - **Text-based interaction** can be problematic, especially for children who do not know how to type (Walter, Borgman & Hirsh, 1996, referenced in Hourcade, 2008).

- Using pointing devices

  - **Age-appropriate devices** concerns facilitating for the most appropriate input device for children. While studies show that the mouse often is the most appropriate (Jones, 1991; King & Alloway, 1992; King & Alloway, 1993; Revelle & Strommen, 1990; referenced in Hourcade, 2008) (with touchscreen not being included), Hourcade (2008) experiences that touchscreen always is well received by young children; supposedly because of its more concrete nature.
  - **Pointing** skills are proven to be poorer among younger children than among older children and adults (Crook, 1992; Hourcade, Bederson & Druin 2004a; Joiner, Messer, Light & Littleton, 1998; Jones, 1991; King & Alloway, 1993; referenced in Hourcade, 2008). Hourcade et al. (2004a, referenced in Hourcade, 2008) found through a study that four year olds achieved a level of 90% accuracy with targets that had a diameter of 64 pixels, five year olds achieved the same result with half the size (32 pixels), while young adults achieved 90% accuracy with targets having only 16 pixels diameter.
  - **Dragging** concerns moving an object from one place to another. The drag-and-drop interaction is challenged by click-move-click interaction. In studies done by Joiner et al. (1998, referenced in Hourcade, 2008) the click-move-click interaction came out best with 5-6 years olds, but a study done by Donker and Reitsma (2005, referenced in Hourcade, 2008) showed the opposite result with 5-7 year olds. In any case, both studies show that children can handle both interaction techniques at least from the age of five.

  - **Use of Mouse Buttons** might be problematic for the youngest. A study done by Hourcade, Bederson and Druin (2004b, referenced in Hourcade, 2008) showed that children from five years and up mostly used left mouse button, but that children at the age of four often used a combination of left and right mouse button. A more recent study with four and five year olds, however, found that most of the children used the left mouse button exclusively (Hourcade, 2008).

- Use of Sound

  - There is little research done on the use of sound in interfaces for children, but a study done by Mann, Newhouse, Pagram, Campbell and Schulz (2002, referenced in Hourcade, 2008) found that twelve-year olds did not benefit more from important information presented with sound, than with text, in multimedia educational software.

2.4 Children and Design

When designing technology for children it is important to consider knowledge about children's level of development (Hourcade, 2008). According to Hourcade (2008) this knowledge alone is not sufficient. Children need to be involved in the process as well (Hourcade, 2008). In this section different levels of development separated into approximate age groups will be presented, as well as different roles children can have in the design process.

2.4.1 Levels of Development

Markopoulos and Bekker (2003) state that there is no design that fits all and that design therefore should be driven by knowledge of the target users. As each child is unique their age can only be seen as a rough index of level of development (Gelderblom, 2004). When this is said, some guidelines is needed while the skills and preferences of children are significantly different between children of different age groups. When designing software for young children one should therefore focus on a specific age group (Gelderblom, 2004).

Markopoulos and Bekker (2003) present a discussion of Acuff and Reiher's (1997, referenced in Markopoulos and Bekker, 2003) age groups (based on stages of cognitive, social, emotional, moral and language development in the context of marketing to children), in relation to interaction design. Essential elements which should be considered when designing for each age group are following.

2.4.1.1 0-2 Years

This stage is called *the dependency/exploratory stage* and is the stage of learning, exploration, and discovery. Products for this age group should be very simple and stimulate learning. Examples of products could be an application on a device with touch screen showing different clickable images, buttons, and sliders. This way the children can practice their fine motor skills. Products for this age group usually have friendly colors and display fantasy figures or animals (Markopoulos & Bekker, 2003).

2.4.1.2 3-7 Years

Fantasy and magic occupy this age group, called *the emerging-autonomy stage.* At this stage they have need for stimulation, love, and safety. Simplicity is important and concepts used should not be too abstract. Children of this age group also develop their initial writing and drawing skills. Games in fantasy worlds, where the user should collect items, play small games, and solve riddles are common for this age group. Functions of buttons are mostly illustrated by symbols rather than text (Markopoulos & Bekker, 2003).

2.4.1.3 8-12 Years

In *the rule/role stage* the interest of the children gradually shift from fantasy to reality and needs for acceptance and success evolve. Products for this age group can be more challenging and complex. A shift also happens according to reading; they go from learning to read, to reading to learn. Products for this age group often have more complex interfaces and look more adult and serious-like than those designed for the younger. More abstract and complex language can also be used with this age group (Markopoulos & Bekker, 2003).

2.4.1.4 13 Years and Up

In the last stage, *early and late adolescence*, the children develop logical skills and abstract thinking. They also become increasingly more independent of parents, with their needs turning towards identity and sexuality. This age group prefers realistic settings over fantasy worlds and they also develop understanding for irony and sarcasm. Products designed for this age group are very much the same as those designed for adults. What is important is that the products should have a realistic look and also relate to activities and interests that appeal to this age group. This age group manages abstract problems and complexity (Markopoulos & Bekker, 2003).

2.4.2 Children's Roles in Design

Druin (2002) presents four main roles children can have in technology design process, which she have identified through literature analysis and research with children as design partners; *user*, *tester*, *informant*, and *design partner*. Even though the roles have distinct differences they are not disjoint as they may include aspects of the other roles. As an *informant*, the child may, for example, be observed while using competing software (*user*) and be asked to test a prototype (*tester*) (Druin, 2002). The different roles, identified by Druin (2002) will be briefly presented.

2.4.2.1 User

The role of *user* is the oldest role identified through literature. In this role the child uses a technology while being observed, videotaped or tested for skills by adults. The goal is to get an understanding of the child's activities. Two main reasons for having children as users is to test general concepts and to better understand the process of learning (Druin, 2002).

2.4.2.2 Tester

Children as *testers*, Druin (2002) has found to be a more recent role. When children take the role as *tester*, they test prototypes of emerging technologies. The goal is to allow children to identify changes needed in products before they are released to the world. Through these tests children help shape the technology (Druin, 2002).

2.4.2.3 Informant

Unlike *testers*, which is not involved until a prototype is developed, *informants* participate in various stages of the design process. They may be involved both before and after technology has been developed. Before, the child may, for example, be asked for input on paper sketches. After, feedback and input on the technology developed may be given (Druin, 2002).

2.4.2.4 Design Partner

The role as *design partner* is quite similar to the role *informant*. The difference lies in the amount of inclusion. As *design partner* the child is an equal stakeholder in the design of new technology and is part of the whole research and design process. In this role children should be able to contribute in any way they can during the design process (Druin, 2002).

2.5 Tools Used for Cancer Education

Some research have been done to find popular tools for educating children about cancer and being ill. The book *Kjemomannen Kasper* seems to be used a lot by the health communities working with cancer sick children in Norway. The University in Oslo has a series of images, *Rasmus på sykehus*, which they use to explain children about being at the hospital, including the different procedures, in a child friendly way. Another tool is *Remission 2*, which is a game made to increase motivation to fight cancer. These will be presented briefly.

2.5.1 Kjemomannen Kasper

A very popular book for explaining cancer to children is *Kjemomannen Kasper* (English: The chemo-man Kasper). This is handed out for free by the Norwegian Cancer Society (The Norwegian Cancer Society, 2015a). The book tells a story about a boy with cancer who gets chemotherapy, and focuses on what is happening in the body when the *chemo-men* (the chemotherapy) comes in to help the cells fight the cancer cells (National Library of Norway, 2012).

2.5.2 Rasmus på Syhehus

Rasmus på sykehus (English: Rasmus at the hospital) is a story told through series of images with associated text used by the Oslo University Hospital. The story presents the sick mouse Rasmus and explains different procedures he has to go through at the hospital, like getting medicine, injections, an intravenous line, anesthesia, enema etc. The story seems to fit many types of hospital visits since it covers a lot. The aim of the image series is to be a useful educational communication tool for parents, pedagogues, nurses, and others who come in close contact with children at hospitals. The pictures can be used to give children information about investigations or treatment they go through, or as support and processing after conducted examinations and treatment (Oslo University Hospital, 2014).

2.5.3 Re-mission 2

Re-mission 2 is a computer game for motivating children and adolescents to fight for their lives against cancer. Scientific research has proven that the game gives the player a sense of power and control, as well as attachment to treatment. The game-play takes place inside a human body where the player fights cancer with different weapons and super-powers, like chemotherapy, antibiotics, and the body's natural defenses (Re-mission 2, 2015).

Chapter 3

Methods and Methodologies

This chapter will present the research methodology used, design science. As well as methods and methodologies used in the process from data gathering to evaluation. Children's role in the process will also be defined, as well as the ethical considerations.

3.1 Design Science Research

When doing research in the Information System discipline Hevner, March, Park, and Ram (2004) mention two paradigms one can follow: behavioral science and design science. The behavioral science paradigm has its roots in natural research science and seeks to develop and verify theories that foresee or explain behaviors of humans or organizations. The design science paradigm has its roots in engineering (Simon, 1996, referenced in Hevner et al., 2004) and is fundamentally a problem solving paradigm in that it seeks to create innovations for expanding the boundaries of human and organizational abilities (Hevner et al., 2004).

This project follows the design science paradigm. Hevner et al. (2004) have developed a set of guidelines for conducting and evaluating design science research. These guidelines should help to ensure that the understanding of the design problem is obtained in the process of developing the artifact. Hevner et al. (2004) mention that each of the guidelines should be considered when using the design science approach, but in a creative way suitable for the specific research project. The guidelines are as follows:

- Guideline 1: Design as an Artifact
  - “Design science research must produce a viable artifact in the form of a construct, a model, a method or an instantiation (Hevner et al., 2004, p. 83)". A functional prototype of a digital storytelling about cancer and handling of difficult emotions for children will be produced. The methods used will be presented in the thesis, as well as the development of the design thorough iterations and a model of the prototype’s architecture. The thesis will also present findings concerning critical aspects according to interaction design in an digital story artifact.
- Guideline 2: Problem Relevance
  - “The objective of design-science research is to develop technology-based solutions to important and relevant business problems (Hevner et al., 2004, p. 83)". Hevner et al. (2004) define a problem as “the difference between a goal state and the current state of a system (p. 85)". As this thesis has more of a human perspective than a business perspective, the system would be the communication of cancer diagnosis between the communicator and the receiver. The current state is the negative emotional impact children usually experience when receiving a cancer diagnoses. The goal state is making children feel more safe when receiving a cancer diagnosis, understanding what cancer truly is and not only the effect of it. The thesis seeks to get an indication to whether a digital storytelling could help children move closer to the goal state when receiving a cancer diagnosis.
- Guideline 3: Design Evaluation
  - “The utility, quality and efficacy of a design artifact must be rigorously demonstrated via well-executed evaluation methods (Hevner et al., 2004, p. 83)". Evaluation of the prototype will be done with children who have had cancer. They will be observed while using the prototype to identify problem areas in the interaction design. The children will then be interviewed. These interviews will seek to get an indication of whether the children think the digital story could be helpful in the process of receiving a cancer diagnosis.

- Guideline 4: Research Contributions
  - “Effective design-science research must provide clear and verifiable contributions in the areas of the design artifact, design foundations and/or design methodologies (Hevner et al., 2004, p. 83)". The main contribution of this project would be knowledge around utilizing digital tools for conveying cancer diagnoses. This knowledge will evolve from interviews with professionals in the initial stage of the project, as well as the evaluation done with children who have experienced receiving a cancer diagnosis. The functional prototype will also be a contribution.
- Guideline 5: Research Rigor
  - “Design-science research relies upon the application of rigorous methods in both the construction and evaluation of the design artifact (Hevner et al., 2004, p. 83)". By rigor Hevner et al. (2004) mean “the way in which research is conducted (p. 87)”. This project uses semi-structured interviews for gathering data, an iterative development methodology (Spiral model) for the development process (herein prototyping) and usability testing (including observation and structured interviews) to evaluate the prototype.
- Guideline 6: Design as a Search Process
  - “The search for an effective artifact requires utilizing available means to reach desired ends while satisfying laws in the problem environment (Hevner et al., 2004, p. 83)". In this thesis important means will be interviews with health care professionals, evaluation of iterations, evaluation of the finished prototype as well as tools and frameworks utilized. Ends will be answers to research questions. Laws will be ethical considerations.
- Guideline 7: Communication of Research
  - “Design-science research must be presented effectively both to technology-oriented as well as management-oriented audience (Hevner et al., 2004, p. 83)". The thesis is written to meet both technology-oriented and management-oriented audience. The artifact will be presented in such technical detail that it enables the artifact to be implemented. As the system in itself should be easy to use, functioning like a book handed to a patient receiving a cancer

diagnosis, a detailed description of how to apply the artifact within the organization was not needed.

3.2 Data Gathering

3.2.1 Semi-Structured Interviews

Much medical and psychological knowledge was needed to develop a story about cancer and emotions. This knowledge was established through interviews with professionals who have experience with cancer sick children. Semi-structured interviews were used as they work well for in-depth investigations, where the primary purpose is *discovery* (Oates, 2006a). As the goal of the interviews was to gather as much information as possible from an area where the interviewer had minimal knowledge, it was considered that semi-structured interviews would be most helpful. In semi-structured interviews one tend to have a list of topics/questions, which do not necessarily have a specific order to be presented in. With this structure, the interviewer was able to add additional questions along the way when the interviewee came across problem areas for which there was no prepared questions (Oates, 2006a).

3.3 Development

3.3.1 Development Methodology

The development methodology used in this project was the Spiral Model (Boehm, 1988). Figure 3.1 illustrates the methodology. The radial dimension represents the increasing cost of the project, while the angular dimension represents the progress made in completing each cycle in the spiral. Each cycle (iteration) in the development process involves the same sequence of steps: determine objectives, alternatives, constraints; evaluate alternatives, identify and resolve risks; develop and verify next-level product; plan next phases (Boehm, 1988).

As there were few restrictions according to the technology and the design of the prototype, the approach of this methodology seemed to be suitable for this project. This approach allowed the design to evolve and take form through iterations. A simplified version of the methodology was used. Requirements were established in the beginning, a conceptual

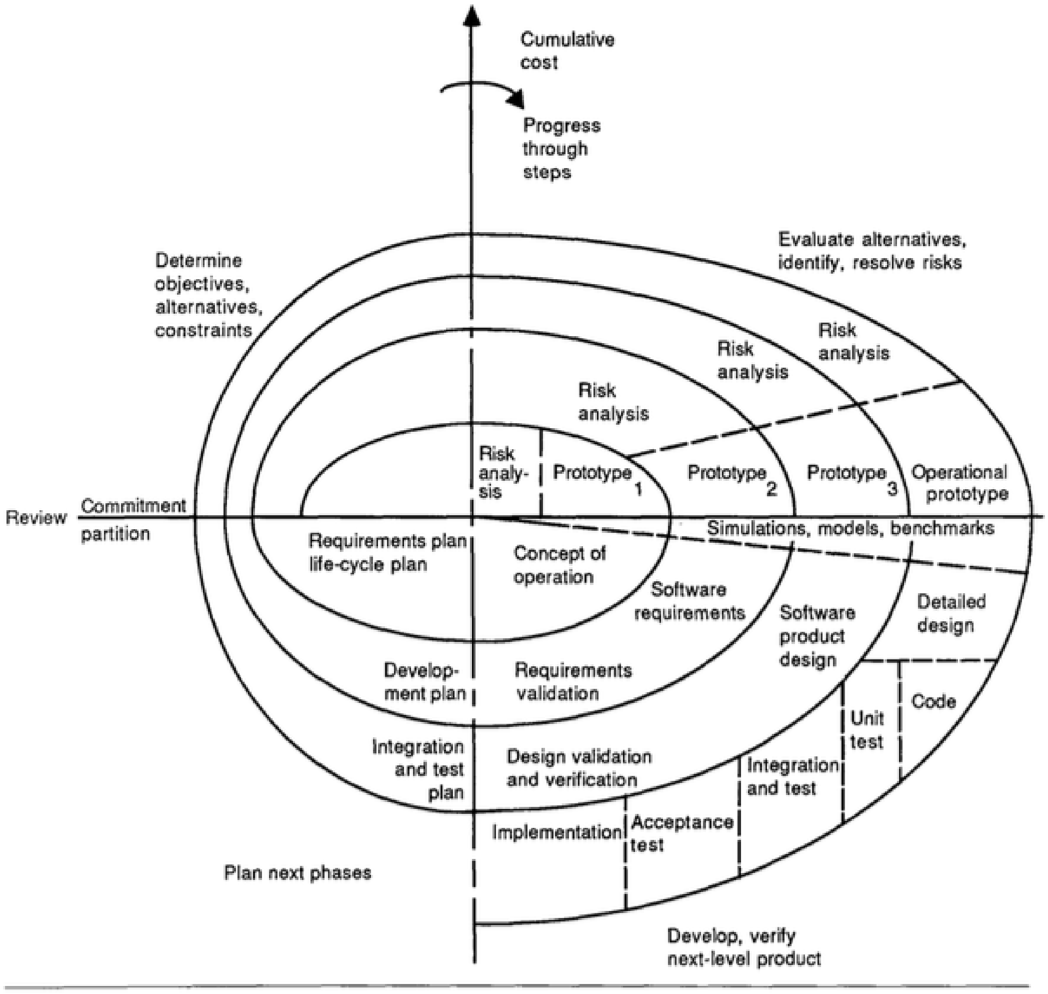


FIGURE 3.1: The spiral model, from "A Spiral Model of Software Development and Enhancement" by Boehm (1988).

model was developed by using them, and each iteration (spiral) after this consisted of three steps. Those are: developing a new design idea (if necessary), implementing elements of the design, and evaluating the design. For each iteration where the design was evaluated to be insufficient, a new design idea was developed in the next iteration. The spiral continued as long as inadequacies were discovered in the evaluations.

3.3.2 Prototyping

Prototyping was used throughout the whole development phase. Rogers, Sharp, and Preece (2011d) define a prototype as a "manifestation of a design that allows stakeholders to interact with it and to explore its suitability (p. 390)". A prototype can be anything from a paper sketch to a fully implemented prototype. A prototype which is quick and easy to make, like a paper sketch, are called low-fidelity while high-fidelity are prototypes which look more like the final product and are done using materials expected to be in the final product (Rogers et al., 2011d). This project has utilized both the types.

Low-fidelity prototypes were used during the development process to easily manifest design ideas. As low-fidelity prototypes are quick to make they are effective for exploration of alternative design and ideas (Rogers et al., 2011d). According to Rogers et al. (2011d) this is particularly important in the early stages of development. A disadvantage, however, is that they are limited according to usability tests (Rogers et al., 2011d), and can therefore be insufficient for evaluating whether to build further on the design idea. To solve this a high-fidelity prototype was developed in parallel through each iteration. In the early iterations of the project only small fractions of the design were implemented; to avoid the risk of spending too much time implementing functionality which would be omitted later. The function of the high-fidelity prototype in these iterations was to get a feeling of how the finished prototype would be by utilizing the design ideas explored by the low-fidelity prototypes. This approach was used to support experimental design solutions. When a suitable design solution was identified the high-fidelity prototype was fully implemented. This resulted in a functional high-fidelity prototype ready to be evaluated.

3.4 Evaluation

The evaluation had two goals: identifying problems in the interaction design and getting an indication to whether the prototype could be helpful in the process of a child receiving a cancer diagnosis. Many adults believe they can evaluate a product on behalf of children because they have been children or have children (Hanna, Ridsen, & Alexander, 1997). According to Hanna et al. (1997) this is rarely the case. They state that no amount of evaluation done by adults will uncover all the issues that children will reveal (Hanna et al., 1997). Testing with children was therefore highly desirable. The ones who were able to give the best feedback in relation to the prototype's usefulness when receiving a cancer diagnosis were children who have experienced it. The goal was therefore to do usability tests with children who have had such experience.

Regarding the age of the testers, Norwegian Social Science Data Services (NSD) accepted the lower limit to be five years. They did, however, dissuade against using children this young (NSD, personal communication, 8th September, 2014). In addition, Hanna et al. (1997) remark that usability testing with children from the age of six are easier than with the younger because of their experience of doing tasks and following directions from adults in school. With these aspects in mind, and considering the researchers lack of experience regarding usability testing, it was safer to set the lower limit of testers to the age of six. To make sure the methods used in the evaluation worked as intended, a pilot study was conducted in advance. Following are the methods used in the pilot test and the usability tests.

3.4.1 Pilot Study

A pilot study is a small trial study where the goal is to make sure the method is feasible before starting the main study (Rogers, Sharp, & Preece, 2011c). In this pilot study role play of the usability test was used since it was not possible to conduct test with children.

3.4.1.1 Role Play

Role play is a practice where individuals knowingly take on a character role in a constructed scene (Simsarian, 2003). According to Simsarian (2003) role play can provide additional insight and can be used at every stage of the design process. In this pilot study it was used to get insight into doing usability testing with a child. The tester imagined being a child and acted like one.

3.4.2 Usability Testing with Children

According to Rogers, Sharp, and Preece (2011f) the goal of usability testing is to test whether the product being developed is usable by the intended user population to achieve the tasks for which it was designed (p. 476). The tasks, for which it was designed, was to make children feel safer when receiving a cancer diagnosis. This would be a difficult aspect to measure. The best way would probably be to test the prototype with a diversity of children when receiving the diagnosis and compare their experience of cancer with the experience of children who did get the diagnosis without using the prototype.

Even with this approach the validity of the findings would be questionable because of different factors like: different children reacting differently, the child's prior knowledge about cancer, the communication methods of the doctor, the child's understanding and concentration, parents' reactions etc. This approach would, however, not be feasible due to both ethical issues and time limit of the project.

The goal of the usability testing was instead to get an *indication* to whether a digital story application could be helpful in the process of receiving a cancer diagnosis. To uncover this, the prototype was tested with children who had experienced receiving a cancer diagnosis. For the digital story application to be helpful its interaction design and content should also work well, which was evaluated. As one of the research questions regards the interaction design this was also a main focus of the evaluation.

To be prepared for usability testing with children, the guidelines made by usability engineers at Microsoft, Hanna et al. (1997), were followed to the highest extent possible. In usability testing a combination of methods is often used to collect data (Rogers et al., 2011f). Two main methods were used: observation and interview. During the interview a method for expressing experience through use of images were also applied, AXE.

3.4.2.1 Observation

The first part of the usability testing was to observe the children when using the prototype. The technique *participant observation* was used. This involves the observer taking part in the situation is such way that the test-subjects are aware of this (Oates, 2006b). Using this technique the role of the observer could either be *overt*, the one observed knows the observer is doing research, or *covert*, the observer takes a role as a *normal person*. The observer's role in this observation was *overt*. This was assumed to work best since the tests were conducted in controlled settings.

There are also several types of *participant observation*. The type used was participant-observer, which includes being an observer with the possibility to participate in the situation (Oates, 2006b). This observation type made it possible for children to feel free to ask questions if they were unsure of anything. It was assumed to be less intimidating for the children as it allowed for relaxed communication between the test-subject and the observer and was therefore chosen. It was also chosen as many of the guidelines in "Guidelines for usability testing with children" by Hanna et al. (1997) included communicating with the children during the usability tests.

During the observation difficulties with the interaction design was noted, as well as facial expressions indicating user experience. The actions on the screen were recorded to allow the researcher to go through it in more detail at a later time.

3.4.2.2 Structured Interviews

After the test-subject had gone through the story a method was used to gather qualitative information. Research has found that children from the age of six have the cognitive and language capabilities to be interviewed (Rich, 1968; Yarrow, 1960; referenced in Docherty and Sandelowski, 1999). Interview was therefore chosen as method for gathering qualitative information regarding the interaction design, as well as the test-subject's thoughts around whether this tool could be helpful in the process of receiving a cancer diagnosis.

The type of interview used was structured interviews. Structured interviews are identified by pre-determined, standardized and identical questions for every interviewee (Oates, 2006a). This seemed to fit best for this purpose in order to compare the answers between the testers, and at the same time allow for more detailed answers than a questionnaire. Audio recording was used to allow the interviewer to have full focus on the process of the interview.

3.4.2.3 Anticipated eXperience Evaluation

Anticipated eXperience Evaluation (AXE) is an approach for evaluating concept ideas at an early stage, using contrasting images-pairs with a scale between them, to stimulate participants in reflecting on their experience of the concept. Reasons for using images is that it is difficult to describe experiences with words and that words can be interpreted in endless ways (Gegner & Runonen, 2012). Even though AXE should be used at an early stage, it was seen to be relevant at the stage of evaluation as well since the goal of the method is to measure experience. As the study was done with children a simplified version of AXE was used. The children were presented with two contrasting images, one of which illustrated the user experience goal, and one which illustrated the contrast of the goal. The children were then expected to pick the one they felt best depicted their experience of using the prototype.

The images used within this method was mainly found on Internet by searching for images illustrating the user experience goals. The available selection was limited due to copyright.

3.5 Multiple Processes

Some methods were used in more than one process of the project run. These will be presented in this section.

3.5.1 Conceptual Model

Johnson and Henderson (2002) describe a conceptual model like “a high-level description of how a system is organized and operates” (p. 26). A simple conceptual models was used for presenting the idea of the digital story application to the professionals in the data gathering process. Before starting the design of the prototype a more detailed conceptual model was constructed based on the established requirements. This was done to have a clear and holistic idea of the digital story application in mind when starting making the design.

3.5.2 Qualitative Data Analysis

Qualitative data analysis was used to analyze the data from the interviews with the professionals, as well as the data from the usability testing with children. The first step in qualitative analysis is to get a overview of the data and identifying patterns (Rogers, Sharp, & Preece, 2011b). The analysis technique used was *Categorizing data*. With this technique data is divided into elements which are then categorized (Rogers et al., 2011b). Some categories were obvious (topics brought up in the interview questions) and other were identified during the analysis.

3.6 Children’s Role

In this project the role of the children was *testers* (see Section 2.4.2.2). Having children more involved in the design and development process as *informants* (see Section 2.4.2.3) or *design partners* (see Section 2.4.2.4), would be interesting. These approaches were not taken because of the limited time and ethical considerations. When having children as *testers*, professionals were able to evaluate the prototype before involving the children. The importance of this will be explained in more detail in the following section.

3.7 Ethical Considerations

Ethical issues were taken into consideration following the methods used. Norwegian Social Science Data Services AS (2015) requires that the project should be reported to them if personal information should be processed with computer based equipment, or with manual systematization of sensitive information, arranged by name / identity number. As this this project should process personal information both in the initial process (with professional) and in the phase of testing (with children), as well as handle sensitive information (children with cancer), the project was reported and approved (See Appendix K for receipt of approval).

The project followed NSD's guidelines. These include storing and deleting of data, as well as access to data. Getting written consent from all participants was also important. When doing research with children, there are three aspects which should be thoroughly considered; *consent*, *benefit and harm of research* and *confidentiality* (The Norwegian National Research Ethics Committees, 2009).

Regarding *consent*, and according to the legal perspective, guardians should always give their consent on behalf of minors (until the age of 18). Children can then agree on participating or not (The Norwegian National Research Ethics Committees, 2009). When recruiting children to test the prototype their parents were contacted. If they gave their consent further agreement was made to meet.

Benefit and harm of research must be considered in context of the project's theme. The Norwegian National Research Ethics Committees (2009) states that increased damage or discomfort on the participant should result in increased benefit to the participant (The Norwegian National Research Ethics Committees, 2009). Since the topic of this research is a sensitive subject, this was important to consider. To ensure that the research would not overstep the limits of damage and discomfort, professionals gave their personal opinions to whether the prototype was safe to test with children or not. If some of them believed it would be unsafe to test with children, a new evaluation plan, not including children, would have been developed (NSD, personal communication, 7th October, 2014). According to the aspect of benefit, the participation in itself would not necessarily benefit the child participants, but rather inform them. The value of the participants' contribution was, however, utterly expressed; telling them that their help might help children with cancer in the future.

Independently of the participant's age the participant's *confidentiality* is an important ethical principle. All material was therefore only accessible by the student and canceler of the project. All audio recordings, notes, name lists and other material which could disclose anonymous participants at later times, were to be deleted and shredded at project end. The Norwegian National Research Ethics Committees (2009) emphasizes the importance of preserving confidentiality of the children in relation to their parents. Situations may occur where the children reveal information they do not want to share with their parents (The Norwegian National Research Ethics Committees, 2009). Such situations did not occur since the parents were present during the evaluation.

Chapter 4

Establishing Requirements

As mentioned earlier (in Section 2.3) the four basic activities in interaction design are: *establishing requirements*, *designing alternatives*, *prototyping* and *evaluating* (Rogers et al., 2011h). These steps are all covered in this project. In this chapter the first activity, *establishing requirements*, is covered. *Designing alternatives* and *prototyping* is covered in Chapter 5 and *evaluating* in Chapter 8.

4.1 Conceptual Model

To start the design process more insight into the problem space was needed. This data should be gathered through professionals working with children affected by cancer. For them to understand the possible benefits of the prototype they should have an idea about what this digital storytelling should entail. For this purpose a conceptual model was developed (see Section 3.5.1).

The model was developed based on the theory (in Chapter 2). Emotions were included in the story as research shows that getting a cancer disease is tightly linked to experiencing difficult emotions (Fottland, 2004) (see Section 2.1). As this model could not be too detailed due to the limited data, the model developed was a simple sentence. The conceptual model was defined as follows:

> *A digital storytelling about a character who gets a cancer diagnosis - where the focus is on what is happening in the body, as well as what the character is experiencing emotionally.*

Some sketches were also made to give some simple examples of what the character(s) in the story could look like (see Figure 4.1). The characters in the sketches did all have expressive eyes, to convey the emotional aspect (Fjellanger & Babic, 2014) (See Appendix L).

FIGURE 4.1: A collection of sketches done before project start

4.2 Data Gathering

With the concept ready, four professionals were interviewed. All interviewees gave their written consent to participate in the study using the informed consent form from the Appendix A. All of them also gave their consent for publishing their names in the thesis, which was a voluntarily option. The interviewees were as follows:

- Dorota Malgorzata Wojcik, who has a PhD in medicine with specialization in pediatric oncology. She has worked all her life with children's oncology, and is currently employed at Haukeland University Hospital.
- Marianne Bøe, who is a nurse with postgraduate education in oncology nursing. She has mainly been working at the Children's Clinic at Haukeland University Hospital and has also been working at the Norwegian Cancer Society for three years.
- Marianne Straume, who is a psychologist and specialist in clinical child and adolescent psychology. She was the head of the psychological work with cancer diagnosed children at the Children's Clinic at Haukeland Hospital for several years.
- Vivian Fløysand Berland, who is a deputy of the board in the Norwegian Children Cancer Society, where she has been an active member since 2000. Her engagement

started after her son got cancer at the age of 1. He recovered after 4-5 months following the treatment. In addition her daughter underwent a kidney transplant at the age of 11.

The interviews was adjusted to each person, but some questions were presented to all of them. These were as follows:

1. What are your thoughts about digital storytelling as a tool for conveying cancer diagnoses to children?
2. For which age group do you think this tool will be most beneficial?
3. In a digital storytelling to inform children about a cancer diagnosis
    (a) what do you think about meeting a character who gets a cancer diagnosis where the story focuses on what is happening inside the body, as well as what the character experiences emotionally?
        i. Do you have other ideas for the story plot?
    (b) which cancer type will you recommend focusing on, when the goal is that as many as possible should be able to relate to it?
    (c) what medical information do you think is important to include in such a narrative?
        i. Any specific symptoms?
        ii. Any specific treatments / operations?
        iii. Other?
    (d) what do you think about informing about the possibility of death?
    (e) do you have any thoughts about what the characters in the story should be like?
4. Do you think any of the characters shown here (Figure 4.1) are suitable for such a story?
    (a) If yes,
        i. which?
        ii. what features is it that makes the character suitable?
    (b) If no,

  i. why not?
  ii. can you describe a character type you think would be ideal?

The interviewee who is a mother of child who have had cancer (Vivian Fløysand Berland) also got questions regarding how her child reacted to receiving the cancer diagnoses and how it was conveyed to him. She was also asked what she thought was important when a cancer diagnosis is conveyed to a child. The doctor (Dorota Malgorzata Wojcik) and the nurse (Marianne Bøe) where asked how cancer diagnoses are conveyed to children at their hospital today and if they used any forms of metaphors or other tools in this process. The psychologist (Marianne Straume) was asked her opinion about what was important when conveying cancer diagnoses to children. She was also asked about children actual reactions to cancer diagnoses and which emotions the story should entail. The transcribed interviews can be found in Appendix C, D, E and F.

4.3 The Data

The data gathered from the interviews, transcribed and analyzed (see Section 3.5.2 for method description), are further presented.

4.3.1 Communication of Cancer Diagnoses

How the cancer diagnoses is communicated to children depends a lot on the age of the child as well as the type of cancer (D. M. Wojcik, personal communication, 21st October, 2014). As a mother of a child who had cancer at the age of one, Berland told that her son did not understand anything of the diagnosis (V. F. Berland, personal communication, 23rd October, 2014). When the children are old enough to understand, however, Wojcik emphasized that it is important that the children are enlightened about the diagnoses (D. M. Wojcik, personal communication, 21st October, 2014).

Who is conveying the diagnoses to the children do vary depending on the parents wishes. Some parents want a physician to tell their children whilst other parents want to convey it themselves after a conversation with a physician. Bøe expressed that the communication method is direct as the word cancer is used (M. Bøe, personal communication, 22nd October, 2014).

4.3.1.1 Essential Information

30 years ago children with cancer were not informed about their condition. Straume herself had a cousin who died of cancer without him getting any information about the disease from the hospital. As of that time society has come to the understanding that information helps. Openness has been more valued and knowledge about one's own condition is obvious today (M. Straume, personal communication, 10th November, 2014).

All of the interviewees agreed that the children should learn about the diagnosis, and should receive correct information. According to Wojcik this information can only be given to the children if their parents agree, which they mostly do (D. M. Wojcik, personal communication, 21st October, 2014). Straume did not agree on it being possible to hide this information for the patients, especially if they were to spend a lot of time at the hospital among other cancer patients and medical staff who then had to keep track of with whom one could use the word *cancer* and not (M. Straume, personal communication, 10th November, 2014). If children do not get this information, they will likely imagine a lot of things. In todays society, with accessible information, they may find their diagnoses through different information channels (D. M. Wojcik, personal communication, 21st October, 2014).

Further detailed information given depends on the child. If the child is interested in the long term perspective, information about treatment and side effects are presented. These conversations always end with optimistic information like prognosis since many types of pediatric cancer have relatively good prognoses. For cancer types with less good prognoses the focus lies on communicating hope and the possibility of defeating it, but at the same time communicating that it requires a tough treatment and a lot of time spent at the hospital (D. M. Wojcik, personal communication, 21st October, 2014).

Bøe also emphasized the importance of conveying that cancer occurs randomly, explaining that it is an error that occurs in the body, but we do not know why. This information is important because parents and children sometimes can feel guilty thinking the disease has occurred due to something they have done or have not done (M. Bøe, personal communication, 22nd October, 2014).

4.3.1.2 Conveyance

From a motherly perspective Berland thinks honesty in the information given is the most important element; explaining everything as well as possible. She stated that honesty also entails being honest about the unpleasant factors like pain, as well as factors we do not know (V. F. Berland, personal communication, 23rd October, 2014) - e.g. how the outcome could be.

Straume also empathized that the information should be honest, as well as concrete and simple. By simple she referred to age specific, appropriate to the child's level of development. With the goal being that the information should make the children feel safer, the information should also be truthful and gentle, conveyed with hope, and not intimidating. It is therefore critical to explain that there are many available treatments for the illness and that some of them can cause side effects, but emphasize that this is what it takes to become healthy. When children receive this information it is very important that they are accompanied by their parents; parents should always know as much about the illness as their children. In this way children can confront their parents if they want to discuss it or have more questions after receiving the information. This also applies to other information sources like books and digital storytelling (M. Straume, personal communication, 10th November, 2014).

Metaphors At Haukeland University Hospital, Wojcik stated that metaphors rarely are used in the process of conveying cancer diagnoses to children. Wojcik herself is not using any metaphors, she rather adjusts the language to the child's age (D. M. Wojcik, personal communication, 21st October, 2014).

Both Wojcik and Bøe spoke about some magnetic images (color images in hard plastic), available at Haukeland University Hospital, which are not being used. They are, however, used at other children's hospitals which are treating cancer. The images depict different types of cells and medicines. Cytostatics are, for example, represented as golden drops whilst antibiotics are depicted as stars. As cancer can be perceived as a vague theme Bøe thought metaphors like these should be used more often, even with older children (M. Bøe, personal communication, 22nd October, 2014).

Upon receiving the diagnosis the book *Kjemomannen Kasper* (see Section 2.5.1) is used a lot, both for children with cancer and for child relatives (M. Straume, personal communication, 10th November, 2014). This book explains cancer and chemotherapy in a simple and child friendly manner. It uses non intimidating metaphors to help the children understand a topic that is very abstract and difficult to understand. In her work as psychologist Straume uses a lot of metaphors with both children and adults (M. Straume, personal communication, 10th November, 2014). Bøe also uses this book in her work with the children after they have recieved the diagnosis. In addition she uses metaphores like *angry cells* when talking with the youngest children (M. Bøe, personal communication, 22nd October, 2014).

4.3.2 Children's Immediate Reactions to Cancer Diagnosis

Children's responses to cancer diagnosis depend on the child's age and their experience with cancer. Both Bøe (M. Bøe, personal communication, 22nd October, 2014) and Straume told that it depends a lot on the reactions of the parents. To be startled or shocked, angry, scared, and sad are common reactions to cancer diagnosis. Insomnia and rush of thoughts is also normal. Some even have the positive response of determination and courage (M. Straume, personal communication, 10th November, 2014). Bøe also mentioned guilt as a normal reaction for both children and parents (M. Bøe, personal communication, 22nd October, 2014).

4.3.3 Digital Storytelling for Conveying Cancer Diagnoses

All the interviewees formulated, in different ways, that digital storytelling would be relevant due to children's knowledge and use of technology today. They were all positive to the idea. Wojcik meant this would be an easy way to communicate the information to the children (D. M. Wojcik, personal communication, 21st October, 2014). Bøe has experienced that children get easily distracted and unfocused during conversations about cancer. The reason for this might be because of the vagueness of the theme. She further mentioned that it might be easier to capture their attention by showing something on a computer screen. She thought this would make it easier for them to gather their thoughts and understand the message, especially in the beginning when they have so many thoughts and questions rushing through their heads constantly. Bøe also remarked her fascination for children managing iPads and tablets from a very young age (M. Bøe, personal communication, 22nd October, 2014). Berland told that use of online videos, made to prepare children in different age groups for operations (by Oslo University Hospital), had a reassuring effect on her daughter (V. F. Berland, personal communication, 23rd October, 2014). Straume remarked that information is one of the elements that betters the possibilities of mastering difficult situations as it seems to reduce anxiety. Tools that help increase children's understanding will therefore always be interesting (M. Straume, personal communication, 10th November, 2014).

4.3.3.1 Age Group

As this is a storytelling application the users of it must be old enough to memorize a story, which is expected to start at the age of four. A two-year-old will not be able to hold on to the information. Apart from this Straume did not mention any specific age group, but mentioned that the tool could be helpful for any age group as long as it is customized for them (M. Straume, personal communication, 10th November, 2014). Berland agrees on this (V. F. Berland, personal communication, 23rd October, 2014). Wojcik, however, thought that the tool might be most beneficial for children between the age of 6 and 11. She believed the interactivity could be too demanding for the youngest children, and that it might be boring for children over the age of 11 (D. M. Wojcik, personal communication, 21st October, 2014). Bøe, on the other hand, mentioned that a story which is customized for a specific age group still can be used with younger and older children. Both Bøe and Straume (M. Straume, personal communication, 10th November, 2014) use the book *Kjemomannen Kasper* (see Section 2.5.1) with both younger and older children than the age group the book is intended for (M. Bøe, personal communication, 22nd October, 2014). While younger children only look at the images, older children can understand the text as intended (M. Straume, personal communication, 10th November, 2014). It might be perceived as childish by the older children, but they will get from it an increased understanding of the disease. Bøe recommended customizing the story for a younger age group, so that it can be understood and used by a wide age span. While the main group of children cancer patients at Haukeland University Hospital is between the age of 3 and 10 years (according to Bøe) this can also be taken into consideration. For the younger children Bøe believed the magnet images would be more beneficial (M. Bøe, personal communication, 22nd October, 2014).

4.3.3.2 The Concept

The concept (see Section 4.1) was well received by the professionals. Wojcik liked the idea of focusing on the emotional perspective in addition to the medical, but stressed the importance of the way it is presented (D. M. Wojcik, personal communication, 21st October, 2014). Straume also enjoyed the idea, but was a little unsure about mixing the two perspectives. She thought both perspectives were very important, but stated that it is important to separate them from each other; not necessarily by making two different stories. She thought it would be too much for the children, especially the young ones, if all this information is mixed. It is important that the character in the story understands what cancer is, that the actual information is presented before emotions come into play. Another solution is to make it possible for the user to choose what to watch - the actual information or the experience of the character (M. Straume, personal communication, 10th November, 2014).

Berland has also found the idea enjoyable. As *Kjemomannen Kasper* (see Section 2.5.1) takes on the perspective of the medicine, she thinks it will be also interesting with a story presenting the perspective of the cancer patient (V. F. Berland, personal communication, 23rd October, 2014).

Bøe liked the idea as the two perspectives being interrelated. She mentioned several factors which can affect one's emotional state like living with a disease, loosing contact with friends, unpredictable life, not going to school, isolation in conjunction to treatment, and the effect of the treatment. It is important to convey that it is acceptable to experience different emotions and express them. The younger children (about 3-6 years) are better at expressing emotions, while she has experienced that the older children often are holding their emotions inside. Bøe underlined this with an example of one patient at the hospital, a young boy which always is very polite, even during very hard periods of treatment. She wants them to know that it is okay to feel sad and angry, that these are natural reactions. She also mentioned that this information would be useful in other contexts, e.g. for child relatives or for children with mentally ill parents (M. Bøe, personal communication, 22nd October, 2014).

4.3.3.3 Emotional Content

Regarding the emotional content Straume recommended including the core emotions: scared, sad, startled and uneasy. She also emphasized the importance of including positive emotions as well, such as hope and thankfulness (that one becomes more thankful for things than earlier). She further recommended focusing on how to cope with difficult emotions. Giving examples like talking to parents, seek solace and thinking that things can be better even though they feel bad right now. She proposed an interactive part in the application where the children themselves can fill in what helps them when they experience different difficult emotions (M. Straume, personal communication, 10th November, 2014). Bøe also mentioned actions which can help when dealing with difficult emotions: closeness with parents, play with friends, visit from friends, watching a movie, listen to music, and escaping reality with a fantasy travel (M. Bøe, personal communication, 22nd October, 2014).

Bøe mentioned something she had learned from Straume on an earlier occasion; one can have a face outward which does not reflect the emotions felt within. One can smile even though one feels sad. She thought it would be good to show the fact that the face and the inside do not always correspond to each other. This could be done by showing one emotion in the face and visualizing other emotions which usually are invisible by placing it somewhere on the body, for example, in the head or in the stomach (M. Bøe, personal communication, 22nd October, 2014).

4.3.3.4 Medical Content

Cancer Type Cancer in the central nervous system is the most frequent cancer type with solid tumors among children. Leukemia, which is not solid, is the most frequent of all children cancer types. Wojcik recommended focusing on leukemia in the story. She mentioned that there are several forms of leukemia. While the general information is the same for the different forms one does not need to go into more detail about the different forms (D. M. Wojcik, personal communication, 21st October, 2014).

Bøe and Straume (M. Straume, personal communication, 10th November, 2014) recommended talking about cancer on an even higher level. They both believed one could talk about cancer without relating it to a specific diagnosis or cancer type. Bøe stated that a cancer cell is a cancer cell whether it exists in the head, the skin, a foot, or is floating in the blood. It will in any case require tough treatment (M. Bøe, personal communication, 22nd October, 2014). Straume thought *Kjemomannen Kasper* (see Section 2.5.1) had captured it well by telling that cancer cells may behave differently; sometimes they float around in the blood and at other times they clump together and must be surgically removed (M. Straume, personal communication, 10th November, 2014). They both believed the same story could be used for different cancer types.

Symptoms All the interviewees are, for different reasons, against informing about symptoms. Bøe mentioned that many of the symptoms are very vague. Few patients feel sick from the cancer itself. The reason they consult a doctor is often because the parents have a feeling of something not being as it should with the child. Examples of symptoms may be fatigue and headache which could be symptoms for innumerable other things (M. Bøe, personal communication, 22nd October, 2014). Berland believed focus on symptoms would unnecessary cause concern. She thought it would be acceptable if the use of the application should be limited to children who already have received the diagnosis, but not if it should be publicly available (V. F. Berland, personal communication, 23rd October, 2014). Wojcik did not believe it was needed since the patients already know the symptoms when they come to the doctor (D. M. Wojcik, personal communication, 21st October, 2014).

Treatment and Side Effects All four interviewees recommended focusing on side effects of treatment rather than symptoms of the cancer. Bøe thought this was very important since the patients may come to the hospital in good shape and get sick from the treatment. It is important that the children as well as their parents understand that it is the medicine that make them feel sick and not the illness itself (M. Bøe, personal communication, 22nd October, 2014). Straume has also added that it is the treatment the patient must live with, not the cancer; since the patient usually does not feel the cancer itself. She meant the focus mainly should lie on the treatment - why it is important, possible side effects and how it can affect the life of the patient. While treatment can be very individual the story should not give too much information about the treatment, e.g. how much time they need to spend at the hospital. Not everything can be said in advance (M. Straume, personal communication, 10th November, 2014).

Side effects of cancer treatment may be severe pain, loss of appetite (M. Bøe, personal communication, 22nd October, 2014), nausea, vomiting and hair loss (D. M. Wojcik, personal communication, 21st October, 2014).

Surgery and Radiotherapy It is very important that the children get thorough information in advance of surgery and radiotherapy, but it might be difficult to include in the story since surgery and radiotherapy can cover a multitude. What is common for surgery and radiotherapy is that they take place in different hospital departments, and not the one the patient usually stays at. Chemotherapy, for example, takes place in the medical department, while operations take place in the surgical department. If one was to mention any common information about surgery or radiotherapy it should be this (M. Bøe, personal communication, 22nd October, 2014).

Both Wojcik and Berland mentioned that the story should inform about the central venous catheter, which many cancer patients must use. This is a type of Hickman catheter with a drain connected to the heart, inserted close to the collarbone. The catheter is used for medication, blood samples and fluids to avoid too many syringe stings (D. M. Wojcik, personal communication, 21st October, 2014). Children receive anesthesia when the central nervous catheter is inserted. Berland's daughter was a little scared in advance of surgery because of anesthesia. Berland therefore thought it would have been helpful for children if the story presented some reassuring information about getting anesthesia (V. F. Berland, personal communication, 23rd October, 2014). According to Wojcik the story should also focus on how it is to live with a catheter, mentioning that it must be handled with ease and that there is as risk of infections (D. M. Wojcik, personal communication, 21st October, 2014).

Wojcik also mentioned bone marrow control, which leukemia patients must undergo. This is a very painful procedure, but children are sedated; they sleep through the procedure without feeling pain. If this were to be included in the story, Wojcik recommends to focus on conveying that the children will sleep through it (D. M. Wojcik, personal communication, 21st October, 2014).

4.3.3.5 Characters

The interviewees were presented with the four sketches as shown in Figure 4.1. Bøe mentioned that it was important that both boys and girls could relate to the character, but she did not think that a boy could relate to any of these characters. For boys she would have a cool character with caps or something similar, it should not be too girly. She also suggested a more neutral figure, or the possibility to choose between different characters fitted for different ages and genders. Apart from this, Bøe enjoyed sketch number 2 and 3 (Figure 4.1) (M. Bøe, personal communication, 22nd October, 2014).

Straume proposed to include a character of each gender who got to know each other at the hospital, or else have a more generic character like an animal. She stated that children identify with animals. By choosing the options of a story with two characters, one can present a wider range of emotions for the children to recognize (M. Straume, personal communication, 10th November, 2014).

Berland also thought that both genders should be able to identify with the character, as in *Kjemomannen Kasper* (see Section 2.5.1) - where the character neither is a male or female. She also suggested having the possibility too choose between two characters, a boy and a girl. As Bøe, Berland also mentioned the idea of having different characters to meet different age groups. In addition she mentioned the possibility of customizing the story for different age groups, as well. She commented, when watching the different sketches, that the character must not only be sad. Hope must also be signaled. She favored the sketch number 2 (Figure 4.1) since it shows that it could be good to have someone in the armpit through the difficult times (V. F. Berland, personal communication, 23rd October, 2014).

Wojcik did not think she had sufficient basis to be able to say much about how the characters should be. Her advise was to contact the play therapy department at the hospital or to get inspiration from movies or cartoons which are popular among children today. She added that the characters should be updated after some time as they would be outdated and not popular anymore (D. M. Wojcik, personal communication, 21st October, 2014).

4.3.3.6 Informing about Cancer Being Deadly

Straume told that it was important that the children were informed about cancer being a deadly disease in a safe way together with their parents. If this is not mentioned, they surely will find this information from other sources. If the patient for instance receives this information from another child, the patient will probably not get explained the small probability of this happening, which can cause fear and uncertainty. If this information is presented for them through other sources the children may also be insecure about why their parents and medical personnel have withheld this information from them. Straume therefore thought this information should be a part of the story, but in a subtle way since most do recover from the disease. An example would be to tell that this is an illness in which one can die if one does not get treatment for it. Examples of illnesses people died from in older times, but for which there exist medication today, can be presented. Straume has also mentioned that this information only could be given with the parents consent (M. Straume, personal communication, 10th November, 2014).

Berland did not want to answer to whether this information should be presented in the story or not, due to lack of knowledge of how a child's mind works. From a motherly perspective, however, she thought this information should be given considering the possibility of them getting to know children at the department who will pass away. She further stated that it should be told in an orderly and honest way, but with a positive focus on medication. Most children survive, but there are a few which can not be saved (V. F. Berland, personal communication, 23rd October, 2014).

Bøe told that most children know that cancer is a deadly illness. She herself prefers to get to know the children before she tells about this. She also believed that this information is given by the physician, not necessarily when receiving the diagnosis, but in the beginning. And that it is given together with information about lots of great medication being available for the treatment. Focusing on the positive is important. The medical staff always meets the child and its parents with a positive attitude believing the child will become healthy (M. Bøe, personal communication, 22nd October, 2014).

Wojcik stated that this is a difficult question. She said that most children get this information, except the youngest. She did, however, not believe it was wise to present this information in the very beginning. She therefore recommended having an open ending, telling that most children will get healthy. She also said that the story might end with the character getting healthy since 86% of the children with the most common type of Leukemia survive (D. M. Wojcik, personal communication, 21st October, 2014).

4.3.3.7 Additional

Scope There are different perspectives a story like this can take; it can simply focus on telling about cancer or it can have a broader focus including preparation for the difficult things. It depends on how extensive the story shall be. Straume mentioned that it already exist preparatory stories for radiology and operations (M. Straume, personal communication, 10th November, 2014). Both Wojcik (D. M. Wojcik, personal communication, 21st October, 2014) and Straume mentioned that the story should be short and simple. Straume also added delimited (M. Straume, personal communication, 10th November, 2014).

Berland recommended building the story in several stages, so children will not be overwhelmed by a huge story. If children are presented with all the information at once, the process might seem very long. She mentioned that her son's treatment period lasted for four to five months when he had four chemotherapies, each lasting three days (V. F. Berland, personal communication, 23rd October, 2014). Wojcik recommended including some optimistic information about the patients not having to spend all their time at the hospital (D. M. Wojcik, personal communication, 21st October, 2014). Straume expressed that she thought it was a good idea to include children in the evaluation of the prototype as they might be the ones to give the best overall feedback (M. Straume, personal communication, 10th November, 2014).

Siblings Both Berland and Bøe (M. Bøe, personal communication, 22nd October, 2014) expressed that focus on siblings is also important in a situation where a child gets cancer. Both mentioned that siblings often are excluded since the focus is on the sick child and its parents. This may leave the siblings with a lot of thoughts and unanswered questions according to Berland. She therefore would wish to have a story with the perspective of a sibling of a child with cancer. (V. F. Berland, personal communication, 23rd October, 2014). Bøe is also passionate about this topic. She often finds that siblings say that they are tired of friends, family, and neighbors turning to them and asking how things are going with the sick one. Siblings are often unseen. Other things siblings experience is that they have to be adept in the home, with the parents and with the sick one. They sometimes miss their sick sibling, or they might be mad at them for taking up so much space. Feeling mad might again lead to guilt. Guilt can also be felt in cases where the sibling believe their brother/sister got sick because of them. They might, for example, have been fighting right before the diagnosis was given (M. Bøe, personal communication, 22nd October, 2014).

4.4 The Requirements

With the data showing that the initial concept was well received (see 4.1 and 4.3.3.2), the development could continue to build on it. Requirements were then established. Rogers, Sharp, and Preece (2011e) define a requirement as “a statement about an intended product that specifies what it should do or how it should perform” (p. 355). Requirements can be classified into different groups (Rogers et al., 2011e). Usually one tends to distinguish requirements into functional and non-functional requirements. Functional requirements define what the system should do whilst non-functional requirements define what constraints there are on the system and the development of it (Rogers et al., 2011e). In this context the requirements gathered concern the content of the story and will therefore be presented as *content requirements*. Requirements that are more vague and regards the story presentation in its entirety are presented as *meta content requirements*.

User experience goals and usability goals are also types of requirements (Rogers et al., 2011e). The content requirements, meta content requirements, and user experience goals are based directly on the data gathered. Usability goals, on the other hand, which belong to a more technical arena, are determined by the researcher based on the data gathered and the context. The established requirements are further presented (Requirements that might not be obvious from the analysis are explained in Section 4.4.5.):

4.4.1 Content Requirements

1. The story shall explain what cancer is
2. The story shall present information about treatment (chemo therapy)
3. The story shall present information about side effects of treatment
    (a) nausea (vomiting, loss of appetite)
    (b) hair loss
4. The story shall communicate that it is the treatment that make the patient feel sick and not the cancer

5. The story shall talk about cancer in general and not a specific type (see Section 4.4.5.4 for explanation)
6. The story shall present optimistic information
7. The story shall communicate that cancer occurs randomly
8. The story shall communicate that it is natural and acceptable to feel emotions
9. The story shall advise the users to express their emotions
10. The story shall show that what one feels on the inside does not always correspond to what the face is showing
11. The story shall give examples of emotions one can experience (both good and bad), these are:
    (a) scared
    (b) sad
    (c) angry
    (d) startled
    (e) uneasy
    (f) hopeful
    (g) thankful
    (h) brave
12. The story shall give advice to what helps when one experiences difficult emotions, these are:
    (a) talking to/being close to parents
    (b) seek solace
    (c) thinking that things can be better even though they feel bad right now
    (d) play with friends
    (e) watching a movie
    (f) listen to music
    (g) escaping reality with a fantasy travel
13. The story shall be divided into two smaller stories, one with a medical perspective and one with an emotional perspective

4.4.2 Meta Content Requirements

1. The story shall be short and simple
2. The information shall be conveyed in an honest, truthful, gentle, non intimidating, concrete and simple way (appropriate to the children's level of development)
3. Children from the age of five shall be able to use the application (see Section 4.4.5.3 for explanation)

4.4.3 User Experience Goals

1. Hope
2. Safety
3. Relatedness - The user should relate to the main character

4.4.4 Usability Goals

For explanation for those not chosen, see Section 4.4.5.1.

1. Effectiveness - is important to consider to make the prototype focus on what it is supposed to do.
2. Utility - is important to consider as the system should provide the right kind of functionality to let the user do what they want to do.
3. Learnability - is important to consider to make the system as easy to learn as possible.

4.4.5 Clarifications

4.4.5.1 Omitted Usability Goals

Not all of the *usability goals* (see Section 2.3.1) were relevant for this application. As it should support learning through a story at one's own pace, *efficiency* was not a goal. *Safety* was neither important as the application should not allow for the user to do changes to the application at this stage. This kind of safety should not be confused with the user experience goal *to feel safe*, which is very important for this application. It is covered in the user experience goals (Section 4.4.3). Lastly, *memorability* was not taken into consideration since the application not necessarily should be used more than one time, when receiving the diagnosis. It is also difficult to test the application's support of *memorability* as it would need a long term follow-up, which would exceed the duration of this thesis.

4.4.5.2 The Scope

There is a lot which can be told about cancer, so defining the scope was critical before developing the actual story. Wojcik and Straume mentioned that the story should be short and simple (see Section 4.3.3.7, paragraph: Scope). Keeping this in mind, the scope was limited to include the most essential information. Extra information, like that of siblings, was therefore not included at this stage. Extended functionality, like interactivity supporting possibility for the user to input data (see Section 4.3.3.3), was also excluded for now.

4.4.5.3 Age Group

The age group was set to 5+, meaning five to be the recommended lower age, but with no higher age limit. This decision was based on the professionals' recommendations and reflections (see Section 4.3.3.1). Wojcik recommended the target group to be 6-11 years. Straume stated that children start being able to take in a story at the age of four. Five was considered a good lower age, thinking they would be able to take in a story by then. For the younger children, Bøe mentioned that magnet images probably would be more beneficial. As two of the professionals thought the tool could be useful for children of all ages, and since the tool probably could be used with both younger and older children than what it was intended for, no upper age limit was set. The story should be simple enough for a five-year old to understand it and entertaining enough for older children to use it. Even younger children should be able to use it together with adults, who could show them the images and explain them in simple words. The intention was to make the application available to as many as possible.

4.4.5.4 Cancer Type

Both Bøe and Straume mentioned that it was possible to talk about cancer without specifying which type it was (see Section 4.3.3.4, paragraph: Cancer Type). This idea was used to capture as many patients as possible. By focusing on cancer in general it would not be relevant to give information related to specific cancer types, like bone marrow control and prognosis. Surgery and radiotherapy were not considered to be relevant either since there is a little one can say about this in general. Information about Hickman catheter and anesthesia, on the other hand, could be relevant for all cancer patients. This information was, however, not included at this stage of development with the intention to keeping the story as brief and simple as possible.

4.4.5.5 Deadliness

Information about deadliness of cancer was omitted as not all interviewees were positive about including it (see Section 4.3.3.6). Wojcik did not think it was wise to give this information too early in the process. And Bøe stated that she preferred to get to know the children before she gives them this information. It might also be safer to deliver such sensitive information in person. Since all parents need to consent to this information being presented to their child, this information could also restrict the use of the application; resulting in excluding a group of patients.

Chapter 5

Prototype Development

When moving from requirements to design, a conceptual model (see Section 3.5.1) should be made based on the requirements (recommended by Rogers et al. (2011d)). At this stage the conceptual model helped clarify what should be developed.

5.1 Second Conceptual Model

The conceptual model was based on the content requirements (see Section 4.4.1). The numbers of these requirements, as represented in Section 4.4.1, are used to highlight the connection between them and the coceptual model, in the text. The concept was a digital story presented in a web application. The story consisted of to sub stories (13); one about *cancer* and one about *emotions*. Following Berland's recommendation (see Section 4.3.3.7, paragraph: Scope), the stories were split into several views, just like turning pages in a book. The two stories are following presented.

5.1.1 Cancer Story

> *The user meets a girl who gets cancer. The narrator in the story is a cell from inside the girl's body. The user is able to look inside her body to learn what a cell is and about different kinds of cells. Then the cancer cell gets introduced. The story then show what is happening when cancer cells appear in the body and how they can act (1 and 5). The narrator tells that cancer cells occur randomly (7). Further the story presents chemotherapy and show how the cancer cells disappear when the girl starts her treatment (2 and 6).*

> *Then on the outside of the body, the user can see that the girl gets sick from the treatment and loses her hair (3). The narrator explains that she gets sick from the medicine and not the cancer itself (4).*

5.1.2 Emotion Story

> *In the second story the girl meets a boy at the hospital who also has cancer. Here the narrator talks about emotions, and it is shown that the two can have different emotions inside, which do not always correspond to what the face is showing (10). Both good (6) and bad emotions should be mentioned (11). The narrator expresses that it is natural to experience different emotions (8) and advises the users to express their emotions (9). Further the story gives examples of what might help when experiencing difficult emotions (6 and 12).*

5.1.3 Remaining Requirements Considered

How the meta content requirements and the user experience goals were considered are further presented. The usability goals were considered during the design process. These considerations can be found throughout Section 5.3. In the following paragraph, the numbers of the meta content requirements as presented in Section 4.4.2 are used to elusidate the connections to them in the text. The same is done for the user experience goals (see Section 4.4.3) in the subsequent paragraph.

Meta Content Requirements The conceptual model was cut down to only include the information presented in the content requirements to keep it as short and simple as possible (1). The information presented was based on the data gathered, believed to be honest and truthful (2). Metaphors and non-intimidating images should be used to explain the information in a child friendly, gentle, concrete and simple way (2). As five year olds have not yet started going to school, they might not be able to read. To make the application available for children who can not read, the use of text should be avoided whenever possible (3). The information should be communicated through audio (3). Rogers et al. (2011a) also state that children often prefer to listen to narratives in multimedia or web-based learning materials rather than to read. Listening requires less cognitive effort (Rogers et al., 2011a).

User Experience Goals With these techniques mentioned hopefully the young users would feel safe when using the prototype (2). The optimistic information presented might wake hope in the children (1). To make the children feel related, the story should present both a girl and a boy (3).

5.2 Tools Used

Through the development process different tool were utilized. These tools and how they were used will now be presented briefly.

5.2.1 Balsamiq Mockups

Balsamiq Mockups (Balsamiq Studios, 2015) is a wireframing tool that was used to create the initial sketches of the interaction design. Its drag-and-drop interface was helpful to make the mockups fast and easy to make. The interaction design changed several times during the development and this tool was instrumental in the process of planning redesign.

5.2.2 Adobe Photoshop

Adobe Photoshop (Adobe Systems Incorporated, 2015a) is a raster graphics editor, which was used to make the artwork in the application. Its ability to work with different layers in an image was very helpful.

5.2.3 Brackets

Brackets is an open source text editor, which supports real-time connection to the browser (Adobe Systems Incorporated, 2015b). Changes made in the CSS and HTML were instantly visible without the need to refresh the page. This, in addition to its minimalistic and clean design made it a pleasant experience to work with. The editor was used to write the source code of the high-fidelity prototype.

5.2.4 Burndown Chart

A burndown chart (Burndown Chart, 2015) was used to keep track of the process. In this tool one was able to create a project, register tasks with an estimate of how many days they would take to complete. These estimates could be adjusted and tasks could always be removed and added. One was also able to edit remaining days of a task. This flexibility was proven to be very helpful. The tool was very beneficial by always giving an indication of how the process went in relation to the estimates. Figure 5.1 shows the diagram. The rings on the blue graph is where data have been plotted, usually to mark tasks as done. The reason for it ending two months later than estimated was that it took much longer time to recruit children participants for usability testing.

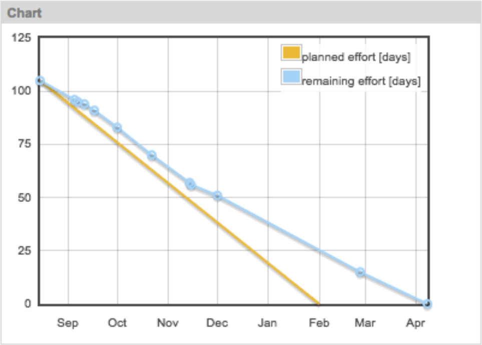


FIGURE 5.1: A burndown chart showing the intended development process as compared to the actual process. From Burndown Chart (2015)

5.2.5 GitHub

GitHub is a platform for collaboration, code review and code managements both for shared and private projects (GitHub Inc., 2015). It builds on the text based version control system Git (AOL Inc, 2014). In this project GitHub was used exclusively for version control and backup. The reason for using it was mainly because of its desktop application, which is very intuitive and easy to use.

5.2.6 Audio

5.2.6.1 Logic Pro X

Logic Pro X is a recording and MIDI production studio for recording, editing and mixing audio (Apple Inc., 2015). This program was used to record the audio clips of the narrator.

5.2.6.2 Audacity

Audacity is a free open source, cross-platform software for recording and editing sound (Slashdot Media, 2015). This program was used to transform the frequency of the sound files from the standard 440hz to 432hz. It is believed that 440hz might cause emotional distress (Horowitz, 2010). 432hz and 444hz on the other hand are said to be more natural, harmonious and therapeutic (Horowitz, 2010). As the user experience goals were to make the user feel safe and hopeful, using this frequency could possibly be helpful.

5.3 The Development Iterations

The development of the prototype was more a creative process than a structured one. When new art ideas appeared they were designed. The foundation of the prototype's framework was developed at project start. This allowed new design ideas to be implemented fast in the high-fidelity prototype (see Section 3.3.2). The development process endured four iterations, where both the interaction design and the artwork took new turns. At the end of each iteration the design was evaluated through a discussion with a fellow student, which was very helpful and inspired many changes. Ideally there would be usability tests with children at the end of each iteration, but due to limited time and lack of participants this was not feasible.

In this section the overall design process will be presented. Detailed design and art decisions for the finished prototype can be seen in Chapter 6. The technical details are explained in Chapter 7.

5.3.1 First Iteration

In the first iteration the idea was to build the prototype very similar to a text book, as described in the second conceptual model (see Section 5.1). The main page (See Figure 5.2) should present two buttons, one for each book/story. The button for the *Cancer story* should be bigger than the *Emotion story*, as this was the main story. If the user would want to watch the *Emotion story* first, however, the design allowed that.

The design inside each story (See Figure 5.3) was very simple as it consisted of two buttons, back and forward, and a menu with a *home button*. In the middle of the window an image was shown. All information should be presented in audio and icons

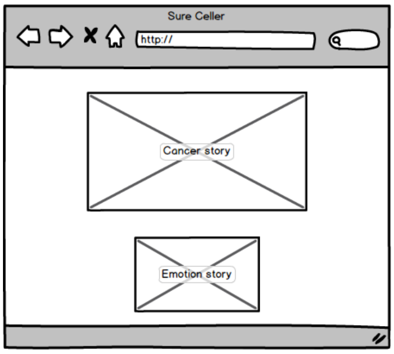


FIGURE 5.2: The interaction design of the main page

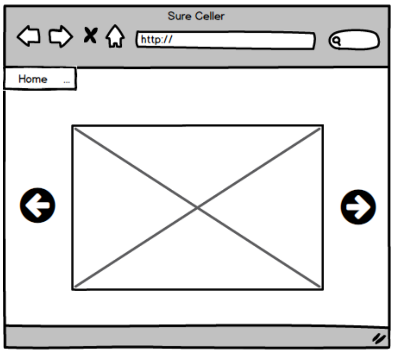


FIGURE 5.3: The first interaction design for the stories

should be used instead of text. The *home button* in the menu should also include an icon. The design was made easy to support the usability goals. As the goal of the prototype was to educate children about cancer and emotions, having an interaction design that was not distracting was important for the prototype's *effectiveness*. Making the interface simple would also support the *learnability* by making it easier to learn how to use. How to support *utility* was a little more unclear since it was difficult to foresee what functionality children would want in an application like this. Including fun and engaging interaction might enhance *utility* in this kind of prototype. Clickable elements were therefore added.

Some art were also made in this iteration. The two main characters were developed, a boy and a girl (see Figure 5.4). Models to make children understand how small a cell actually is were also made (see Figure 5.5).

FIGURE 5.4: The first main characters

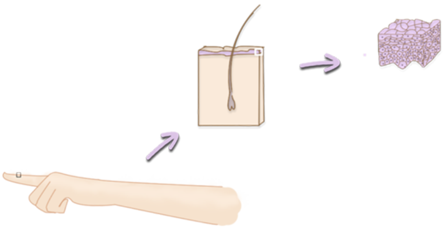


FIGURE 5.5: Figures explaining the size of a cell

Cells were also designed. To communicate the difference between cancer cells and regular cells the metaphors *happy cells* and *angry cells* were used. This idea was inspired by Bøe's statement about her using metaphors like *angry cells* when explaining cancer to children (see Section 4.3.1.2, paragraph: Metaphors). When designing the cells in the story the focus was to make them child friendly and kind looking; emphasizing the difference between good and angry cells, as shown in Figure 5.6 (where the green cell looking angry is the cancer cell).

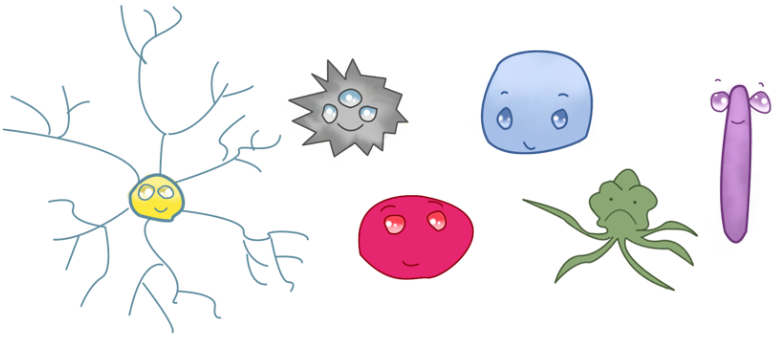


Figure 5.6: The first design of the cells

5.3.1.1 Evaluation

To evaluate this design the images made were implemented into the framework to get an understanding and feeling of how the finished prototype would look like with this design. Some of the images were clickable. In Figure 5.5, for example, one had to click on the arm to see the next frame. The evaluation revealed that this interaction design probably would be too simple and boring for older children even with the ability to click on elements. The simple interaction design seemed to support *effectiveness* and *learnability*, as assumed. The support for *utility* on the other hand, was supposedly too poor even with clickable elements. A more compelling interactivity should be used. The challenge was that it still had to be simple enough for small children to use it.

5.3.2 Second Iteration

In the second iteration the main goal was to find a compelling interaction style, suitable for both younger and somewhat older children. In this process the framework Skrollr (see Section 7.3.1) was identified as a good tool. This framework allowed images to change properties, like position, depending on the user's scroll position. By scrolling, images could move around in the window. This seemed both compelling and simple. With this in mind, the interaction design was changed from having a range of different views (See Figure 5.3) to having one single view containing the whole story (See Figure 5.7). Since the new interaction idea simply involved scrolling, the two usability goals *effectiveness* and *learnability* seemed not to be affected in any bad way. *Utility* would probably be better supported with this interaction style as it would allow for a more dynamic and vivid user experience. The ability to click on elements was still included. The design of the main page was kept (See Figure 5.2) since it seemed to have work well.

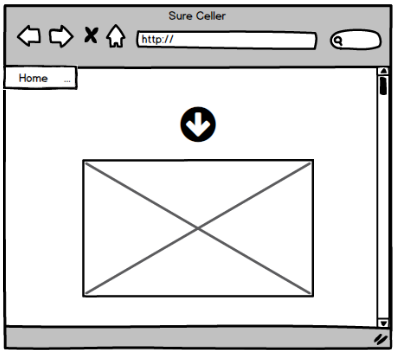


FIGURE 5.7: The second interaction design for the stories

During this iteration it was also decided to make the art more relatable by making it look like it had been colored by a child with a paint brush (as shown in Figure 5.8). Gif-files were also made to illustrate how cancer could move through the body (leukemia) or accumulate, making solid tumors. Figure 5.9 shows the images of the Gif-file illustrating cancer cells gathering and making a tumor.

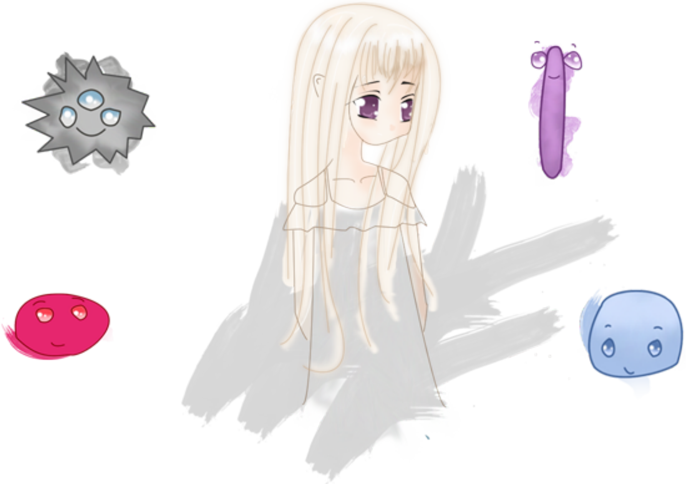


FIGURE 5.8: The painted design style

The new interaction design was then ready to be implemented together with the new art (See Figure 5.10) so that it could be evaluated. However, early into the implementation

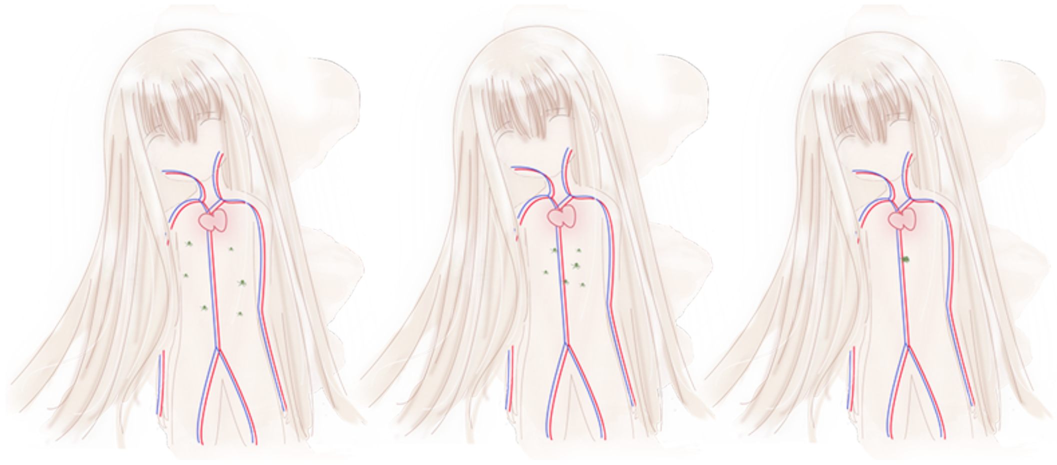


Figure 5.9: Images for the gif-file illustrating cancer cells gathering - making a tumor

process a big problem occurred. In the previous iteration with many different views each view would have an own audio clip. With the new design solution, using a single audio clip for the whole view, playing independently, could be confusing since there would be no connection between the audio clip and which image were being shown. A different approach, suitable for the scrolling functionality, was therefore developed. This solution entailed playing different audio clips in relation to different scroll positions. This worked by having the audio clips play between specific ranges of scroll positions (e.g. between 300 and 500). At each scroll position the corresponding images were shown.

5.3.2.1 Evaluation

Audio clips were implemented into the prototype for the sake of testing the design. The evaluation revealed that the solution of audio clips playing according to scroll position, even with just a few images, would be confusing and reduce *effectiveness*. If a user would scroll too fast he would suddenly miss out on an audio clip. One other case was that if the user wanted to scroll up to look at some images again, the currently playing audio clip would stop and another one would begin. Confusing the user would probably also affect *learnability* in a negative way. *Utility*, on the other hand, was evaluated as being well supported because of the engaging interaction technique (the scrolling). Eventually it was decided that this design was not an optimal solution.

In addition, the art style was evaluated to be too comprehensive since it was very detailed and time consuming. It was also evaluated to lack entirety, as the cells and the children were characterized using different design styles. The new artwork also seemed to be more artistic rather than child friendly.

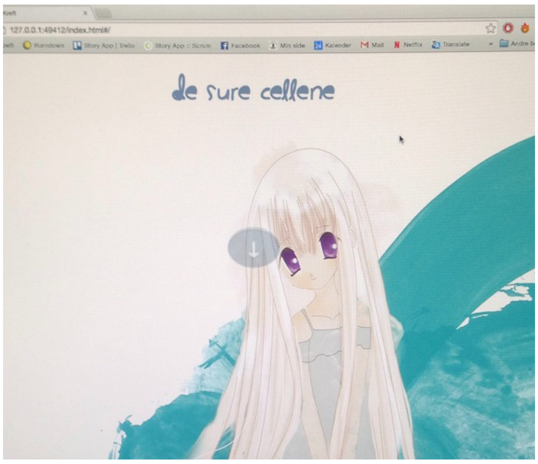


Figure 5.10: A screen capture of the design implemented in the second iteration

5.3.3 Third Iteration

To resolve the design challenges resulting from the previous iteration a combination of the design from the first and second iteration was developed. The combination was chosen to combine the good things from the previous design. *Effectiveness* and *learnability* from the first, and the *utility* from the second design. The solution offered several views, with the possibility to scroll to see moving images.

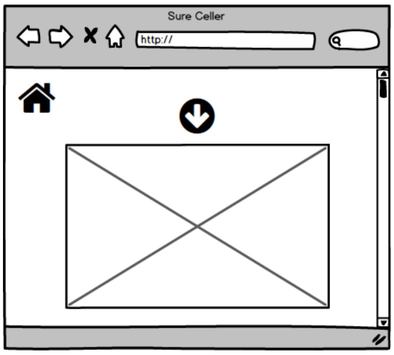


Figure 5.11: The third interaction design for the stories. Here: on the top of the page

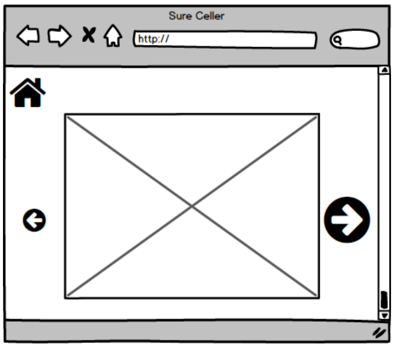


Figure 5.12: The third interaction design for the stories. Here: on the bottom of the page

In this way each view could have only one main audio clip, and the user could scroll freely up and down when listening to the audio. Figure 5.11 is illustrating being on the top of the page where there is an arrow indicating to scroll down. When the user reaches the bottom of the page, buttons with arrows pointing back and forward appear (see Figure 5.12). The right arrow is bigger than the left as this is the arrow taking the user further into the story and would be used more. The home menu was also exchanged with a single icon to make the interaction easier for the children.

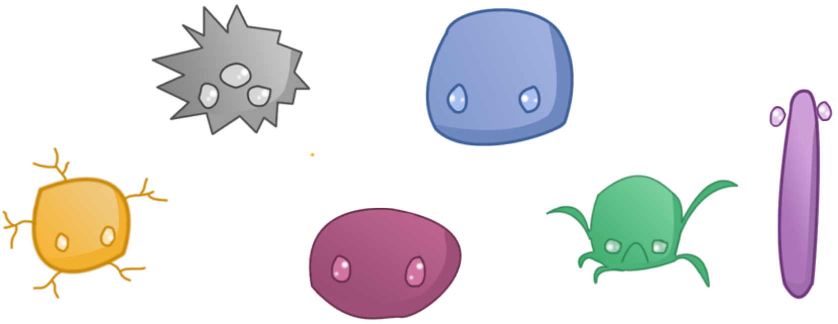


FIGURE 5.13: The third design style of the cells

In this iteration the art also went under a total redesign making it more simple and holistic (see Figure 5.13). Many changes were made to make the design and the process more simple and feasible. Instead of having a narrator cell, the main figure should now be the narrator and everything should also happen in its body. This was an androgynous figure made on the basis of the narrator cell in the earlier design (see Figure 5.14). By making it androgynous there was no longer need for two main characters. Instead of including Gif-files for showing cancer cells in the body, the illustration was made more interactive by having cancer cells appear one by one when scrolling (see Figure 5.15). The design of the cancer cells was adjusted to make them look *sour* instead of *angry*, as *angry cells* might be intimidating for the smallest children.

5.3.3.1 Evaluation

The new design and artwork made was implemented and then evaluated. With this design *effectiveness* and *learnability* seemed to be supported by keeping the interaction functionality simple, and relying on clicking and scrolling only. Even though it was simple, the freedom to control movements of the figures made the interaction vivid and fun. This, together with the ability to click on elements, was evaluated to make the *utility* enhanced. The artwork was also evaluated to work well. This design could therefore be further built on.

FIGURE 5.14: The narrator in the story

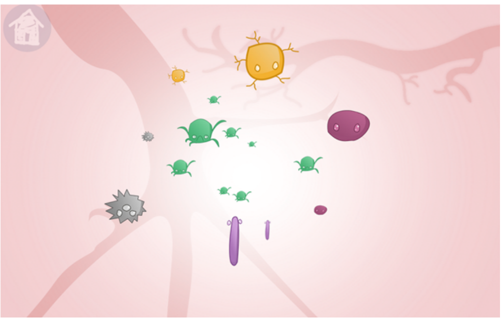


FIGURE 5.15: Screen capture: cancer cells appearing

5.3.4 Fourth Iteration - Finalizing the Prototype

Having achieved a working design, the rest of the story could be implemented to complete the prototype. In the fourth iteration all art for the two stories was created and implemented, building on the results of the previous iteration. In the *Cancer Story* art was made to explain chemotherapy and how this could remove cancer cells. Images for explaining side effects of treatment were also made. In the *Emotion story* colors were used to visualize emotions (See Figure 5.16). The emotions included were *happiness*, *anger*, *fear*, and *sadness* (For explanation of the color choices, see Section 6.3.1.2). Anger, fear, and sadness were included as they are very different emotions and can easily be separated from each other in a visualization. Happiness was included to represent positive emotion as well and was chosen since it is an easy recognizable emotion. Hopeful, thankful, and brave would probably be harder to relate to for younger children. Although not all the emotions from the requirements were visualized they were all mentioned in the story script (see Appendix J).

FIGURE 5.16: Emotion visualized in colors. From left: happiness, anger, fear, and sadness

Figure 5.17 shows how the colors were used to visualize the emotions of the character. The character on the right also visualizes how emotions felt inside (here: sadness), not always correspond to what is shown on the outside. Further artwork was made to tell a little about what helps when one experience difficult emotions. It was also shown that one can experience positive emotions in spite of being sick. Some of the art is shown in Figure 5.18.

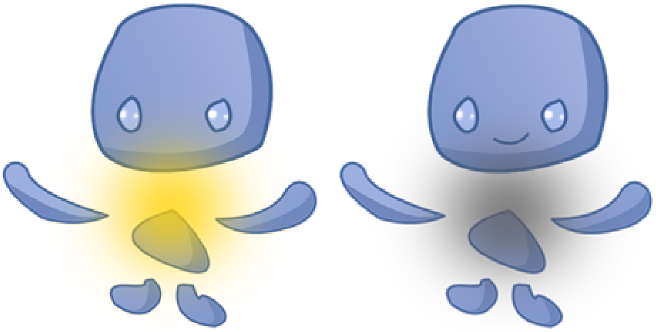


FIGURE 5.17: Colors visualizing emotions. Left: the figure feels happy. Right: the figure feels sad, but smiles

During this iteration the story scripts were also developed in detail, recorded, and implemented into the prototype. Cells and emotion related colors were made clickable. The cells would tell who they were and what they do when clicked on. Likewise, the emotion colors would tell which emotion they illustrate.

FIGURE 5.18: Different images from the story, used to give advise on what helps when experiencing difficult emotions

5.3.4.1 Evaluation

At the end of the fourth iteration the prototype was once again evaluated and no error could be found. All usability goals seemed to be intact since last evaluation. This made it ready for testing with children.

Chapter 6

Design and Art

This chapter will present details of the design and the art which were not mentioned in the overall presentations of the design in Section 5.3. Design decisions, the story script and how it came to be, as well as decisions made in relation to the art, and the process of the making of the art, will all be explained. At the end, art and design considerations done in relation to the chosen age group will be presented.

6.1 Design Decisions

Design decisions according to design principles, both general and for children, will be explained in this section.

6.1.1 Design Principles

The design principles (see Section 2.3.3) was always kept in mind when designing. Design choices of the finished design will now be presented and justified.

According to *visibility*, buttons which show the way further in the story were pulsating. *Feedback* were simply given by reactions. When the user clicked on the cells, they stared talking. When the user went further in the story, the narrator started talking etc. Regarding *constraints* this was considered in relation to the access to the *next* and *previous* buttons. Having the buttons there constantly could be distracting, and make the user go further without having explored all the scrolling functionality at each page. The initial idea was to make them visible when the audio track had finished playing. As this would be cumbersome if the user wanted to navigate freely back and forth in the story, the buttons rather appeared when reaching the bottom of the page. *Constancy* was used all the way. Every page in the story had the same layout, with the same buttons. The *home*-button was always on the top of the page on the left hand side, and the *previous*(left side) and *next* (right side) buttons were always at each side of the page, when the scrollbar had reached its end (See Figure 6.1).

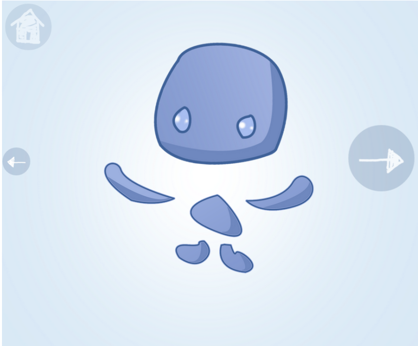


FIGURE 6.1: A screen capture of the prototype, showing the navigation buttons

The navigation buttons, all had the same style and colors. Only the story content was varying. The style of the final art was also consistent and holistic. To strengthen *affordance* the buttons that should be clicked were pulsating discreetly, making them draw attention, but not too much. The buttons all got darker when hovered over, indicating that it was a button and not just an image. At the top of the first page an arrow-icon pointing down appeared, moving fast down and slower up again to guide the user to scroll down.

6.1.2 Design Principles for Children

The design principles for children were also considered. Regarding *visual design*, the buttons as shown in Figure 6.2 all used icons instead of text. The icons were all recognizable object that children probably are known with. They were distinguished from the background by having a darker color. All the buttons were made big enough for children to click on them. As children from the age of four have good pointing accuracy on icons with size of 64 pixels (Hourcade et al., 2004a, referenced in Hourcade, 2008) no button were made smaller than this. This was done to support the youngest users. The smallest button was the one navigating to the previous page. The button for the next page was much bigger, 150 pixels, as this was the one the user probably mostly would want to click. This was also the one which was pulsating. The home button was 100 pixels. The only text used in the application was text for the title of each story. Visual complexity was also avoided. The most complex feature was the scrolling-technique.

Figure 6.2: The navigation buttons

According to *interaction styles*, this was made as easy as possible, without being boring. Reversibility was supported in the way that the user always had the possibility to go back to the previous page inside each of the stories. Actions were rapid, as there were no time-consuming tasks in the application. Whenever the user clicked on a button, or a clickable icon, a reaction would come immediately. Incremental actions have been utilized in the sense that each story consisted of four rather similar stages (the different pages). Menus and text-based interaction were not used.

Before the development started there were uncertainties to which *pointing device* the application should be designed for. The touchscreen was the most preferred one due to its concrete nature (Hourcade, 2008). Because of programming prerequisites and time available, however, it was decided to make a web application used with the input device, mouse, and not an android or IOS application. The idea was to make a web application which could be further developed to be used at different devices. Making the design appropriate for touchscreens was therefore kept in mind all through the design process. As mouse was the chosen pointing device, making the icons big enough for children to click on them was critical, as explained earlier in this section. This was also kept in mind for the clickable images in the story. As studies show that five-year old children mostly use the left button when using a mouse (Hourcade et al., 2004b, referenced in Hourcade, 2008), restricting the functionality of the right mouse button in any way was not seen as a necessity. Dragging techniques was not considered since they were not used.

Even though studies done by Mann et al. (2002, referenced in Hourcade, 2008) did not find *sound* more beneficial than text, this application used sound instead of text to make it available for children who can not yet read.

6.2 Story Script

In the making of the story script, the requirements of the prototype (see Section 4.4) was the main guide. Elements were also taken from the Norwegian Cancer Society's guide on how to talk about cancer to children (The Norwegian Cancer Society, 2015b). This was also a good guidance for child friendly formulations. The script, translated to English, together with an image of each page, can be seen in Appendix J. The URL to the prototype can also be found here.

6.3 Art Work

In this section decisions made in relation to the art made will be presented, as well as the process of the making of the art.

6.3.1 Art Decisions

6.3.1.1 Character Design

The design of the characters was made on behalf of the data gathered from the professionals presented in Section 4.3.3.5. Making the character(s) relatable for both boys and girls was communicated to be very important. To fulfill this, two approaches were mentioned: having one character for each gender or having a neutral character.

In the first development iteration, the approach of having two characters were chosen (see Figure 5.4). This decision was made on behalf of Straume's statement of having the possibility to show a wider range of emotions by using two characters. As none of the characters made in relation to the first conceptual model (see Section 4.1) excelled as clear favorites by the professionals (see Section 4.3.3.5), none of them were directly used. Features from sketch number 2 and 3 (see Figure 4.1) were, however, used as these were mentioned in a positive way by one or two of the professionals. For the boy, Bøe's advice to make him cool and not girly was followed. When the redesign was done in the third iteration of the development (see Section 5.3.3) the second approach, having a neutral character, was used.

6.3.1.2 Colors Choices for Emotions

The color choices for representing the different emotions were based on the study done by Naz and Epps (2004) because of its large amount of data. The research was done with 98 collage students, who expressed what emotions different colors brought up in them. According to the research achromatic colors were the kind of colors that had most hits on negative emotions (Naz & Epps, 2004). As the application should be colorful the use of achromatic colors was avoided as much as possible. Her findings regarding colors with principle hues were therefore used the most. Emotional associations with these colors showed that the emotion *angry* had highest frequency (28) on the color *red* (Naz & Epps, 2004). *Sadness* had its highest score on the color *purple* (13) and also some at the color *blue* (8). *Happy* had a distinguishable score at the color *yellow* (74). *Fearful* had its only scores at *purple* (5) (Naz & Epps, 2004). As it seemed, the emotions *sadness* and *fearful* shared the same color. Since *fearful* only had scores on *purple* and since *sadness* had a very high score on *gray* (from the achromatic colors) (Naz & Epps, 2004), *fear* were represented by *purple* and *sadness* by *gray*. *Blue* could not be used, since this was the color of the character in the story.

A similar study was done by Boyatzis and Varghese (1994) with 60 children between the age of four and seven. The children where shown different colors and then asked what the color made them feel. The results of this study did not have as distinguishable results as the study done with collage students and was therefore difficult to depend on. To illustrate pink, red, yellow, blue, and purple all had very steady deflection on *happy* (Boyatzis & Varghese, 1994). This study was therefore used in addition to the study done by Naz and Epps (2004) to control that the color choices was not total contradictory to associations children had done. As *yellow* had a high score on *happy* (Boyatzis & Varghese, 1994), this combination could be used. *Sadness* had highest score on *gray* (Boyatzis & Varghese, 1994), and could definitely be used. The scores for *angry* were very even, ranging from 3-24, where *black* was the most chosen (Boyatzis & Varghese, 1994). As *black* was not a desired color and since *red* had a hit of 9 (Boyatzis & Varghese, 1994), *red* seemed to work well. The other colors with higher scores than *red* were *gray* and *purple* (Boyatzis & Varghese, 1994), which had already been used, and *brown* (Boyatzis & Varghese, 1994) which had not been considered in the other study. *Fearful*, or similar emotions, were not included in this study and therefore kept *purple*. The final relations where therefore:

- Happiness: yellow
- Anger: red
- Fear: purple
- Sadness: gray

6.3.2 The Making of the Art

The art was made by doing sketches by hand with paper and pencil. These sketches was then either captured by camera or scanned, so they could be further worked with in Photoshop (see Section 5.2.2). In Photoshop the sketches were used as guidelines. Contours was drawn and the figures were colored. Figure 6.3 shows an example of this process. When the art got a total redesign in the third iteration (Section 5.3.3), the art was made directly in Photoshop, building on the art made earlier.

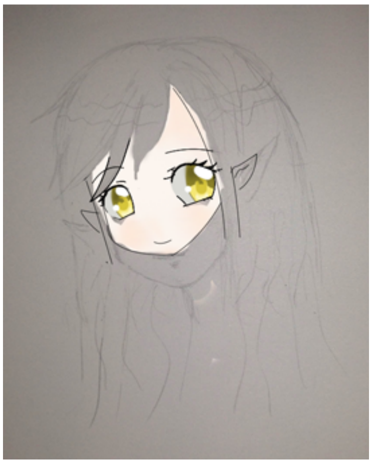


FIGURE 6.3: How sketches were used in Photoshop

The figures 6.4, 6.5 and 6.6 show the process of the development of the art. Starting from sketches (Figure 6.4), to being colored (Figure 6.5), and then being totally redesigned (Figure 6.6) based on the previous design.

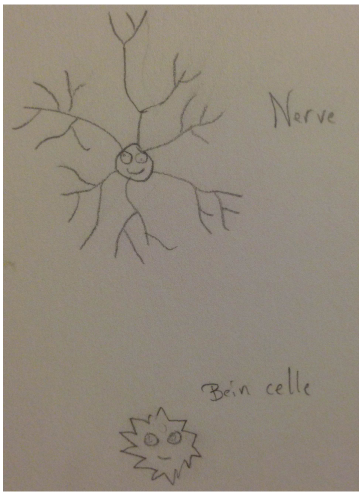


FIGURE 6.4: Sketch of cells

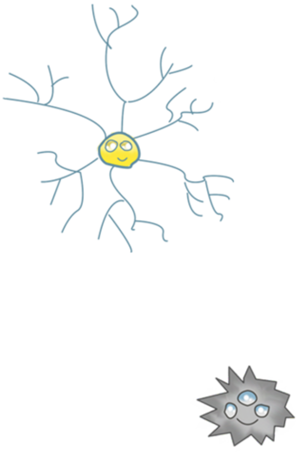


FIGURE 6.5: Cells colored in Photoshop

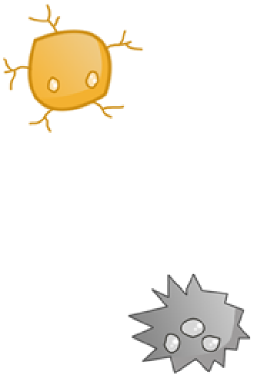


FIGURE 6.6: Cells redesigned

6.4 Design and Art According to Age Group

As the age group for the prototype was set to 5+ (see Section 4.4.5.3) the guidelines for designing for *the emerging-autonomy stage*-group (3-7 years) (see Section 2.4.1.2) were followed. Simplicity and concreteness were important aspects, and symbols were used instead of text. Even though the topic was realistic and serious, it was important to make the art express fantasy and magic instead of being too realistic. This was evaluated to have a calming effect by making the topic less intimidating. Having the overall art give a loving and safe expression was also important. To strengthen this impression a lot of colors were used, as well as kind-looking characters (apart from the cancer cells), a friendly narrator voice, and funny sound effects. To make the cancer cells less frightening they were changed from being *angry* to being *sour* during the development process (see Section 5.3.3). Even though the design was customized for the youngest it was also believed to be well received by older children as it was not to childish; having a minimalistic, clean and modern design, appealing narrator voice, and an engaging interaction style (scrolling).

Chapter 7

Implementation

In this chapter the technical details of the prototype will be presented. These are the languages, frameworks, libraries and style sheets used, as well the architecture of the prototype.

7.1 Languages

The languages used to develop the prototype is HTML, CSS and JavaScript. HTML (HyperText Markup Language) is a language for defining the structure of a web page (W3C, 2013). CSS is a language used for defining the presentation of the web page such as layouts, colors, and fonts (W3C, 2013). And JavaScript is a light weight programming language used to make static HTML pages more dynamic (Flanagan, 2002).

7.2 Frameworks

7.2.1 AngularJS

AngularJS is a web application framework for single-page applications (Google, 2015a). This framework operates with two-way data-binding between models and views (HTML), making these automatically synchronized (When the model changes, the view changes, and vice versa.). The result is dynamic web pages (Google, 2015a). The reason for using this framework was mainly because a single page application seemed to be a good idea when making a digital story consisting of multiple pages (which was the initial idea). The data-binding was also proven to be very useful later in the development process, especially for synchronizing audio clips with the talking narrator in the view. A moving gif-file would be visible when the audio clip played while a still image was shown when the audio finished. Using data-binding, the images updated fast after the audio started and stopped.

7.3 Libraries

7.3.1 Skrollr

Skrollr is a stand-alone parallax scrolling JavaScript library (Prinzhorn, 2015). The library make it possible to set CSS properties of HTML-elements depending on the horizontal scroll position (Prinzhorn, 2015). This made it possible to make the web pages more dynamic, fun and alive by making figures move when scrolling. Source code by aarosil on Stackoverflow was used to integrate Skrollr into AngularJS (Stack Exchange Inc, 2015).

7.3.2 Howler.js

Howeler.js is a lightweight web audio JavaScript library, which is not dependent on other libraries (GoldFire Studios Inc., 2015). Among other things the library supports playback of multiple sounds at the same time, fade in/out sounds, and chained methods (GoldFire Studios Inc., 2015). Howler.js therefore made it possible to have sound effects play at the same time as the narrator spoke. It also made it possible for audio clips to fade out when scrolling down. The chained methods made it possible to have smaller audio clips pause the main audio clips when starting, and making it resume when finished. This technique was used for the clickable cells and emotion-color-dots.

7.3.3 Flash Kit Sound FX

Flash Kit Sound FX is a site with a large list of shareware and freeware sound effects (QuinStreet Inc., 2015). Sound effects were used for a more fun interaction. Examples are: sounds of cells *popping up*, and the sound of the narrator swallowing the medicine.

7.4 Style Sheets

7.4.1 CSS3 Animation Cheat Sheet

The CSS3 Animation Cheat Sheet is an easy to use set of plug-and-play animations (Angular, 2015). This style sheet was used as it provided an animation which was highly suitable for the icon indicating to scroll down (the *bounce animation*). The *pulse-animation* was also used on buttons leading on the way further in the story. It was suitable because of its calm demeanor; it made the buttons stand out but did not steal too much attention.

7.5 Architecture

The prototype was, as mentioned, a functional single page web application using the AngularJS framework. The architecture of the prototype is illustrated in Figure 7.1, and will now be explained.

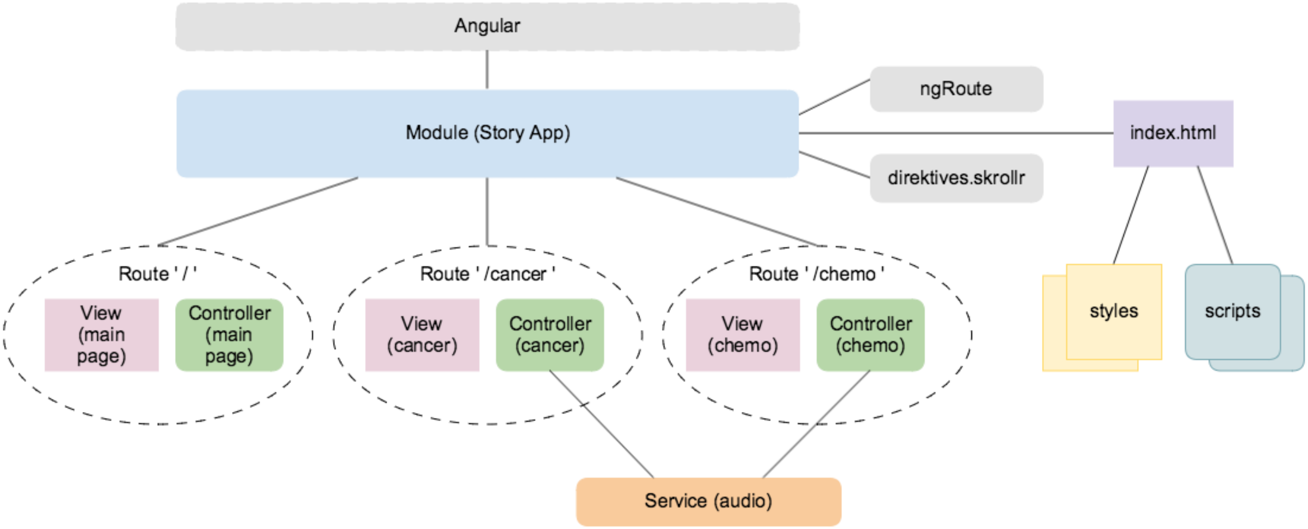


FIGURE 7.1: The architecture of the prototype using the AngularJS framework

The prototype had one module, *Story App*. The module could be though of as a container for the different parts of the application (controllers, services, directives etc.) (Google, 2015b) . Google (2015b) recommend having a module for each feature. Since this was a rather small application, only a single module was made. One of Angular's built-in modules, *ngRoute*, was injected into *Story App* to enable defining routs for the different views with their controllers, as seen in Figure 7.1. Here three pairs of views and controllers are shown, but since each page in the story had its own view and controller, there were really nine pairs. The views contained HTML elements, which were put into the index.html-page when their route/path were used. This is how the AngularJS framework supported the single-page functionality. The logic for each view was kept in its belonging controller which communicated with the view through data-binding, named *scope*. Google (2015d) defines scope as an object which operates as the glue between controller and view. Data defined in scope was accessible both from the view and the controller. And changes made to scope were automatically synchronized in both locations.

For functionality that is utilized by several controllers, services could be made. The service *Audio Service* was therefore constructed. This feature was used by every page which plays audio; all except the *main page*. To synchronize playing of audio tracks and the narrator's image, to make image moving when talking or still otherwise, *root scope* was used. Every Angular-application has one single root scope, and all other scopes are its descendants (Google, 2015c); they all have access to it. This way, the right image (determined by the Audio Service) could always be accessed anywhere in the application.

The index.html file held all paths to style sheets and scripts (libraries, controllers, services and directives). All had to be registered here to be accessed. The module also got skrollr.directive injected, which enabled the use of Skrollr (see Section 7.3.1) in the AngularJS application.

Chapter 8

Evaluation

It was considered that children who have had cancer were the ones who could give the most valuable feedback of the prototype because of their knowledge and insight into the problem area. The prototype had to be approved by professionals, before it could be tested with children (see Section 3.7). This chapter will present the two evaluations done; professionals evaluation and usability tests. Results from the pilot study for the usability tests will also be presented briefly.

8.1 Health Care Professionals' Evaluation

The health care professionals participating in the evaluation were the ones interviewed at project start. All the professionals thought it was safe to test the prototype with children. Wojcik could not give her approval, however, as all approvals to test with children had to go through the department (D. M. Wojcik, personal communication, 10th March, 2015). In addition to their opinions about the prototype being safe, all gave some valuable feedback on the prototype as well.

Pros Straume liked that the main figure was neutral (M. Straume, personal communication, 16th March, 2015). Wojcik mentioned that she liked the color and the voice. She said it was a pleasant experience to go through the story, and thought the story presented cancer in a way that was not scary (D. M. Wojcik, personal communication, 10th March, 2015).

Cons Straume (M. Straume, personal communication, 16th March, 2015), Berland (V. F. Berland, personal communication, 11th March, 2015), and Bøe (M. Bøe, personal communication, 4rd March, 2015) all thought some words were too difficult for children. Words mentioned were *harmony* and *oxygen*. Berland also suggested to have a more open ending, telling that the children should ask parents, physicians, nurses or others if they had any questions after going through the stories (V. F. Berland, personal communication, 11th March, 2015). The story says "one may have to go to the hospital several times". Since one usually has to go to the hospital more than once, Bøe thought the sentence should be changed to: "usually one have to go to the hospital several times". Bøe also suggested to have the narrator talk first, then tell the user to scroll down. She also thought it was a bit confusing that the head of the main character was moving when it was talking (M. Bøe, personal communication, 4rd March, 2015).

8.2 The Pilot Study

Before the usability tests, a pilot study (see Section 3.4.1) was conducted. To best simulate the main study, doing the pilot study with a child would be most valuable. Since there was no possibility to include a child at this time, role play (see Section 3.4.1.1) was used. The pilot study was very helpful in that it uncovered several issues. Quite few of the questions needed to be formulated in a more child friendly way. It also uncovered some practical issues like the importance of having the recording program ready and cleaning the desktop to avoid distraction. Some difficulties were also found in asking about user experience. How do one explain *hope* to a child? It was therefore decided to use images instead of words to define user experience. This technique is taken from the method Anticipated eXperience Evaluation (AXE) (see Section 3.4.2.3).

8.3 Usability Testing

The goals of the usability testing were to get an indication of whether the prototype had potential to be a good tool for conveying cancer diagnoses to children or not, and to identify problem areas in the prototype's interaction design. For this, measuring usability and user experience goals were important, as they are essential in interaction design (Rogers et al., 2011i). In more detail, the usability testing should seek to get information about the following aspects:

- The children's thought about the prototype
- Children's understanding of cancer when receiving the diagnosis, and the possible benefit from a digital storytelling in this regard
- Degree of fulfilled user experience goals
- Degree of fulfilled usability goals
- Needed improvements of the prototype

To get information about these aspects two methods were used, observation (see Section 3.4.2.1) and interviews (see Section 3.4.2.2). At first the testers were introduced to the prototype, and then they were asked to go through the stories. Their actions on the screen were recorded. Afterwards they were interviewed. Firstly, they were asked to retell what was special about a cancer cell; to capture what they remembered. Then they were asked what they though about computers and games to find out if they enjoy the technology on a regular basis. Further they got some questions about the prototype and it's content, and a few questions related to the process of receiving a cancer diagnosis. At the end they were asked to define their user experience in the scope of the user experience goals (see Section 4.4.3) through images. This was done with the method, AXE (Section 3.4.2.3).

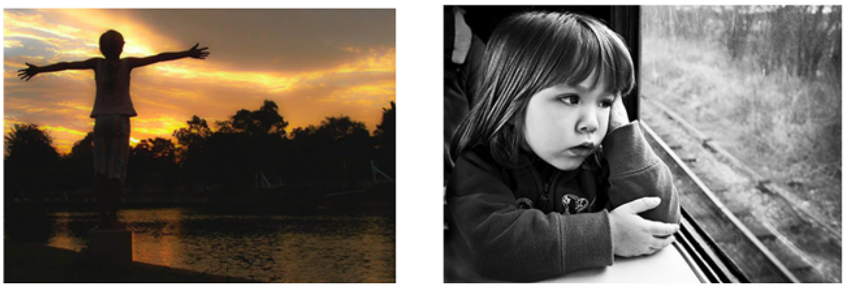


Figure 8.1: Left: hope (by Luis G. Leme, via Flickr - Creative Commons, changes done)
Right: without hope (by Stuart Richards, via Flickr - Creative Commons)

The images chosen is shown in Figure 8.1 and Figure 8.2. Figure 8.1 shows the contrasting images regarding hope, where the left image is the one illustrating hope, and the right image is illustrating hopelessness. The images for the second usability goal are showed in Figure 8.2, where the left image is illustrating safety, and the image on the right is

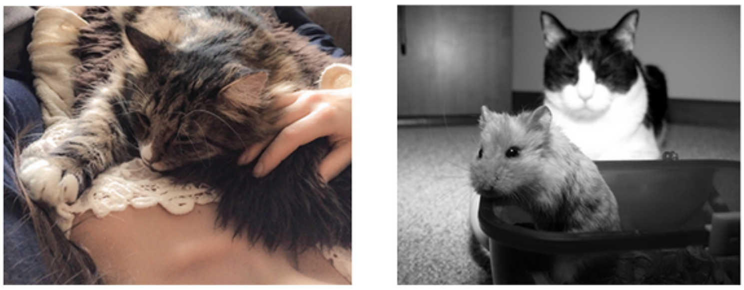


Figure 8.2: Left: safe (by Maiken B. Fjellanger)
Right: unsafe (by frankieleon, via Flickr - Creative Commons)

illustrates feeling unsafe. The third usability goal, which is about being able to relate to the main character, was measured with a question regarding what they thought about the character. All the interview-questions can be viewed in Appendix G

8.3.1 The Child Participants

The process of finding children with the needed criteria to test the prototype was not an easy process due to sensitive personal data. However, four interested families have responded positively. According to Virzi (1992), approximately 80% of the usability issues will be uncovered after only five subjects. This indicates that the results of the usability test will be valuable, despite having few participants. Regarding representative selection, this could not be taken into consideration due to the limited availability. One of the families could not participate in the laboratory because of personal reasons. This child did instead watch a video (screen record) of the prototype, and answered the interview questions she was able to answer from home with assistance from her father. To avoid misunderstandings, her interview was adjusted to having written questions regarding user experience instead of images. This evaluation can be found in Appendix I. The three remaining children took part in the usability tests in the laboratory environment, accompanied by one of their parents. The transcripts can be found in Appendix H. Here are the basic demographics of the participants:

T1: boy, 12 years.

T2: girl, 12 years.

T3: girl, 14 years.

T4 (from home): girl, 9 years.

8.3.2 Results of Usability Tests

To analyze the interview transcripts, the technique used was Categorizing data (see Section 3.5.2 for description), which proved to be helpful during the data gathering process. To ease the process, the tool NVivo (QSR International Pty Ltd, 2015) was used this time.

The screen records were thoroughly watched when problems identified were noted. These notes, together with the notes taken during the observation were studied. This section will present results according to the four first aspects mentioned in Section 8.3: *The children's thought about the prototype* (Section 8.3.2.1), *Children's understanding of cancer when receiving the diagnosis, and the possible benefit from a digital storytelling in this regard* (Section 8.3.2.2), *Degree of fulfilled user experience goals* (Section 8.3.2.3) and *Degree of fulfilled usability goals* (Section 8.3.2.4). The last aspect, *Needed improvements of the prototype* (Section 8.4), will be presented in next section, as this takes the comments from the professionals into consideration as well.

8.3.2.1 Children's Thoughts

Going through the story T1, T2 and T3 all thought it went well to use the prototype, T2 said that it was instructive and T3 said that it was fun.

Likes and Dislikes When the testers were asked if there was anything they did like about the prototype, T2 answered that she liked the ability to click on things, T3 said she liked the characters, T1 uttered "I think it was just fine", while T4 did not mention anything. Regarding dislikes, however, only T4 had some comments. She did not like the dialect in the prototype, which is *North Norwegian*, she wanted the local dialect *Bergensk*. She also said she thought the characters were odd.

Story Script T4 and her father also gave some critique about the story script. They mentioned that it is difficult to meet all needs. For some children, this story would probably be enough, but most likely not for all. Some would want more information, T4, for example, would like to learn more about the different cancer types. Another critique was that the story gave the impression that chemotherapy makes one healthy, which not always is the case. T4 has incurable cancer. They mentioned that even small children get relapse, and some die. They recommended to rephrase the script to say that chemotherapy might make one healthy.

8.3.2.2 Receiving of Cancer Diagnosis

Difficult to Understand All of the children thought it was difficult to understand what cancer was when they received the diagnosis. T3 and T4 expressed that they were very young at the time, both only four years old.

Using Prototype to Understand T1, T3 and T4 thought that it might have been easier to understand cancer if they were introduced to this prototype at that time. T1 looked a little bit unsure when answering, it might have been a difficult question for them to answer. T2 did not get the question by mistake.

Learning When they were asked how they learned about cancer, T1, T2, and T3 answered that they used the book *Kjemomannen Kasper* (see Section 2.5.1). While T4 was told about it. T2, who got the disease at the age of four expressed her liking of the book and thought it was a good way to learn about the disease. T1, who were a few years older when receiving the diagnosis, apparently did not like the book as much thinking it was difficult and boring. His parent also mentioned that T1 had thought the book was childish at the age of 10; he had been embarrassed when they were to tell his class about cancer using this book. T1's parent therefore thought this digital storytelling would capture the children of this age better since it was more modern. When the testers were asked whether they would like to learn about cancer through a book or a game (digital storytelling) like this, they all answered that they would prefer a game.

Computers and Games The children were also asked their opinions about computers of different types, and games. Regarding use of computers, T1 and T2 answered that they though it was fun, T3 said she used it often and thought it was all right, while

T4 said she liked iPads best. Concerning games, T2 and T4 said that they often played games, T1 confirmed that he liked doing it, while T3 did not play so much, but rather used other applications like the image application Instagram.

Difficult Emotions The testers were also asked if they remembered if the physician said anything about difficult emotions when they received the diagnosis. None of them did remember this, but all, except T2, thought it would be good to learn a little about difficult emotions when receiving the diagnosis. T2, who disagreed, gave the explanation that she did not want to know in advance if she was going to be sad.

8.3.2.3 User Experience

Hope Regarding the user experience goal, *hope*, T1, T2 and T3 all chose the image representing hope. T4 who evaluated from her home, on the other hand, who got questions about if she felt hopeful answered “No”. She also wrote that the lack of hope was due to knowing what she had could not be cured (incurable cancer).

Safety T1, T2 and T3 all choose the picture illustrating safety. T4, on the other hand, answered “No” to whether the story made her feel safe.

Relatedness The last user experience goal about the user being able to relate to the main character, also follows the same pattern. T1, T2 and T3 did all enjoy the main character. T1 and T2 said that it was funny, while T3 said that all the characters in the story were adorable. T4, however, thought the characters in the story were odd.

Other At the first two tests, one extra observer joined to observe the children while using the prototype. They both often had indications of suppressed smiles, but were probably tens due to they having to perform in front of three adults. Another interesting observation was that T1 answered “Yes” to the narrator, when he asked the question “Can you see it?”. These observations might be indications of user experiences like *fun* and *engagement*. In addition experiences like *instructive* (T2) and *fun* (T3) have been expressed, as mentioned in Section 8.3.2.1, paragraph: Going Through the Story.

8.3.2.4 Usability

Effectiveness The main goal of the application is to educate children. To test how well the prototype is doing this, the testers were asked a control question to see what they could remember from the story. The one who tested from her home did not receive this question because she would be able to watch the video again to answer the question. The question was: “What is special about cancer cells?”. T1 answered “They are negative”, T2 said “That they can hide, and that they did not care about the others”, and T3 said ”It was sour cells, or something. Or bad. I don’t remember exactly”. The results show that they all remember correctly, T2 in more detail than the other two.

Utility To find out if the prototype provided the right kind of functionality the screen records were the main source of information. The recordings revealed that the ability to click on things obviously was an issue. T3 seemed to have difficulties in knowing what to click on and what not. She asked if she should click on the cancer cells. She also hovered the cursor over one of the *emotions*-buttons in the emotions-story, but suddenly changed her mind before clicking and clicked on the *next*- button instead. She probably doubted if they were clickable. T1 also seemed a little bit unsure whether to click on all the cells at the first page, or to go further to the next page when the narrator said so. He also had some troubles making right mouse button clicks four times during the test, but he managed to get out of them by himself. T2, on the other hand, did not seem to have any difficulties knowing what to click on and not. She had also uttered her liking towards the ability to click on things, in the interview.

The screen recordings also revealed that the scrolling functionality was troublesome. All the testers had some kind of trouble with the scrolling. The details of these troubles will be presented in the following paragraph. Difficulties with scrolling were also articulated. On a question about if the children could think about something that would make the story better, T3 suggested automatic scrolling. On a question regarding the scrolling, T1 mentioned that he found it a little confusing. His father than asked him if he would prefer having the narrator talk first and then tell him to scroll down. T1 agreed upon that.

Learnability To find out if it was easy to learn to use the prototype, the screen recordings were studied. Everything seem to be intuitive, except for the click and the scroll functionalities. While the click functionality did not seem to have a learning curve, the scroll functionality did.

T1 and T2 seem to be confused with the scrolling in the beginning. T2 did not understand what to do in the beginning of the first page and was shown how to scroll. After this she seemed to understand it fully. She did even explore scrolling up and down as the narrator spoke. T1 did not understand that he should scroll down at the second page. He stood still and listened to the narrator, and when the narrator was finished and told to go to the next page, he did not find the *next*-button since he had not scrolled down. He asked what to do and received the hint to scroll down. At the third page he seemed to have understood the functionality. T3, on the other hand, did not understand the scrolling until the last page (page 8). She stood still at the top of every page (except the last) until the narrator had finished talking, then she scrolled down. She even stood still at pages where the picture was empty, and when the narrator said to scroll down. At the last page she started scrolling simultaneously as the narrator spoke. She also uttered that she finally understood the functionality at the last page.

8.4 Improvements Needed

All summed up, the problem areas identified through the evaluation in it's whole are following presented.

Scrolling Scrolling seemed to be the biggest usability problem is the prototype. The possibility to scroll freely did not apply well to most of the children who tested the prototype in the laboratory (two out of three). Bøe did also express dissatisfaction towards this solution. Both she (see Section 8.1, paragraph: Cons) and T1's parent (see Section 8.3.2.4, paragraph: Utility) did mention the solution to clearly separate when to scroll and when to listen. Another solution suggested by T3 was automatic scrolling (see Section 8.3.2.4, paragraph: Utility). However, the scrolling functionality did have a learning curve (see Section 8.3.2.4, paragraph: Learnability). This could therefore be a topic for discussion.

Clicking As T1 and T3 did seem to have difficulties in knowing what to click on and not (see Section 8.3.2.4, paragraph: Utility), clickable elements should be distinguished from the other elements. A possible solution is to make them fade in and out as the *next*-button, as seemingly nobody doubted the *next*-button being clikable.

Story Content As mentioned by the professionals (Section 8.1, paragraph: Cons) words difficult to understand by children, should be reformulated, like *oxygen* and *harmony*. Being more honest in the information is also important. This entails being more clear on that one most likely needs to go to the hospital several times (suggested by Bøe in Section 8.1, paragraph: Cons). The story should also express that chemotherapy might make you healthy, not indicating that it will make you healthy (as suggested by T4 and her parent in Section 8.3.2.1, paragraph: Story Script). An open ending, suggested by Berland (Section 8.1, paragraph: Cons), could also be considered. Bøe's statement about the moving head of the character being confusing (Section 8.1, paragraph: Cons), was not taken into consideration since none of the children had indicated negative attitude towards this. T4's statements about the characters being odd and that she did not like the dialect (Section 8.3.2.1, paragraph: Likes and Dislikes), were not considered at this point either, as the three other children had not utter any dissatisfaction regarding these aspects.

User Experience Three out of four gave indications of all the user experience goals being met. As the one child who was asked questions instead of shown images gave negative answers, the methods' possible influence on the answers should be discussed. Regarding the user experience goal *relatedness*, whereby all received a question, the same child, who also tested from her home, was the only one who was negative. The test environments possible influence on the children's answers should therefore also be considered.

Chapter 9

Discussion

In this chapter different aspect of the research will be discussed, such as the methods and methodologies used, the prototype and the research questions. Lastly, the results according to design science research will be shortly summarized.

9.1 Methods and Methodologies

The main methods and methodologies used throughout the research process are presented in detail below.

9.1.1 Interview

Interview was used both in the initial process; for gathering information from professionals (see Section 3.2.1), and in the evaluation process with children (see Section 3.4.2.2). Using interview with professionals proved to be very useful, as all of them provided a lot of information. The chosen structure, semi-structured interview, supported this very well in that it opened up for new topics. The qualitative approach allowed for learning and deep insight into the domain space. Having chosen a quantitative approach instead would probably not have provided the same depth of understanding.

Interviews with children, on the other hand, did not provide much depth; since their answers were very short and to the point. In this case, a longer questionnaire with concrete questions might have been more useful for getting more appropriate data. In this way, one could formulate different questions regarding the same topic, to get more data regarding same issues. This would have been useful because some of the children sometimes looked unsure when they answered. A question most of them seemed unsure about, was the one about whether they though it would be good to learn about difficult emotions when receiving a cancer diagnosis. In the wake of the interviews, an understanding about this being an unclear question has risen. The children might not have understood the possible benefits of this information. This should probably have been explained in more detail before the question was asked.

Using an online survey, in form of a questionnaire, together with a video of the prototype could have been a good way to gather useful additional data. Using this approach, it would have been easier to get a greater data basis, regardless of the graphical location. The results of the evaluation, also show that the child who tested from her home, was more critical than the ones participating in the usability tests at the test laboratory. This might indicate that that children dare to be more honest and critical when being home in a safe environment, rather than in a laboratory with strangers. As the data basis is limited, one should not over-conclude on such findings. The differences could be explained with varying preferences. The opinions from the one who evaluated from her home may also be affected by the fact that the story did not take into consideration children in her situation, incurable cancer, as she was the only one with this condition. She mentioned that this had an effect on her user experience (see Section 8.3.2.3, paragraph: Hope). The differences of her only watching a low-quality screen capture of the prototype, while the other interacted with the prototype, may also have influenced her opinions. It would have been valuable to obtain more feedback from children from their homes. That would give a basis to better explain positive and negative feedback, in relation to test environment.

9.1.2 Observation

The observation (see Section 3.4.2.1) gave valuable feedback regarding the interaction design and also indication of user experiences. Using screen capture was critical, as many details would be missed without the possibility to review the process. The observation type *participant-observer*, was helpful in that all of the children asked some questions along the way and some needed hints on how to go further. However, it could be expected that children felt more stressed since they were observed. In such case they rather asked for instructions and hints to do the right thing and answer correctly. The idea behind choosing the observation type *participant-observer*, was to make the children feel more relaxed. However, most of the children seemed to be shy and discomfortable by having a stranger watch them, even with the ability to ask questions along the way, in addition to having a parent next to them.

If the children were alone in the room, with their parent, they might have managed the problems they encountered by themselves; without an element of control which could be related to being observed. Even though the children were all explained that it was the system that were tested, and not themselves, two of them (T1 and T3) seemed to be afraid of doing anything wrong. It would have been interesting to see the results of observations where the children did not know they were being observed such as by hidden camera.

9.1.3 Anticipated eXperience Evaluation

Reliability and validity of the results provided by the use of Anticipated eXperience Evaluation (AXE) (see Section 3.4.2.3), can be discussed. The results show that each of the usability testers chose positive images (illustrating hope, and safety), while the one tested from her home, who got the information presented in text, answered “No” to both of the user experience goals. The methods used might have affected the answers given, but the answers might also have been given simply because of her condition (incurable cancer). The fact that the testers had to pick one of the images, might have forced them to chose one, even though they did not actually feel hopeful or safe when using the prototype. They might also have been biased to pick the image they liked the best, or simply picked the one they thought were *the right one*; the one they thought were preferred by the researcher. Children often answer what they think the adults want to hear (Docherty & Sandelowski, 1999). If they were asked whether they felt hopeful or not, and safe or not, the outcome might have been different. The outcome might also have been different if the use of a scale would have been applied to two contrasting images, which is the true use of AXE, and not the simplified version. The reason for simplifying was to make it easier for the children. Nevertheless, this might not have been the case, and should be further explored. The images chosen could also have been tested in some way before being used for more trustworthy results. A way in which they could be tested could be to show children the images and asked how they made them feel.

The placement might also have affected the answers. As discussed in the previous section, the environment may effect the level of honesty when answering the questions. Using a combination of these methods, based on both images and words, could have been interesting. This would give a more precise indication towards the effect of the specific method.

9.1.4 Pilot Study and Role Play

The use of pilot study (see Section 3.4.1) prior to the actual study, was very useful, as it had uncovered details which should be facilitated before the usability tests. If the pilot study suggested changes to the methods used in the actual study, new pilot studies, including the changes, should be done. A second pilot study, including the use of AXE (see Section 3.4.2.3), could have revealed weaknesses with this method, which might have resulted in using both methods, the text-based questions and the images.

Regarding role play (see Section 3.4.1.1), this was both a fun and engaging method to use. As the actor managed to put himself in the role of a child very well, this provided valuable feedback. If the actor had not succeeded, however, the results might have been poor. A possible risk would be that it could result in more focus on the role play than on the actual tasks.

9.1.5 Development Methodology and Prototyping

Using the simplified version of the Spiral Model (see Section 3.3.1) as development methodology worked well for this project. The model allowed for creative unfolding, as it did not restrict the process in any way. The iterative approach, with evaluation on each end, allowed for the design to develop and strengthen through each iteration. As there were few restrictions on the design and the implementation of it, it worked well to use an approach which supported exploration of creative ideas as they appeared.

Limitations to this approach would be the time aspect. It was difficult to set a due date, and hard to say how long in the process one had come. First when a satisfying design was established, one could get an indication of the remaining time aspect. With that said, using a burndown chart (see Section 5.2.4) on the side was helpful for getting an indication of how much work was left according to estimates and remaining time. The tool was also helpful in that estimates always could be changed, and tasks could be added and deleted along the way. This approach would, however, probably not work well in situations where it is important to adhere to deadlines. It would probably not work very well in a team of more than one developer either, as there was no structured plan for the implementation. A structured plan would restrict the creativity in this process, and was therefore not used. The model could, however, be used together with a more restricted plan if preferred.

The use of both low-fidelity and high-fidelity prototypes (see Section 3.3.2) were valuable. The low-fidelity prototypes was helpful in that they allowed for creative ideas to be captured fast. And the parallel prototyping of the high-fidelity prototype was very useful for setting the design ideas into a realistic context. If the evaluations were restricted to the use of low-fidelity prototypes only, not all the problems identified with the high-fidelity prototype would be exposed; especially not the technical ones. A drawback by developing a high-fidelity prototype in parallel was the extra time required. The development process might have been much faster without following this approach. Even though only small parts of the design were implemented, a lot of time was used for implementing functionality which was later discarded.

9.2 The Prototype

Different aspects of the prototype will be discussed in this section. As the age of the evaluators were in the rage of 9-14, the prototype may not be suitable for the lower age group (from five years). Further testing should be done to identify issues related to this age group. It has been observed that the prototype may be suitable for older children in spite of it's child friendly and simplistic design. Having in mind the children's thoughts about the prototype (see Section 8.3.2.1), as well as the user experiences indicated (see Section 8.3.2.3). This should, however, be taken with reservation because of the possible weaknesses of the methods used in the evaluation (see Section 9.1).

9.2.1 Technical Choices

Regarding the technical choices made for the implementation, the use of the framework AngularJS (see Section 7.2.1) could be discussed. The functionality utilized from this framework is *rooting*, supporting single page application, and *data-binding*. The prototype might have functioned just fine without being a single page application. The way the prototype is implemented now, it is not possible to move from one page to another by using the navigation buttons without JavaScript being activated. This problem would have been avoided by having the buttons pointing to another HTML-page. With that said, the playing of sound is also done with JavaScript, so the system would not have been very useful without it being activated. Data-binding is critical for the prototype to work in accordance with movement of narrator corresponding to audio tracks. However, there might be smaller frameworks supporting data-binding.

9.2.2 Design and Art Choices

The evaluation revealed some weaknesses of the design. Scroll functionality was one of them. Solutions mentioned were clear separation between when to listen and when to scroll, and automatic scrolling (see Section 8.4, paragraph: Scrolling). However, the usability tests did also indicate a learning curve of this functionality (see Section 8.3.2.4, paragraph: Learnability). When the user first had understood the functionality, it worked well. They all seemed to understand the functionality during the test, some faster than others. T2 understood it at the very first page, T1 at the third page and T3 at the last page (page 8). This might indicate that the functionality could work well if the application would present a demo of the usage first, making the user practice using the functionality.

Knowing what to click on and not was also a problem detected through the evaluation (see Section 8.4, paragraph: Clicking). The problem only applied to the icons which were not clearly differentiated from the background. All clickable elements should therefore be somehow differentiated from the background. Regarding clicking, one of the testers did make some right button mouse clicks (see Section 8.3.2.4, paragraph: Utility). He managed to undo them himself, but this could be a problem with younger users. However, research have fund that most of the children in a group of four and five year olds used left mouse button exclusively (Hourcade, 2008). This observation could therefore be an exception, and might also be due to using an unfamiliar computer.

The choice of art was received well by the majority of the children; only one was presumably dissatisfied in that she uttered that the figures were odd. Therefore, it could be concluded that the art was suitable for the story. To be more certain about this, having children take the role as *informants* (see Section 2.4.2.3) throughout the design and development process, would have been helpful. This way the children could have been presented with the art ideas, and give their feedback to whether they liked it or not. The practical limitations such as timeframe of the thesis and availability of the small patients where the restraining factors which could be overcome in a bigger project with more resources.

9.2.3 Content

Whether the story contains sufficient information or not is difficult to say. As the project ambition could not be to develop a fully usable tool, but to get an indication of the usefulness of such a tool, diving into the details of the content would cross the lines of the project scope. With that said, the information presented is based upon the reflections and ideas of health care professionals who have fully approved of it as being safe to use by children.

However, some critical weaknesses of the content were found, and should be corrected. Corrections related to clarity and honesty are highly important. The story should be more clear on that one often needs to go to the hospital several times, and that chemotherapy *might make* one healthy. The story should be true on to the fact that the therapy is not simple and should not mislead the conclusion that the outcome of the treatment is always positive. This study has shed light on the importance of honesty according to children with incurable illness, to avoid making them feel left out. There is a fine balance between giving hope and being honest. Both are equally important.

The choice of including difficult emotions was well received with the professionals (see Section 4.3.3.2). Most of the children also though it would be helpful to learn a little about difficult emotions at the time of receiving a diagnosis. None of them seemed to remember whether they received information about this at the time of receiving the diagnosis (see Section 8.3.2.2, paragraph: Difficult Emotions). There was, however, one child who did not want to learn about difficult emotions at this stage. She explained she did not want to know it in advance if she were to experience difficult emotions in the future (see Section 8.3.2.2, paragraph: Difficult Emotions). Having the stories divided into two different parts might therefore be helpful. That would allow to show the story about emotions to the child at a later time when those difficult emotions would unfold.

9.3 Answering the Research Questions

As mentioned in the introduction, this research project has two research questions (see Section 1.1). One practical and one technical. These are following discussed.

9.3.1 Practical Research Question

How will digital storytelling function as a tool to enlighten children about cancer upon receiving a cancer diagnosis?

To answer this research question, data gathered from health professionals and from the evaluation will be considered. All the professionals formulated in different ways that digital storytelling would be relevant due to children's knowledge and use of technology today (see Section 4.3.3). As mentioned in Section 2.1.3, and by Straume in Section 4.3.3, getting information is one important mastering technique in difficult situations. It is said to reduce difficult emotions like uncertainty and tendencies for depression (Van Dongen-Melman et al., 1986, referenced in Fottland, 2004), as well as anxiety (M. Straume, personal communication, 10th November, 2014). If the tool can help children understand the disease better, if only a little, it will be of interest.

All the children interviewed answered that they thought it was difficult to understand what cancer was when they received the diagnosis. On a question about whether they thought it would help them understand the disease better if they had been presented with a digital story like this, three of them said yes (The last one did not get the question by mistake). One of the children looked a little bit unsure, so it might have been difficult for them to know this. As there were some difficulties with the prototype, it might not have been an ideal tool at its present stage, but it could easily be further developed. As the research question is more general, and does not focuses on one specific digital storytelling application, the prototype had a purpose to provide an indication of the usefulness of such an application.

Taking on the more general perspective, all the children were somehow familiar with technology; all expressed that they used either computers or tablets. Regarding games three said they either did it often or liked it, while the oldest of them preferred other applications, like the image application Instagram. These findings do confirm to some degree the health professionals insight into children's knowledge and use of technology today (see Section 4.3.3). The relevance of this kind of learning tool is therefore present and clear. This is further enhanced by the fact that all the children said that they would prefer to learn about cancer from a digital storytelling/game rather than a book. In addition, one of the testers had found the book *Kjemomannen Kasper* (see Section 2.5.1) to be difficult and boring at a young age, and too childish at the age of 10 (see Section 8.3.2.2, paragraph: Learning). He found it humiliating when his class should learn about his disease using this book. His father thought a more modern tool, like digital storytelling, would suit the older children better.

Based on these findings it could be implied that a digital storytelling application seems to be an appropriate tool for educating children about cancer when receiving a cancer diagnosis. As the findings show that children both are familiar with this kind of technology, and prefer learning by game over learning from book, this type of technology might function well for communicating on their level. According to Bøe's experiences, children get easily distracted and unfocused during conversations about cancer (see Section 4.3.3), so she believed a tool like this might help capture their attention. As the children all seemed focused when using the application, this could prove her point. The findings of possible user experiences like *fun* and *engagement* (see Section 8.3.2.3, paragraph: Other), may also support this. The results also show that all the children remembered and could render particularities about cancer cells to some degree. If they could remember the information better by getting it from a digital story application than from other mediums like a book, or a conversation, can not be concluded on behalf of this study. The evaluation did not provide any feedback on this particular assumption. The possible value of the digital story application, found through this research, is therefore based on the statements by the children and the health care professionals, as well as the perception of children's experience of the prototype.

9.3.2 Technical Research Question

How can the interaction design in a digital story application be made to optimally support intuitive interaction for children in the selected age group?

For a digital story application to be well received, the interaction design is important. There are countless ways to take in relation to design. This project used a set of *design principles* (see Section 2.3.3) in addition to the *usability goals* (see Section 4.4.4) established for the project as main guidelines for the interaction design. To answer the technical research question the findings of the evaluation will be considered. Even though the application is designed to be used by children all down to five years old, the group of testers in the laboratory were in the age rage from 12 to 14, so the answer can only speak for children in this age group.

The usability goals was highly considered throughout the development process. As they were perceived to be more vague than the design principles, it was not as straight forward to facilitate for them as with the design principles. The result of the evaluation also revealed this, as the main issues of the prototype concerned the usability goals *utility* and *learnability* (discussed in Section 9.2.2). This research therefore suggest that it is highly important to thoroughly faciliate for usability goals when designing a digital story application.

Regarding design prinsiples, findings of the evaluation show that the design principle, *affordance*, is critical in a digital story application. Even though the principle was taken into consideration, it was not done thoroughly enough with the clickable images. This problem area both covers the usability goal, *utility*, as it regards lacking functionality (Rogers et al., 2011i), and the design principle, *affordance*, since it concerns the lack of attributes making it intuitive to use (Norman, 1988, referenced in Rogers et al., 2011i). Clickable images should give a visual hint about them being clickable, even though the narrator in the story explains that this is the case.

The results of the usability tests also show that concreteness is important in the aspect of the usability goal, *utility*. Having concrete instructions on what to do, either listen or scroll, or optionally just watch (automatic scrolling) were the expressed preferences by two out of three children. *Concreteness* might therefore be a goal in such applications. *Concreteness* does, however, not necessarily mean changing the functionality as it is. It might also be supported by having a demo teaching the functionality to the children before they start going through the stories. This solution is based on the discussion of the learning curve of the scroll functionality (found in Section 9.2.2). The concreteness of them being instructed on how to use the application might be sufficient.

To answer the research question, following a combination of the general design principles presented in Rogers et al. (2011i) and design principles for children presented by Hourcade (2008), as well as thoroughly facilitating for usability goals with focus on making the interaction as concrete and evident as possible, seems to support intuitive interaction design in digital story applications for children in the age of 12-14. These findings should, however, be further tested with all these aspects considered in the design. Other difficulties may emerge with changes done to support higher *affordance* and *concreteness*.

9.4 Results According to Design Science

The design science approach was utilized in this project as the guiding principle for the whole project. Following the guidelines by Hevner et al. (2004) for doing design science research, was very helpful for securing the holistic structure of the research conduct. The final results of the research, following these guidelines are: a functional prototype developed and evaluated using well defined methods. The technical details of the prototype are explained to the extent to which it can be developed. Results are also given in the form of answers to relevant research questions. These regards the advantage of a digital story application for informing about cancer diagnosis, and critical findings for interaction design supporting intuitive interaction in such an application for children in the age group that the story tool was evaluated with. The thesis is also written in a way that is receptive for both technology-oriented and management-oriented audience.

Chapter 10

Conclusion

This thesis has shed light on the area of communication of cancer diagnoses to children. As children today utilize technical devises from a young age, the thesis wanted to get an indication on whether technology could be used to help children learn about cancer in the form of a digital storytelling prototype. How the interaction design could support intuitive interaction in such an application was also a focus area of research.

Data gathered from professionals possessing knowledge about children with cancer was used to establish requirements regarding the content of the story, as well as to define user experience goals. The prototype was further developed in a creative process through iterations following a set of design principles in addition to the user requirements. When the prototype was finished, it was evaluated through usability tests with children who have or have had cancer. The usability tests entailed observation, when children were observed using the prototype, and an interview, where they were asked different questions regarding the prototype and how they experienced its relevance in connection to cancer diagnosis.

The results gave an indication that digital storytelling could be helpful for children in the process of receiving a cancer diagnosis. It seemed to capture children's attention, increase their understanding of cancer, and it was the their preferred way of learning. According to the interaction design, the results showed that it was useful to carefully follow design principles. *Affordance*, was a principle which was not thoroughly facilitated for here, which resulted in design weaknesses. Another major aspect found to be important to consider in relation to interaction design in digital story applications, was *concreteness*. These are points of improvement.

This approach has provided a good framework for development and has given a functional artifact that could be evaluated. The artifact was well received by children and professionals working with cancer sick children. The findings in this research indicate that the need for such technology is existing.

10.1 Future Development

Future development concerns resolving the shortcomings in the prototype, found through professionals evaluation and usability testing. These are: changing difficult medical words to more child friendly words, changing sentences that could be misinterpreted, strengthen *affordance* and *concreteness* (according to scrolling and listening). Adding a more open ending, suggested by Berland (see Section 8.1, paragraph: Cons), could also be done.

To make the application more available some additional technical refinements are needed to support the most used web browsers. For even wider use, the design could be developed to be responsive; to support use on different devices and screen sizes. Having support for use on iPads and tablets would make the use of the application more flexible. Use on touchscreen would also probably benefit the youngest children, due to its concrete nature as mentioned by Hourcade (2008).

The application could also be further developed to include more stories. Siblings of cancer sick children was a topic both mentioned by Bøe and Berland (see Section 4.3.3.7, paragraph: Siblings). A story about, and for siblings, would therefore be interesting.

Testing the prototype with children as young as five years should also be done to identify design issues related to the youngest target users of the tool.

Appendix A

Informed Consent Form: Interviews

Forespørsel om deltakelse i forskningsprosjektet

"Digital historiefortelling som verktøy for formidling av kreftdiagnoser til barn"

Bakgrunn og formål Dette forskningsprosjektet er en del av et mastergradsstudie ved Institutt for informasjons- og medievitenskap ved Universitetet i Bergen. Forskningsprosjektet søker å svare på hvorvidt digital historiefortelling vil kunne fungere som formidlingsverktøy for kreftdiagnoser for barn. Prosjektet kan sies å ha to fokusområder; et psykologisk med fokus på tilrettelegging av historiefortelling for barnevennlig læring, samt et teknisk med fokus på interaksjonsdesign.

For å kunne utforme en best mulig historie blir leger, psykologer og andre aktuelle fagpersoner intervjuet angående det faglige. Disse utvelges basert på deres stilling samt anbefalinger fra eget nettverk.

Hva innebærer deltakelse i studien? Deltakelse i studien innebærer å delta i et fagrettet intervju på om lag 30 minutter. Alle intervjuer vil tas opp på lydbånd. Det vil også føres skriftlige notater underveis.

Hva skjer med informasjonen om deg? Alle personopplysninger vil bli behandlet konfidensielt. Det er kun student og veileder for prosjektet som har tilgang til personopplysninger. Personopplysninger (både skriftlig og i form av lydopptak) lagres ikke direkte med navn, navn vil byttes ut med et referansenummer. Navneliste med koblingsnøkkelen vil lagres på ekstern lagringsenhet. På denne enheten vil ikke selve oppgaven eller annet materiale med bruk av disse referansenumrene lagres.

Deltakere i studien vil ikke kunne gjenkjennes i publikasjonen med mindre de selv godkjenner at deres navn kan publiseres.

Prosjektet skal etter planen avsluttes 1. Juni 2015. Ved prosjektslutt vil alle filer med personopplysninger slettes (bortsett fra navn på personer som har samtykket til at deres navn kan presenteres i oppgaven). Navneliste/koblingsnøkkel vil slettes og alle lydopptak samt notater ført under intervjuer vil slettes og makuleres.

Godkjenning av prototype Etter at prototypen er ferdigstilt, skal den potensielt brukertestes på barn. Av sikkerhetsmessige årsaker er det ønskelig at personer som deltar i undersøkelsen prøver ut den ferdige prototypen og oppgir sin mening om prototypen kan testes på barn eller ikke. Om det konkluderes med at den ikke bør brukertestes på barn, er tanken at psykologer brukertester applikasjonen på vegne av barna.

Frivillig deltakelse Det er frivillig å delta i studien, og du kan når som helst trekke ditt samtykke uten å oppgi noen grunn. Dersom du trekker deg, vil alle opplysninger om deg bli anonymisert.

Dersom du har spørsmål til studien, ta kontakt med

Student: Maiken Beate Fjellanger - 95267138 - maikenfjellanger@gmail.com

Veileder: Ankica Babic - 55589139 - Ankica.Babic@infomedia.uib.no

Studien er meldt til Personvernombudet for forskning, Norsk samfunnsvitenskapelig datatjeneste AS.

Samtykke til deltakelse i studien

Jeg har mottatt informasjon om studien, og er villig til å delta

____

(Signert av prosjektdeltaker, dato)

☐ Jeg samtykker til å delta i intervju

☐ Jeg samtykker til at mitt navn kan publiseres i oppgaven

☐ Jeg samtykker til å se over den ferdigstilte prototypen og oppgi min mening om prototypen kan brukertestes med barn eller ikke

Appendix B

Informed Consent Form: Usability Tests

Forespørsel om deltakelse i forskningsprosjektet

"Digital historiefortelling som verktøy for formidling av kreftdiagnoser til barn"

Bakgrunn og formål Dette forskningsprosjektet er en del av et mastergradsstudie ved Institutt for informasjons- og medievitenskap ved Universitetet i Bergen. Forskningsprosjektet søker å svare på hvorvidt digital historiefortelling vil kunne fungere som formidlingsverktøy for kreftdiagnoser for barn. Prosjektet kan sies å ha to fokusområder; et psykologisk med fokus på tilrettelegging av historiefortelling for barnevennlig læring, samt et teknisk med fokus på interaksjonsdesign.

Når prototypen er ferdigstilt vil den brukertestes på barn om dette godkjennes av psykolog. Barn vil velges ut via pasientregistre. Om dette ikke lar seg gjøre, vil barn rekrutteres via skole.

Hva innebærer deltakelse i studien? Deltakelse i studien innebærer å prøve ut den ferdige prototypen og deretter svare på noen enkle spørsmål for å finne ut hva barnet synes om prototypen (om lag 30 minutter totalt).

Skjermbildet fra brukertesten vil tas opp og intervjuet vil tas opp på lydbånd. Det vil også føres skriftlige notater underveis.

Eventuelle ulemper ved å delta En ulempe ved å delta vil kunne være at det er et følsomt tema, som gjerne kan oppleves vanskelig for noen. Det kan dog nevnes at fagpersoner som har blitt intervjuet i sammenheng med utforming av historien har sett over prototypen og gitt sin godkjenning på at den kan brukertestes med barn.

Hva skjer med informasjonen om barnet? Alle personopplysninger vil bli behandlet konfidensielt. Det er kun student og veileder for prosjektet som har tilgang til personopplysninger. Personopplysninger (både skriftlig og i form av lydopptak) lagres ikke direkte med navn, navn vil byttes ut med et referansenummer. Navneliste med koblingsnøkkelen vil lagres på ekstern lagringsenhet. På denne enheten vil ikke selve oppgaven eller annet materiale med bruk av disse referansenumrene lagres.

Ingen deltakere i studien vil kunne gjenkjennes i publikasjonen.

Prosjektet skal etter planen avsluttes 1. Juni 2015. Ved prosjektslutt vil alle filer med personopplysninger slettes. Navneliste/koblingsnøkkel vil slettes og alle lydopptak samt notater ført under intervjuer vil slettes og makuleres.

Frivillig deltakelse Det er frivillig å delta i studien, og barnet kan når som helst trekke seg uten å oppgi noen grunn. Dersom barnet trekker seg, vil alle opplysninger om barnet bli anonymisert. Om barnet ikke vil delta i studien, eller senere velger å trekker seg, vil dette ikke ha noen innvirkning på barnets forhold til behandlere og/eller lærere.

Dersom dere har spørsmål til studien, ta kontakt med

Student: Maiken Beate Fjellanger - 95267138 - maikenfjellanger@gmail.com

Veileder: Ankica Babic - 55589139 - Ankica.Babic@infomedia.uib.no

Studien er meldt til Personvernombudet for forskning, Norsk samfunnsvitenskapelig datatjeneste AS.

Samtykke til deltakelse i studien

Jeg har mottatt informasjon om studien, og mitt barn

____

(Barnets navn, blokkbokstaver)

forstår hva deltakelsen innebærer og ønsker å delta i studien.

____

(Signert av foresatt, dato)

Appendix C

Interview Transcript: Wojcik

Interview: Digital storytelling as tool for conveying cancer diagnoses to children

Dorota Malgorzata Wojcik has a PhD in medicine, with specialization in pediatric oncology from Poland. She has worked all her life with children's oncology, and is currently employed at Haukeland University Hospital.

Tuesday 21st October 2014 at 16:45 - Pediatric Clinic at Haukeland Univerity Hospital

Interviewer (M): Maiken Beate Fjellanger
Interviewee (D): Dorota Malgorzata Wojcik

M: So, the first question is: do you think it is OK that your name is used in the master thesis or do you prefer to be anonymous?
D: Difficult to say, but if it is better for you, you can use my name. It is OK.
M: OK. I can also send you the transcribed interview.
D: Yes, OK. Mhm.
M: Mhm. So what education do you have?
D: All my education are from Poland, because I am coming from Poland, and I finished the medical university. And there I was working all my life with children's oncology. So I have specialization in the children's oncology, in the children's chemacology from the paediatrics.
M: OK, great.
D: And I have PhD.

M: Yes, em.. I will just check that everything is OK (With the recording device). I think so. In which way do you convey cancer diagnoses to children?
D: It is difficult to answer very shortly because that depends on the type of cancer, but maybe the most it depends on the age of children.
M: OK.
D: So the smaller children they couldn't communicate, they couldn't understand this. They are very,

very small children, because we are treating children from they are new borne until, nowadays, until 15 years of age. Sometimes we have older children also. So that depends if they can communicate and... but we think that it is important that all the children get this information - that they have the cancer. Of course it is not like this: I'm coming to talk the first time with the children, and I just give the diagnosis. So we work with this process. It is a kind of process where we get help from the psychologists.

M: OK. Em, so which information do you think it is important to convey to the children that understand?
D: I think that the first information is that they have the cancer, but of course it depends also on the parents, because sometimes, not very often now a days, but sometimes parents don't want to give this information to the children.
M: OK.
D: So, first you have to ask the parents if they agree or not.
M: OK.
D: And if they not agree, you are not allowed to talk about the cancer.
M: Mhm.
D: Off course, you are working after this with the parents to change their mind, because the children are now very wise - they are looking at the Internet for films, they are talking together, they have Facebook and other things. So we think that it is better that they will get this information from the start, from when we started the treatment. No by chance somewhere (else), then the children can imagine themselves many, many things. So the best if they get this information from us, not just look for the Internet and try to find: "what is this? What for?", because in Internet they can find different, different things, not exactly fitted for them.
M: Mhm.
D: So, but if the parents agree, so the first information that we give the children that's the cancer, but we try in the first moment avoid the word: 'kreft' or cancer. So we're talking about the "svulst" (eng.: tumor), some pathologic cells, but in the final end we got to say that it's the cancer.
M: Yes.
D: Sometime it's easier, and sometimes it's more complicated, but we end it with saying that it's the cancer. And that's the most important information. I think so. But then we talk - yes, there is a lot of talks when the children come and get the diagnosis - so we talk about the diagnosis. We talk about the treatment and that depends on the age - sometimes the children are very focused what the short times, so when I can go home, when we can go back. For some children the long perspective is more important, so we talk about the treatment: They have to go get the cytostatic, and the side-effect because it is very aggressive treatment, but in the final we would like to give them some kind of optimism. And that's why we talk about the prognosis - off course not all the cancers have good prognosis - because many children's cancer have relative good prognoses, never 100%, but relative good prognoses. So we try to use this information that there is still chance. And still can beat the prognosis. Of course if there is good prognosis for the children, we say: "very good prognosis of the cancer", but it's sometimes very bad, so we say: "but still there is some percent of children which can be healthy after the disease". But the way to be healthy is quite, it's the tough way because it's a lot of treatment, it's a lot of being here, and the complications. So the diagnosis, the cancer, the complicated treatment, the complications, but ending with the optimism.

M: OK, very good. Em, do you use some metaphors or other things to make the information more understandable?
D: I try to, em, we have this other things to help us or nurses, but when I'm talking with the children, I try to use the simple - it does depend on the age, you know - more complicated with the older children, and with the small children quite not that complicated, but not metaphors.
M: So this presentation you talked about (magnet images) - when do you use them? Is that when they get the diagnosis or?
D: Yes, it's from the process of the getting of the diagnosis. From the beginning, yes.

M: OK. Em, do you have any thoughts around digital storytelling as a tool for conveying cancer diagnoses to children?
D: I think that it's wise to do this, because the world is now so modern and all the children looking for the iPad, or computers, or for the telephones, you know, the mobiles and the smart phones and so. I think that it would be the easiest way to show some information or to give them some information.

M: Yes, good. Em, which age group do you think will benefit the most from a digital story application?
D: I was thinking about this, so I'm thinking maybe the older children. Of course that depends on how the story will be, or look like, yes? So for the small children also.
M: Mhm, but what do you mean by small children?
D: I think they that can watch films, you know, even small children, 2-3 years old. They can look for some stories.
M: But the interaction-part, how old...?
D: If they should interact with this I think children in the school age, the first class. This group and older.
M: So, which age group do you think will need this information the most?
D: That depends how you build this information because maybe this children between for example 6 and 10, 6-11, but that depends - the older children are quite wise, so maybe it will be too boring for them to play with this. They need something more, you know. That depends how you build this. So maybe this group that can understand can play with this, and maybe not the older children.

M: OK, mhm. In a digital storytelling to inform children about cancer, what do you think about the idea about a history that presents a figure who gets a cancer diagnosis, and focuses on how it experiences it itself, and what's happening in the body? So, you get the emotional and the physical aspect.
D: Yes, I think that is very OK, but of course the way how you show this is very important, but it's OK. So you think to present somebody who just got the cancer?
M: Em, the character in the story, yes. Em, yes, so you think it will be good?
D: Mhm.

M: Do you have any other ideas?
D: I was thinking a lot about this, but you know, I have the old children, so I think that it's the best if you can ask the parents and then we have the kind of "leketerapi" here. So they play with the children almost every day, so I think that maybe they have more ideas. I was thinking that that's, if you choose some characters - so now a days you should see what's the most popular between children - I don't know

- in the films in the comics or something like this. But it should be changed after some years because they will be not so popular after some years.
M: The character?
D: Mhm.
M: How it looks like or?
D: Mhm.
M: OK.
D: Because you see for the fairy tales they are changing characters.
M: Yes, true.
D: Films and... yes.
M: So you think it is smart to look for inspiration in what's popular?
D: From somebody who's playing with children. Maybe parents and maybe this people from "leketerapi" here.

M: Yes, OK. Which cancer form will you recommend to use, and why?
D: There is a, I think, the most often cancer. And there is two most often cancer. The most often cancer from the hematologic side is leukemia, and we have different kind of leukemia, but general information is the same. So this most often children have leukemia. And for the solid tumors it's completely different. With leukemia they don't get the tumor, you know, the "svulst". For the solid tumor the most popular is the tumor in the central nervous system. So if you just will focus on one group of children, the most popular is leukemia.
M: OK.
D: And there are different kinds of leukemia, but if you choose general information that you can show for the different kinds of leukemia.
M: OK, so if we use this leukemia. What symptoms are important to have in the story?
D: The symptoms... I think that you should. I think - but you can do what you want - it's very important for the children that it is a very short story, quite simple stories.
M: OK.
D: And not very complicated stories, with different things. And then I would focus on the.. For the symptoms of leukemia. But then they are coming with the symptoms, so they know the symptoms. So maybe the symptoms or side effect of treatment, because there is a lot of side effect of treatment.
M: OK, so focus on that is stead? OK.
D: Mhm, so I think that they have to get the cytostatic and to get the cytostatic they all have to get a central venous catheter, it's a kind of Hickman catheter, so it's not giving veneflon in stead. So there is also the story and then are the complications: The vomiting, loosing the hair and this kind.

M: OK, so focusing on that. OK. Are there any special treatments or operations, which should be in the story?
D: No, I think that this, the, because all the children have this, you probably don't know what is, the Hickman catheter. It is the central line catheter, so you putting the end to the heart. And it's a small operation before we started to treat. And there is the line the catheter so we put the card by the venosystem here (pointing on the collarbone) and sometimes it's under the skin here some equipment,

so you put the needle when you want to give the medicament. You can put the needle once a week, and they keep this, and sometimes -more often for leukemia - this dren is coming under the skin and you need to give medicament and infusion, and you just put it into this dren, everything. Medicament, liquids, everything. And if you need the blood test, you also take the blood from this. So it's something they have extra here (pointing on the collarbone). It is something they have to protect. They can get local infection. Must be very careful about this, and you know, in sterile condition, change this. So I think that it's the most important thing in this situation.
M: So with leukemia there are no operations except from this one?
D: We take the bone marrow control, and the bone marrow we take usually from the hips, the posterior site. Also we take, or give cytostatic to the spinal cord. So we have the small anesthesia. They are in the beginning quite often, then not so often. They take the bone marrow in anesthesia, and take this spinal fluids and give cytostatic to the spinal cord.
M: OK, so I heard that that can be very painful?
D: It's anesthesia. The adult doesn't use the anaesthesia, and it's painful. For all the children we are using anaesthesia, so it's not painful 'cause they are sleeping, like in an operation. We have the room here for the operation, the anaesthesiologist come here and make a station. So they are sleeping, they don't feel anything, and then we make these procedures.
M: So will you recommend having that in the story and focus on that they sleep?
D: Yes.

M: OK, do you think about something else that can be important for the actions in the story?
D: Yes, I think that if you build this story, so you are going to say that's the cancer, there will be the bone marrow controls, liquids control and these unpleasant things, and this catheter - so you have to put some optimism in this. So then leukemia, the treatment looks like, in the first period they are almost all the time in the department around one month - that depends on the clinical things, but usually one month - and then they are coming only to get some cytostatic, some kind of cycles and then go home. So you can also focus on the breaks, they can go home and almost do anything, but not everything. That depends on the situations, so some optimism that you don't need to be all the time in the hospital with all this not nice procedures.
M: So in the beginning you are on the hospital a lot?
D: Yes, and then the leukemia treatment is two and a half year.
M: OK.
D: But the end the most of this treatment it's just taken as tablets, and only coming here for control sometime.
M: So is it always two and a half year?
D: Yes, for the acute lymphoblastic leukemia, the most often leukemia. For the myeloid leukemia, half a year. That depends on the leukemia. But for this most often leukemia, it's two and a half year.
M: OK, do you think it would be good to have that in the story as well?
D: Yes, but you can say that it's for some type of leukemia, because now we have discussed to different types of leukemia. For some leukemia it's shorter and some leukemia a long time. But the most popular leukemia, long time.
M: OK, but in the story - if we choose to have leukemia - do you think it is necessary to define which

type it is?
D: No, I don't think so, so maybe we skip to say how long. You can say long, because it's long treatment. You have the pneumonia it's one-week treatment or maybe two weeks max, but for leukemia it's month. So it's a long time.

M: Do you have any thought about the character - or you told me that I should look for what's popular?
D: Yes, I think so. I was thinking, no, I can say, look like Barbie or look like - I don't know what's the most popular between the children now.

M: OK, good advice. What do you think about the informing about death, or do you think it should be avoided?
D: This is a very difficult subject, a difficult story, and then I was thinking about this, and I think that we inform most of the children, not all the children. No very small children, but more of the children, especially the big children. If they are going to die, they are going to die. But I don't think that it is wise from the beginning.
M: No.
D: So when I think about this, I was thinking that you should just leave the open story. You could say that most of the children can be healthy and that's all. So you give the information that not all... So maybe, maybe you can say: of course some of children can die, but I think that maybe the more optimistic to say: most of the children can be healthy.
M: But do you think, for the character in the story, do you think it should get healthy or not?
D: Like final end?
M: Yes.
D: You know, if we talk about the most popular leukemia (other leukemia have not this good prognosis) we have now 86% that can be completely healthy. So it's quite good prognosis, so I think that the final end the child should be healthy, but you should have the information, or maybe even repeat this information that not all the children get healthy.
M: OK, OK. Not give false...?
D: Not say that they will die maybe, but for most children... Yes.

M: Yes, OK, thank you. Em, so what, there is some different character types I have here, but do you want to say a meaning about them or do you still think that I should...?
D: I have no idea.
M: No idea? No, so...
D: No idea, I think that maybe you have to test it with the children this, or maybe you can ask this women from the leketerapi. They can test this - what is the most attractive with the children.
M: OK.
D: I have completely no idea.

M: OK, it's OK. Em, do you have any other thoughts around the topic?
D: I was thinking that, of course, it's a difficult topic. We can discuss this for one week and still it would not be enough. But I was thinking that different information for different children. I was thinking that it is wise to give the children the information that they have the cancer, also that, I told you,

we usually don't do it in the first line. So we are working with the children to give them finally this information. Some children need the longer time, some shorter. Nowadays the most kind of leukemia have very good prognosis, so we can give them a lot of optimism. So in this program there should be given a lot of information, and also this information that there is many side effects of the treatment, and many procedures (catheter, anesthesia). Some children, of course they have pain, they need the pain treatment. We try to cover this pain, sometimes it is possible, and sometimes it is not. They have the nausea, they vomiting. We have many medicaments, so we try to protect them, but it is sometimes not possible to protect them all. And then complications, a lot of infections come here because of this cytostatic treatment. So they have to get this information that it is not easy, it will be a lot of complications. We are sending them home, but when they get the fever - which happens quite often - they have to come here, it is not possible to treat it at home with antibiotic. They have to come here and get to antibiotic intravenously. So they have to get the information that it can be difficult, in some way, but at the final end it is very optimistically. So I think that's important. When I talk with the parents the first time, I think that for me the first talk is very difficult and important. And the last talk is very important. And the first talk is because you are sitting with the parents, and usually the children was completely healthy, and you have to sit in front of them and tell them the child has the cancer. It is really a tragedy for the family. But then when I talk more and more, they are so in shock that they don't remember anything, so I have to repeat this the day after, or the day after. But I talk a little bit about this treatment, and about the plan for the treatment, but at the final end I give some optimistic information - but as I told you sometimes it is more optimism that other times. And the end of the story, the children can be healthy. So when we finish the treatment we make all this controls once more to see that everything is ok, and then we say, "you are healthy". And then we say "you have to be in our clinic to control next.. Usual 5 years". So they have to come from the beginning once a month for example, and then 3 moths, and then half a year, and once a year until 5 years after the end of the treatment.

M: OK.

D: But some of them can get relapse, and not many children get the relapse, but some of them can relapse. Also there is the information that they are completely healthy, that this relapse can happen all the life. **M**: OK, do you think that will...?

D: No, but if you have some place to put this information - not very strong, but somewhere - you can put it, but if not, just make what is the most important that they can be also completely healthy.

M: Thank you...

D: And they will be visiting us only sometimes to take the blood tests.

M: OK. You mentioned some books earlier. What was the name of the books that you can recommend me for inspiration?

D: I think that I don't have this. The Kreftforening makes this, and nurses were using this and there are some other books so I found just now. But there were some other books. I don't have these books here.

M: Kjemomannen...?

D: Was something about leukemia, the Kasper.

M: Yes, Kjemomannen?

D: I don’t know, but about a Kasper. The small boy and he gets leukemia. I think that was translated to Norwegian. I was looking just now, but I don’t think that I have this book here now.

M: OK, great. Thank you very much.

D: I hope that was helpful for you. If you have some more questions just let me know.

M: Yes.

Appendix D

Interview Transcript: Bøe

Interview: Digital storytelling as tool for conveying cancer diagnoses to children

Marianne Bøe is a nurse with postgraduate education in oncology nursing. She has mainly been working at the Children's Clinic at Haukeland University Hospital and has also been working at the Norwegian Cancer Society for three years.

Wednesday 22st October 2014 at 12:15 - University of Bergen

Interviewer (M): Maiken Beate Fjellanger
Interviewee (B): Marianne Bøe

M: Så da er første spørsmålet om du synes det er greit at navnet ditt oppgis i oppgaven?
B: Ja, det går helt fint.
M: Ok, supert. Hvilken utdanning har du?
B: Tok sykepleierutdanning i, jeg var ferdig i 1988. Og så jobbet jeg på barneklinikken fra 1989 til 2011. Og innimellom der tok jeg videreutdanning i kreftsykepleien. Og så jobbet jeg i kreftforeningen i 2011 til nå, 2014, så begynte jeg tilbake på barneklinikken i 2014.
M: Ok.
B: Ja, så jeg er tilbake på den avdelingen som jeg sluttet på.

M: På hvilke måter formidler dere kreftdiagnoser til barn?
B: Ja, jeg tenkte litt på det, og så tenkte jeg - altså nå har jeg vært borte fra klinikken sant i tre år. Sånn at jeg måtte høre litt med kollegaene mine - hvordan jeg gjør det i dag. Og så kjenner jeg også litt på dette hva man ønsker å gjøre, altså det med teori og hvordan det er i praksis. Og jeg ser at, altså den gruppen som vi har, det er fra 0-15 år, og der er det jo legen som informerer. Veldig ofte så ønsker foreldrene at legen skal si at barna har kreft, av og til så er det foreldrene som forteller det, men da snakker de først med legen i forkant. Så hvordan vi informerer. Det er veldig direkte, og bruker ordet kreft og snakker om sinte celler - det kommer også an på aldersgruppen. Hvis det er små barn så bruker de den boken "Kjemomannen Kasper".

M:Ja, jeg har sett litt på den. Jeg har skjønt at den brukes mye?

B: Den brukes veldig mye, både for barn som er syk og barn som er pårørende - så brukes den veldig mye.

M: Jeg har inntrykk av at de forstår?

B: Ja, den forstår de. Og til og med store barn så bruker man gjerne den. Holdt på å si, ungdommer, så kan den brukes for den gir et veldig godt bilde på friske celler og syke celler, der legene informerer og sier at årsaken til at de har blitt syk ikke er på grunn av noe de har gjort, eller foreldrene eller søsknene har gjort. Det er sånn som skjer. Det er rett og slett en feil i fabrikken som en kan kalle kroppen. Altså da skjer det en feil og hvorfor det skjer, denne feilen, det vet en ikke.

M: Så det, jeg kan spørre deg, så det er kanskje litt greit å få med da i en sånn historiefortelling? Dette med at det ikke er deres feil, for jeg har skjønt det slik at det er flere barn som får litt sånn skyldfølelse.

B: Ja, det er de veldig klar på, og veldig klar på foreldrene også. Kanskje nesten de har mer skyldfølelse enn det barnet har. Altså foreldrene opplever jeg veldig ofte at lurer på om det er noe de har gjort, eller ikke gjort, eller burde ha gjort, men en er veldig tydelig på det både for foreldre og barn at dette er ikke noe de kan klandres for. En vet ikke hvorfor barn får kreft. Det er bare en type øyekreft hos barn som er på en måte arvelig, men eller så vet en ikke hvorfor barn får kreft, så det er vi veldig tydelig på når vi snakker med barnet. At de rett og slett har vært uheldig for å si det sånn. Det å forklare at det ikke er noe de har gjort eller ikke gjort, det er veldig viktig, og så bruker en rett og slett det at det er en feil - at det har blitt dannet celler som ikke skal dannes. Hvorfor det skjer, vet en ikke, men at disse kreftcellene krever en tøff behandling. Så jeg kjenner litt på at jeg var litt sånn usikker, som sagt så spurte jeg noen kollegaer nå, men altså det er, hvordan vi informerer: vi bruker Kjemomannen Kasper, vi snakker om sinte celler og det er det legen som sier. Men så har vi og noe som vi kaller magnetbilder, og det er da jeg tenker teori og praksis. De ønsker vi å bruke, det er en type hard plast fargebilder som viser liksom ulike celletyper i kroppen og sinte celler, altså disse kreftcellene, og ulike cytostatica eller cellegift og de er formet som en type gulldråper og mye antibiotika som er formet som stjerner sånn at en har litt sånn visuelt bilde. Og det ønsker vi å bruke, men det ser jeg nå når jeg er tilbake at det blir ikke brukt, så det er noe jeg har lyst til å få inn igjen for dette er en modell som opprinnelig ble laget i Sverige av 2 sykepleiere som jobbet med barn. Modellen heter "se - høre - gjøre bilder" . Denne modellen bidrar til økt forståelse av sykdommen og gjør informasjon om kreft og behandling mer forståelig for barnet, familien og nettverk. Det er der de begynte å bruke det, og jeg vet rundt omkring på andre barnesykehus hvor de behandler kreft, så bruker de disse bildene. Så det er en koffert som jeg tenker at familien skal få og kan bruke, men vi må på en måte introdusere de for denne kofferten og begynne og fortelle om de bildene og da blir det veldig visuelt, litt om kroppen og hen friske celler dannes og det kan egentlig brukes på mange ulike diagnoser, men det er spesielt tenkt for barn med kreft eller barn som er pårørende til noen med kreft. Så som sagt i teorien så ønsker vi at det skal bli brukt, men jeg ser nå som jeg er tilbake, nå har jeg vært tilbake i knapt tre uker, så ser jeg det at det blir dessverre ikke brukt. Men det er også en fin måte å informere barn på. Så per i dag så er det egentlig legene som formidler kreftdiagnosen til barn, det er det ikke vi sykepleierne som gjør.

M: Ok. Ja, så da har du egentlig svar på det med metaforer og...

B: Ja, men jeg kunne ønske at det ble brukt mer metaforer eller bilder. Altså det er lettere å, altså jeg tenker hvordan skjønner en 5-åring hva en kreftcelle er? Det er veldig vagt og det der å, gjerne for en

15-åring og, å se et bilde av en klump som er sur eller sint - altså det er et veldig godt bilde å bruke sånne - den der kofferten da eller disse magnetbildene. Så jeg tenker det er kjempe viktig å formidle, litt sånn bruke noen metaforer eller bruke noen bilder for når de er inne på sykehuset nylig diagnostisert, de har kanskje vært der et par dager, og er kjempe utrygg, kjempe redde - og så tenker jeg: hvor mye forstår de av det som vi sitter å forteller til de? Det opplever jeg, foreldre som forteller at de (barna) hører ikke hva vi sier fordi de følger med på den fuglen utenfor vinduet eller lyden av en eller annen boremaskinen uti gaten.

M: Er det fordi det blir for høytsvevende for de eller?

B: Ja, altså de er ikke konsentrert fordi de er kanskje så engstelig, ikke nødvendigvis for høytsvevende, men de klarer ikke å konsentrere seg. Som om en hadde hatt et bilde eller vist noe på en pc eller et magnetbilde, kanskje det hadde vært lettere for de å forstå. For det der å samle tankene, de har tusen tanker som slår mot de hele tiden. I hvert fall når de er så nye. Så er det noe annet når de har vært der en måned eller to måneder.

M: Ja, da har de på en måte vendt seg til det?

B: Mhm, så er verden blitt mye tryggere for de. Så det er veldig utrygt den første tiden når en skal informere foreldre og barn eller søsken, så er det lett for å, det der på motta informasjon når man er sånn i sjokk det er kjempe vanskelig for de.

M: Det kan være at barna også kjenner på følelsen til foreldrene?

B: Ja, veldig. Så ser de at mor eller far sitter og tørker tårer eller sitter og griner eller sitter med litt sånn steinansikt. Og de leser ofte foreldre som en åpen bok altså så det... Det å snakke med foreldre for seg, det ønsker veldig mange foreldre at de vil snakke med legen først og så snakker en sammen med barna etterpå. Eller noen velger også å - vi kan snakke med barnet vårt og så kan legen supplere etterpå. Men det er egentlig lite metaforer, lite bilder som blir brukt i informasjon synes jeg, så det kunne jeg ønske meg at vi var flinkere å bruke og så vet jeg det at jeg har noen bilder liggende, men de blir ikke brukt. Litt sånn kinkig egentlig.

M: Men hva er dine tanker rundt digital historiefortelling som et hjelpemiddel for formidling av kreftdiagnosen til barn?

B: Ja, da når jeg sendte den meldingen til deg i går, så tenkte jeg på: digital ja, men det er jo det du tenker å lage. Sant og da, jeg så på de bildene her, og da blir det via pc, at en kan bruke det. Jeg tror jo at det er kjempe nyttig. For når jeg ser på barnene helt ned i 2-års alder som sitter med pc eller iPad, det er helst det de sitter med, og ser på bilder eller bruker den når en gjør, kanskje ikke vonde ting men ulike prosedyrer som de synes er ubehagelig eller de er litt redd eller de ikke vil, så bruker de iPaden helt bevisst. Så ser de på bilder eller ser på en eller annen film eller noe sånn. Så jeg tenker sånn digital historiefortelling, det tenker jeg går rett inn hos disse.

M: Så bra.

B: Så jeg tror det kan være kjempe nyttig.

M: Ok, så bra. Det er litt sånn at det faller så naturlig for de å bruke disse. De har vokst opp med de sant.

B: Ja, jeg blir helt. Når jeg ser nå når jeg er tilbake igjen, og ser hvor små de er når de sitter og trykker og skal ha bildet frem og sant. Det er fascinerende å se hvor tidlig de begynner. Jeg husker når jeg begynte altså da var det litt sånn: ånei, de skulle ikke se for mye på video, men jeg ser at det er kjempe nyttig med den digitale verden. Både det å følge med på for eksempel skolearbeid og ha kontakt med venner og bruke det når de gjør ulike prosedyrer så blir det på en måte litt sånn tanke flykt. Så jeg tror at digital historiefortelling kan være veldig nyttig, for det er liksom på deres nivå. De er forbi det der med tavle og tegning, litt i tiden.

M: Ja nettopp. Hvilken aldersgruppe tror du kunne fått mest utbytte av en sånn applikasjon?
B: Egentlig alle aldre, faktisk.
M: Fordi nå når jeg skal lage ned så må jeg på en måte, jeg kan jo bare lage den for en alder. Fordi, sånn som jeg ser for meg, så vil den jo være litt forskjellig hvis den er på en måte til fra 10-15 eller hvis den er fra 5-10.
B: Det som jeg tenker er hvis en lager noe for eksempel for fra 5-10 så kan den også brukes av de som er eldre. I hvert fall sånn som jeg har gjort det... Eller det som jeg har erfaring med Kjemomannen Kasper som er litt sånn barnslig bok for de på 10-12-14 år. Når jeg har brukt den, når jeg for eksempel har vært på skolebesøk - ja, det er jo elever da - men når jeg har informert barn enten de er syk, venner eller pårørende, så har jeg brukt Kjemomannen Kasper. Så har jeg sagt til de at dette er gjerne litt barnslig for deg, men det gir en økt forståelse. Sånn at jeg har på en måte advart de litt om at dette kanskje er litt lavere nivå enn det du er på, men vi bruker det uansett fordi det er så viktig. Men så er det noe med det når de lærer og hører selv om det er på et litt mer barnlig nivå, så lærer de mye likevel. I min erfaring så tenker jeg det er bedre å legge seg på et litt lavere nivå for eksempel 5-10 år, men det er jo stor forskjell på en 5åring og en 10åring, men da kan en bruke det på en 12-åring eller si det at vi bruker dette og du synes kanskje det er barnslig med vi synes den gir en god informasjon. Og så har en jo gjerne flere barn mellom 5 og 10 år enn det en har på 14 eller på 2 år. Mellom 3-10 år er gjerne den hovedgruppen en ser at en har, så ja 5-10 år for eksempel kunne vært en grei aldersgruppe, for da kan man bruke det med de som er eldre. Og så tenker jeg de som er yngre, det er vanskelig å forklare en 2-åring om kreft, men en kan for eksempel, når jeg tenker på disse magnetbildene vi har, så kan jeg vise to bilder der jeg har en sint kreftceller og en god celle og så si noe om det at du får medisin fordi det er sånne sinte celler i kroppen din. Ja, og så forklare det på et vis, men det er å forklare en 5-10 åring, det tenker jeg at kan være veldig nyttig med en digital fortelling.

M: Ok. I en digital historiefortelling for å informere barn om kreft, hva synes du om ideen om en historie om en figur som får en kreftdiagnose og at man fokuserer både på hvordan figuren opplever det følelsesmessig og hva som skjer inni kroppen?
B: Ja, em. Ja for da tenker du det at du både forklarer hva som skjer i kroppen og så litt hvordan følelsene ja...
M: Ja. Jeg leste en artikkel der det kom frem at barn ofte opplever masse forskjellige følelser i tilknytning til diagnosen, og liksom formidle det at det er naturlig å føle forskjellige følelser.
B: Ja. Og det tenker jeg er kjempe viktig for det henger egentlig så mye sammen. En ting du kan forklare er litt sånne faktiske ting som diagnose, om sykdom og behandling. Og noe som henger like sammen med det er hva de opplever, det og få en sykdom - om det er skam, om det er skyld eller om de trekker seg inn i seg selv, så det der å forklare noe ved hjelp av det digitale i forhold til hvordan det er å leve med sykdom, dette med at du mister kontakt med vennene, du får en uforutsigbar hverdag, du

får ikke gått på skole, du kan ikke være med i gjengen sånn som før fordi du blir mer isolert i forhold til behandling og det som den gjør med deg. Sånn at du mister litt kontrollen på det livet som skjer utenfor sykehuset, så jeg tenker det er kjempe viktig for måten de takler sykdommen sin på. En ting er det medisinske, altså vi må gi de medisiner om de vil eller ikke, sånn at det må de bare følge med på. De har ikke noe de skulle sagt, fordi de skal bli frisk, og det vil (ønsker) de jo. Da gir en medisiner selv om de ikke vil så må en jo gjøre det.

M: Er det mange som er motvillig til å ta medisiner?

B: Nei. Altså en ting er det med å ta tabletter, at de ikke vil ta de.

M: Ja, fordi det er vondt å svelge.

B: Ja, og synes det er dumt og er lei og sint og sånn, men dette med å ta - altså de får jo de fleste medisiner intravenøst, sånn som cellegift og sånt, så det er ikke mange som er motstander av det.

M: Nei.

B: Men det på en måte har de ikke så mye de... altså de må gjøre det, og det vet de og det forstår de. Men dette med hvordan å være - hvis jeg kan komme med et eksempel da så nå har vi en gutt på 14 år og han er nettopp begynt med å få behandling, han har vel vært inne en måneds tid, og jeg opplever han som veldig snill, veldig dannet, så jeg tenker av og til at: jeg lurer på hvordan du egentlig har det inni deg? Om du har lyst til å bare be meg komme meg ut. Men jeg opplever, altså han er nok en veldig snill og dannet gutt - han kommer opprinnelig fra et annet land, så jeg tror at han er litt sånn når det gjelder helsevesen og sånn da skal man svare fint og ikke være sint og sånn. Men så tenker jeg at en 14-åring som opplever så mye vanskelig som han gjør nå, så har jeg så lyst å formidle til han at han trenger ikke smile og si tusen takk og være så høflig hver gang. Det er helt greit om du ikke svarer meg og det er helt greit om du protesterer litt, og det sier jeg også til foreldre. Det er heller de yngre som protesterer fordi de har ikke det filteret. Så jeg opplever at han er veldig høflig og veldig snill, kanskje han tror at hvis han er høflig og snill så får han en god behandling.

M: Ååja...

B: Og hvis jeg protesterer, så er de ikke så greie mot meg. Sånn at jeg opplever litt det at jeg skulle ønske av og til at det er helt greit, at jeg kan si til han at - det kommer jeg kanskje til å si også på en fin måte - at om du er litt sint eller sur så er det helt greit, det er en normal reaksjon. Du trenger ikke å være så smilende og grei mot meg - det er jo veldig hyggelig at han er det, men hvor naturlig er det når han ligger der med kjempe ubehag i munnen og er utslått? Sånn at det er litt at jeg har lyst å si til han det at det er helt greit at du bare ligger med hodet under dynen, du trenger ikke svare meg så høflig. Og jeg mener ikke det at han skal svare meg stygt, men altså han trenger ikke være så veldig høflig hele tiden for da er det lettere i forhold til yngre barn så mangler de som oftest litt av det filteret. De bryr seg ikke om de viser til meg, eller oss personalet, hvor sint de er på foreldrene. Og gjerne de kan være sint på oss at "nei, jeg vil ikke ta den medisinen" eller "nei, jeg vil ikke ta den blodprøven nå". Mens en 14-åring gjerne ikke sier så mye, bare holder det inni seg. Nå vet jeg ikke helt om jeg svarte på spørsmålet.

M: Jo.

B: Så jeg opplever av og til at disse litt større, de skjerper seg litte grann, så er det gjerne foreldrene det går ut over. Da er de mer hissig, eller sint og mer normal reaksjon, men det er foreldrene som hører det; mens 3-4-5-6-åringene der får foreldrene høre det, men vi kan og høre det. Og det sier jeg av og til

foreldrene at det at de har en reaksjon, at ikke de vil, at de kjefter, det er helt sunt og normalt. Men selvfølgelig hvis det er noen som - så er det noe med grenser også som jeg merker når de er på sykehus at vi skal ikke tolerere alt. Hvis det er en som kjefter eller slår, det er av og til de slår etter oss og da er de fortvilet og sint, og da må jeg si til foreldrene at de kan på en måte ikke tolerere det. Noen foreldre er så fortvilet og lei og sier det at det er helt greit du må bare slå. Det er litt der med grensene også. Det er lettere for en 4-5-6-åring å gi beskjed hvordan en har det enn for en tenåring, for de skjerper seg mer altså.
M: Nettopp.
B: Så jeg tenker det - litt tilbake til spørsmålet - det med å vise følelser tenker jeg at er kjempe viktig bit av det med å bruke historiefortelling. Fordi det følger sånn med det å få den behandlingen, så gjør den behandlingen noe med deg.
M: Ja.
B: Og det tenker jeg at det kan brukes mye på barn generelt som pårørende. Om en har kreft eller om en er pårørende til barn med kreft eller pårørende til noen som har psykisk syke foreldre. Så det der med at når en har det vanskelig i ulike situasjoner, at det kan man bruke, en kan bruke digital historiefortelling til å snakke rundt om hvordan en reagerer når en har det vanskelig. Så om en er pårørende eller om en er syk selv, så er det viktig å få det frem. For det er noe med det at de skal leve videre når de er frisk eller når, hvis de er pårørende, så skal de leve videre når den i familien som er blitt syk, er blitt frisk eller er død for eksempel.

M: Ja, mhm. Skal vi se, har du noen andre ideer til historien eller... Enn det som er sagt nå?
B: Nei, altså jeg synes egentlig det med både å forklare om diagnosen, sykdom og behandling, og hva det gjør med en når en er syk, det med opplevelsen eller hva som skjer inni kroppen og det med det psykiske og den biten, jeg synes egentlig det - det er sikkert flere ting, men ikke sånn som jeg kommer på. Jeg synes det er to fine ting.

M: Ja. Hvilken kreftform ville du anbefalt å tatt utgangspunkt i og hvorfor?
B: Egentlig så trenger en - jeg tenker umiddelbart at en trenger ikke å ta utgangspunkt i en spesiell form for - en spesiell diagnose. De som vi har på barneklinikken, det er alle typer kreft. Det er blodkreft, kreft i hodet, i en fot, mage, nyre ja... Lymfesystemet. Så jeg tenker at en kan på en måte snakke om det å få kreft som en diagnose selv om det ikke er en - altså det er en stor sekkediagnose så finnes det mange ulike undergrupper. Men kanskje jeg tenker på det for når jeg tenker på disse magnetbildene som vi har, så tenker jeg at kreftcelle om den er i blodet eller sitter i hodet eller om den sitter i huden eller i et bein så låser en seg litt om en tar utgangspunkt i en spesiell diagnose. Det er veldig lett å forklare eller enkelt å forklare synes jeg hvis en har kreft i blodet for da sitter det i blodbanen. Men at en kan si noe om at kreftcellene kan sitte mange ulike steder og at en kreftcelle er en kreftcelle om den sitter i hodet eller i blodet eller i magen eller i et bein, og så krever den tøff behandling. Så umiddelbart så tenker jeg at nei, en trenger egentlig ikke å ha en spesiell diagnose. Altså en kan ha en - selv om kreft er mange ulike ting, så er det på en måte en slags type sekkediagnose så en kan bruke samme type historie hvor den kreften sitter. Da bilder du deg ikke opp, fordi de får veldig mye samme behandling. Altså de får cellegift, men det er x antall forskjellige typer cellegift ut ifra hvilken diagnose. Men de får cellegift og

mange får strålebehandling - og det er også uavhengig av diagnose. Og en del får kirurgi. Og tabletter får noen. Sånn at en kan fint fortelle om kreft uten å knytte det opp mot en spesiell diagnose tenker jeg.

M: Ja, men det høres veldig interessant ut og lurt ut ja. Hvilken medisinsk informasjon mener du det er viktig at kommer frem i en sånn fortelling? Noen spesielle symptomer, behandlinger eller operasjoner?
B: Jeg tenker symptomer, da tenker du symptomer på sykdom?
M: Ja, liksom sånn på forhånd. Eller synes du det trengs?
B: Det er egentlig ikke så veldig relevant, men nå blir det sånn hva jeg tenker, for det at mange av de symptomene de har er litt sånn uspesifikke. Det er veldig få som er veldig syke. Veldig mange foreldre opplever at barnet deres, det er noe, men de klarer ikke sette fingen på det. Veldig mange har gått til fastlegen eller vært innom på legevakten og - neida det er bare influensa eller nei det er sikker noe som går. Dra hjem og vent. Og det har vi flere eksempler på at foreldrene kjenner at det er noe med barna, men de er ikke sånn veldig syke. Og så kan de gå en stund og så blir de mer og mer slapp - så en del av symptomene kan være, ja for eksempel han 14-åringen jeg snakket om, han hadde vondt i et kne. Sant og ja, det er jo mange - voksesmerter - det er mange ting du kan henge den smerten på. Andre som har blodkreft er litt sånn uspesifikke at de er slapp og litt sånn har feber og, men så er det mange rundt de som kanskje har det samme. Så de symptomene er veldig vage, men det som jeg tenker mer med medisinsk informasjon, det er i forhold til hva behandlingen gjør med de. For de fleste er rimelig frist når de kommer inn, de er litt slapp eller har litt vondt eller hatt blod i urinen eller har litt hodepine - så det er veldig få som er veldig syke. Så de er i ganske bra form når de kommer inn og så begynner de på behandling og så blir de veldig syk av behandlingen. Så det med å informere de om at det ikke er kreftsykdommen som gjør at de er syk, men det er medisinene. Og det og å forklare at du kommer inn for å bli frisk av en alvorlig sykdom og så blir du bare dårligere og dårligere, spesielt de første ukene, første månedene. Så det å forklare det til ungene tror jeg er kjempe viktig, og til foreldrene. For de opplever at de kommer inn og så blir de syk av den medisinen de skal bli frisk av, kanskje har kjempe vondt, kjempe dårlig, klarer ikke spise, har mye smerter - så det tenker jeg at er veldig viktig å få frem at det er medisinen som gjør at de blir syk.
M: Så de blir syk for å bli frisk.
B: Ja, så de er jo ikke like syk hele tiden, men de første månedene så er det ganske mange som er ganske dårlig og alt dette er bivirkninger av medisinen. Så det tenker jeg er kjempe viktig å forklare de. For det er også en del som kan bli redd og usikker fordi de bare blir dårligere og dårligere - så forklare det - det går an å forklare til en 5-åring og en 6-åring og en 10-åring og sånn, men til en 2-åring er det kanskje vanskelig å forklare, så den beste trøsten for de er å ha foreldre som er trygge. Det gjelder jo alle, men spesielt de yngste fordi det er de som på en måte formidler tryggheten til et barn. Så det med bivirkninger og behandling og de symptomene de da har pga bivirkninger tenker jeg at være veldig viktig å få frem. Og der også er det ikke diagnoseavhengig. Det og er på en måte medisinen som gir ulike bivirkninger, det kommer an på hvilken type medisiner en får, så det kan en ta utgangspunkt i det å ha kreft og det trenger ikke være en spesiell diagnose.
M: Ok, men operasjon?
B: Ja, det og tenker jeg at. Operasjoner eller strålebehandling er kjempe viktig at de får informasjon om. Noen foreldre tenker at de kvir seg litt til å informere barna fordi det kan virke skremmende. Det gjelder egentlig alt, men hvis en tar utgangspunkt i operasjon og strålebehandling og egentlig alt, så tenker jeg

at informasjon er kjempe viktig, for det å lure på operasjon da ser en gjerne noe voldsomt for seg, og strålebehandling også. Men det å få faktisk informasjon - gjerne ved å se bilder - f.eks. strålebehandling da får de komme bort og bli kjent med avdelingen. Operasjon da kommer gjerne kirurgen på vår avdeling og forteller, så det å sette litt ord - gjerne ikke så mye bilder du kan vise med en operasjon, men forklare litt hva som skjer, og en trenger jo ikke forklare så veldig detaljert. Det er ikke nødvendig. Men forklar litt hva som skjer, de får sovemedisin og hvor de våkner og hvordan de vil se ut når de våkner. Vil de ha masse slanger? Vil de ha - hen det er bandasje? Stor eller liten? Har de f.eks. amputert en fot eller arm. Bare forklare hvordan det - hvordan bandasjen vil være eller... Så det der å forklare konkret, og da er de jo litt kjent, da kjenner vi jo som regel barnet, når de skal begynne på strålebehandling eller ha en operasjon. Sånn at vi vet om dette er et veldig engstelig barn sånn at vi må kanskje forklare litt, eller om det er et barn som tåler mer - men det å forklare konkret, det gjør - jeg har aldri opplevd at det skremmer barnet selv om gjerne foreldrene tenker at nei vi må ikke fortelle så mye. Vi skal ikke fortelle alt. Nei, kanskje de ikke trenger å fortelle alt, men mest mulig konkret: hvordan det vil være før operasjonen, når de sovner, etterpå, hen de vil være, hvor tid de kommer tilbake på avdelingen. Og det samme med stålenehandling: hvordan maskinen vil være - og der vil det være lettere å ta de med bort så de får se denne maskinen og trykke på litt knapper slik at maskinen beveger seg og slikt. Men konkret, rett informasjon tenker jeg er kjempe viktig. Og er det noe vi tenker at dette vil være smertefullt for barnet, så er det viktig å si det også at "dette vil gjøre vondt".

M: Men i en sånn fortelling da, synes du - da blir det jo litt spesifikt - tenker du - eller hva kunne man sagt i en sånn fortelling hvis en skulle hatt det med?

B: Tenker du men bilder eller med informasjon?

M: Jeg er helt åpen til alt jeg. Eller synes du... Trenger man å ha det med eller?

B: Det kan være vanskelig å lage en fortelling på operasjon eller strålebehandling. Strålebehandling er en ting, med operasjon det kan være mange ulike ting. Så jeg tenker det som er viktigs der om en kan formidle noe i den fortellingen at du vil få god informasjon om det du skal gjennomgå, fordi det er vanskelig å formidle det med en digital fortelling. Om en f.eks. skal amputere en fot under kneet eller en skal operere bort en svulst i hodet, eller en skal operere bort en nyre på grunn av svulst der, så er det så ulike prosedyrer, men det er noe som er felles og det er at de skal på en annen avdeling, men det kan være vanskelig å formidle det med bilder eller digital fortelling, men å si noe om at det er viktig at du får snakke med de som skal - det er ikke alltid man får snakke med kirurgen, men at en får god informasjon på avdelingen om det som skal skje. Det eneste med strålebehandling er det at barna får være med bort på avdelingen sammen med foreldre og se på avdelingen. Men det er ikke så lett når de skal opereres. Men det er kanskje vanskelig å lage - da må du kanskje lage mange forskjellige bilder - vi har de der magnetbildene, der har vi jo ulike bilder, men vi har vel ikke noe akkurat for operasjon, men det som er felles som en kunne sagt noe om eller hatt noen bilder av er at da er man ikke på sin faste avdeling, da blir de på en annen avdeling, når de skal opereres. Og at de våkner opp på en annen avdeling. I hvert fall hos oss og på andre sykehus som jeg vet de behandler barn med kreft så er det der de får medisinsk avdeling der de får cellegift og behandling og så er det kirurgisk avdeling som har det med operasjon - så det er to ulike steder. Men hvordan en skal gjøre det med bilder og sånt det er jeg litt usikker på, men at en kan ha et sett med bilder at da er man på en annen avdeling. Men det kan godt hende at det finnes en god måte å gjøre det på, hvis du f.eks. snakker med de som jobber på kirurgisk, altså barnekirurger f.eks. - at de hadde hatt noen gode ideer, men jeg kommer ikke på noe nå annet at det er forskjellige steder, fysiske steder, at de er på en annen plass når de opereres og når de våkner. Litt usikker på hvordan en kan gjøre det på en god måte.

M: Har du noen andre tanker om hva som kan være viktig å få med i handlingen, i selve handlingsforløpet på en måte?
B: Hvis en har snakket litt om bivirkninger og hva det gjør med en, følelser... Nei. Jeg tenker litt på det der psykiske, psykososiale biten, men det er jo mer på følelser, hvordan de har det. Jeg tenker litt sånn langt da når de skal tilbake igjen til hverdagen når de er ferdig behandlet. Nei, jeg tror at det med bivirkninger eller hvordan du har det når du er i behandling og så det med hva det gjør med deg, altså den psykiske biten, at det kan være gode ting i en sånn fortelling. Ja, jo kanskje litt det med hva hjelper deg hvis du har det vanskelig. Det er kanskje vanskelig for en 2-åring å si litt om det, men der ser vi at dette med avledning og lek eller kos med foreldre, eller musikk eller klovn at det kan hjelpe.
M: Ha det gøy?
B: Ja, gjøre noe kjekt. Litt sånn virkelighetsflukt. Og det tenker jeg også - at kanskje det kunne vært en del av fortellingen. Hva hjelper når 14-åringen ligger der og egentlig er utslitt etter behandling og egentlig bare har lyst til å reise hjem? Eller 10-åringen er sint? Eller 5-åringen ikke vil. Å snakke noe om virkelighetsflukt - hva hjelper når den 10-åringen ikke vil eller er sint. Og han eller hun vet at han må bare ligger der eller være på avdelingen. Jeg kan ikke reise hjem. Om det kunne vært noe å ha med i en sånn fortelling, ja hva gjør en da når du ikke vil? Hva ville du gjort? Om en har en type fantasireise, eller ser på film, eller høre musikk eller ha besøk av venner - det er ikke alltid det går. Bruke iPad eller Facebook. Det der med en sekvens om ting som kan hjelpe når en har det vanskelig. Og det også er uavhengig av diagnose. En 2-åring lever mer her og nå, kanskje lettere enn en 10-åring eller en 14-åring. Men det med å ha med den litt psykiske biten og ting som kan hjelpe når du sliter eller er lei deg eller du har det vanskelig eller vet at du må være på sykehuset til behandling. Om det er noe en kunne hatt med.
M: Ja, absolutt.
B: Det går jo litt over i det psykososiale, men om det kan være en del, kanskje.

M: Ja. Har du noen tanker om hvordan karakterene i fortellingen bør være?
B: Nei.
M: Det er litt vanskelig akkurat det.
B: Ja. Tenker du sånn som, for jeg så jo litt på de bildene.
M: Ja, det er bare eksempler som jeg har laget da.
B: Sant, og da tenkte jeg at det må være noen som kan relateres både til gutt og til jente. Akkurat nå har vi tre jenter mellom 3 og 5 år som kom på avdelingen ganske nylig diagnostisert med kreft og jeg ser at noen av disse hadde falt veldig i smak hos noen av de jentene. Men han på 14 tror jeg ikke hadde funnet seg igjen i noen av disse. Så hatt noe som er litt sånn både - kanskje litt sånn nøytralt enn gutt/jente.
M: Sånn som den bamsen der da? Den er jo kanskje litt sånn? Eller synes du det bør være en person mer?
B: Nei, det kunne godt vært en bamse, men det som jeg savnet her på disse bildene var litt mer en sånn

type gutt. For vi har gutter som er litt eldre altså 10-12 år, så det å både, altså bamsen kan være veldig god å ha både for mindre barn og for jenter 4-6 år, synes det er veldig kjekt med kos og bamser og litt sånne ting, mens litt større gutter de ville gjerne hatt en gutt med caps eller... Litt mer så de kunne identifisere seg med. Det må ikke bli for jentete.

M: Men det er litt vanskelig å lage noe som skal treffe begge deler.

B: Ja, det er det. Men om du kunne hatt to ulike, en som kan treffe, eller kanskje flere, en som kan treffe små enten de er gutt eller jente, en som kan treffe litt større gutt og jente. Det tenker jeg at, ja for her ser jeg ingenting som kan treffe han gutten på 14 og så har vi en på 12 også. Sånn at det må være litt tøffere bilde, ikke nødvendigvis så veldig tøff, men litt mer kul. En litt kulere. Og den nummer 1, den var nesten litt sånn trist, men de er jo litt sånn triste og, de er jo ofte det.

M: Tingen her er på en måte å formidle følelser og fokusere mye på øynene. Så om de er redd eller trist eller... Så ble det bare jenter for jeg synes det var lett.

B: Ja, jeg likte veldig godt de nummer 2 og 3. Ja. Og den bamsen og den var litt sånn - for det tenker jeg er kjempe viktig med følelser - det tenker jeg er en veldig god ide. Følelser og bilder. Og så er det jo også noen som er trist og lei inni seg, men når vi ser på de så ser de ikke lei seg ut i det hele tatt.

M: Så kanskje på en måte å formidle at det er inni.

B: Ja, inni, men utenpå så ser de helt vanlig ut.

M: Ja.

B: Eller kanskje de ser sint ut, og så er de egentlig veldig trist og lei eller litt sånn spørrende. Det er noen som, det har jeg lært hos Marianne Straume.

M: Ja, hun skal jo faktisk også bli intervjuet.

B: Ja, veldig bra. Hun har jeg lært masse av. Der har jeg lært dette med at de kan ha et ansikt utad mot oss og så er det noen helt andre følelser de har inni seg fordi de tør ikke - litt sånn som han 14-åringen - kanskje han er veldig redd inni seg eller veldig sint, men det er ikke det jeg ser. Jeg ser han som en veldig høflig og dannet gutt som kanskje tar seg veldig sammen fordi han ikke vil vise meg sine følelser, og det er på en måte greit. Det er ikke lett når man er 14 år og være frisk å vise følelser og det er kanskje enda vanskeligere når en er syk. De blir så sårbar. Men dette med å formidle at det ikke er sikkert ansikt og det inni stemmer overens, men igjen så er det veldig lett å se på en 2-åring og en 5-åring fordi de har ikke det filteret, de bare kjører på med følelser og det er på en måte litt trygt og greit for da vet vi hen vi har de.

M: Så får de de responsene som de trenger.

B: Ja, sant. Mens han 14-åringen, kanskje han er livredd, men det klarer ikke jeg å se i det hele tatt. Og det tror jeg gjelder tenåringer, at de gjerne skjuler følelser, så er det foreldrene som gjerne får skyllebøtten. Veldig interessant at du skal snakke med henne også, kjempe bra. Så jeg synes det er veldig bra det med å ha ulike figurer, både følelser som du kan se i ansiktet, men og kanskje følelser som sitter inni magen eller i hodet, som vi ikke kan se, eller i beinet.

M: Det er veldig interessant for det er noe som lett kan tegnes og vises visuelt.

B: Det og er noe du kan ta utgangspunkt i å snakke med de om at her er en som faktisk ser glad ut, men så ser du inni at da har hun tårer eller skjelving eller masse spørsmålstegn.

M: Så over til et litt vanskelig spørsmål: Hva tenker du om informering om døden?

B: Ja, jeg synes ikke det er så veldig vanskelig. Og igjen så har jeg lært mye av blant annet Marianne

Straume og Britt Ingunn Wee Sævig som er en sykepleier som har jobbet på Barneklinikken. Og så ser jeg også, av mye erfaring også at det å informere om døden, det kommer veldig an på hva foreldrene ønsker også. F.eks. nå har vi en 3-åring som får lindrende behandling hjemme der foreldrene tenker at han vet at han skal dø, fordi han vil at alle skal være med inn når han skal legge seg. Så de oppfatter at han vet at han skal dø.

M: Så hver gang han skal legge seg?

B: Ja, så vil han at de skal være med inn. Og ellers så tenker jeg at det er mange måter å formidle det at ikke du blir frisk. Noe er det du leser om i avisen om at det er oppgitt av legen og sånn, men en kan allikevel få behandling sånn at en har det så god som mulig, men jeg tenker det er viktig å informere om at en ikke skal bli frisk. Men av og til så er det foreldrene som ikke vil at vi skal informere barnet fordi at de er redd for hva det kan gjøre med barnet. At de skal bli mer redd, eller at de skal bli lei eller... Men jeg opplever veldig ofte, eller ikke sjelden, at barnene kjenner det selv at dette ikke går bra. Og de merker det på foreldrene fordi de leser foreldrene ofte som en åpen bok. Men det er viktig å spille på lag med foreldrene og barnet. Men jeg tenker det er viktig å formidle til barnet at det ikke er medisiner som kan gjøre barnet frisk av kreftsykdommen, men det er medisiner som kan gjøre at barnet har det så bra som mulig. Sant altså smerter eller hva det nå skal være, det er gjerne smerter de er mest bekymret for da. Vi har medisiner, sant det er ikke slik at nå skal du bli sendt hjem og dø, vi har medisiner som vil hjelpe deg sånn at du har det bra den tiden du har igjen. Men det kommer helt an på hvor gammel barnet er og hva foreldrene ønsker. Jeg vet opp igjennom årene så har vi hatt utfordringer der foreldrene ikke ønsker at vi skal si til barna at ikke de skal... Det barnet har vært stort, men foreldrene ønsker ikke at vi skal si til barna at det ikke er mer behandling som kan gjøre de frisk. Så det har ofte vært vanskelige situasjoner der, men jeg tenker at en åpen dialog med barnet og foreldrene, men da må vi ha foreldrene med på laget, at det er kjempe viktig, og så er det mange måter å fortelle at du skal dø på. Altså dette med å si at nå skal du dø, det er ikke mer medisin, det er jo ingen god måte, men ja... Jeg opplever også at barn har en liten ide om det gjerne før vi kommer og forteller det. Og så det å trygge de på at vi vil være der og gjøre det beste for både de og foreldrene, gjøre de mest mulig trygg i den situasjonen de skal inn i, men det er jo en kjempe vanskelig situasjon. Men det er kjempe viktig å ha foreldrene med på laget også, og ha en god dialog. Å gjøre barnet mest mulig trygg. Om det er å kanskje ikke snakke om døden fordi de ikke vil, kanskje de ønsker å snakke om døden med noen andre som ikke er foreldre eller ikke er oss. Enten en psykolog eller en onkel eller en eller annen som har lenger avstand til de enn foreldrene, kanskje det at foreldrene snakker med barna om døden blir for nært. For noen blir det for nært, for andre er det veldig bra at de bruker foreldrene. Men jeg tror på åpenhet og at vi trygger barnet i å spørre hvis han eller hun lurer på noe. Altså de har aldri vært borti dette før, de har ingen erfaring, barnet, sånn at å trygge de på at hvis det er noe de lurer på så må de spørre enten oss eller foreldrene, de må ikke kvi seg for å spørre, de må ikke være redd. Mange er redd for å spørre foreldrene fordi det uroer de eller bekymrer foreldrene. De vil skåne foreldrene. Men det om vi kan trygge foreldrene og barnet det at lurer du på noe så er det bare å spørre, og vi svarer så godt og ærlig som vi kan.

M: Men sånn i en sånn fortelling da, tenker du, altså dette vil jo da være i startsfasen, tenker du at man skal gi noe informasjon om at man kan dø eller at man ikke kan bli frisk eller?

B: Veldig mange barn, når de får vite at de har kreft, så, i hvert fall når de er så stor at de vet du kan dø, så vet veldig mange om at kreft ja det kan jo man dø av. Jeg opplever vel at noen leger formidler på et eller annet vis at dette er en alvorlig sykdom og at hvis du ikke får behandling så kan du faktisk dø av sykdommen. Men det er kanskje litt større barn og så kan de kanskje si det til foreldrene også. Men jeg synes personlig det kan være greit når jeg kjenner barnet litt og at jeg kan spørre andre som har hatt kreft, ja så kjenner de kanskje en oldemor eller en nabo som er 70-90-100 år og som har dødd av kreft, så kanskje si noe om at kreft kan du faktisk død av, men at det er veldig mange som blir frisk og spesielt barn for da har vi så god behandling.

M: Nettopp.

B: Men jeg vet ikke helt om legene sier det til barnet når de får diagnosen, men jeg vet at mange barn har tenkt den tanken at dette kan jeg dø av fordi jeg vet at naboen min på 90 år døde av kreft for eksempel. Og så er det at kreft er forskjellig hos en 80-90 åring enn hos en 5-åring, så jeg tror nok at det døden blir nevnt, kanskje ikke akkurat når de får diagnosen, men i begynnelsen. At dette faktisk er en dødelig sykdom, men vi har mange gode medisiner, og omtrent alle får gode forhåpninger når de kommer inn og begynner på behandling. For da er det det, det er heller unntaket, men da er det det man går ut ifra at her får man behandling for å bli frisk. Å det er det vi sier til foreldre og det er det vi sier til barna: vi tror at du skal bli frisk. Men når en ser at det snur, så er legen også flink med å informere at det snur. Hvis ikke medisinen virker eller man ser at man må bytte medisin eller, så jeg føler de er ærlige og det blir nok nevnt stort sett, tror jeg, dette med at kreft er noe en kan dø av, men vi tror ikke du vil dø fordi vi vil gi deg behandling. Altså tar utgangspunkt i at du skal bli frisk. Svarte jeg på spørsmålet? Nå detter jeg litt ut. Jeg ser at jeg har lett for å spre meg litt med informasjonen.

M: Ja, men det er veldig interessant informasjon, så det er veldig bra. Ja, da er det vel bare siste spørsmål: Om du har noen andre tanker rundt tema?

B: Ikke det med døden, tenker du mer sånn generelt?

M: Generelt.

B: Jeg synes det er kjempe spennende med digital fortelling for å gjøre det konkret og så er det noe det at hvis man begynner med å fortelle om noe så kan en spinne videre på det.

M: Ja.

B: Altså du kan fortelle mye hvis du viser et bilde, og begynner et sted, f.eks. med følelser. Hvis du snakker med et barn, en 5-åring f.eks., om en som smiler, altså 5-åringen er pasient og smiler, og så inni seg så er det f.eks. sinne eller noe sånt, så snakker du om barnet om det så kan den historien eller den fortellingen gå veldig langt ut og du kan fortelle om hvordan det er å være sint og hvorfor de er sint og hva som hjelper og så kan du knytte opp imot venner. Altså hvordan har du kontakt med vennene dine, tror du mamma og pappa er sånn sint? Og hva med søsken? Altså det er jo også veldig spesielt også dette med søsken. Det brenner jeg mye for. En ting er å være pasient og få fulle og hele oppmerksomheten, da er du midtpunktet, når du er pasient. Foreldrene også er ganske mye midtpunkt, men søsken de kommer mye lenger ut. De står litt sånn mellom barken og veden. Opplevd mange søsken som forteller at de er så lei av at venner og familie og nettverk hele tiden spør de. Det er kanskje litt store søsken. De spør hele tiden hvordan går det og sånn, og alle er bekymret for den som er syk. Og de faller liksom utenfor.

M: De blir liksom ikke sett?

B: Nei, veldig ofte. Jeg tror nok at generelt... Det er da barn som er pårørende. Enten disse barna har syke søsken eller syke foreldre, så er det nok mer oppe i tiden. Blant annet denne boken som kom, nå står det helt stille. En ny bok som kom nå i slutten av september, om da pappa var syk eller da pappa fikk kreft.

M: Ja, mener jeg har lest den tittelen.

B: Ja, sånn at jeg tenker at barn som pårørende virkelig er på vei inn. Mye mer nå enn det var for 20 år siden. Så når du fikk den loven også i 2009 at dette med barneansvarlig, og at man skal være mer obs på barn som pårørende. Men det opplever jeg på avdelingen også at søsken de står litt sånn i en mellomposisjon. De skal være flink hjemme, flink for foreldre eller sånn og savner de også den som er syk. Jeg opplevde en som, hun var 8 år og hadde en søster på 3 år som var syk, og denne søsteren på 8 hadde ikke lyst å komme på besøk på sykehuset fordi første møtet hennes med sykehuset det var når søsteren hennes som var syk var sint eller lei. Hun hadde en uheldig opplevelse på sykehuset. Mens hun som var syk savnet søsteren sin så veldig. Og foreldrene sa: Hva gjør vi? Eldstemann på 8 hadde ikke lyst å komme på sykehuset, og hun som var syk savnet søsteren sin. Og eldstemann på 8, når jeg snakket med henne også, så sa hun at hun var så lei av alle de som kom på skolen og spurte. Da var det både venner og familie og naboer og sånt som lurte på hvordan det gikk med søsteren. Så det er også et tema som kanskje en kunne tatt med i en digital historiefortelling, men da blir jo ikke det bare barn, da blir det pårørende også - søsken som pårørende.

M: Ja, men det er et veldig bra tema for videreutvikling.

B: Videre, mhm ja. Sant så du har barnet og så har du den søskenbiten som er... Det kan være kjempe vanskelig å være søsken. For de også ønsker jo å beskytte foreldre, kanskje de er sint på den som er syk fordi han eller hun tar så mye plass.

M: Og samtidig så har de gjerne dårlig samvittighet fordi de er sint på de...

B: Ja, for du blir jo ikke sint på en som er alvorlig syk. Kanskje de har skyldfølelse for at de føler skyld for at søsteren og broren ble syk for at de kanskje nettopp kranglet og så ble de innlagt like etter på det. Så søskenbiten den også tenker jeg er kjempe viktig å ta med, for de kan være i en veldig sårbar situasjon. Lett for å bli glemt.

M: Ja, det er interessant.

B: Så det var vel det som jeg tenker.

M: Ja, da har vi kommet gjennom.

B: Jeg trodde det var mange flere spørsmål. Veldig spennende det du skal gjøre. Det er det.

Appendix E

Interview Transcript: Berland

Interview: Digital storytelling as tool for conveying cancer diagnoses to children

Vivian Fløysand Berland is a deputy of the board in the Norwegian Children Cancer Society, where she has been an active member since 2000. Her engagement started after her son got cancer at the age of 1. He recovered after 4-5 months with treatment. In addition her daughter underwent a kidney transplant at the age of 11.

Thursday 23st October 2014 at 14:30 - Norwegian school of economics

Interviewer (M): Maiken Beate Fjellanger
Interviewee (V): Vivian Fløysand Berland

M: Nå har jeg spurt deg, synes du det er greit at navnet ditt oppgis i oppgaven eller foretrekker du å være anonym?
V: Det er helt i orden at det blir opplyst.
M: Ok, og hvor lenge har du vært engasjert i Barnekreftforeningen?
V: Det har jeg vært siden 2000, og da er det... - altså min sønn var syk i 1995, så gikk det noen år før jeg engasjerte meg. Slik at jeg var ikke involvert i Barnekreftforeningen - som den gangen het Støtteforeningen for kreftsyke barn, der det ble endret for noen år siden til Barnekreftforeningen. Og da engasjerte jeg meg - selv om vi for lengst var ferdig med behandling og alt i 2000 - fordi at jeg ønsket å gjøre en jobb for barnekreftforeningen. Og hvis de kunne bruke meg så hadde jeg lyst til å bidra der.

M: Når barnet ditt fikk påvist kreft, hvordan ble det formidlet?
V: Ja, og da er jo det at han var bare 1 år, så det var jo ikke så mye å formidle til han annet at det bare er å være til stede under operasjon og behandling.
M: Forstod han noe av det eller?
V: Ikke egentlig. Altså så lenge mamma og pappa var der så var det helt greit. Jeg tror ikke han reflekterte over.. Sant 13 måneder er jo ikke akkurat så... så mye han kunne forstå ut ifra det. Og han hadde relativ kort behandlingstid, vel 4-5 måneder så var han ferdig behandlet. Slik at han hadde ikke

noe lang behandlingstid, så det gikk jo veldig fort.

M: Ja, så var det jo dette spørsmålet om hvordan han reagerte på kreftdiagnosen?

V: Ja, og det visste han ingenting om, så han hadde nok ingen formening om det.

M: Så når de er så små så er det på en måte ikke vits å forklare de noe om...

V: Nei, det var ikke poeng i. Så han var bare med på det som vi gjorde og det var helt greit.

M: Men hva tenker du er viktig når man skal formidle kreftdiagnoser til barn som på en måte kan forstå det? Når de er gamle nok til å forstå det.

V: Det er jo veldig vanskelig da. For hvordan... Altså det kommer jo helt an på alder, hvordan de er som type, men jeg tenker at - og dette er jo sagt før lydopptaket begynte å gå - at dette er mine tanker rundt det, det er ikke noe studie eller noe, det er bare ting jeg tenker omkring det. Sånn som vi gjorde det - vi har valgt å være ærlig. Være ærlig på all informasjon som blir gitt. Selv om dette ikke har noe med den saken å gjøre, så har jeg også en datter som nettopp i januar ble nyretransplantert, som også er en alvorlig diagnose. Hun fikk en nyre av meg i januar. Så vi har visst det i noen år før hun ble transplantert. Hun er 11 år. Så vi kom i den problemstillingen, og det er jo litt av samme - og vi valgte hele tiden å være ærlig. Så hun visste det vi visste om ting. Og det kan jo også relateres til kreft. Altså en trenger ikke mane ut noe at sånn og sånn, men å være ærlig om at vi må gjøre sånn - og i min datters tilfelle - vi skal til Oslo, vi skal være lenge borte, du skal gjennom operasjoner, det kan være vondt, men du får smertestillende. Prøve å forklare så godt som mulig. Og i det tilfelle reiste vi jo til Oslo og hun fikk se Rikshospitalet, besøke alle avdelingene, så hun på en måte var klar over at dette er det vi skal. Og det tror jeg er en god ting på forhånd. Å være ærlig og prøve å forklare... Og å være ærlig på det at: nei, det vet jeg faktisk ikke. Det vet jeg ikke hvordan blir, eller hvordan er, eller hvordan det blir gjort. Det vet jeg ikke. Sånn at jeg tror det er en god måte å nærme seg på.

M: ja. veldig fint. Ja, så hva er dine tanker rundt digital historiefortelling som et hjelpemiddel for å formidle kreftdiagnoser til barn?

V: Ja og det er jo veldig i tiden. Og det igjen kobler jeg tilbake til min datter - litt mer relevant siden hun er litt eldre - hun fikk også se en video som Rikshospitalet hadde liggende ute på sine sider der de kunne se på operasjoner. Der de kunne se et barn som - på en måte alle tingene, der de skulle legge inn veneflon og sånne ting - og gjerne se litt sånne videoer.

M: Var det tegnede videoer eller?

V: Neida, der hadde de en ekte video der de fulgte et barn. Om dette barnet skulle gjennom en operasjon, det vet jeg ikke. Men de hadde en som skulle - nå husker jeg ikke helt hva det skulle gjøre, dette barnet - men de var jo ikke med på selve operasjonen, bevares, det var de ikke, men i forkant av alt. Sant, de fikk møte operasjonssykepleier, de fikk hilse på anestesilegen som kommer å forteller at i morgen skal du få legge inn en veneflon, du skal gjennom en operasjon. Sant, du får en maske over ansiktet. Og da fikk de liksom sett hele forløpet. Og så får mamma være med inn på operasjonshallen, sånn at mamma er der, eller den som er med deg, helt frem til du sover, og da sover du og når du våkner så er du ferdig, og da er det de tingene som skjer etterpå. Det var veldig greit, da viste de et barn på en 5-6 år og så hadde de en som var i ungdomsalder, som på en måte kanskje ikke tør å vise at de er litt redd - og i det hele tatt. Så de hadde liksom to forskjellige ståsteder der de liksom kunne intervjue noen som skulle inn til operasjon for eksempel. Så det var et nyttig verktøy å bruke den typen ting.

M: Men hvilken aldersgruppe tror du vil få best utbytte av en slik applikasjon?

V: Det kommer jo litt an på hvordan den er bygget opp. En sånn type videoer og sånt, den kan du jo spisse mot både de som er unge og de som er eldre. Slik at dette er alle. Men for min Richard, som han heter, så var jo han for ung til å forstå noe av det, men en kan tenkes at symboler kan brukes til de små ungene. Det som du kjenner deg igjen i er gjerne ikke så skummelt. Så hvis det kan lages på en iPad slik at det er gjenkjennbare symboler på de forskjellige tingene, så kan det være et nyttig verktøy for de aller minste. Når de blir eldre så er det jo andre, altså type videoer og alle typer andre ting som er... Så jeg tror at hvis man styrer det litt mot de forskjellige aldersgruppenes forståelse, så tror jeg at det er et nyttig verktøy. For igjen som jeg sa, det som er gjenkjennbart er en trygghet enten du er 5 eller 1, eller 25 og 50 for den del.

M: Ja.

V: Så tror jeg at det er en trygghet. Det en kan kjenne igjen.

M: I en digital historiefortelling for å informere barn om kreft, hva synes du om ideen om at historien fremstiller en figur som får en kreftdiagnose og at du fokuserer både på figurens følelsesmessige opplevelse av det og i tillegg hva som skjer inni kroppen?

V: Nå, kjenner du til Kjemo-Kasper? Det er jo på en måte den figuren som vi bruker som er vinklet fra den andre... Den er jo vinklet fra til å være medisinen. Så den figuren er jo ikke pasienten. Den figuren er den som kommer inn i kroppen og på en måte gjør at du mister håret og blir litt sånn kvalm i magen og sånne ting. Så har du sett boken?

M: Ja.

V: Kjempe skjønn. Den får jo alle sant. Og så har de jo den bamsen. Den har min sønn liggende på rommet sitt.

M: En bamse?

V: Ja, selve Kjemo-Kasper. Han er jo litt sånn stor og så har han jo briller for han ser jo litt dårlig. Og så skal han da bite disse sure kreftcellene. Så det er jo en veldig grei måte å tilnærme seg de minste på, men samtidig så kan den jo faktisk være litt god for de som er litt større også. For vi har jo vinklingen barnekreft og det er jo opp til 15 år, men vi har jo også opp til 18 hos oss da. Men de fleste som får kreftdiagnose er jo rundt en.. altså det er jo av de minste barna som på en måte har de hovedfokusene på leukemi og sentralnervesystem sant. Så det er jo derfor den figuren har kommet inn som en litt sånn kjæledegge. Jeg synes det er en fin måte å på en måte få normalisert det og forklart det enkelt, og de som får en kreftdiagnose. Selv om de gjerne er en 15-16 år, så har ikke de vært der før, sant sånn at å få forklart ting på en enkel, forståelig måte for alle, tror jeg er en grei måte å nærme seg ting på.

M: Så du vil heller anbefale å se på det på det perspektivet på en måte, eller hva tenker du?

V: Hva..?

M: Om å liksom bruke Kjemomannen Kasper-perspektivet - at du ser på det fra medisinsk side?

V: Nei, ikke nødvendigvis. Neida, det er jo på en måte allerede brukt kan du si. Selv om ikke der er en digital... Så har jo vi på en måte den. Så det er veldig greit å både ha en på pasientens perspektiv og ha den. Selv om jeg ikke finnes kreativ til å kunne tenke ut en figur eller noe sånt, så absolutt - det er en god ide.

M: Ja, har du noen andre ideer til historien eller?

V: Nei, som da sagt så er jeg ikke så veldig kreativ, for vi føler liksom at vi har Kjemo-Kasperen som er den som på en måte forteller og formidler. Og sykehuset, slik som Rikshospitalet og de, de bruker Rasmus-figuren. Kjenner du til den?
M: Nei.
V: Nei. Rasmus er en liten mus som formidler en masse utav disse forskjellige... Et lite tips er å gå inn på Rikshospitalet sine barnesider, der har de brukt Rasmus på sykehus. På noen av de er det tegninger og noen tror jeg at er videoer - og deriblant er jo disse videoene som jeg fortalte om - operasjon. Og der har de noe hvor Rasmus får satt inn en veneflon, der Rasmus skal i en operasjon, der han skal få denne masken over ansiktet. Rasmus skal på de forskjellige undersøkelsene, enten det er røntgen eller det er en CT-maskin eller i en MR - alle lydene som kommer - altså sant - så Rasmus er på en måte pasienten. Og så alle som er operert på Rikshospitalet får en sånn liten Rasmus-figur. Så bare se litt på den så har du på en måte noen ideer der om hvordan de har brukt Rasmus-figuren.

M: Nettopp, det skal jeg gjøre. Hvilken medisinsk informasjon mener du det er viktig at kommer frem i en sånn fortelling? Noen spesielle symptomer, behandlinger eller operasjoner?
V: Symptomer er jo ikke jeg så veldig glad i fordi det er så lett å på en måte... Jeg har brukt som en beskyttelse for meg selv at jeg ikke skal henge meg sånn opp i symptomer. Barnet trenger jo på en måte ikke de opplysningene om symptomer, og at det kan føre til sånn og sånn.
M: I forhold til bekymringer eller?
V: Ja, jeg tenker kanskje det, men samtidig så tenker jeg å være ærlig på ting, men dette er jo min personlige mening - sant fra et psykologisk synspunkt kan det godt hende at det vil bli sett på med en annen vinkling. Men jeg tenker at kanskje ikke symptomer er nødvendigvis det som trenger å være først ute. Men da tenker jeg... ting som, hvis det har en effekt av en medisin sant, så har vi jo det i forhold til at... - sant som Kjemo-Kasper sier at når medisinen sant... Så mister du håret fordi han har jo ikke briller. For å forklare dette med medisiner og sånne ting. Så det tenker jeg at er veldig greit å ha med. Men akkurat symptomer, hvis du tenker på symptomer på sykdommen, så hvis den skal være rettet mot barn, og <u>når</u> skal den være rettet - altså skal den være rettet mot de barna som har fått sykdommen? - sant siden du har de og de symptomene, så kan legene si at det er det som gjør at det er en del utav det å ha kreft - da er symptomer helt greit å ha med tenker jeg. Men sant, da har du på en måte allerede fått den, men hvis den er tenkt til å nå ut til allmennheten, så trenger gjerne ikke barn den informasjonen. Våre barn de vet veldig mye og er det større barn så har de Internett, så de leiter og sånt.
M: Ja, men det er det som er litt skummelt også fordi på Internett så... skrekkhistoriene og...
V: Det er det de gjør sant, og da tenker jeg at det å på en måte å linke det opp mot symptomer når du allerede har fått diagnosen, sant, fordi da er det dette som kan si at det er kreft sant. Den typen ting tenker jeg.
M: Er det noen behandlinger eller operasjoner du tenker bør være med i fortellingen?
V: Ja, altså det er jo, mange av disse innebærer jo operasjoner. De aller fleste må jo gjennom en operasjon for faktisk å kunne få behandling. Fordi de må gjerne ha inn et Hickman Kateter, så de slipper å få veldig mye sprøyter og sånne ting. Sant, så de må i en narkose og på en måte ha noe som forteller om hvordan det er å få en narkose - det er veldig greit. Min datter var veldig sånn... - ikke i forkant siden vi hadde snakket om det - men akkurat det var litt skummelt. Så å ha... hvordan er det når jeg får narkose? Litt skummelt, så plutselig var det over, og så var det ikke skummelt i det hele

tatt. Så noe som kan visualisere...

M: Den opplevelsen...

V: Av å ja. Det er litt ok sant, for de fleste må gjerne få det. Sant, for Leukemi har gjerne to og et halvt års behandlingstid, men da må de jo gjennom noen operasjoner. Først for å få lagt inn det (kateteret), og så kommer cellegiften og alt det andre i ettertid. Så inni en vedlikeholdsfase, så er det gjerne intensivt igjen. Det går litt sånn i stadier. Så det å på en måte ha noe som forteller litt om det som de fleste får, kan være greit å ha.

M: Har du noen andre tanker om hva som er viktig å få med i handlingen?

V: Ja, altså jeg er ikke så kreativ, men kanskje være realistisk - tiden - min sønn han hadde bare 4-5 mnd. selv om han hadde to operasjoner, så er det gjerne noen som får cellegift etterpå. Så er det noen som får stråling, mens han hadde kort - men sant at det kan ta litt tid å få dette her. En må være sikker på at alt... Være realistisk. Sant at en kan bli dårlig og sånne ting, kvalm, veldig greit å få det med. Men sant det kommer an på hvor gammel ungen er, skal du favne om alt i en engang og si at "jøss værsågod - dette er det som skjer" eller skal vi ta det stegvis? Sant - sånn at det på en måte kunne bygges opp som en slags etappe, sant. Sånn som det første vi gjør det er sånn og sånn, og så neste etappe så er det gjerne cellegiften som skal gå over sånn tid. Men sant det er jo delt inn i protokoller dette her, slik som min sønn da som hadde 4 cellegifter, og de gikk over 3 døgn. Slik at når han skulle inn til en av disse her kurene, som de kaller det, en kur - så var den på en måte på tre døgn. Og han var inne på sykehuset i 3 døgn. Så kanskje fremstille det litt etappevis, hvis ikke kan det virke veldig lenge. Så kanskje litt sånn stykkevis og delt. Sant at du kanskje får noen trappetrinn - at dette skal vi gjennom, men vi går steg for steg.

M: Ok, veldig bra. har du noen tanker om karakteren i fortellingen? Hvordan den bør være? Nå sa du at du ikke var så kreativ...

V: Jeg er ikke det da, men kanskje. Jeg så det var noen tegninger og sånt, og det er jo på en måte noe som, altså vi har jo denne Kjemo-Kasper som på en måte er litt sånn - han er ikke hverken jente eller gutt, så en som på en måte kan være både og, som de kan identifisere seg med hvis det skal være en som skal være pasienten på en måte.

M: Tenker du litt mer sånn hvis det er en jente - at det er en litt mer guttete jente eller?

V: Ja, eller så måtte det på en måte være en både-og.

M: En både-og ja.

V: Ja, sant at du har en som følger en jente og så har du en som følger en gutt. Slik at de har på en måte en som er spesifikk. Eller så må det på en måte være en som er både-og.

M: Ja, eller ingenting.

V: Ja, en dukke eller kanskje ikke en dukke, men en figur av en eller annen sort som er litt sånn - sant at den er som en tegning - en som både faktisk kan være jente og gutt, sant. Men det er klart at skal det deles inn i alder, så er det jo utfordring at... Altså hvilke utfordringer får en som er ungdom i forhold til en som er en liten som har mamma og pappa med seg - og spørsmål - hva tenker de om det her. Kanskje det kan være en jente og en gutt sant. At det kanskje kan være en som er delt inn i ungdomsbiten og en som er for de som er yngre sant.

M: Ja, og hva tenker du om informering om døden?
V: Ja og det er jo et vanskelig spørsmål selvfølgelig, kommer helt an på hvor gammel barnet er selvfølgelig - og dette vet jo vi. Det kommer an på hvor gammel de er. Disse ungene kommer jo inn i en verden som er et livs mareritt for foreldrene. De opplever å bli kjent med andre på avdelingen, opplever å miste noen av de... sant. Det er ikke nødvendigvis at de vet om det fordi de er jo inne på kurer sant, så er de hjemme igjen, så er de inne igjen, men så spør de gjerne etter sant og sånne ting. Jeg tenker at det er ikke noe vi skal stikke under en stol å si at det ikke eksisterer. Men informere på en ryddig og ærlig måte at vi sant, vi har medisiner og de skal gjøre deg frisk igjen og ha en positiv utgang, men samtidig informere om at det er noen som de ikke klarer å redde. Men dette er så tungt spørsmål at jeg tenker at jeg ikke kan svare om du bør ha det med eller ikke, fordi jeg har ikke kjennskap nok til hvordan et barnesinn fungerer, slik at det tror jeg er opp til en psykolog å besvare. Men jeg tror at unger tåler sannheten omkring ting og en trenger ikke å utbasunere det... for har du en 8-åring så vet de dette likevel tenker jeg. Men det må formidles på en måte som fagfolk, tenker jeg, må være innom å kvalitetssikre - hvordan det skal formidles på en ordentlig måte.

M: Ja hvis, nå har jeg jo disse karaktertypene, så jeg lagde en til i går da som var litt mer androgyn da.
V: Ja, dråpen! Mhm. Han var jo skjønn da.
M: Ja? Så var det jo nesten bare jenter, men det var fordi at de var lettere å tegne synes jeg. Så det var ikke noen annen grunn til det. Så er det noen av disse karakterene som du kunne tenkt hadde passet bedre enn andre eller?
V: Jeg så litt på de, jeg tenker at det er jo en tøff ting for et barn å få kreft, sant så hun sa veldig lei seg ut det, men samtidig så må vi jo, må være noen som på en måte - det er jo ikke bare trist. Så må signalisere litt sånn håp og litt sånn. Jeg likte hun her fordi at hun har med seg han lille kompisen her som viser at det kan være godt å ha noen i armkroken i denne tiden her. Slik at jeg synes hun var litt skjønn.
M: Ja, nummer 2.
V: Mhm. Men det var jo bare mine... Sant.

M: Ja, men veldig interessant. Ja, har du noen andre tanker rundt tema? Sånn avslutningsvis.
V: Nei, ikke sånn spesielt, men sant, jeg har jo mye erfaring - altså jeg jobber jo på leir for kreftsyke barn. Som er Barnekreftforeningen som arrangerer den leiren som heter "Ferie med mening".
M: Ååja, om sommeren?
V: Ja, i juni. En fantastisk - det er da for familiene til de som får et kreftsykt barn. Der de får komme å være sammen i en uke og det gjelder også søsken. Så det som jeg kunne tenke meg kunne vært med i en - det er det at søsken har ikke så veldig mange arenaer der de kan treffe andre søsken å få vite andre ting. Så dette kan også vinkles fra - ikke bare pasienten, men altså en app som kan - eller en digital som kan gi litt til de søsknene.
M: Det er veldig interessant.
V: Fordi at barnekreftforeningen har fokus på ikke bare det kreftsyke barnet, men hele familien. Sånn er det jo på en måte for voksne også - får de kreft så influerer det hele - men i større grad for barn fordi at søsken som skal på en måte få - altså de sitter med mange spørsmål og tanker omkring dette her. Så det å også innlemme de i noe, slik at du på en måte har en søsken app.

M: Ja, for det kom faktisk frem i intervjuet i går også, at søsken ofte føler seg utenfor. At alle spør hele tiden de om hvordan den andre har det, så de blir på en måte glemt oppi alt dette.

V: Ja, sant for de får ikke... Altså besteforeldre, tanter og onkler og alle disse her, de er på en måte utenfor. Du har det syke barnet og foreldrene og så kommer søsknene - de er gjerne med på sykehuset i blant, men de får ikke... Og de treffer gjerne ikke andre. Så på denne "Ferie med mening" så treffer de andre som har søsken. Og så har vi jo fagpersoner inne som kan være med å lage litt, så å på en måte ikke glemme søsken. Så kanskje få med litt at det er søsken som også spiller inn i denne. Ja, og liksom spørsmål som søsken har - om det er ting som de lurer på. Det kommer jo an på hvor gamle de søsknene er da. Så det, sant at en også har det med i en digital.

M: Veldig, veldig bra. Men da er vi ferdig.

V: Ja, så bra da.

Appendix F

Interview Transcript: Straume

Interview: Digital storytelling as tool for conveying cancer diagnoses to children

Marianne Straume is a psychologist and specialist in clinical child and adolescent psychology. She was the head of the psychological work with cancer diagnosed children at the Children's Clinic at Haukeland Hospital for several years.

Monday 10th November 2014 at 10:00 - Center for Crisis Psychology (Bergen)

Interviewer (M): Maiken Beate Fjellanger
Interviewee (S): Marianne Straume

M: Så da er første spørsmålet om du synes det er greit at navnet ditt oppgis i oppgaven eller om du foretrekker å være anonym?
S: Det er greit at det oppgis.
M: Ja, supert. Så hvilken utdanning har du?
S: Jeg er psykolog med spesialist innenfor klinisk barne- og ungdomspsykologi.

M: Ja, hvilke elementer er det viktig å tenke på når man skal formidle kreftdiagnoser til barn? Det skal jo være en sånn digital historiefortellingsapplikasjon - så liksom sånn - hva er viktig å tenke på når man på en måte skal lage en fortelling for å formidle kreft til barn?
S: Ja, det må jo være sannferdig, konkret og enkel - altså tilpasset det utviklingsnivået, sant. Hvis du ser på Kjemomannen Kasper så er det gjort som en historie som barn skal kunne kjenne igjen. Målet må være at barna skal bli tryggere av denne informasjonen - dvs. at den må være nøktern, lite skremmende, sannferdig og nennsom - så må det også formidles med håp - at dette er en sykdom som det finnes mye behandling for, og at behandlingen kan gi bivirkninger, men at det er det som skal til for å bekjempe sykdommen. Men det er veldig viktig at den er konkret og alder-spesifikk og at det er en informasjon som alltid skal formidles med foreldre til stede.
M: Ok, det er viktig?
S: Ja, det er viktig at foreldrene er til stede og vet det samme. Barn skal ikke sitte aleine noen gang

- de kan selvfølgelig gå tilbake til Kjemomannen når - eller til en informasjon når de vil - men når det skal presenteres for barnet skal foreldrene alltid være til stede.
M: Ok, det visste jeg ikke.
S: Og det handler om at de skal vite det samme. Og nå snakker jeg om barn spesielt - kanskje når man har en 15 åring kan man diskutere det når man blir så stor. Men barn da skal foreldrene være til stede. De skal kunne vite mer enn barna, slik at barna skal kunne gå til foreldrene dersom de er usikker på noe eller vil diskutere noe eller får nye spørsmål når de ser på det.

M: Ok, mhm. Brukes det metaforer eller andre virkemidler for å gjøre informasjonen mer forståelig?
S: Ja, det gjør en jo sant - i Kjemomannen Kasper gjør man jo det, sant, for å kunne hjelpe de å få grep om noe som egentlig er så abstrakt og vanskelig å forstå, så må man konkretisere og symbolisere og bruke metaforer som ikke er skremmende. Vi bruker veldig mye metaforer i arbeid med barn og med voksene også. Og det er det som er brukt - sant, de har jo laget en historie om - en helt egen historie for at barna skal forstå det.

M: Nettopp. Hvilke reaksjoner er det vanlig at barna opplever når de får kreftdiagnose?
S: Det er veldig avhengig av alder, det er avhengig av foreldrenes reaksjoner og det er avhengig av hvilken erfaring de har med kreft. Og så vil det forandre seg, sant, for det ene er å få informasjon, det andre er at de faktisk skal tåle ganske mye - sånn at de reaksjonene vil forandre seg når de er dårlig, ikke kan være på skolen, møte andre barn som kanskje dør av kreft, så kreft er jo ikke bare å få diagnosen - det er jo bare et bittelite steg i et veldig langt forløp. De skal jo være - de mest vanlige kreftformene slik som leukemi for eksempel er det mange flere som blir frisk av, men det krever også en mye tøffere behandling enn det gjorde for 20 år siden. Sånn at de reaksjonene på kreft vil handle om informasjon og hvilken kreft det er og hva det kan bety, og så vil reaksjonen også preges av det den behandlingen koster de - sant at de blir isolert, må være mye borte fra skolen, fra vennene sine - påføres mye ubehag. Ser hva dette koster foreldrene deres og familien. Så reaksjoner er ikke noe som man har og så blir de borte, de vil forandre seg over tid. Hvis du er 2 år så skjønner de ikke mye av å få kreft, men du skjønner veldig mye av at foreldrene er veldig redde - det kan de reagere på, sant. Hvis du er 5 år så vet du gjerne heller ikke så mye om kreft hvis ikke du har en tante som døde av det eller noe annet, så da er plutselig kreft forbundet med død. Så det også vil jo være en referanse for barn. Mens en 10 åring vil jo vite om kreft enten kanskje de har opplevd det på nært hold eller ikke, fordi de er så moden eller kognitivt utviklet at de forstår mye i seg selv uten å måtte se på foreldrene for å forstå det eller uten å ha opplevd det nært i livet sitt. Så dette vil forandre seg avhengig av alder, erfaring med kreft og selvfølgelig foreldrenes reaksjoner. Hvis foreldrene blir vettskremte så vil det påvirke alle barn.
M: Det er vel ikke sånt som er så lett å skjule heller kanskje, for barna plukker det opp? **S**: Ja, det gjør de, men foreldre er jo forskjellig. De har jo også gjort ulike erfaringer sant.
M: Ja, nettopp. Tanken er jo litt sånn - nå er ikke det bestemt - men jeg ser for meg en historiefortelling som og skal formidle at det er naturlig å oppleve forskjellige følelser - og sånn akkurat når du får en kreftdiagnose - har du noen eksempler på hvilke type følelser som er vanlig?
S: Det å bli forskrekket, sant eller det vi kaller sjokk kan være en reaksjon. Noen blir kanskje sint, noen blir redd, noen blir kanskje lei seg. Noen synes det blir vanskelig å sove fordi de får mye å tenke på. Ja, det kan være mye forskjellig. Og noen tenker kanskje "Ok, dette er kjipt, men jeg skal klare det".

M: Så veldig masse forskjellig?

S: Ja, veldig mange forskjellige følelser og gjerne mange på en gang. Så det vi hjelper barn med, det er jo å tåle at barna har så mange - så kan det skifte veldig sant - man kan være glad og optimistisk et øyeblikk, men så skjer det noe kjipt - man kjenner seg ikke så bra, så er det litt vanskeligere igjen. Så det er ikke slik at man går gjennom hele forløpet med bare en følelse. Det varierer jo veldig. Så man har et stort register som man veksler mellom. Men så er jo barn tilpasningsdyktig, så mange opplever jo glede og håp og kan glede seg over ting og til ting som vi som står utenfor synes er vanskelig å forstå.

M: Hva er dine tanker rundt digital historiefortelling som et hjelpemiddel for formidling av kreftdiagnoser til barn?

S: Altså beskriv hvordan du tenker deg...

M: Det blir på en måte en... Det blir som en bok bare at den er mer interaktiv da. At du på en måte kan klikke litt på figurene, så kan det kanskje komme en stemme eller sånn - sånn at den blir mer levende. Mer levende bok.

S: Det tror jeg høres veldig bra ut. Vi er jo på jakt etter hjelpemiddel og det som kan hjelpe barn å forstå ting bedre. I en vanskelig situasjon så er informasjon veldig viktig - uansett hva som skjer så er informasjon en av de tingene som vi tenker gir bedre mestringsmuligheter. Først og fremst så gir det mindre angst ofte. Fordi hvis ting skjer rundt en og en ikke vet hvorfor og hva - for 30 år siden så ble jo ikke barn informert. Så vi har jo gått veien, som er erfaringsbasert - på at informasjon hjelper. For en gang var det sånn at foreldrene ikke fikk være med barn på sykehuset, de (barna) fikk ikke informasjon. Og de to tingene har vi sett at er skadelige for barn. En har jo beveget seg mer og mer mot åpenhet og det er jo en selvfølge i dag at barn skal få vite hva som feiler de. Det var det ikke når jeg var ung. Jeg hadde en fetter som døde av kreft og han tror jeg ikke fikk vite det - i hvert fall ikke av sykehuset, hva som feilte han. Så det var ikke vanlig da. Mens nå er det det. Men så er det jo det at barn beveger seg i en avansert verden, og dette er jo avansert og vanskelig å forstå - og ikke bare diagnosen, men alt det som kommer etterpå sant. Blodverdier og isolasjon, det er veldig mange medisinske ting de skal forholde seg til. Behandlingen, bivirkninger av behandlingen. Konsekvenser av behandlingen, hensyn de må ta - som de må forstå grunnen til. Så det er veldig mye vanskelig informasjon som vi skal hjelpe barn og forstå. Så alle hjelpemidler er velkommen for å si det sånn. Og det er jo slik barn forholder seg til informasjon - mye mer enn hva jeg gjør, de på min alder gjør - så det å finne en måte å informere barn på som er tilpasset det de er trygg på, som de behersker, er veldig bra. Så lenge det er trygt og et godt verktøy.

M: Ja, nettopp. Hvilken aldersgruppe tror du kunne fått best utbytte av en digital historiefortellings applikasjon?

S: Det er vanskelig å vite - det kommer an på hvordan den er.

M: Ja, jeg har hatt flere intervjuer og alle...

S: Hvis den er tilpasset 10-åringer så er den best for 10-åringer. Men jeg begynte jo med Kjemomannen helt ned til 4 år og bare viste bilder og så tilføyde jeg teksten etter hvert. Og barn lærer gjennom erfaring - det er ikke sånn at en 5-åring forstår det, en 7-åring forstår det og en 10-åring forstår det. Sånn er det jo ikke. En 5-åring som har gjort noen erfaringer er i stand til å bygge på de erfaringene med ny informasjon. Mer enn en 5-åring som ikke har gjort den erfaringen. Så en 5-åring som ikke har vært

på sykehuset kan ikke forestille seg så mye om sykehus før de har vært det, mens en 5-åring som har tilbrakt et år på sykehus vil kunne bygge på den erfaringen og lære mye mer enn en som ikke har vært der. Så ny kunnskap bygger både på den modenheten barnet har, men også på tidligere erfaring. Slik at men en gang man begynner å forklare barn noe, hvis du klarer å forklare noe på det alderstrinnet, så vil jo det være like bra for alle alderstrinn tenker jeg, men da må det være tilpasset akkurat det alderen. For du forsøker jo å få små barn til å forstå. Nå vet ikke jeg om det er mulig å hjelpe en 2-åring på den måten. For en 2-åring handler det mye mer om erfaringer - de klarer ikke å holde fast på informasjon, så der ser jeg for meg at det er vanskelig. Men så snart et barn er i stand til å ta inn noen historier, og det begynner man med i hvert fall i 4-års alder - i og med at du kaller det historiefortelling, så må jo barna være i stand til å ta inn en historie. Da kan de ha nytte av det.
M: Men tenker du en historie ville vært mest til hjelp for de yngre barna eller?
S: Nei da tenker jeg hele veien.
M: Alle sammen? Altså hvis jeg kan lage en som kan fange mange da eller?
S: Ja, hvis du skal lage en.
M: Ja, jeg har jo ikke tid til så veldig mye.
S: Nei, men hvis du tenker generelt så må du tilpasse til alder. Men det jeg ser i Kjemomannen er at de leser den i - for det er jo noe med... Det som er viktig at. Nå må jeg tenke litt høyt, for jeg er jo ikke noe data-menneske. Det kan være deler av den, noen av de figurene de skal trykke på kan være greit for en 5-åring, mens en 10-åring ville kunne ta inn mer av det en historie forteller. Så kanskje ha noen hovedpunkter som et yngre barn også kan få tak i sånn som bildene i Kjemomannen, mens eldre barn kan ta inn hele teksten og stille spørsmål. Og ting som er så vanskelig å forstå som kreft ser vi jo at selv eldre barn kan ha glede av Kjemomannen, fordi den gjør vanskelige ting enkelt - og det tar ingen skade av. Det vil jo ikke skade noen, det vil bare bli kjedelig jo eldre de er.

M: Ja, nettopp. I en digital historiefortelling for å formidle barn om kreft, hva synes du om ideen om en historie som fremstiller en figur som får en kreftdiagnose, og figurens opplevelse av det - altså følelsesmessige opplevelse og det som skjer inni kroppen til figuren. Hva tenker du om det? Altså begge deler - eller ser du for deg at det hadde vært bedre å vinkle det på en annen måte?
S: Egentlig litt vanskelig å si, for det er to ulike informasjonsnivå du egentlig snakker om. Det ene er det faktiske - altså hva sykdommen er, hva den handler om, hvilke konsekvenser, det de skal lære om sykdommen sin. Det andre er hvordan - det er mer psykologisk læring sant. Jeg tenker begge deler - det blir jo viktig å skille det på en måte, ikke dermed si at det er to forskjellig historier, men sant. Det er vanskelig å se for seg at det skal gå helt hånd i hånd. Så fikk han kreft, og så ble han lei seg, men først må han jo forstå hva kreft er før de følelsene kommer inn. Det ser jeg ikke helt for meg. Begge deler er kjempe viktig, men en må jo først få inn den faktiske informasjonen, tenker jeg.
M: Ja, først det og så...
S: Ja. Eller at en kan velge mellom det sant. At en kan velge å bare trykke seg gjennom den faktiske informasjonen og så se hvordan var dette for Per eller Pål eller. At en kan velge det når en er klar for det. For hvis en bare har fått vite at en har kreft så er det ikke interessant å forholde seg til følelsene sant.

M: Hvis vi skal ha med dette med følelser - hvilke følelser mener du det er viktig å formidle? Så man

kan formidle at det er normalt å oppleve mange forskjellige følelser, og om det er noen spesielle følelser man skal fokusere på i historien? -Hva du tenker om det.
S: Det er disse vanlige kjernefølelsene: redd, trist, forskrekket, urolig.

...

Så er det også viktig å ha positive følelser med, sant at etterhvert så kan en...
M: Ja, presentere det og...
S: Ja, det er kjempe viktig. At en kanskje kan bli mer glad for ting som en ikke var glad for før og en kan glede seg til nye ting og så går det an å - altså det er noe med mestring av de vonde følelsene, det må jo også være med sant. Hva kan en gjøre hvis en er lei seg eller redd? Så det er ikke å bare beskrive og gjenkjennes men også hva kan hjelpe når en har det sånn? Og der kan en også, på en måte, i og med at det er digitalt - hva hjelper meg når jeg er lei meg. At det kan bli en interaktiv bit der. Men i hvert fall er det viktig å få med det som kan oppleves som ubehagelige følelser, og håp om at gode følelser også er med.

M: Har du andre ideer til historien? Noe du kommer på?
S: Hva tenker du på da?
M: Jeg bare tenker på handlingen generelt. Er det noe du tenker med en gang at ville være viktig å ha med i en slik fortelling?
S: Det er jo laget en del slike skriv fordi unger skal jo gjennom - i tillegg til å vite at de har kreft er det jo også masse prosedyrer og sykehushverdagen. Så det er jo mange ting man kan velge. Det kommer jo an på hvor omfattende det skal være. Det ene er jo å få vite om selve sykdommen og at det finnes behandling nå i kan ta modellen Kjemomannen Kasper - det er jo det jeg er vant til å bruke og tenke på. Men så er det jo mange andre ting sant de skal sove på sykehuset. Og det er jo laget - på ulike avdelinger - skal du ta røntgen så er det noen forberedelser på det, og operasjoner finnes det noen forberedelser til. Veldig mange får operert inn sånne små Hickman, men det kommer an på hvor omfattende det er, det vet jeg for lite om. Men det er mange ting en kan ta med som mange barn må gjennom. Det er vel noen av de der. Så det kan være enten bare det med kreft, eller det kan være en forberedelse på en av de tingene på de tingene som er kjipe, som de blir vant til etterhvert. Men jeg synes det er veldig ok at det skal inneholde følelser, men det må også være gode - altså skille mellom ubehagsfølelser - altså de man ikke vil ha så mye og disse gode følelsene. Og hvordan man kan håndtere disse vonde, snakke med foreldrene og søke trøst.
M: Men det er veldig bra, jeg hadde ikke tenkt på det.
S: Og tenke på at ting kan bli bra selv om det er vondt akkurat nå.

M: Nettopp. Anbefaler du å ta utgangspunkt i en bestemt krefttype når formålet er at flest mulig skal kunne relatere til historien?
S: Nå er det jo forskjellig. Det å ha hjernesvulst er jo en stor gruppe og leukemi er en stor gruppe. Og hjernesvulst det er veldig spesielt, den er annerledes enn de andre, men vi har brukt Kjemomannen til alt sant for det snakker de om svulster og det at det flyter fritt rundt, så der synes jeg de har grepet det bra. Men konsekvensene av å ha hjernesvulst er jo også mye verre. Fordi at det påvirker gjerne barnet i sterkere grad. De må operere eller at de forandrer seg, og det er ferdigheter de mister, senvirkninger

er jo størst hos disse barna. Nå er jeg ikke i daglig kontakt med barneklinikken lenger, så jeg jobbet jo der fast før, da kunne jeg dette mye bedre. Nå er det jo 20 år siden jeg sluttet, men jeg jobber fortsatt innimellom med de ungene, men jeg har ikke daglig virke i Barneklinikken. Men sånn som de har gjort i Kjemomannen så synes jeg de har gjort det greit for der snakker de om kreftcellen og at den oppfører seg ulikt. Noen ganger flyter den rundt i blodet som er mest vanlig, og noen ganger kan de klumpe seg sammen så de må opereres bort. Slik at der ville jeg brukt medisinsk veiledning på det, men mest mulig generelt er vel greit siden de møter jo andre barn i ulike typer kreft.

M: Hvilken medisinsk informasjon mener du er viktig at kommer frem i en slik fortelling? Noen spesielle symptomer?
S: Nei.
M: Eller behandlinger eller operasjoner?
S: Behandlingen er viktig tenker jeg, slik som Kjemomannen, fordi det er den de skal leve med. Kreften er jo ikke den de lever med på sykehuset, det er jo behandlingen. Så lenge det går bra, så er det jo behandlingen sant. Hvis ikke du må amputere eller - ja, det er jo også behandlingen. Men du kjenner på en måte ikke kreften, men behandlingen. Så fokus vil jo da være på behandlingen og kunnskap rundt den - hvorfor den er viktig og hvilke bivirkninger den kan gi og hvordan det kan påvirke livet. Men det er også viktig å ikke skremme barnet i fremtiden - for vi vet jo ikke hva som kan skje. Noen barn blir kanskje mye isoler og må mye ekstra på sykehus og får mye komplikasjoner. For andre følger de protokollen ganske greit og det er forutsigbart. Så man kan ikke ta alt på forhånd. Det er viktig å formidle disse store linjene: at man blir passet godt på, at man vet mye om kreft i dag, at de fleste barn blir frisk. Det må jo være medisinsk grunnlag for det. For man kan på en måte ikke forutsi alt, ta sammendraget først så kommer detaljene etterhvert. Så det er det store bilde du må ta her, så vil jo barn lære etterhvert og så vil de ikke ha så mye behov for denne måten å få informasjon på. Fordi de lærer seg ting underveis.

M: Disse spørsmålene har jo vært litt oppe tidligere, men har du noen andre tanker om hva som kan være viktig i historiens handling?
S: Nei, ikke på dette nivået, på dette tidspunktet.

M: Nei. Har du noen tanker om hvordan karakterene bør være?
S: Vanlige barn. Hvis ikke du lager noen figurer eller nei det der har jeg ingen formeninger om. Til det er jeg for lite... Kjemomannen er jo et barn som blir - Kjemomannen er jo på en måte - her er jo behandlingsfokuset sant.

M: Hva tenker du om informering om døden i en slik fortelling?
S: Ideelt sett så tenker jeg at det skal være med som en del av det, men det skal på ingen måte tones høyt opp for nå blir de fleste friske. Det er derfor det er så viktig at foreldrene er med, fordi dette snakker vi om med alle foreldrene - vi sier jo at alle foreldrene bør informere om at kreft er noe man kan dø av. Noen velger å la vær. For de tenker på et eller annet tidspunkt vi de møte det og da skal de ha fått vite det på en ordentlig måte av voksne og ikke når barn sier "OJ, kreft er jo noe du kan dø av!". Så derfor er det så utrolig viktig at det blir sagt, men det må gjøres skikkelig og det må foreldrene være enig i. Og noen må få forklart hvorfor det er så viktig, noen gjør det av seg selv. Selv om vi tror

at ditt barn skal overleve, så vil vi risikere at for det første at det kan møte et og annet barn eller høre om noen. Hvis ikke har snakket med dem om det da, kan de bli veldig redd fordi da forstår de ikke at - da har man ikke forklart hvor liten sjanse det er for eksempel. Så det bør...
M: Så det blir noe stort...
S: Ja, og hvorfor har de ikke sagt det til meg? Skal det skje med meg? Men hvis en har forklart at hvis en ikke får behandling så er det noe en dør av, men nå har en så fin behandling. Så kan en bruke eksempler på sykdommer som en døde av før, men som man ikke dør av lengre sant. Fordi behandlingen gjør at man blir frisk.

M: Ja. Så her er noen karaktertyper da som du kan se.
S: Dette er jo slikt som barn selv egentlig. Dette var jo veldig kjønnstydelig.
M: Ja, det var det, så det er i grunn egentlig det at det var lettere å tegne jenter. Men jeg har fått litt kommentarer på det da, at kanskje noe som er mer kjønnsnøytralt.
S: Ja, eller begge deler. eller et eller annet. Dyr, barn identifiserer jo seg med dyr, men det vil jo gjøre at den øvre aldersgrensen. Nei, den ble litt for lite ja (Vanndråpen viste hun tydelig misnøye med).
M: Litt skummel kanskje?
S: Ja, litt for ja...
M: Litt for lite personlighet?
S: Ja, eller jeg vet ikke helt hva. Men jeg tenkte at den - men det er som sagt. Barn relaterer jo seg til dyr. Vi bruker jo syr i historier av og til når vi snakker med barn og skal hjelpe barn. Identifiserer seg med bamsen som skal få narkose og de øver seg på bamsen sin for at de skal bli trygg i en situasjon. Bamsen skal få - en skulle gi bamsen sprøyte, men ungen nektet fordi bamsen skulle ikke få så vondt. Men jeg tenker kanskje at det er tryggest med en figur, men den må være mer kjønnsnøytral eller at du bruker begge to - to som blir kjent på sykehuset.
M: Men en som er mer kjønnsnøytral - er det på en måte...? Så da kan det ikke være en jente- eller guttefigur?
S: Nei, altså det vil jo... Identifiseringen vil gjerne bli, jeg vet ikke. Det er vanskelig å si. For meg er det vanskelig å bestemme seg, men en kan jo bruke to som møtes på sykehuset og blir kjent der fordi de har samme sykdom. Og de kan ha ulike følelser og de kan kjenne seg igjen i forskjellige - litt mer å velge i. Ulike krefttyper, men noe likt.
M: Ja, sant, sant. Hvilke trekk er det ved karakterene som gjør at du sykes at de egner seg eller eventuelt ikke egner seg? Nå har du nevnt dette med at det ble for...
S: Ja, det tror jeg er det eneste jeg kommer på.
M: Og den der ble litt sånn (Vanndråpen)?
S: Ja, den var - for meg - men altså for barn. Nå er mine barn voksen så jeg har ikke fulgt med på barne-tv og jeg vet ikke hvilke figurer de forholder seg til og hva som er naturlig for de.

M: Ok. Har du noen andre tanker rundt tema nå på slutten?
S: Nei, jeg tenker en må jo prøve seg frem, og dette er jo litt sånn prøving og feiling og jeg tenker barn må være. Jeg har ingen problemer med å se at ikke barn skal være med i dette, å utvikle det. Og at dette kan gi veldig mening til barn i en viss alder og være med å diskutere dette. Og de er gjerne de som kan gi de beste tilbakemeldingene. Men jeg liker den ideen om at det skal være tilgjengelig både for det

rent informasjonsbiten - men jeg tror det må skilles fra følelsene - tenker jeg umiddelbart. Hvis ikke blir det gjerne for mye for de å. Spesielt de minste ungene. Litt større kan en jo sjonglere litt mer med. Men informasjon skal jo være ganske avgrenset og kort og tydelig. Jeg tenker det må komme for seg selv, slik at... Og så er det da følelser i en annen bit da. Men at man kan si at det er noe som er vanskelig. Sant det er jo noe vanskelig som har skjedd, man har jo kommet dit og det er en vond stemning. Men det blir jo aldri denne måten man får den - eller jo kanskje - men først så får jo ofte foreldrene informasjon sant. Og så ungene. Nå vet jeg ikke helt hvordan de gjør det. Det er jo også en ganske vanskelig situasjon. At ungene vet, det husker jeg var mange dilemma, at ungene vet at det er noe vanskelig som skal fortelles fordi de har tatt prøver og slikt og så snakker de med foreldrene først og så sitter de igjen. Samtidig så var det viktig å få sagt det til foreldrene slik at de kunne være delaktig i det å fortelle det til barna.

M: Jeg har skjønt det sånn også at foreldrene skal bestemme om barna skal få vite om det er kreft eller ikke.

S: Nei, det tror jeg slettens ikke.

M: Å, for jeg har intervjuet en lege skjønner du og hun mente. Og hun sa det.

S: Hvor jobbet hun da?

M: På Haukeland.

S: På Barneklinikken?

M: Ja.

S: Det var nå veldig rart. Du kan ikke velge å ikke fortelle til en 10-åring at han har kreft, det tror jeg ikke at man kan. Det vil jeg forundre meg, at de godtok det. Fordi de vil jo få vite det av de ved siden av. Og det å ikke få vite hvilken sykdom du har virker jo helt rart. Du kan jo ikke behandle - nei, det ville jeg synes var veldig rart. Det vil jeg i så fall ikke bifalle.

M: Nei, det gjelder kanskje bare de minste da. Eller var det gjerne?

S: Men det er i hvert fall ingen grunn til at de ikke skal få vite det? Nei, det bifaller jeg i hvert fall ikke. Man må bruke ordet kreft, man kan ikke lage en applikasjon uten å bruke ordet kreft. Det blir jo helt.

M: Nei, nei, nei.

S: Nei, det vil jeg syntes var rart. Da synes jeg verden har tatt et steg tilbake.

M: Ja, absolutt.

S: For det er jo helt umulig å forvente at et helt sykehuspersonale skal klare å la vær å fortelle om sykdommen. Det vil jo være et helt umulig krav til personalet også, å huske hvem de kan snakke med det om og hvem de ikke kan snakke med det om og. I hvert fall navnet på sykdommen.

M: Ja, det må jo være utrolig slitsomt.

S: Ja, og hvis barnet spør en gang da? Skal de si: Nei, dette kan jeg ikke si til deg?

M: Jeg var på en konferanse for litt siden og presenterte den ideen da, og da var det en som kom bort til meg og fortalte om. Han var trener på et fotballag og der var det en av guttene som hadde hjernesvulst, kreft, og han visste det ikke selv, men alle andre visste det, fordi at foreldrene var så bestemt på at han skulle ikke vite det. Og han synes jo selv av dette var helt forferdelig. Og han selv følte jo seg slapp og alt dette her, men han visste ikke hvorfor. Så det er jo noen tilfeller, men dette var kanskje ikke i Norge, det var en svensk konferanse. S: Altså foreldre har jo den absolutte myndigheten, men det er veldig rart at man lenger ikke skal kunne bruke ordet kreft. Jeg trodde ikke det var mulig å ikke bruke det ordet om de blir behandlet på sykehuset. Hvis de ikke er på sykehuset så går det jo an. Men i den grad det f.eks. er en leukemi-pasient som skal tilbringe så mye tid på sykehuset og få cellegift, så tenker jeg det nesten er umulig å gjennomføre. Men hvis det er en sykdom som er oppdaget som 2-åring og det ikke er mer å gjøre, og han er blitt 10 år og den vokser sakte, så kan foreldrene bestemme det. Det kan de for da omgås de ingen andre, men jeg kan ikke se for meg at legene kan tenke seg at det skal være mulig å gjennomføre i en leukemi behandling eller en aktiv behandling med en unge som er i stand til å forstå at en ikke er i stand til å bruke ordet kreft. Det synes jeg det er vanskelig å forestille seg.

M: Det kan være jeg har misforstått også.

S: Men det er foreldrene som bestemmer, det har du rett i. Og det f.eks. å snakke om man kan dø av det eller ikke det bestemmer foreldrene. For det trenger ikke være en daglig diskusjon på sykehuset, men ordet kreft tenker jeg er vanskelig å være sikker på at ikke skal bli sagt hvis de er i en aktiv sykehusbehandling.

M: Det var kanskje dette rundt informering om døden, at det var det også.

S: Det kan hende med hjernesvulst, hvis dette er til - for hjernesvulster kan gjerne være behandling i lang, lang tid fordi at svulsten ligger i ro og de har tatt alt eller at den vokser så sakte sant, eller det bare er en operasjon og ut igjen. Men skal de ta cellegift og ligge inne, så synes jeg det er vanskelig å si at det er mulig. Men det er foreldrene som bestemmer hva ungene skal vite, det er helt riktig. Men jeg tror nok legene vil bruke mye press på.

M: Ja, for hun sa jo det at hvis det var slike situasjoner så ville de alltid prøve å overtale foreldrene til å på en måte la de få snakke om det. Så jeg tror ikke det er ofte det skjer.

S: Men det kan være, med hjernesvulst kan det gå fordi de ikke alltid er til behandling, det er ikke alle som skal ta cellegift f.eks. Og hvis de bare skal ta stråling så er de ikke sammen med de andre barna. Altså en stråling og ut igjen. Å ikke bruke ordet kreft, å kalle det klump i hjernen f.eks. Det er ikke alle hjernesvulster som er kreft heller. Men det er like farlig fordi det vokser i hjernen. Så lenge det vokser er det farlig. Så men hjernesvulst går det faktisk an. Men det som er ille, som man bør ta veldig alvorlig er jo det at alle andre vet det - det er utrolig krenkende for et barn at alle andre vet det og ikke de.

M: Absolutt.

S: Men det går an, når det er en slik tilstand.

M: Ok, men da er vi jo ferdig. Tusen takk for...

S: Ok, da blir det spennende å se resultatet. Det som er viktig med et slikt informasjonsverktøy er at det fritar ikke foreldrene fra deltakelse sant?

M: Nei.

S: Det fritar ikke - voksne skal være en del av den informasjonen akkurat som før, men godt kunne bruke det. Man kan godt se i Kjemomannen aleine, men introduksjonen må skje sammen med foreldrene slik at alle vet det samme.

...

S: Jeg tror og at dialog med barn må jo være veldig meningsfylt, altså noen som har vært der en stund i forskjellige aldre, så tror jeg det er den beste hjelpen du kan få.

Appendix G

Questions for Usability Tests

Control question

1. What is special about cancer cells?

Questions

1. How old are you?
2. What do you think about using
    (a) Computers and iPads/tablets?
    (b) Computer games and mobile games?
3. How did you experience going through the story?
    (a) Was there something that was difficult?
    (b) Was there something you did like or dislike?
    (c) What do you think about the figure?
    (d) How did you experience scrolling down simultaneously as listening to the narrator talking?
4. Can you think of something that would make the story better?
5. When you learned that you had cancer in the body, did you think it was difficult to understand what it was?
    (a) Do you think it would have been easier if the doctor had showed you this story?
    (b) Did the doctor say anything about difficult emotions?
        i. Do you think it would have been good or bad to learn a little about emotions?
    (c) How did you learn about cancer?
        i. Did you read in books or something else?
        ii. Would you rather learned about cancer through a book or a game (digital storytelling) like this?

1. What did you feel when you went through the story:
    (a) 1 (hope) or 2 (without hope) (See Figure 8.1)
    (b) 3 (safe) or 4 (unsafe) (See Figure 8.2)

Appendix H

Interview Transcript: Usability Tests

Usability Test 1

Tuesday 7th April 2015 at 16:00 - University of Bergen

Interviewer (M): Maiken Beate Fjellanger
Tester 1 (T1): Boy, 12 years
Parent (P1)

M: Så da er det bare et lite spørsmål for å vite litt om man husker litt. Og da er det: husker du hva som er spesielt med kreftcellene? Ut ifra historien.
T1: Ehm...
M: Det er helt greit om du ikke husker. Men hvis du husker.
P1: Husker du forskjellen på en kreftcelle og ikke?
T1: Ja, at de er negative.
M: Ja, ok. Da er det litt andre spørsmål. Hvor gammel er du?
T1: 12.
M: Ja, og hva synes du om å bruke datamaskiner og iPad og nettbrett og sånn?
T1: Jeg synes det er gøy, jeg.
M: Ja, så du synes det er kjekt. Liker du dataspill og mobilspill og sånt og?
T1: Ja.
M: Hvordan synes du det var å gå gjennom fortellingen?
T1: Det gikk fint.
M: Ja. Var det noe som du synes var vanskelig?
T1: Nei, ikke noe spesielt.
M: Ok. Var det noe du likte eller ikke likte?

T1: Jeg synes det var helt fint, jeg.

M: Hva synes du om figuren da?

T1: Jeg synes den var morsom.

M: Så kjekt. Ehm... Og så det å skrolle nedover, samtidig som du hørte på at han snakket, synes du det var greit? Eller synes du det var litt forvirrende, eller?

T1: Det var litt forvirrende.

M: Det var litt forvirrende ja? Ok. Kan du tenke deg, altså vet du noe hvordan det kunne vært bedre? Eller det er kanskje litt vanskelig?

T1: Ja, det er vanskelig.

P1: Liker du bedre hvis... først snakker de, så sier de "nå kan du skrolle videre... til neste side"?

T1: Mhm, ja.

M: Ja, ok. Så det hadde vært litt bedre?

T1: Mhm.

M: Ok, men det er veldig bra tips. Ehm, ja, når du fikk vite at du hadde kreft i kroppen, synes du det var vanskelig å forstå hva det var for noe da?

T1: Ja.

M: Ja. Tror du det kunne blitt lettere hvis du hadde fått en sånn historie av legen?

T1: Ja, sikkert.

M: Ikke så veldig, eller litt? Du var litt usikker i fjeset. Kanskje litt...? Og husker du om han sa noe om vanskelige følelser og sånt? Den gangen.

T1: Nei, husker ikke.

M: Tror du det hadde vært bra eller dumt å vite litt om følelser?

T1: Sikkert bra.

M: Ok, og så hvordan du lærte om kreft. Så du i bøker, eller?

T1: Ja...

P1: Du leste vel i den "Kjemomannen Kasper", en bok som kreftforeningen gir ut, men den er litt sånn - han synes den var veldig vanskelig og kjedelig da. Selv der til 4 år, så var han 10 år, men selv den gangen så ble den sånn litt flaut når de skulle vise til klassen, sant?

M:Ååja, ja.

P1: Så den der hadde nok fenget mer. Sant for de gikk tilbake til skolen for å fortelle litt hva han gikk gjennom og ja... før det skulle begynne igjen. Og da husker jeg du synes du sa at boken var litt "barnehage".

T1: Ja.

M: Ja, så det ble litt barnslig?

P1: Ja.

M: Ja, nettopp. Så denne var ikke så barnslig da eller?

P1: Nei, altså den er jo litt moderne. Det var vel helst boken i seg selv som var litt, ja, grei for yngre unger, men ikke når du har kommet til den alderen der, sånn som du, at du var begynt å bruke disse her iPad og iPod og alt dette her.

M: Ja, nettopp. Så er det et siste spørsmål om hvordan du helst vil lære om kreft. Gjennom en bok eller gjennom et spill, sånn som dette?

T1: Et spill.

M: Ok, og til slutt har jeg noen sånne bilder da. For å forklare litt sånn hvordan du følte når du gikk igjen historien. Og det kan være litt vanskelig. Men hva følte du mest... følte du deg mest som hun eller som hun når du gikk gjennom fortellingen? Var det liksom sånn... Altså hva følte du inni deg? Følte du litt sånn håp og modighet eller litt sånn...

T1: Sånn (Peker på bilde 1).

M: Ok. Og så har vi to bilder til. Og da er det litt om du følte deg litt som den katten der, trygg, eller om du følte deg litt sånn utrygg som den.

T1: (Peker på bilde 3)

M: Ok. Yes, da var det det. Det var supert. Tusen takk for hjelpen. [...]

P1: Nei, for det var liksom. Vi har savnet litt det der... for det er klart de sitter veldig mye med det elektroniske hjelpemiddel. [...] Og da var det med den der boken og bamsen, det var litt for de litt yngre.

M: Ja, nettopp.

P1: Vi merket litt sånn på skolen når de skulle informere og. Så ble det veldig kontrast. For da. Altså figuren trenger ikke være så gjennomført, men her ser en egentlig hva det handler litt om da. Så jeg tror den der var positiv, alt i alt.

M: Supert.

Usability Test 2

Tuesday 7th April 2015 at 16:30 - University of Bergen

Interviewer (M): Maiken Beate Fjellanger
Tester 2 (T2): Girl, 12 years

M: Skal vi se, jeg skal bare se om fortellingen er flink å lære bort da - så husker du hva som var spesielt med kreftcellene?

T2: Em, at de kunne gjemme seg? Og de brydde seg ikke om de andre.

M: Ja, sant. Ok, da var det litt andre spørsmål. Hvor gammel er du?

T2: Jeg er 12 år.

M: Ok, hva synes du om å bruke datamaskiner og iPads?

T2: Jeg synes det er veldig gøy.

M:Hva med dataspill og mobilspill og sånn?

T2: Ja, jeg gjør det jo ofte.

M: Ja? du liker det?

T2: Ja.

M: Ja, Ok. Hvordan synes du det var å gå gjennom denne fortellingen?

T2: Jeg synes det var lærerikt og bra.

M: Var det noe som var vanskelig, synes du?

T2: Nei.

M: Var det noe du likte eller ikke likte?

T2: Ja, jeg likte at jeg kunne trykke på ting.

M: Ok, noe du ikke likte?

T2: Nei.

M: Nei. Hva synes du figuren?

T2: Jeg synes den var morsom.

M: Hvordan synes du det var å skrolle nedover samtidig som du hørte han snakket? Var det litt forvirrende, eller?

T2: Nei, egentlig ikke.

M: Du synes det var greit?

T2: Ja.

M: Ja. Ok. Dette er sikkert litt vanskelig, men vet du om noe som kunne gjort fortellingen bedre?

T2: Hm.. egentlig ikke.

M: Nei, ok. Når du fikk vite at du hadde kreft i kroppen, synes du det var vanskelig å forstå hva det var for noe da?

T2: Ja, litt, men jeg fikk en sånn bok som jeg fikk lese i.

M: Ja, var det den Kjemomannen Kasper eller?

T2: Ja.

M: Synes du det var greit å lære fra den, eller?

T2: Ja.

M: Ok, sa legen noe om vanskelige følelser? Husker du det?

T2: Nei, det husker jeg ikke.

M: Nei, ok, men tror du det hadde vært bra eller dumt hvis han... sa det?

T2: Det hadde vært litt dumt.

M: Litt dumt? Ok, hvorfor synes du det da? Synes du det er litt skummelt, eller?

T2: Ja, hvis du vet at du blir lei deg da så har du ikke så veldig lyst til å vite det.

M: Ok, sånn ja, så du tenker kanskje det er bedre å vite det etterpå kanskje? Med tiden?

T2: Ja.

M: Ok. Mhm. Hvordan vil du helst lært om kreft? Gjennom en bok eller et spill, sånn som dette?

T2: Et spill.

M: Ja, okei. Okei. Da er det litt sånn for å... Jeg har noen bilder her. For å vise litt sånn... Det er litt vanskelig å forklare hva man føler, så da er det kanskje lettere med bilder. Så... når du gikk gjennom fortellingen, hva følte du på en måte mest som hun der eller følte som hun der litt sånn trygg og håpefull og klar for å kjempe?

T2: Sånn (Peker på bilde 1).

M:Ok. Og så har vi to andre bilder - Av den katten der som har det ganske trygt og godt, og så har du en mus der som er litt sånn utrygg. Det er kanskje litt vanskelig, men...

T2: Mest den (Peker på bilde 3).

M: Ja. Men det er bra, da var det alt. Veldig bra. Tusen takk for hjelpen!

Usability Test 3

Tuesday 7th April 2015 at 18:00 - University of Bergen

Interviewer (M): Maiken Beate Fjellanger

Tester 3 (T3): Girl, 14 years

Parent (P3)

M: Da er det et lite spørsmål fra fortellingen, og da... Om du kan svare på hva som er vanlig for, eller hva som er spesielt med kreftcellene? Fra fortellingen. Det er helt greit om du ikke husker.
T3: De var sånne sure celler, eller noe sånt. Eller dårlige. Jeg husker ikke helt jeg.
M: Neinei, men det er helt i orden. Ehm, ja. Hvor gammel er du?
T3: Jeg er 14.
M: Ja. Ehm. Hva synes du om å bruke datamaskiner og nettbrett og iPads og sånt?
T3: Ehm. Jeg bruker det ofte selv, så jeg synes jo det er veldig greit.
M: Ja? Mhm. Hva med dataspill og mobilspill og sånt?
T3: Jeg bruker ikke det så veldig ofte. Jeg har sånne andre apper, som Instagram, som jeg bruker.
M: Ok, ja. Hvordan synes du det var å gå gjennom fortellingen?
T3: Det var gøyt. Det var litt enklere når jeg skjønte at jeg skulle skrolle samtidig.
M: Ja, nettopp. Så du skjønte det til slutt?
T3: Ja, helt på slutten.
M: Ja, så det burde kanskje vært bedre forklart da? På begynnelsen?
T3: Ja.
M: Var det... Ja, så du synes akkurat det med skrollingen var litt vanskelig. Var det noe annet du synes var vanskelig?
T3: Nei.
M: Ok. Var det noe du likte spesielt eller ikke likte?
T3: Jeg like figurene, jeg. De var skjønn.
M: Hva synes du... eller hvordan synes du det var å skrolle nedover samtidig som du hørte på fortelleren snakke? Det var jo det vi snakket om før. Du synes det var litt vanskelig?
T3: Ja, men det var enkelt da jeg først skjønte at jeg skulle gjøre det.
M: Ok, så du synes det var greit da?
T3: Ja.
M: Ok. Kan du komme på noe som hadde gjort fortellingen bedre?
T3: Kanskje hvis det var sånn automatisk skrolling, slik at jeg bare fulgte med på historien.
M: Ok, hadde du syntes det hadde vært gøyere?
T3: Det hadde vært litt enklere.
M: Ja, jeg bare tenkte at det kanskje kunne vært litt kjedelig, men jeg vet ikke.
T3: Jeg vet ikke.
M: Når du fikk vite at du hadde kreft, ehm, synes du det var vanskelig å forstå hva det var da?
T3: Jeg tror... Jeg var bare 4 år gammel da så det er litt lenge siden.

M: Ja, ehm, ja, nettopp. Men hvis du hadde vært 4 år, tror du på en måte du hadde skjønt det lettere hvis du hadde en slik fortelling?

T3: Det tror jeg, ja.

M: Ja. Husker du om legen sa noe om vanskelige følelser?

T3: Nei.

M: Nei, det er såpass lenge siden så. Men tror du det vil være bra eller dumt å få vite litt om følelser når man får en diagnose?

T3: Jeg tror det ville vært ganske bra, jeg.

M: Ja. Og så, hvordan lærte du om kreft? Så du i bøker, eller noe annet?

T3: Jeg hadde en sånn liten bok da, men, jeg vet egentlig ikke helt.

P3: Det var en slags billedbok med en figur som het...

M: Kjemomannen Kasper?

P3: Ja, Kasper, sant. Så det var vel den tilnærmingen den gang da. Og den finnes jo enda.

M: Den brukes jo veldig mye i dag, har jeg skjønt. Mhm. Men, ville du helst lært om kreft gjennom en bok eller et spill som dette?

T3: Akkurat nå ville jeg nok lært det bedre gjennom et spill.

M: Ok. Da er det bare en liten ting igjen. Og da er det for å snakke om brukeropplevelsen, som handler litt om sånn hva man føler når man bruker et system eller et program eller. Og da har jeg noen bilder, så hva du følte inni deg når du brukte systemet. Så mest på den siden, eller mest på den siden - mer sånn - ja - det skal illustrere håp da. Om det vekker håp eller om det ikke gjør det.

T3: Jeg tror den.

M: Da er det to til som går på trygghet. Der er en katt som er trygg, så har du en mus som er på en måte litt utsatt. Så bare si akkurat det du mener.

T3: Jeg tror den.

M: Ja, ok. Yes, det var egentlig det. [...] Tusen takk for hjelpen.

Appendix I

Evaluation from Home

An evaluation done from home of a 9 year old girl with incurable cancer, and her father. The evaluation is done of a screen record walk-through of the prototype. They answered the interview questions they were able to. Here questions about user experience is used instead of images, to be concrete and avoid misunderstandings. Control question were omitted since it was not in controlled settings; the child would be able to watch the screen record multiple times.

Tuesday 7th April 2015

1. Hvor gammel er du? *9 år.*
2. Hva synes du om å bruke
    - (a) Datamaskiner og iPads/nettbrett? *Liker best ipad*
    - (b) Dataspill og mobilspill? *Spiller en del på ipadden*
3. Hvordan synes du det var å gå gjennom fortellingen? *Helt greit*
    - (a) Var det noe som var vanskelig? *Nei*
    - (b) Var det noe du likte eller ikke likte? *Rare figurer, og likte ikke dialekten. Ville ha bergensk.*
    - (c) Hva synes du om figuren?
    - (d) Hvordan synes du det var å skrolle nedover samtidig som du hørte på fortelleren som snakket?
4. Vet du om noe som hadde gjort fortellingen bedre? *Litt om de forskjellige kreft typene*
5. Når du fikk vite at du hadde kreft i kroppen av legen eller mamma og pappa, synes du det var vanskelig å forstå hva det var for noe? *Ja (var fire år).*
    - (a) Hadde det blitt lettere å skjønne hvis legen hadde vist deg denne fortellingen? *Ja, kanskje.*
    - (b) Sa legen noe om vanskelige følelser?
        - i. Tror du det er bra eller dumt å få vite litt om følelser? *Bra.*

   (c) Hvordan lærte du om kreft? *Ble fortalt.*
      i. Så du i bøker, eller noe annet?
      ii. Ville du helst lært om kreft gjennom en bok eller et spill (digital fortelling) som dette? *, det var greit med digital fortelling.*

Så et spørsmål som kanskje er litt vankelig, men bare svar så godt du kan.

1. Fikk fortellingen deg til å føle
   (a) Håp (at du fikk lyst til å hjelpe kroppen med å kjempe mot de sure cellene) eller ikke? *Nei. Vet at det hun har, ikke kan kureres.*
   (b) Trygghet? *Nei.*
   (c) Andre ting du følte (f.eks. kjedet deg)? *Ikke noe spesielt.*

Comment Vi snakket en del om dette, og det er klart det er vanskelig og treffe alle. For noen er dette sikkert nok info, andre trenger sikkert mer info. Ellers ble det sagt at cellegift gjør deg frisk. Det er vel ikke helt rett.Og jeg tror det er viktig og være korrekt. For selv små barn ser andre får tilbakefall og noen som dør. Så mtp. troverdigheten i fortellingen, så vill jeg formulert det slik at cellegift kan gjøre deg frisk.

Appendix J

Story Script with Images

URL to the prototype: http://sureceller.com/ (note: it may not support all browsers)

Note: The script is translated from Norwegian to English.

Figure J.1: The main page, presenting the two stories

First story - Sour cells

Page 1

Into: This is the story about the sour cells. Scroll down to start the story.

Hi! My name is Blue and now I am gonna show you what caner is. To understand what cancer is, vi must understand what a cell is. Inside our bodies, there exists millions of small happy cells.

Every cell has a special job in the body. If you click on the different cells, they will tell which kind of cell they are, and what their job is. The cells does not live as long as a human, so they give birth to new cells quite often. The cells live in harmony with each other and are kind with each other.

Scroll down to the blinking arrow and push it, to see what happens when cancer occurs in the body.

When clicking on the cells (all with different voices):

Hair cell: Helloo, I am an hair cell. My job is to see to that the hair is growing out.

Bone cell: Hiii, I am a bone cell. My job is to take care of the skeleton in the body.

Nerve cell: Heya, I am a nerve cell and my job is to send messages around in the body.

Blood cell: Hey, I am a blood cell, and my job is to carry oxygen og nutrition around in the body.

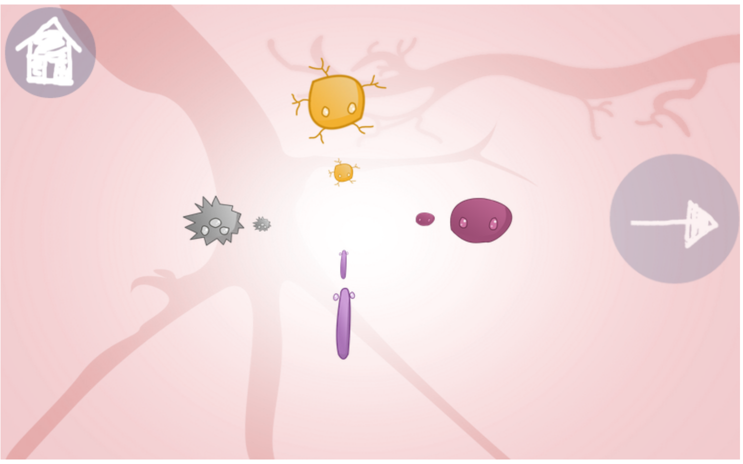


Figure J.2: Capture from the first page in the *Cancer story*

Page 2

Some times one of the cells gives birth to a sour and unhappy cell, which will not live in harmony with the other cells. These we call *cancer cells*. The sour cells does not care about the other cells and gives birth to new sour cells so fast that they push away all the other cells. Then the happy cells can no longer do their job. Some times the sour cells can become so many that they make lumps in the body. These lumps can come every where in the body. Sour cells can also swim around in the blood.

What is important to remember is that it is nobody's fault when a sour cells i born in the body. It is totally random. Since the sour cells become so many in a short time, the body does not manage to make them go away by itself. The body must therefore get help to get rid of all the sour cells. That is why we go to the doctor and get medicine which is called chemo therapy.

Push further to see what happens in the body when we get chemotherapy.

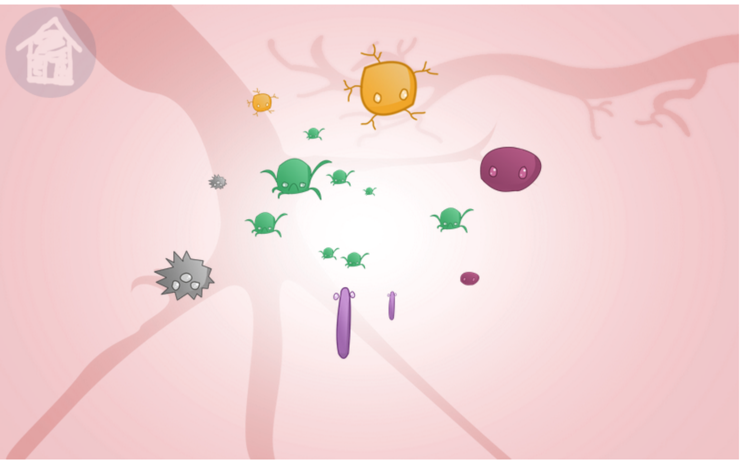


Figure J.3: Capture from the second page in the *Cancer story*

Page 3

We might get chemo right into the blood, or through a thin plastic tube, or we can get it as tablets. When the chemo gets into the body, it makes the sour cells unable to give birth to more sour cells, which make them disappear. Some of the sour cells manage to sneak away from the chemo. Because of this, we might have to go to the hospital several times to get chemotherapy to help the body get rid of all the sour cells in the end.

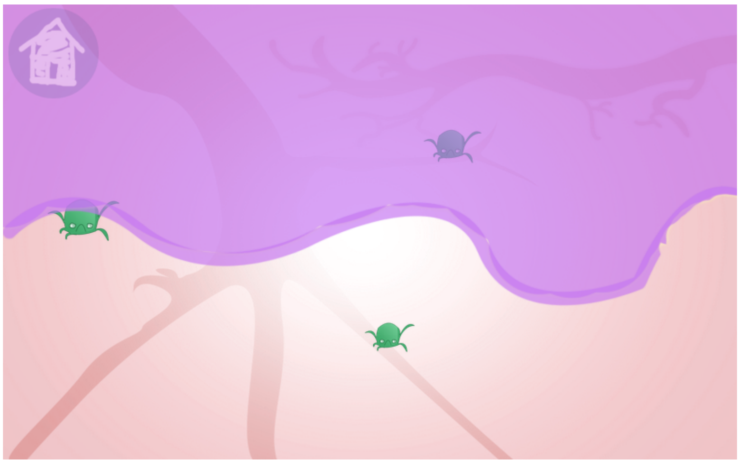


Figure J.4: Capture from the third page in the *Cancer story*

Page 4

What is a bit silly with chemotherapy, is that it can also damage some of the happy cells. Hair cells are often damaged that makes you lose your hair. Most people are not happy about this, but it's important to remember that the hair grows out quickly again when we stop chemo. Chemotherapy might also damage some cells in the stomach, which makes us to feel nauseated and might have to throw up after taking chemo. Then it is important to remember that it is not the cancer cells that make you feel bad, but the medicine. So one must feel a little bad to be completely healthy.

When you have cancer, you may feel lots of different things. To hear a little more about this, scroll down and press the flashing image.

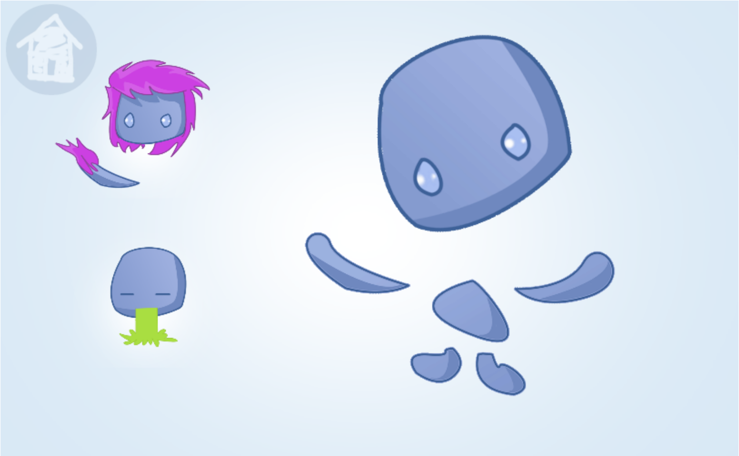


Figure J.5: Capture from the fourth page in the *Cancer story*

Second story - The emotions

Page 1

Emotions are something we experience every day, but when you one are sick, one might feel little extra on different emotions. Although some emotions are unpleasant, they are not dangerous.

Emotions is normally something we can not see, but to make it easier to understand I will use colors to show different emotions better. If you scroll down a little, some color dots will appear on the page, if you click on them you will see which emotion they represent.

Emotions:

Red: angry

Yellow: happy

Purple: afraid

Gray: sad

Click further to hear more about the different feelings.

Page 2

Some are scared when they get cancer, some are angry, others are sad, some are startled. One can feel uneasy, or feel that it is unfair. There are lots of different feelings you can get. It is not dangerous to experience these

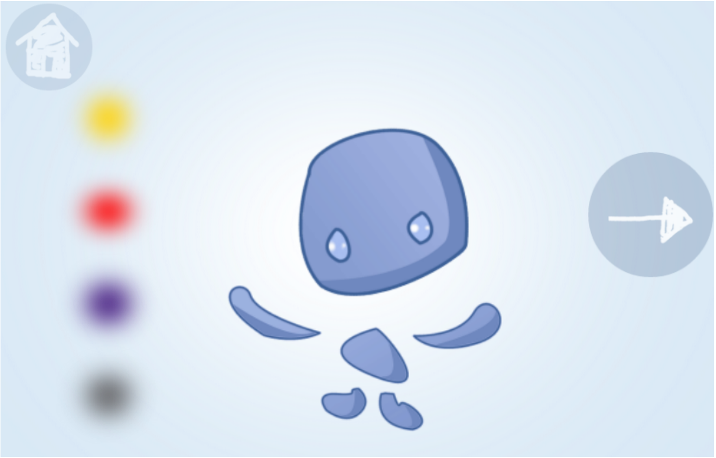


Figure J.6: Capture from the first page in the *Emotion story*

emotions, it is completely natural and part of being human. But emotions are something we know inside us, and others may not always know what we feel inside us. If you scroll down a bit, you see how I am sad inside me, but you can not see it in my face. I can even smile and look happy even if I feel sad. Can you see it? If it was not for the gray color, you had never known that I was sad now. If we do not show what we feel, nobody else can know what we feel - and they can not understand us or help us with our feelings. So it is important to show what we feel or tell it with words.

Click further to hear a little about what can help when we are experiencing difficult emotions.

Figure J.7: Capture from the second page in the *Emotion story*

Page 3

One thing that helps when you experience difficult emotions is to talk with, and seek solace in, parents or others around you. It also helps to think ahead, and think that things can be good even though it is hard right now.

Other things that can help are to listen to music you like, draw or paint, play with friends, watch fun movies or fly away in a fantasy travel. Perhaps you can think of other things that make you happy?

Click further to hear about the good feelings one can experience, even when having a hard time.

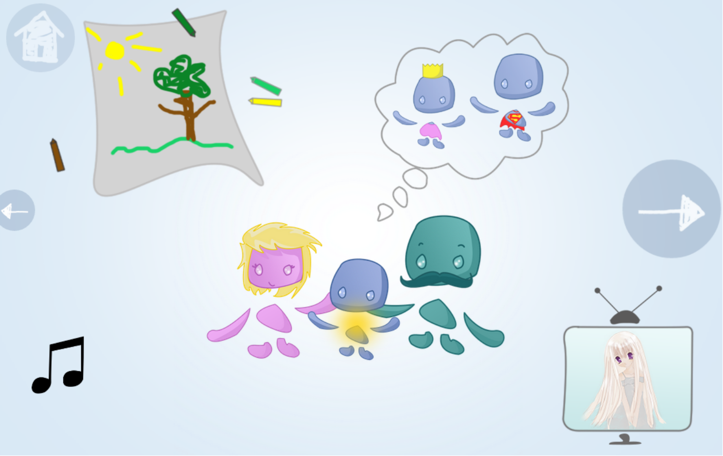


FIGURE J.8: Capture from the third page in the *Emotion story*

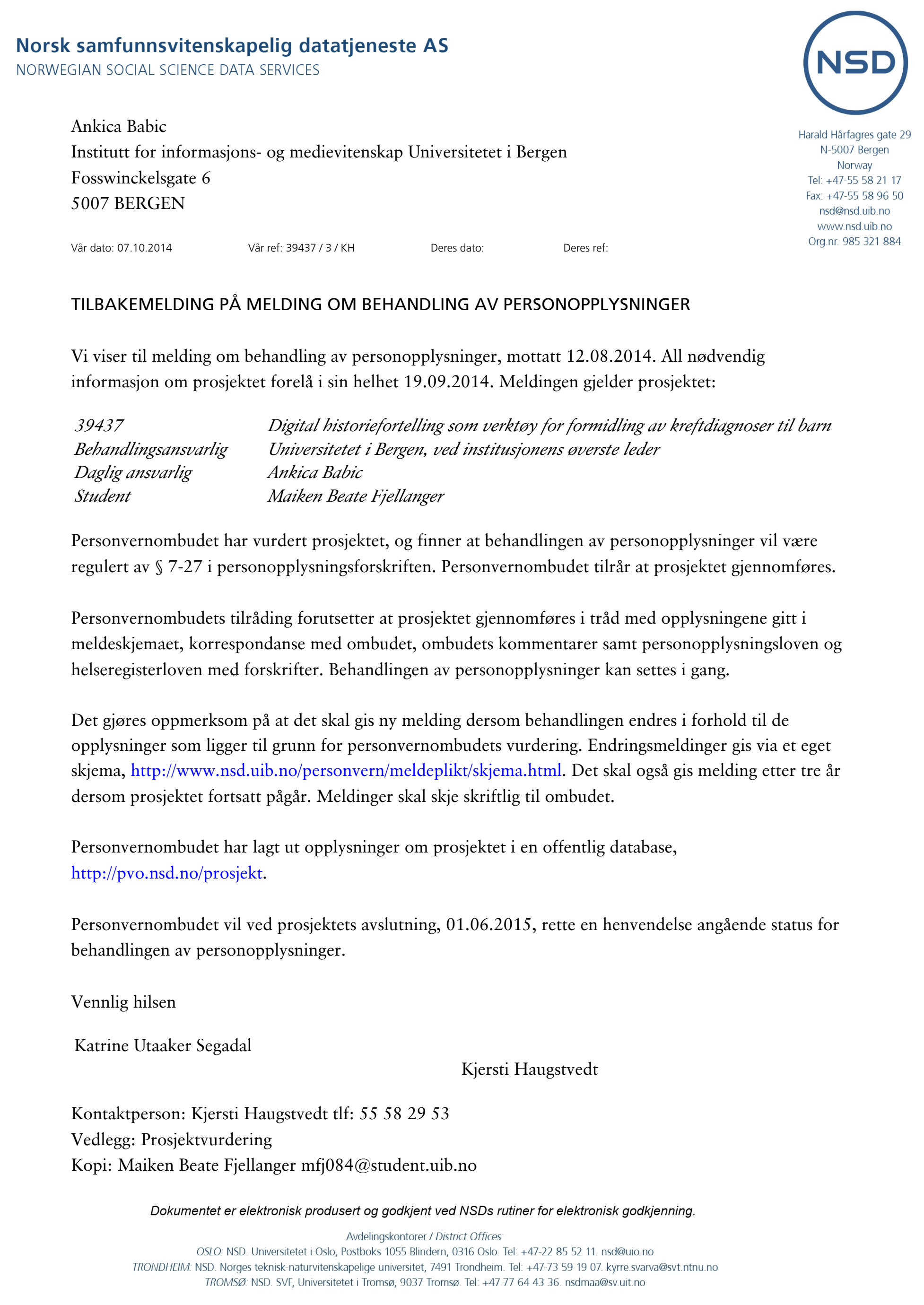
Page 4

It is not only difficult emotions we experience when we are sick. Some can feel brave and strong, and ready to help the body get rid of the sour cells. Another thing that is nice with going through such a disease, is that one might learn to appreciate thing one usually not thought about - like being healthy - how nice it is. One also experience a lot of love and care.

FIGURE J.9: Capture from the fourth page in the *Emotion story*

Appendix K

Approval from NSD



Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

NSD

Harald Hårfagres gate 29
N-5007 Bergen
Norway
Tel: +47-55 58 21 17
Fax: +47-55 58 96 50
nsd@nsd.uib.no
www.nsd.uib.no
Org.nr. 985 321 884

Ankica Babic
Institutt for informasjons- og medievitenskap Universitetet i Bergen
Fosswinckelsgate 6
5007 BERGEN

Vår dato: 07.10.2014 Vår ref: 39437 / 3 / KH Deres dato: Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 12.08.2014. All nødvendig informasjon om prosjektet forelå i sin helhet 19.09.2014. Meldingen gjelder prosjektet:

39437	*Digital historiefortelling som verktøy for formidling av kreftdiagnoser til barn*
Behandlingsansvarlig	*Universitetet i Bergen, ved institusjonens øverste leder*
Daglig ansvarlig	*Ankica Babic*
Student	*Maiken Beate Fjellanger*

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/meldeplikt/skjema.html. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, http://pvo.nsd.no/prosjekt.

Personvernombudet vil ved prosjektets avslutning, 01.06.2015, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Katrine Utaaker Segadal

Kjersti Haugstvedt

Kontaktperson: Kjersti Haugstvedt tlf: 55 58 29 53
Vedlegg: Prosjektvurdering
Kopi: Maiken Beate Fjellanger mfj084@student.uib.no

Dokumentet er elektronisk produsert og godkjent ved NSDs rutiner for elektronisk godkjenning.

Avdelingskontorer / *District Offices*:
OSLO: NSD. Universitetet i Oslo, Postboks 1055 Blindern, 0316 Oslo. Tel: +47-22 85 52 11. nsd@uio.no
TRONDHEIM: NSD. Norges teknisk-naturvitenskapelige universitet, 7491 Trondheim. Tel: +47-73 59 19 07. kyrre.svarva@svt.ntnu.no
TROMSØ: NSD. SVF, Universitetet i Tromsø, 9037 Tromsø. Tel: +47-77 64 43 36. nsdmaa@sv.uit.no

Related Academic Publications

From *16th Nordic-Baltic Conference on Biomedical Engineering and Medical Physics & 10th Medicinteknikdagarna*, 14th - 16th October 2014 in Göteborg, Sweden.

DIGITAL STORYTELLING AS A TOOL FOR CONVEYING CANCER DIAGNOSES TO CHILDREN

Maiken Beate Fjellanger
University of Bergen, Norway

1. Introduction

The experience of receiving a diagnosis of a life-threatening illness will be difficult for many, especially for children as they often have inadequate knowledge and understanding of what this entails (Fottland, 2004). It is therefore important that they receive thorough and accurate information about the disease together with the diagnosis, and that this information is presented in a child-friendly way. This is the essence of this project. The type of diagnosis chosen for this project is cancer, as research shows that this diagnosis evokes difficult emotions for many children (Fottland, 2004). According to Fottland (2004) many children have the perception that cancer implies death.

The project goal is to create a digital storytelling tool that presents a story of a child that gets a cancer diagnosis and how the story main character experiences it, as well as what is happening in the body as the treatment develops. This way children will learn about the emotional as well as the medical aspects of the disease. The project has two focus areas; a psychological to facilitate the story-telling in a child-friendly learning way, as well as a technical with focus on interaction design.

2. Method

Prior to the development various information holders (such as cancer doctors and child psychologists) will be interviewed to form a knowledge base that can help form the story. Focus groups with parents of children with cancer will also be held. A story will be designed, drawings will be made and a web application will be developed on this basis. Children will then be observed once they will have the prototype ready for them to test. This will help inquiring data about the interaction design. In addition, the children will be interviewed to extract qualitative information about their experience of using the prototype and learning from it.

3. The prototype and the expected results

The prototype will be a responsive website that can be used on different devices (mobile, tablet, computer etc.). The application will function like an e-book, where different elements / characters in the story will be interactive to make the characters in the story more vivid. Conveying emotion will be emphasized in order to make the children aware that it is natural to go through different stages of emotions when faced with a cancer diagnosis. However this is still a proposal that will be discussed in interviews with child psychologists. *Figure 1* shows a couple of suggestions for the main character in the story.

Figure 1: Suggestions of the main character in the story

The project is expected to provide an indication of whether digital storytelling would work well as a knowledge source for children with cancer diagnoses. The feedback from the user testing will be used to improve the interaction design of the prototype. A list of items most important for development of digital storytelling tools will be formulated.

4. Conclusion

This project could contribute to the thought processes around child-friendly informing regarding the cancer diagnosis, and possibly how information technology can be utilized in this context. Cancer diagnoses could be presented differently from their treating doctors. With such a tool, the children will receive the diagnosis in a manner that is carefully customized for them. Hopefully, this research could open up new mind-sets in relation to children and diagnostics in general.

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