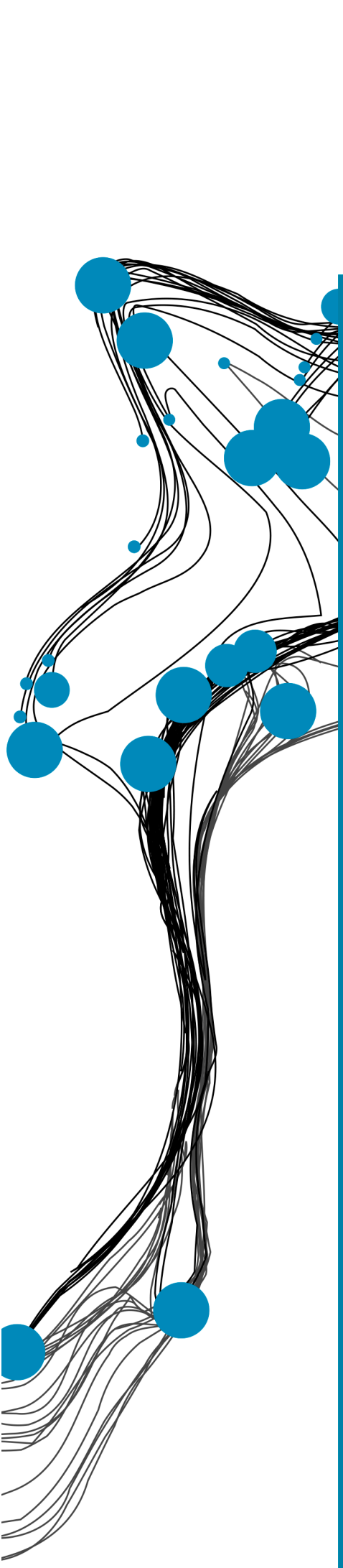

UNIVERSITY OF TWENTE.

Faculty of Electrical Engineering,
Mathematics & Computer Science

Creating an interactive infographic to communicate awareness for diffuse intrinsic pontine glioma

Q.I. Vafi
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Supervisors
ir. ing. R.G.A. Bults
dr. K. Zalewska

Creative Technology
Faculty of Electrical Engineering,
Mathematics and Computer Science
University of Twente
P.O. Box 217
7500 AE Enschede
The Netherlands

Abstract

Parents who have a child diagnosed with Brain Stem Cancer, also known as DIPG, currently face a hard time understanding what the disease exactly is and does to their child. The available information about DIPG is often too scientific for the average human to read. This study aims to determine how this problem can be targeted in order to decrease the gap between the medical world and the families trying to understand terms they have never heard of before, and to find a way on how to effectively communicate Brain Stem Cancer to these affected families.

To help these affected families, an interactive infographic has been created. The infographic illustrates a journey that the affected family can walk through, while coming across different types of topics related to DIPG such as possible treatment, medication, research done and more. The user can decide for themselves which topics they would like to know more about, by clicking the topic. The interactive infographic aims to give the user general important information about DIPG while making them feel comfortable and without feeling overwhelmed by the amount of information. If they do not feel ready to know about a particular topic yet, they can decide to not inform themselves and only read the topics that they would like to read.

The interactive infographic was positively received by the client, the Tobias Sybesma Foundation, and by the participants from the user evaluation. They think that the interactive infographic radiates calmness and includes a good amount of understandable information about DIPG, which indicates that the interactive infographic can be an effective way to communicate DIPG.

Acknowledgements

Conducting research on how to effectively communicate DIPG to families affected can be a very tough subject. I feel very honoured that the Tobias Sybesma Foundation, in particular Reitse Sybesma, has given me this opportunity to work on such a personal matter of his. His personal story and motivation has been very inspiring and he has been an extremely helpful, open-minded and supportive client. I am very thankful to have gotten him as my client.

I also would like to show my appreciation for my supervisors Kasia Zalewska and Richard Bults, who have helped me throughout and have given me the motivation to keep going. I took a little longer finishing my graduation project, but they made me feel that there was nothing wrong with doing so and they kept supporting me. Thank you for all the help.

Table of content

1. Introduction

In this introduction, the context of this thesis, the challenge and the research question are described. There will also be a description of the outline of this thesis to know what to expect.

1.1 Context

DIPG, short for Diffuse Intrinsic Pontine Gliomas and better known as Brain Stem Cancer, is a rare terminal disease which affects only a handful of children every year in the Netherlands of the age around 8 and 11. When looking at what DIPG exactly does, we have to look at what is happening inside of the brain, in the midbrain, pons, or medulla to be exact, which are located in the brain stem. These parts of the brain are responsible for functions like regulation of the cardiac and the central nervous systems which includes consciousness and the sleep cycle, and respiratory (Sciacca et al. 2019). When a child is affected by this disease, it will lose mobility and have more trouble talking. Brainstem cancer consists of a heterogeneous group of tumours which are created inside these parts of the brain, but mostly in the pons. For the last five decades, DIPG has been the main research focus due to resistance to radiotherapy and chemotherapy, and due to the interoperability. Research on this specific cancer is conducted at clinical hospitals that are not keen on sharing their research results with others, because of competition between the researchers. Because of this, a possible cure or treatment might take longer than needed (Chen et al. 2020).

Unfortunately, there is still no known cure for DIPG, which means that if a child is affected by it, there is no chance to survive. As said in the text above, hospitals are quite competitive, this makes them not work together, which results in them not sharing information. But when doing this, it only takes more time and will take more children's lives to find a cure.

When looking into the awareness of what DIPG exactly does, there is still a lot of uncertainty about the understanding of it by affected parents and children. Like mentioned above, DIPG is such a rare disease, a lot of people are not that familiar with it. Parents and children who are dealing with DIPG, are still not sure what exactly happens in the body of the affected child. But when a child battles a deadly disease, parents often want to know exactly what happens and will happen with their child (Fisher 2001). The available information is often too scientific for the average human to understand. By making the information understandable and readable, the affected families can understand exactly what DIPG implies.

1.2 Challenge

As said above, since DIPG is such a rare disease, it won’t ring a bell by a lot of people. Using the term Brain Stem Cancer will give them a bit more understanding that we are talking about a type of cancer, but it is still quite unclear. Since it’s such an aggressive disease, it is important to bring more awareness to the people who don’t understand what it is, but are already affected by it. When your child has a terminal disease, the first thing you would want to know as a parent is: What exactly happens to my child, and why? There is a lot of literature on the internet about DIPG, but a lot of them use medical terms which could be confusing for parents. That is why there is a need for a tool (e.g. video, animation, or a game) that would clearly explain DIPG for affected parents to comprehend, and create more awareness for the disease.

1.3 Research Question

The following question needs to be answered:

How to effectively communicate the terminal disease DIPG to families affected?

However, the focus will be mostly focused on the parents who have a child with DIPG:

Sub: What is the preferred communication modality to let the affected parents comprehend how their child is affected by it
Sub: Can the product be designed in such a way that it raises awareness and understanding for DIPG?

1.4 Outline

This thesis is divided into a total of 8 different chapters. The context, challenges and the research question of this study are introduced in Chapter 1. Chapter 2 is dedicated to background study, which includes a literature review, an assessment of the state of the art for this project and the expert opinion. The applied design process, as well as the tools and techniques that will be employed throughout the design process, are described in Chapter 3. The ideation process is outlined in Chapter 4, and the chosen concept is further specified in Chapter 5, allowing the realisation phase to begin in Chapter 6. In chapter 7 the prototype is evaluated, this is done by a questionnaire and lastly, in Chapter 8, a conclusion and future recommendations are presented.

2. Background research

This chapter includes four different sections. It focuses on a literature search, state of the art search and expert opinion. The last section is a conclusion, to look into connections between the background research and the research of this thesis.

2.1 Literature review

Bringing awareness for brain stem cancer for children

According to DIPG.org [1], brain stem cancer is a rare disease that affects around 150 – 300 children, mostly between the ages of 8 and 11, every year. It is a form of cancer that affects the pons, which is the bridge between several parts of the nervous system, which is located in the brain. Since it is such a rare disease, a lot of people have heard of it, yet many people are unfamiliar with the disease. By letting people emotionally connect to the disease, the subject 'brain stem cancer' will have more impact on people and they will have a better impression. This way people will become more aware of DIPG. For that purpose, knowledge is required to be able to determine how to inform people about the disease. Therefore the focus and goal of this paper is giving insight into the question: How to effectively communicate the terminal disease DIPG to families affected?

This paper consists of three parts, the first part will explain more about DIPG, the second part focuses on why it is necessary to bring awareness of this disease to light, and the last part focuses on the best ways to communicate information about DIPG to create more awareness.

What is DIPG?

DIPG is short for Diffuse Intrinsic Pontine Gliomas, which simply means the spreading of cancer in the pons part of the brain. As seen in [2], brainstem cancer is quite a rare and aggressive type of cancer which has no effective treatment and has a median survival time under a year. When looking at what it exactly does, it is important to look at what is happening inside of the brain. The parts that are affected by DIPG are the midbrain, pons, and medulla, which are located in the brain stem. These parts of the brain are responsible for functions like regulation of the cardiac, the central nervous systems which includes consciousness and the sleep cycle, and respiratory according to [3]. Brainstem cancer consists of a heterogeneous group of tumours which are developed inside these parts of the brain, but mostly in the pons. This is also why DIPG is the spread of cancer in the pons. For the last five decades, DIPG has been the main research focus due to resistance to radiotherapy and chemotherapy, and due to the lack of interoperability. When looking at cancer research, [4] mentions that it is quite a competitive world, which makes it less appealing for researchers of different medical institutions to work together. There is a lot of competition between the researchers. Because of this, a possible cure or treatment might take longer than needed. Both Sciacca et al. [3] and Chen et al. [4] state that the outcomes for DIPG are minimal, which is caused by the lack of communication between researchers.

[4] indicated that DIPG has been the main research focus of the past fifty years. As mentioned earlier, [2] stated that DIPG is not curable yet, and [1] claims that around 150 – 300 children pass away every year worldwide. When multiplying this number with the past fifty years of research, a total of around 7.500 – 15.000 children who were diagnosed with DIPG, might have passed away because of poor communication. Therefore, it is necessary

for medical institutions to collaborate to find a cure, to prevent more children passing away from DIPG.

Why bringing awareness for DIPG is necessary

As mentioned in the previous sections, creating more awareness for DIPG is a necessity, since it is such a rare disease. For people who have no connection to DIPG, it might not be important to know what it is. Thus, according to [6], it is most important to bring awareness to the families affected by the disease. As mentioned on the previous page, brainstem cancer is a very aggressive type of cancer. When a child becomes affected by it, it is important for the parents and the child to know what exactly will happen. Next to this, Ziółkowska et al. [6] state that cancer is the second-highest cause of death among children, so when a child has been diagnosed with any type of cancer, it can have an impact in disrupting and distressing the functioning of the whole family of the affected child. Rosenberg et al. [7] state that parents with a cancer diagnosed child often suffer from anxiety because of possible non-effective treatment and side effects. When there is no awareness of the disease, the parents and child do not know what they can expect which can lead to stress which can have a negative effect on the coping and accepting of the situation.

However, besides bringing awareness, there is also a possible positive side of not bringing awareness to the parents of an affected child or the child itself. Lee et al. [8] have found that awareness can have an effect on the survival time of terminally ill cancer patients when telling them the exact prognosis. Kim et al. [9] reports that there was a better quality of life and a better survival rate in patients that were unaware of being terminally ill. Although not bringing awareness can have a positive effect on the affected person, it would be unethical to keep information from patients [9]. When looking back at DIPG, it could be the parents' choice to keep information from their child about the survival rate of their child, which shows again that it is still important for the parent to know what is happening to their child. But the parents might also decide to give the child the decision to know what is wrong and what will happen. The child might not want to know what they have, or do only want to know about the treatment or cure. [8] and [9] both examine the effect of awareness on the physical and psychological conditions of a terminally ill cancer patient. [8] concludes that giving the patients more knowledge of their prognosis, this might have a positive effect on their quality of life and a positive effect on their survival. [9] states the opposite, it concludes that bringing knowledge to the patients of their prognosis might have a negative effect on the quality of life and on their survival. Since [9] had a total of 76 patients who were unaware of their prognosis, and [8] had a total of 33 patients who were unaware, there is more of a preference for the results of [9].

Preferred ways of bringing bad news through verbal communication

The communicating skill of a care professional plays a big role in how the prognosis is articulated to the family and affected patient. Levetown et al. [10] state that having good communication skills is essential within health care. This skill influences patient adaptation to illness, treatment adherence and outcome, disclosure and bereavement. Even though it plays an important role within the recovery of the patient, many mistakes are still made. To give an example, some doctors make use of closed interviewing techniques, so they can manage the time, which could appear non-empathic to the patient [10]. When focusing on the parents, it is important to focus on letting the parents feel comfortable by, for example,

showing interest, that the doctor cares and let the parents feel warmth, since this can have a big impact on the coping process of the parents according to [11]. Even when taking these things into account, there is still a risk that a parent feels treated with no respect or is unhappy with the amount of information provided. Levetown et al. [10] concluded a way to handle this situation as a doctor is to show empathy, respect and try to provide the patient with the amount of information the patient asks for.

Thus, what are the best ways to communicate information? As said above, showing empathy, compassion and by providing the amount of information needed, already makes the parent and/or affected child feel understood. Hegerty, et al. [12] state that there are patients who do not want to be told about their bad prognosis, but they do want to know information about the chances of a cure, treatment, possible side effects and the extent of disease spread. This mainly focuses on what to communicate, not how to communicate that specific information. [12] also discusses the style of communicating patience preferred. The ways mentioned that were not already mentioned above we are: making use of a mix of negative and positive framing of the information, making sure a friend or relative is present, the information is delivered in person and in a comfortable location, being honest about the situation, since this builds hope and trust, and lastly to summarize the information, provide the possibility to ask questions and make sure to explain in layman language. [10] and [12] fit together since [10] discusses the communication skill needed in health care, and [12] focusses on the way a prognosis of a patient is communicated to them. It becomes clear that as well the doctor and the patient can have a preference of how the information is given, since these preferences can differ. When it is clear for the doctor what specific information the patient expects to know, the doctor can anticipate and avoid making mistakes, as mentioned earlier in [10]. Therefore, it is important for the doctor to understand the point of view of the patients to meet this expectation.

Communicating through visual communication

Visual communication plays an important role in social interaction [13]. When making use of visual communication, it can have an impact on the way people speak in discussions. It can change the way someone speaks and it can influence the outcome with reference to what that particular person wants to reach [13]. Visual communication can also be used when communicating information about health. Garcia-Retamore et al. [14] state that research has found that a lot of patients and affected families often have difficulties understanding health-related topics, so by the use of visual aids, this gap can become smaller.

When it comes to the field of quantitative analysis, Raoufi, et al. [13] state that non-experts often lack experience in the interpretation of complex data and results. This is because of the lack of use of visual communication. The non-experts have some trouble with visualisation and interpretation of the data and information, which creates a barrier when it comes to evaluating product sustainability performance. However, the paper [13] concludes that there has not been enough evidence on the effectiveness by visualizing quantitative environmental performance results.

Discussion

This study explored the best way to bring awareness and create the most impact for DIPG to give an understanding of what impact the disease has on the lives of the affected children and parents. Ways to do so is to first assure the family and the patients affected by DIPG are correctly informed by the care professionals with the right amount of information about the disease to bring awareness. The best way to bring this awareness is to educate the doctor responsible for communicating, to inform the family and patients the best way possible. Something remarkable is that some people prefer not to know certain information about their own situation, or that of a child. One of the papers also stated that some patients do not want certain information about their prognosis being told to their family, but that makes it harder to meet the needs of the family, and the needs of the affected patient. When focusing back on DIPG, the affected child might not even have this possibility, since they are not an adult yet. The parents will mostly receive the diagnosis of their child. This gives the parents the decision of how and what they want to tell their child. They can also choose to let the affected child join the consultation, so they have the possibility to ask questions, or they might decide they do not want to know the possible prognosis. With respecting the needs of the affected child and of the parents, there will be a better awareness for DIPG. Besides this, it can also give them a better understanding about the disease, about possible treatment and about what could or will happen to the child. This paper is focused on bringing awareness to the parents and the children affected by DIPG. For further research, a related subject is bringing awareness to the schools and peers of the children who are diagnosed with DIPG.

Conclusion

The goal of this literature review was to research why communicating and bringing awareness for DIPG is important, and research the best and most effective ways to communicate DIPG to families affected by the disease. It has been found that creating awareness can have an impact on the survival time of terminally ill cancer patients when telling them the exact prognosis [8]. However, research [9] has also shown that there is a better possibility for a better quality of life when the patients are unaware of their prognosis. Nevertheless, keeping information about a patient's prognosis can be seen as unethical [9]. When it comes to verbally communicating a terminal disease to a patient and the affected families, it is a must for a care professional to have good communication skills [10], since this skill can influence the patients adaptation to the illness, reaction on treatment adherence and outcome, disclosure and bereavement [11]. Important factors for the care professional to keep in mind, is to show empathy, compassion and by providing the amount of information needed [12]. Communicating this information can also be done by the use of visual communication. This way of communicating can be a big help in the understanding of difficult health-related topics by patients and affected families [14].

2.2 State of the Art

In this State of the Art, four different main topics are addressed. The first main topic focuses on the verbal way of communication, what are the best ways to communicate bad news to families affected by DIPG. The second main topic focuses on the coping of the bad news by the affected families. The third topic looks into the visual way of communication, and if this way of communication is preferred over verbally communicating. This last topic of this State of the Art is looking into another way of communicating, which is called emotional branding. Emotional branding is a popular way of communicating, often used in marketing.

2.2.1 Verbally communicating bad news

The definition of bad news can be bright and broad. It is seen as an unwelcome, annoying or disturbing thing [15]. It could be a conversation where someone announces that someone is laid off, but it can also be a conversation where someone asks if they have a bad disease or not. Besides the fact that it is unfortunate to receive bad news, it could also be hard for the person who is responsible for communicating this bad news. The receiver could react in various ways and feel different kinds of emotions, examples of these emotions are denial, betrayal, sadness, anger, disbelief or bargaining [16]. Besides negative emotions, the receiver could also feel relieved by hearing or seeing the news.

2.2.1.1 Guidelines education for medical students

Effectively breaking bad news to patients and their families is essential, since this shapes their entire healthcare experience [17]. It is important for medical students to overcome stress and awkwardness while bringing the bad news. Dr. Vafi is a surgeon who studied medicine at University of Groningen from 1969 till 1975. After that, he specialized in vascular surgery from 1976 till 1984. After studying 15 years, I questioned him if he had any education in bringing possible bad news to patients or family, and he told me that it was not a relevant subject to teach back then. Since communicating bad news the right way can have a big impact on the patient and the families, it is quite astonishing that there was not any attention paid to this. Fortunately, with the recent education for medical school, it is a need for medical students to master this skill. One of the ways to educate a medical student is to let them follow the SPIKES protocol, shown in the image below.

Figure [1] The six different steps in the SPIKES protocol

Every letter stands for a particular factor to follow. The SPIKES protocol was originally created to bring bad news to cancer patients [18], but this protocol can be used in all sorts of situations.

Setting |The first letter stands for the setting, which indicates the location of where the conversation will take place. It is important to search for a quiet, private and comfortable place so the receiver will feel at ease.

Perception | The second step is to understand the knowledge the patient or family already has of the relevant medical condition, ask them if they would want more information about the condition and ask what they suspect. If there is possible denial, accept this but do not confront it at this stage.

Invitation | Ask if the patient or family would like to know the information about the medical condition or if they would like to know about the possible treatment. If the patient or family declines to know about the details, the doctor accepts this.

Knowledge | If the patient or family do want to know about the medical condition and/or the treatment, explain the disease and/or possible treatment in small pieces and in plain language.

Empathy | Sometimes the E in SPIKES is interpreted as “emotions”, but it has the same guidelines as with the word “empathy”. After breaking the news, it is important to respect the emotions of the receiver of the bad news and respond with empathy.

Summary | Lastly, summarize the given bad news and the possible treatment and medical care. Ask the receiver if they need any clarification and let them know your availability for possible questions at a later date.

To implement the SPIKES protocol and to practice, medical schools make use of SBML. SBML stands for simulation-based mastery learning, and it is used as an instructional approach which prevents low-quality student progress. It is a much preferred way of learning since it has a very good and effective learning effect on students [19]. An example of this is by using actors who act like they are a patient that the medical students have to approach. While the student communicates the bad news, other students and teachers will observe. This way the students might learn from the exercise and the teachers can observe so find possible points of improvement. As seen on the image below.

Figure [2] Using actors for practice breaking bad news for medical students

2.2.1.2 Guidelines for communicating bad news in the field

The Mid Trent Cancer Network, MTCN, has set up a document with the guidelines they have to follow for breaking bad news to patients and their families [20]. They mention eleven different steps:

1. Preparation
2. What does the patient know?
3. Is more information wanted?
4. Give a warning shot
5. Allow patient to refuse information at that time
6. Explain if requested
7. Elicit and listen to concerns
8. Encourage ventilation of feelings
9. Summary and plan
10. Offer availability and support
11. Communicate with the team

When comparing these steps to the SPIKES protocol, there are quite similarities but also a few additions, but the steps above are a bit more detailed.

1. Preparation | For the preparation part, MTCN mentions that it is important to know all the facts, give the patient the possibility to bring someone and to ensure privacy and set the scene. When comparing this to the SPIKES protocol, this is also mentioned in the setting part, but it is less detailed. The preparation stage of MTCN makes sure that the doctor checks the notes of the patient and be sure they know exactly what to tell. There is a possibility the announcer of the bad news might not know if a patient's cancer is on the right or left side of their body. That is why it is essential to communicate with other healthcare professionals. If the doctor might not know everything the patient wants to know, there is a possibility the patient might lose confidence. Besides the information, important aspects are having an interview without interruptions and making sure to sit down at the same level as the patient.

2. What does the patient know? and **3. Is more information wanted?** | Both point 2 and 3 relate to the perception aspect of the SPIKES protocol. The doctor will ask about what the patient knows about the medical condition to understand their knowledge. After this, there is a possibility to ask the patient if they would like more details about the illness. This is to understand what the patient would like to know about their situation.

4. Give a warning shot and **5. Allow patient to refuse information at this time** | point 4 and 5 resonates with the invitation-aspect of the SPIKES protocol. This way the patient is warned that there might be some bad news coming up, and they have the right to refuse to know the information about their disease and/or possible treatment.

6. Explain if requested | This is the sixth step, and this step is the same as the knowledge step of the SPIKES protocol. However, the guidelines of MTCN are explained in more detail. They mention using clear, simple and unambiguous language and the doctor has to make sure to give the information in small pieces for the receiver to process. This way it is easier

for the patient to understand and allow them to convert the information. Besides this, it is also important to avoid overloading the patient with information, use silence to let the information sink in, check if the patient understands and repeat important points.

7. Elicit and listen to concerns and **8. Encourage ventilation of feeling** | Points seven and eight are included in the empathy aspect of the SPIKES protocol. The doctor asks what the patient might worry about and listens to the possible concerns, acknowledges them and gives the patient clarifications if there are possible unnecessary concerns. It is important to let the patient know that they are being listened to and give them the possibility to talk about their feelings, stress or fear. Talking about the issue and showing support can be therapeutic and help the patient with processing the bad news.

9. Summary and plan and **10. Offer availability and support summary** | The last step of the SPIKES protocol is the summary, which correlates to the ninth and tenth step of the guidelines given by MTCN. By summarizing everything, the doctor can list the concerns of the patient and combine it with their professional knowledge. State a plan and determine what is fixable and what is not fixable. Offer to meet again or plan a phone call, and list the possible available days to do so. The patient or family/friends might need more explanation after receiving bad news but need some time to emotionally process it. Lastly, make sure to offer the patient contact numbers for a specialist or for a clinic if needed.

The last step of the guidelines of MTCN is called “communicate with the team”, and is the only one not mentioned in the SPIKES protocol. Just with the first step mentioned by MTCN, preparation, it is important to communicate and document what has been said with other care teams.

2.2.2 Coping with bad news

'Bad news' is a pretty big topic. Someone could perceive something as bad news when another person could see it like it is no big deal. In this chapter, the focus is on different ways to help a child cope with bad news, and different ways of coping with bad news for all ages.

2.2.2.1 Helping children cope with bad news

When children are exposed to the media, there is a big chance they might get confronted with graphic footage, tragedy or other shocking news. Not only has shocking news effects on adults, it can also affect the children watching it. Children are in general more sensitive to the news given to them, like terrorist attacks or earthquakes. They worry more that these situations might also happen to them or their family. However, the age of a child also plays a part on how a child might react to a shocking situation. Children of an older age have a better understanding and are more aware of what they are seeing or hearing.

Even though this is mostly focused on shocking news on the television or in the media, it also plays a part in coping with bad news in general. There are different ways to help children cope with shocking- or bad news.

Communicate with the child

The best way to make the child aware of bad news is to explain it in an age-appropriate way [21]. After explaining the situation, you can ask them if they have any questions and how they feel about it. It is important for the child to express their feelings and respect their capability of coping with the bad news. Not only for the child, but also for the adult so they can take their feelings into account. If the child has an unrelated fear about the situation, the adult can respond to this by addressing this fear without dismissing it by being irrelevant. This helps the child with processing the bad news [21].

Treat the child as equals and try providing the child with the answers they need, but be honest if you don't know how to answer one of their questions, since you don't have all the answers. By not talking down to the child and being honest by the amount of information you can provide, it builds more trust between the child and the adult. However, keep the child aware that there are also good things and remind them that they are being loved [22].

Keep them comforted

As said above, taking the feelings of the child in account is an important aspect of how the child will cope with the bad news. When treating the child as an equivalent, it will create more trust between the child and the adult. Children might have particular fears which are not necessary to have. By addressing these fears and explaining why it is irrelevant, without dismissing them as irrelevant, it might help them with processing the situation [22].

To make sure the child feels more comfortable in other environments, e.g. school, it is important to make the people around the child aware. By explaining the situation to educators and care providers and keeping them informed about the fears and concerns of the child, the people around the child are at the same page as the parent with the way how to approach the child. It might suffer from anxiety or stress, which can have an impact on their workflow and concentration or be worried about particular concerns. By engaging this

team, there is more consistency for the child, which can have a positive effect on the way the child processes the bad news [23].

Limit them to hearing/seeing the bad news
When a child keeps hearing the bad news, which can happen e.g. when they keep hearing about a war somewhere. If you know your child is sensitive about hearing bad news on the tv, it is sensible to censor when repeatedly being exposed to the bad news. By limiting the coverage of the event, the child is aware of the news but enough is enough. However, it is not needed to shield a child from coverage of the bad or negative news since this is not helpful nor practical [24].

Even if you limit the coverage of negative news for a child, the child might still keep thinking about the situation which can cause stress. That is why it is a good thing to distract the child after being exposed to a negative situation. A way to do so is by playing games or do other fun activities to refocus the attention of the child [24].

2.2.2.2 Coping with bad news

When becoming an adult, there are different things which could be perceived as bad news than when you were a child. Losing your job, a relationship breakup or dealing with the loss of a loved one. Besides this, there are also consequences that follow with the bad news; finding a new job, informing friends and family, arranging a funeral, but also coping with the way the bad news has affected your physical and mental state. The negativity of receiving bad news can have an instant reaction on the body, which can activate the flight-or-fight response. The body produces more adrenaline and the mind focuses on the worst-case scenarios. Because of this instant reaction, it is often said to sleep on it. That way the body can calm down and gives the mind the possibility to calmly realize the bad news. There are ways that are the same for coping with bad news as an adult and as a child. However, everyone can react differently to receiving bad news. Some might have trauma or have received the same bad news more often, so they know how to cope with it [25]. When receiving bad news as a parent or child that the child is diagnosed with DIPG, it can have a big impact. Down below are different ways which could be used to cope with the diagnosis of a child with DIPG. These ways of coping can be used by children, as well as adults.

Accepting the bad news

As stated above, it is important to give the body the time to consume the information and give the body the possibility to feel emotions. Putting negative emotions aside can have a negative impact on the mental state and cause more stress. However, people are often tempted to do so to protect themselves. Research [26] has proved that embracing the negative emotions can have a positive effect on the mental state in the long run. Brett Q Ford et al [27] states that people who embrace and accept their emotions are overall better with dealing with stress. Another common thing for people to do besides trying to avoid how they feel, is to avoid the bad news. They shut down everything that has to do with the bad news. However, this often backfires, since the individual might even think more about the unwelcoming news. Besides the effect it has on the mental state, it also affects the physical state. The body feels more tense, it is harder to concentrate, you feel more stressed and it can also have an effect on digestion. By repeating exposure to the bad news, it neutralizes the effect on how it affects the mood and thoughts and you will feel more free to continue with your day [25].

Cognitive reframing

By making use of cognitive reframing, which is a psychological way of trying to reframe the way someone thinks, it can help by seeing the situation from a different perspective. That is also why cognitive reframing is an often used technique by therapists [28]. People often focus on the negative sides of a situation, but by making use of cognitive reframing, they are challenged to look at the situation in a more positive way. This way of thinking can reduce stress, change someone's whole perspective on the situation and let them feel more free of negative emotion [29].

Overcoming adversity

Adversity is an unpleasant or very difficult situation [30]. When having to handle adversity, there are different ways to do so. A few examples are:

- **Write down your feelings**; This is a great way to clear your head by writing everything down on paper. It can help with self-expression, let you reflect better on the situation and makes you think more outside the box [31].

- **Go for a walk in nature**; By surrounding yourself with nature, it can give you a break from reality. It gives you time to take a deep breath and relax. PsychCentral.com states that there are several studies where it is shown that a walk in nature reduces stress and gives the person time to connect with themselves and nature [31].

- **Surround yourself with positive and supportive people**; by having positive people around, it can influence the person who has to deal with adversity, which can lead to conformity. Conformity is the way someone's beliefs or behaviour is changed, so it fits a certain group. It is a way of giving into group pressure [32] . This can be seen in a negative way, but also in a positive one. Being surrounded by positive and supportive people can change someone's behaviour and beliefs to a more positive one. It helps with moving forward and encourages the person to accept themselves.

- **Believe in yourself**; self-confidence and believing in your capabilities to overcome adversity is already a big step in the right direction. Having a positive mindset can have a big impact on someone's method of handling adversity. By believing in yourself, you keep pushing yourself to not give up and keep going, which can lead to the desired results of success [33].

Take care of yourself

Lastly, a way to handle bad news is to work on yourself and focus on self-care. Neglecting yourself can have an even more negative effect on the situation, since it influences the mental health and the physical health of someone. By taking care of yourself and your body, it decreases stress, boosts self-esteem, and overall lifts up someone's mood since it lets you release endorphins, which are natural antidepressants [34].

2.2.3 Visual communication

There are different ways to communicate. Drexel.edu states that there are a total of four different kinds of communication; verbal communication, non-verbal communication, written communication and visual communication [35]. In this chapter, the focus will be on the different types of visual communication, how visual communication is used and if this type of communication has pros or cons.

2.2.3.1 Different types of visual communication

Visual communication is any way of communication where the information is transmitted by the use of objects, materials, imagery, symbols or colours [36]. In this chapter, a total of five different types of visual communication is discussed. Three of these visual communication types, infographics, photographs and videography / animations can also be expressed as visual media:

1. Objects
2. Infographics
3. Chart / graphs
4. Photographs
5. Videography / animation

There are more types of visual communication, but the focus will be on the types that could be useful for this thesis.

Objects

Objects are often used in daily life to address certain situations to the audience. An example of using objects for visual communication, is the use of neon signs on the side of a bar. If someone sees a neon board with a picture of a beer glass on it, it is a way to communicate that that building might be a bar [36]. Another example would be a stop board on the side of a road. When someone sees a stop board, it can be interpreted that that person has to stop at that particular spot.

Infographics

Infographics make part of the three different types of visual media [37]. The main focus of an infographic is to inform, engage and summarize. It is “a visual representation of information or data”, stated by the Oxford English Dictionary [38]. An infographic can include charts, images and text to give more information about a certain topic. Besides communicating information, it is also important to make the poster pleasing for the eye, since the way the infographic is designed can have a big impact on the way people interpret the information. By making the infographic look attractive and making the design engage with the information given, it can help the audience understand and remember the information more easily [39] which can be very helpful in the medical domain when trying to explain complicated topics like DIPG. A good example of the use of an infographic for explaining DIPG, is the one shown in figure 3.

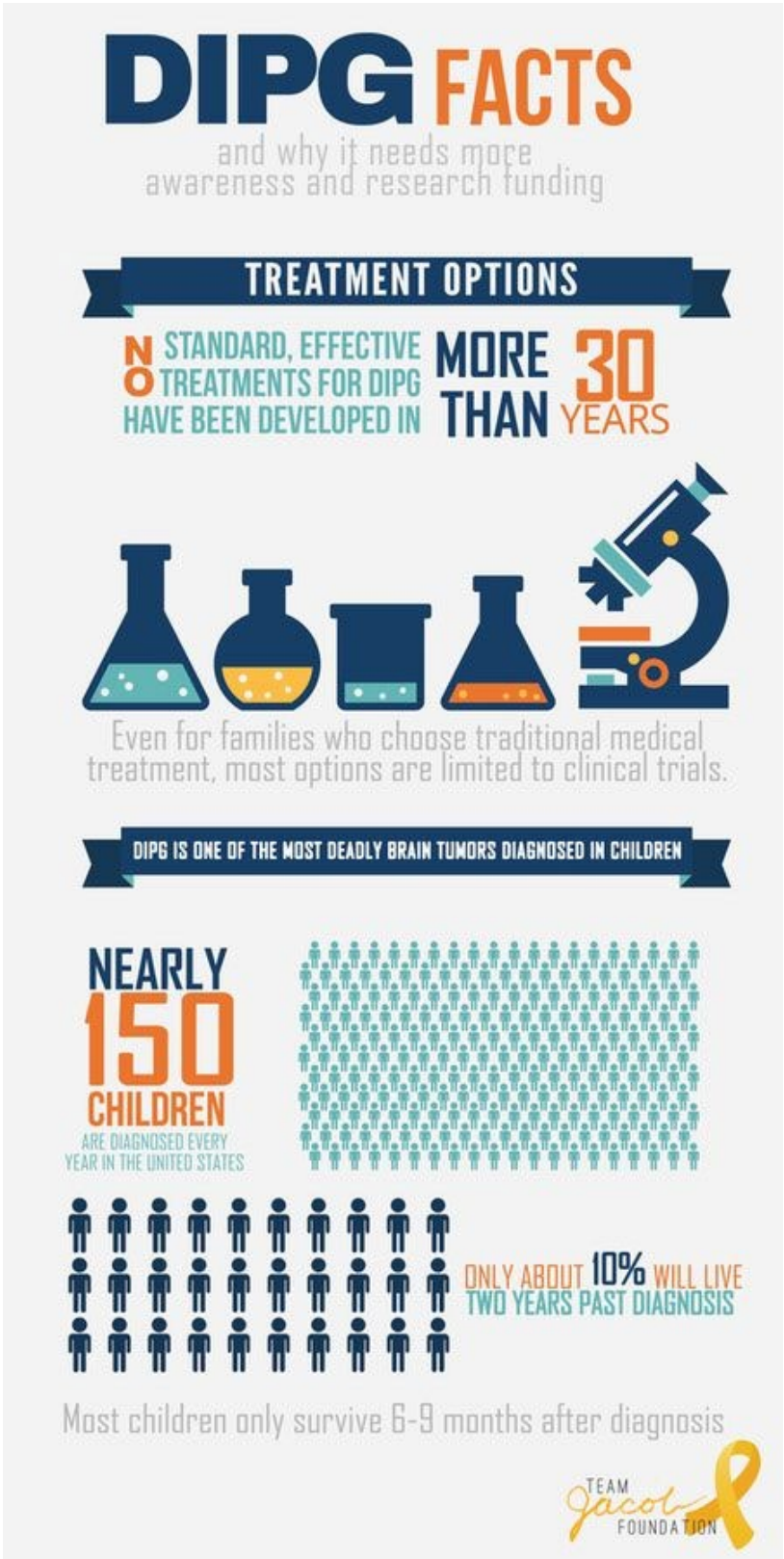


Figure [3] Example use of infographic to explain DIPG

Charts / graphs

Charts and/or graphs are often used in infographics, as seen on the image below [40].

Figure [4] Example use of charts/graphs in infographics

They help visualise data, enhance the awareness of complex concepts, it makes key visions more memorable and makes the claims being told, more believable for the audience [40].

Photographs

Images are one of the three different types of visual media [41]. Photographs can communicate a message to the audience, without using a voice. They are the most common type of visual media being used by online marketing, since, according to puprlecowagency.com, content shown by the use of images can achieve 94 percent more views, compared to content where there was no use of images [41]. An example for using images for visual communication, is an image of plastic in the ocean in a presentation when talking about world pollution. The image communicates to the audience that plastic is part of the problem, since it pollutes the ocean.

Figure [5] An image of waste in an ocean indicates the problem of world pollution

A way to use photography in communicating DIPG, is to show the consequences of what happens with children who are diagnosed with DIPG. An example of this is to show a child with bigger cheeks, which they get because of the medication they receive, or an image of a child who lays in a hospital bed, not being able to move much.

Videography / animation
Videos and/or animations are the last type of the three different types of visual media [42]. While a video is a recording of either still of moving objects, an animation exists of individual images placed after each other [43], which makes it look like a video. When using videos in online marketing, it is easier for the audience to understand what that certain product does and how it is used in real life. Purplecowagency.com states that a total of 78 percent of Internet users watch some type of videos weekly. 55 percent of this 78 percent even watch videos daily. Videography or animation are a good alternative to help with educating. By combining audio or text with images, it can help understand the given information better. This is because images are more quickly processed in the brain than text [44].

2.2.3.2 How to effectively use visual communication

Making use of visuals can be a helpful tool to influence the audience to be engaged, think about and understand the information that is being presented. The different types of visual communication mentioned above can be helpful with different scenarios in the workplace. Visual communication can be used to:

- engaging the audience
- communicating complicated information
- communicate the impact of the data
- transfer emotion by telling a story

There are different strategies to do so, which include the use of data visualization, colour, symbols and icons, shapes and lines and the use of visuals like the three different types of visual media [45].

When looking at the information communicated in the field of healthcare, engineering, technical industry or business, often a lot of this information might be quite boring, or hard to understand [45]. By making use of modern or stylish designs for an infographic, it makes the information more approachable and feel more concrete. Besides this, it also looks more attractive which makes the audience more interested and engaged in what is being told, and can make you stand out as a business [46]. However, it is important to choose a graphic design style which resonates with the target audience, which creates a higher engagement. When adding visuals, it can decrease the time needed to understand particular information.

To visualize the different types of visual communication, it can be put into a presentation. Presentations are often used to give more information about a meeting which has to take place. This way the attendees are informed about the information that is being discussed in the upcoming meeting. It helps clarify possible changes and also keep the team aligned [46].

2.2.3.3 Advantages and disadvantages

Using visual communication can have its pros and cons. Down below, a total of four advantages and four disadvantages are summoned.

Advantages

Symbols can become universal

Symbols can often be used for more than one occasion, and since a lot of people know the different meanings of the symbols, it can even be seen as a shared language among the world-population [47]. They can be quickly recognized and understood. A good example of symbols used are the symbols shown down below, which can be used in the medical world.

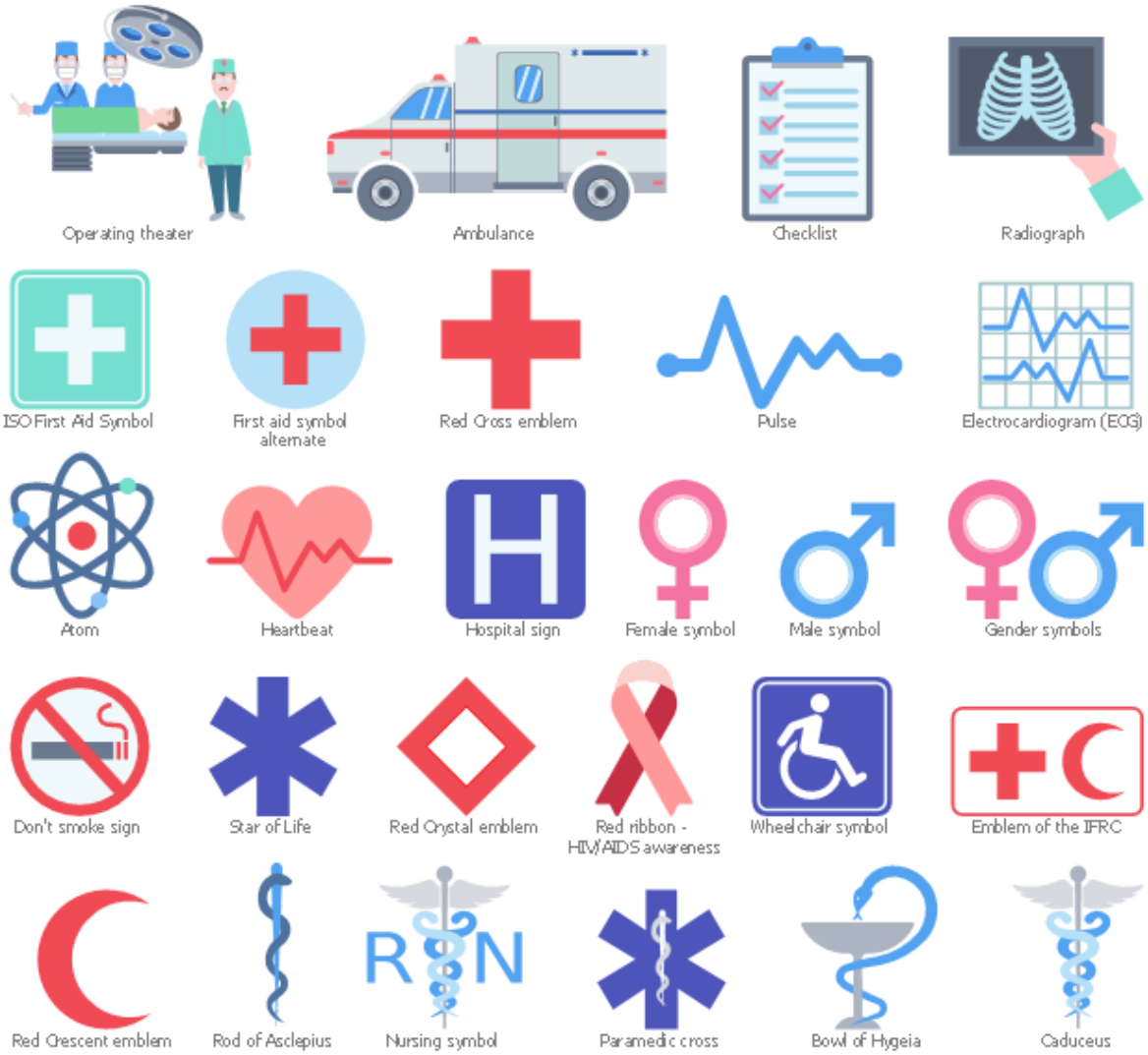


Figure [6] Different universal symbols used in the medical world, which can easily be recognised

Can be used to express different feelings and moods

By using particular colours, it can have an impact on the feelings and the mood of people. A clear example of this is the different colours used by supermarkets. Depending on the colour you use, a particular emotion can be recalled. The image below describes the different types of emotions that can be evoked by the use of a particular colour.

Figure [7] Colours used by consumers in the USA (colour preference can be different in other countries)

Without knowing, the consumer's emotions and feelings are influenced by the colours shown by brands [48] . That is why it is important for a company to choose a colour in their logo or store that suits their personality.

Figure [8] Colour emotion guide - colours strategically chosen by brands to evoke specific emotions

Because certain colours can recall particular emotions, this is why medical logos are often blue or green, like the one of the medical spectrum Twente. This is because the blue colour is typically associated with professionalism, knowledge, trust, cleanliness, focus and calm [49]. And the colour green mostly for health and growth.

Figure [9] Medical Spectrum Twente logo

<u>Can help you conserve your time</u>

When buying a chair from Ikea, you often see an image of the chair on the instructions. Not only gives you an idea about how the chair will look like, this also helps with the construction of it, since you can exactly see where to put everything [47]. This is because the information of an image can be transmitted instantly and processed quicker in the brain than words. So the task can take longer when only working with text [47]. The image in figure 10 gives a clear explanation how to wash your hands, by making use of visual communication.

Figure [10] Clear way of using images as an explanation to wash your hands

Supports oral communication

By using visual aids, oral communication can be more enhanced. However, this is only the case when the visuals are correctly chosen for the particular type of oral information given [50]. Another way to support oral communication or text by the use of visual aids, is to play with the interests of the audience. When writing an article, the goal of the writer is to let the reader read the written text. Visual aids can be used as a tool:

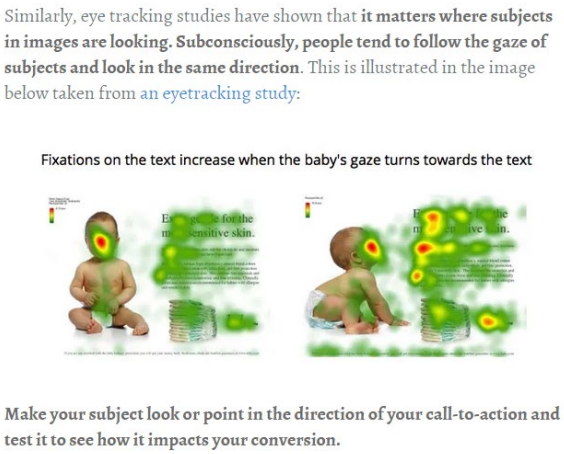


Figure [11] Effective way to let the reader fixate on the text by the use of visual aids

Disadvantages

Incomplete method

Even though Visual Communication is a great way to make the information given more clear, it is often an incomplete method to use. For example presenting a presentation, when only showing pictures, it is hard for the audience to understand exactly what is being presented. To make the presentation comprehensible, some type of oral communication is needed [51].

Design issues and costs

To make clear, interesting and engaging visuals, some sort of knowledge and efficiency is needed to deal with the different types of visual communication. When graphs, symbols, or charts are incorrect, it can create confusion for the audience [52]. This can also have an impact on the costs made by using visuals, when hiring someone with the needed knowledge and skills to make the design. When working in the medical field and wanting to share information by the use of visual communication, not only the designer is needed in the process, but also an expert to give the necessary information to produce the desired product.

Besides hiring experts for the job, the production of the products themselves can be quite expensive. Examples are the use of design programs and possible printing costs, if needed [53].

Can be distracting

By using any sort of visual communication, it can distract from the message one is trying to convey, especially when the visual aid is unclear and shows wrong or irrelevant information. An example of this phenomenon is when presenting a presentation, it is necessary to use the right slides for the information that is being told. When not doing so, there is a possibility that the audience becomes confused and associates the wrong images or other types of visual aids with the wrong information. Especially in the medical domain, this can create a gap in the understanding of the given information by the audience [54]. Another way the audience can be distracted from the necessary information, is when too much information is shown, like the image shown in figure 12. Especially when using visual aids in explaining something medical, it is important to make sure the information is understandable for the audience. Otherwise uncertainty may arise.

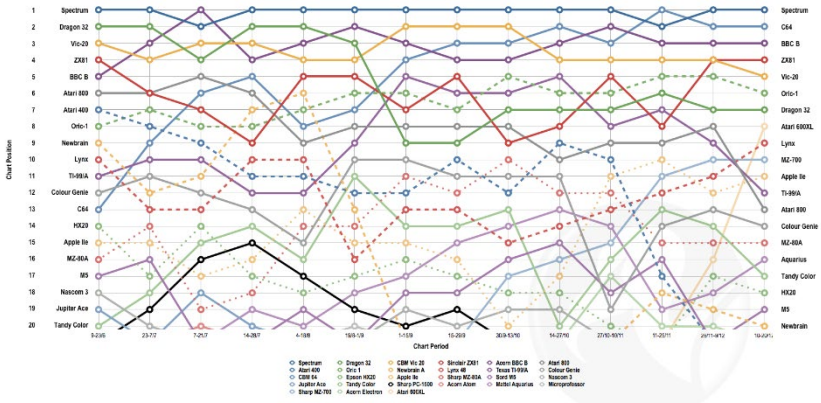


Figure [12] Exaggerated example of using too much information by the use of visual aids

Can take more time

The last disadvantage of making use of visual aids is the time needed to create them. Besides the importance of focusing on conveying the right information and using the right design, this process can take quite some time [55]. Besides creating the visual communication, it can also take time to understand what exactly is meant by the visual aids shown to the audience, while oral communication takes no time to exchange information [55].

2.2.3.4 Emotional branding

Emotional branding is a term used in communication marketing that refers to the practice of building brands that directly appeal to a consumer's emotional state, needs and desires, and is also used by some foundations to raise money. It is a process of forming a relationship with the product/brand and the consumer by triggering their emotions. Emotional branding is successful when it triggers an emotional reaction from the consumer, which means that the consumer desires the particular brand advertised, by feeling a sense of connection or love, that cannot be fully rationalized [56]. It plays with the human desires to love, feel emotional security, to feel powerful and ego gratification [57].

2.2.3.4.1 Psychology behind emotional branding

Referralcandy.com [58] claims that most marketing articles claim that there are only four basic emotions to tackle when making use of emotional marketing. Happiness, sadness, fear and anger. These four are the most common for people to feel, humans feel at least one of these emotions, ninety percent of the time. Referralcandy.com [58] concludes:

Happiness = more shares
Sadness = more clicks
Fear/surprise = more loyalty
Anger/disgust = viral content

An article called "the New Science of Customer Emotions", written by Scott Magids et al. [59]) state that 90% of the buying decisions are made subconsciously, 50% of brand experience is based on emotion and that a human processes visuals 60,000 times faster than text [60]. This concludes that an advertisement by a brand can have a huge part on the buying decisions of the audience. Since 89% of customers don't feel a connection to the brand they are buying, there is a big opportunity for brands to respond to this. So by adding emotional branding, it can have an even bigger impact on the decision making of the consumer.

Happiness

When making use of the emotion happiness for emotional branding, the viewer gets a positive awareness for the brand which is advertised. A way brands create 'brand awareness', is to put their brand in front of their consumer. A way to do so is to repeatedly show the brand so the consumer starts trusting the brand more. Example given by wordstream.com [61], when someone sees a particular brand of toothpaste all the time on tv, they have a preference for that brand when they need to buy a new toothpaste. The consumer chooses that particular brand they have seen on tv over other brands because of the brand awareness that company has created. A popular way of brand awareness in the 21st century is by making use of influencers, which is called 'Influence Marketing', since these people often have a wide range of audience. People follow these influencers on social platforms and look up to them. Seeing the content of their favourite influencers triggers their happiness [62]. If one of those influencers shares positive messages of a particular brand, the followers are more likely to choose that brand over other brands who are not shown by these influencers [58]. After getting the same brands as their favourite influencer, they might share the product online to show others that they got that particular brand too.

Sadness

When looking into the use of sadness in emotional branding, the main focus is to create an emotional connection with the audience by touching on the negative feelings. Exploringyourmind.com [63] states that the purpose of feeling sad is to make a person feel strong, alive and seek for support. It forces someone to stop and focus on what is happening. It makes us reflect on ourselves and focus on what makes us feel sad, this is also the case with anger. When touching on sadness by the use of emotional branding, the consumer experiences this natural response and would want to look into the sadness by clicking on the post of a particular brand. An example of this is from the brand "MetLife" [64]. In 2015, they released a commercial about a girl who tells all the great things her dad is and does. She says that he is the most handsome, he is the smartest and more. But after all the good points, he tells there is a negative point about him, which is that he lies. She continues telling all the lies that he has told, which is that he actually doesn't have a job, that he doesn't have money and that he is tired and unhappy. While she tells this, you see a montage of the dad working hard. At the end of the video, you realize that the girl wrote everything she told in a letter for her dad, which he reads. You see the heart-breaking moment that the father realizes that the daughter knew about the unfortunate things he goes through. But she knows he did it all just to protect her and give her the best he can. It is a very emotional commercial and it touches people's hearts, but when searching about the motives of MetLife, it is simply a company for life insurance. However, the consumer will most likely remember this commercial after seeing it.

Fear / surprise

The third emotion used in emotional branding is fear/surprise. The purpose of feeling fear is to motivate action, focus, avoidance and sometimes even preparation for possible actions someone has to take [65]. When experiencing fear or when someone is surprised, they are most likely to seek reassurance and comfort. When people are exposed to a certain brand in fearful situations, they become more loyal to that brand [58]. Even though this strategy might be effective, it does not always make sense for a brand to scare their potential customers. An example of touching upon this emotion is mostly seen in video games and movies. When the viewers see a particular brand in a fearful situation, they show more loyalty to this brand than when the viewers see the brand in a joyful situation.

Anger / disgust

The last emotion mentioned which is used in emotional marketing, is anger and disgust. Happiness and sadness might touch someone's heartstrings, anger and disgust can provoke emotional reactions from the audience, which can lead to the audience taking action by sharing, commenting or forwarding the particular post. The brands often do not intend to upset the reader, but they mostly try to choose a topic which is already controversial. An example of a controversial topic would be the plastic use and the effects of it for the ocean. When the audience shares these posts from the brands, there is more engagement with the content given, which leads to virality [58].

Benefits of Emotional Branding

By making use of emotional branding, a product can have an emotional connection to the target audience. An example of successful emotional branding is by Coca-Cola, which focused on the 'happiness' emotion. When thinking of Cola, people often think of the classic red can of Coca-Cola. Because of emotional branding, the audience has created a connection with this 'happiness' of Coca-Cola, which makes the audience loyal to the brand and more likely to choose the brand Coca-Cola over other cola brands. Flyingvgroup.com [66] states a total of four advantages of making use of emotional branding.

Know how to be different | by making use of emotional branding, the company is challenged to be different from other brands. By being different and standing out, the company will stand out more for the target audience. Not only by making use of emotion, but the design of the product also plays a part in this. Examples to be more unique as a brand, is by making use of a particular colour pallet or by including real people in the campaigns [67].

Positive brand recognition | a way to create positive brand recognition is to connect to the target audience, by creating an original, authentic and a common mutual understanding. This is the part where the emotion of customers plays a big role. An example of this is the focus on the 'happiness' emotion by Coca-Cola, mentioned in the example above.

Brand loyalty | by creating brand loyalty, the customers are more likely to choose your brand over the other brands. An example of this brand loyalty is the Coca-Cola brand mentioned above. A way to create this loyalty is to create more personalized and human interactions with the target audience.

Higher ROI | by having better ad marketing, this can increase the ROI, which stands for the return on investment. Ways to have better ad targeting is to have more specific campaigns and to be more target-oriented in these campaigns.

2.2.3.4.2 Modes of persuasion

There are different ways to make use of emotional branding. One of the ways to achieve an emotionally powerful brand is by finding a balance between the three modes of persuasion: Ethos, Pathos and Logos, created by Aristotle. The modes of persuasion are normally often used in speech, but these modes can also be used with emotional marketing.

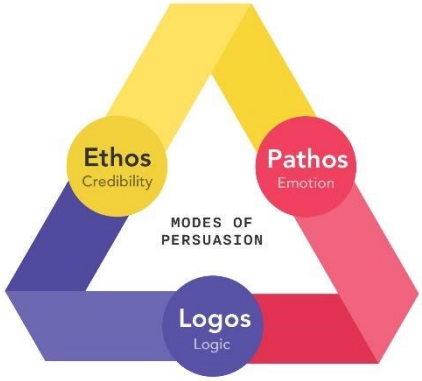


Figure [13] The three different modes of persuasion

Ethos

Ethos is focused on credibility and authority. The goal for the brand is that their words are perceived as credible and moral by the audience [68], so that the audience is convinced of the brand's credibility or character. This makes the audience feel more secure about the product and gives them the feeling that they can trust the brand. The focus in this strategy is often on the design of the product. A way of doing so is by making use of a particular colour-scheme or using authoritative elements, like a badge, to signal credibility to the audience [69].

Pathos

Pathos is focused on emotion and imagination. It aims for the heart of the audience. It makes use of the emotions of the viewer, as explained in chapter 2.2.3.1; "Psychology behind emotional branding". This particular way is mostly used for the non-profit industry, by creating empathy.

Logos

Lastly, logos is focused on logic and reasoning. This one can be seen as the most effective mode of the three modes of persuasion, but it relies on Ethos and Pathos to be successful. Ethos and pathos makes the audience aware of the product the brand sells, logos is the step where the consumer is persuaded that the concerned product which has been made aware, is the most logical to buy. Logos can be seen as the body of an argument [69]. When using this in emotional marketing, by making use of this mode, the consumer sees the product of the brand as the most reasonable choice to choose from the other brands [68].

2.3 Expert opinion

To get more information about the different perspectives about effectively communicating bad news, like the terminal disease DIPG to families affected, two interviews were conducted. The first one is with a doctor, to get a better understanding if the doctor has been educated to bring bad news, and if so, how he is educated. The second interview was conducted with a father who has lost his son to DIPG.

2.3.1 Doctor opinion

For the doctor's opinion, an interview was conducted with Dr. Vafi who has been a vascular surgeon for over thirty years. After studying medicine in 1976 at the university of Groningen, he completed his training at the Westeinde Hospital in The Hague [70].

It is quickly made clear that he has not been taught how to bring bad news to patients or family. The focus of medical school used to be mostly on learning theory about what you have to know to become a doctor. A way to learn how to bring bad news is by experience, so in practice. Fortunately, it was not a common practice for him to give bad news, since he specialized in blood vessels. When talking about how he experienced his first bad news talk, he said he did not remember the first time that clearly, but according to him it went quite smoothly. You keep learning every time you have to do it. Doctors often assume a worst-case scenario, this way it can only be better than expected for the patient and the family.

2.3.2 Parent opinion

The parent interviewed is also the client for this GP. His name is Reitse Sybesma, and he is the father of the twelve year old Tobias Sybesma, who has sadly passed away because of DIPG. This interview was conducted to get a better understanding of what to take into account when communicating with a parent of a sick child, and to understand how everything is perceived from the perspective of a parent.

In the very beginning, when Reitse heard something was wrong with Tobias, he didn’t assume the worst. After rushing to the hospital and seeing Tobias, he could see there was already a bit of facial loss, which is a symptom of DIPG. He also noticed that Tobias reacted a bit differently. At first Reitse and his wife thought he had anaemia or glandular fever, which unfortunately wasn’t the case. When hearing that their son was prognosed with DIPG, there was some disbelief, so it was quite a difficult realisation. As a parent, you put your own emotions aside, the focus is on the child. Besides, there was no time for their own feelings, since everything went very fast. He called it a rollercoaster of emotions. The professionals, doctors, researchers and other medical staff take over, as a parent, you can only watch. Since the doctors used a lot of difficult medical terms, Reitse and his wife made the decision to let Tobias join every conversation. This way the doctors had to explain everything to Tobias as well, in a more understandable way. Another benefit of this decision was that Reitse and his wife did not have to bring any bad news to Tobias.

If Reitse had time to let go of his emotions, he made sure he was very open and honest about them. He said it was a “better way of life when being open about your emotions”. He kept believing that Tobias could recover, “why couldn't he?”

2.3.3 Visual communication opinion

For the visual communication expert opinion, two different TED talks were studied. The first one is called “The simple genius of a good graph”, given by Tommy McCall. Tommy McCall is the founder and CEO of Infographics.com, which is an infographics design and data visualization agency.

He explains that communication is the encoding, transmission and decoding of information. From all sorts of communication, e.g. writing systems, maps or diagrams, the use of graphs is relatively young. Tommy explains that graphs can be seen as visual displays of quantitative information. And that graphics can transmit data with incredible efficiency. “Graphics that help us think faster, or see a book’s worth of information on a single page, are the key to unlocking new discoveries”.

The second TED talk is called “You are fluent in this language (and don't even know it)”, given by Christoph Niemann. Christoph Niemann is an illustrator, graphic designer and an author of children-books.

In this TED talk, when Christoph playfully talks about something he can’t explain, he says “but it can be drawn” and shows a drawing of what he meant. When he explains a particular situation, you see a drawing of what he means in the background, drawn by him. When watching this TED talk, you easily understand what he means and it is also some sort of entertainment while listening to his talk. He says “the deeper something is etched into your consciousness, the fewer details we need to have an emotional reaction”, while showing an image which could be interpreted as an image of Donald Trump. The image works because people are very good at filling in the blanks.

Figure [14] Without explaining, someone can fill in the blanks and understand what is meant

Both TED-talks don’t really indicate that visual communication is better than verbal communication, however this can be seen as logical since both Tommy McCall and Christoph Niemann are experts in the visual communication field.

2.4 Discussion

The important aspects of the literature review and the state of the art was looking into why creating awareness is important, the preferred ways of bringing bad news through verbal communication and look into communicating through visual communication. By bringing awareness, it can have a positive influence on a child patient and the affected family on how they deal with a disease. Not only creating awareness, but also the way the awareness is created can have an influence. Preferred ways to create this awareness by medical workers, is by making use of the SPIKES protocol, which is learned in medical school. However, some health facilities also have made their own guidelines to bring bad news to patients, parents or family. But these guidelines are somewhat similar to the SPIKES protocol. This SPIKES protocol can be a good factor to keep in mind when creating a product that can effectively communicate the terminal disease DIPG to the families affected, since this protocol has been seen as an effective way to bring bad news. The state of the art also focussed on how to cope with possible bad news given. However, there is no certainty that this information can be effectively included in the product, since the focus of the product is to effectively communicate DIPG to families affected, and not so much on how to cope with the information given after using or seeing the product.

The chapter 2.2.3 Visual Communication looked into another way of communication, besides verbally communicating. Visual communication is used to visualize information for the audience to understand. However, this type of conversation also has its advantages and disadvantages. It depends on the goals of the person who wants to give information what type of communication can be the most effective. When looking into healthcare, visual communication is a popular type of communication to explain certain medical terms and to let the audience more quickly understand what is meant [71]. So to answer the sub question "What is the preferred communication modality to let the affected families comprehend how their child is affected by it", the use of visual communication is preferred when talking about health-related topics.

When looking into the expert opinion. You can see the two different perspectives of the doctor's side and the parent's side. Depending on the experience, possible guidelines and education, a doctor can have a big influence on how the parent handles the bad news or situation. When assuming a worst-case scenario, this can have a bigger impact on the patients or patients who are receiving the news, but this way they can also have the most relief when the worst-case scenario doesn't come true. When the patient is a child, and when the parents let the child join the conversations, this is a way to let the doctors explain the situation in a more easily understandable way. However, the conversation should already be understandable when only the parents are attending it. So by making the information understandable for everyone,

The last sub question; "Can the product be designed in such a way that it raises awareness and understanding for DIPG?", is a bit of a hard one to answer when the product has not been made yet. However, there is indeed a possibility that the product can be designed in such a way it raises awareness and understanding for DIPG.

3. Methods and Techniques

In this chapter, different methods and techniques are discussed that are used when developing the product. This chapter is divided into three main sections. The first section is focused on the approaches, which include the design process used when developing the product. The second section discusses the methods used for stakeholder identification and the analysis. In the last section, the requirements needed for the product are identified.

The design process used for developing the product is called “A design process for Creative Technology”, created by Mader and Eggink. Which can be seen in figure [15].

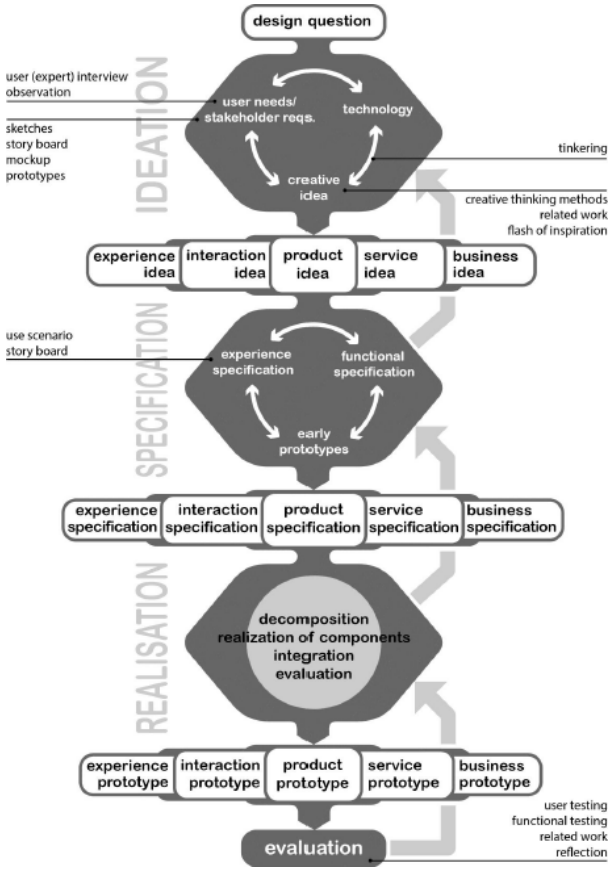


Figure [15] Design process, created by Mader and Eggink

This method is often used in the Bachelor study Creative Technology, at the University of Twente. The process is divided into four main phases:

- Ideation
- Specification
- Realisation
- Evaluation

Each of these phases are explained in the following sub-chapters.

3.1 Ideation

The ideation phase is the starting point of the Creative Technology design process and starts with the design question. This phase is to generate multiple ideas to develop a product [72]. These ideas are used as a course of inspiration for the brainstorm sessions to generate ideas for concepts. However, these ideas also have to match a certain set of requirements. This phase of generating ideas is called the divergence phase. But before generating these ideas, the stakeholders should be identified to see how much there should be communicated with each stakeholder and to understand their involvement in the project.

3.1.1 Stakeholder analysis

To identify the requirements that the final product has to meet, a stakeholder analysis has to be conducted, which will take place in the ideation phase. A stakeholder is a party who shows interest in a product, project or company. Stakeholders are often investors, clients, suppliers, customers or employees from another company [73]. A stakeholder analysis is a process where these stakeholders are identified, grouped and in this process, there will be determined how the groups of stakeholders can be involved and be communicated with throughout the project [74].

To conduct a stakeholder analysis, the stakeholders first have to be identified who will provide requirements which need to be kept in mind while making a tool to communicate DIPG. To do so, a simple table is created with a total of three columns. The first column is meant for the stakeholders, the second column is to identify the role of the stakeholders, and the third column is the name of the stakeholder.

Stakeholder	**Role**	**Name**

Table [1] Table for stakeholder identification

To understand the importance of every stakeholder, a Power-Interest Matrix is made. The power/interest grid is a matrix that is used to classify stakeholders and to know how to approach them efficiently regarding the project. Stakeholders are represented on the grid in proportion to their power and interest in the project [75]. They are divided into four categories:

- high power - high interest
- high power - low interest
- low power - high interest
- low power- low interest

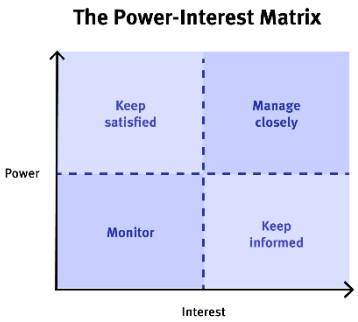


Figure [16] Power-Interest Matrix

After categorizing the stakeholders into the different categories, it has become clear how much power and interest each stakeholder has and how much every stakeholder should be kept in touch with regarding the product. A final concept will be picked and built in the following phases of the design process, based on feedback from these stakeholders.

3.1.2 Requirements

In the ideation phase, the product's requirements are investigated. These requirements are of importance since they help you understand the project risks and constraints. The final product needs to be made with these requirements in mind. A way to receive these requirements is by conducting interviews and brainstorm sessions with the different stakeholders. Stakeholder interviews are an excellent approach to gain a sense of the situation. They help you understand the behaviour of the user, look into limitations, and it helps with the identification of what the stakeholder does not want [82]. Brainstorming is a technique for generating a large number of new ideas quickly about a specific topic. The main characteristic of a brainstorming session is that value judgments are dismissed until all of the ideas have been considered [83].

A way of brainstorming is with the use of a mind map, which is a diagram composed of concepts, texts, relationships, and/or images arranged in a tree structure around a central theme. It is used as a tool for supporting creative processes as well as learning and remembering information [84]. The information conducted out of these interviews and brainstorm sessions can be seen and used as preliminary requirements.

Once these requirements are collected, they will be categorized with the use of the MoSCoW technique. This technique is often used in management, software development and more. The technique was developed by Dai Clegg with the goal to obtain an agreement with stakeholders on the significance they place on each requirement's fulfilment [76]. The technique is divided into four sections, 'must have', 'should have', 'could have' and 'will not have', as seen in figure [17].

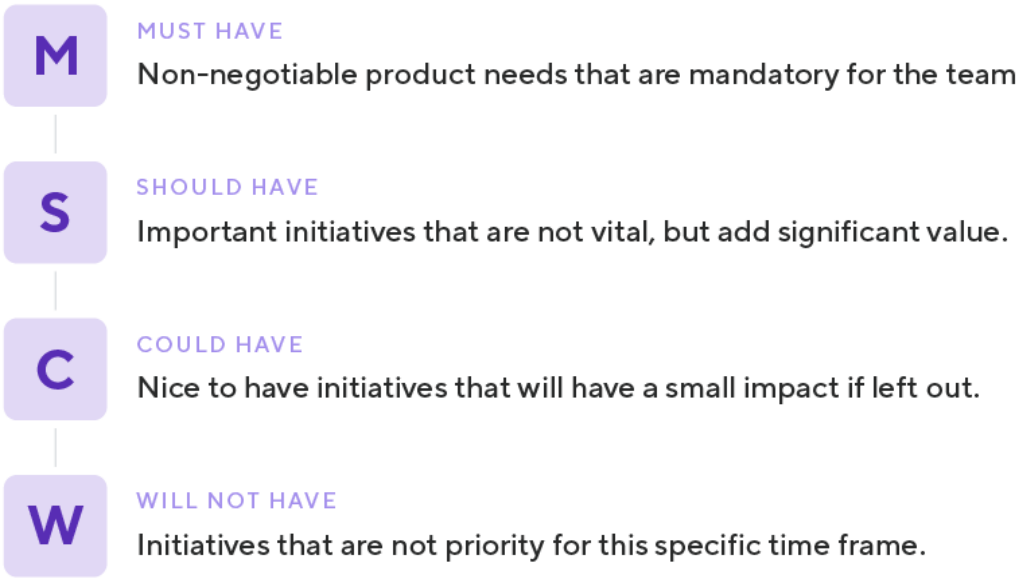


Figure [17] MoSCoW technique

Once these requirements are categorized with the MoSCoW technique, there will be a look into different concepts while respecting these requirements.

3.1.3 Concepts

After generating different concepts, the ideas have to be filtered and defined in the convergence phase, which consists of a process where the design space is reduced, until a final solution is generated. This reduction of design space depends on the requirements and the available information, collected in the ideation phase. The final concepts can be presented and discussed with the stakeholders. A way to do so is by the use of prototypes, sketches or storyboards. After receiving feedback from the stakeholders, the final idea can be chosen, leading to the next phase: specification.

Both the divergence- and convergence phases are integrated in the ideation phase, specification phase and the realisation phase.

3.2 Specification

After developing multiple ideas in the ideation phase, a final idea is developed in the specification phase, so the specification phase is to specify the final concept. Besides this final idea, the requirements that the final idea has to meet are also set up. These requirements can later on be used as a guideline for the final idea in the realisation phase. These requirements can also be used as a checklist in the evaluation phase. This way, the requirements can be taken into account with the final product. The specification phase will also include a scenario, a visualization of this scenario by the use of a storyboard and a lo-fi prototype of the final product which is handled in the design specification. The scenario and the storyboard are used to get a better understanding on how the user might use the product and to see potential problems.

3.2.1 Design specification

A design specification gives detailed instructions on the project's purpose, performance, and construction. It can be used to refer to the quality and standards that should be followed. Materials and goods from suppliers can be precisely specified. It is possible to identify the setup of the product and testing [77]. In the design specification for the final product of this project, there will be looked into the different aspects of the product. Some of these aspects are a Lo-Fi prototype, the colours chosen and why, different topics that will be included in the product and the different illustrations that will be used.

3.2.2 Scenario

A scenario describes how the persona acts in detail from the persona's point of view. It covers everything that occurs before, during, and after the use of a product. A good scenario gives context, which makes it easy to manage during the design phase and can be maintained continuously. The context provided by a scenario implies that the user and the unique tale are central [78].

3.2.3 Storyboard

A storyboard is a series of pictures that illustrate the main scenes. This includes what the setting will look like, who will be present and what actions will take place. It is frequently used as a mock-up for movie sequences, music videos, and television shows, and it can be created by hand or digitally [79]. Creating a storyboard is an essential part of the process of making a product. You could compare a storyboard to a comic strip. It is a series of images that bring the script to life. You will number each picture, also called a cell, and provide it with a description and important information [80].

3.3 Realisation

In the realisation phase, the final idea generated in the specification phase is built into an actual prototype. In this phase, the different design choices and elements for the prototype are explained and presented to the stakeholders. There will be a look into the different tools used to create the prototype, and show how the user interface looks by showing examples of the interface of the product.

3.4 Evaluation

The evaluation phase is the last phase from the design process. In this phase, the prototype is tested by performing user tests and also by interviewing the stakeholders. The product will also be checked if it meets the requirements, which were set up in the specification phase.

The evaluation itself is divided into different stages. The first stage is the planning stage. Here it will be investigated what form of evaluation will be applied. The next stage is the execution of the chosen form of evaluation. The next step is to carry out the chosen form of evaluation. Following that, the outcomes will be examined, and a reflection of these results will take place and it will be determined whether or not the product's requirements have been met [81].

4. Ideation

In this chapter, the ideation phase is discussed. The first subject that will be discussed is stakeholder identification and analysis. After that, the requirements for the project are identified and summed up. After these requirements are clear, a total of five different concepts are given.

4.1 Stakeholder analysis

In this chapter, the stakeholder is identified and analysed their importance in this project. The table given in 3.2.1, Stakeholder analysis, is filled in in table [2]

Stakeholder	**Role**	**Name**
Tobias Sybesma Foundation	Client	Reitse Sybesma
University of Twente	Supervisors	Richard Bults and Kasia Zalewska
Affected parents	User	Reitse Sybesma, a parent and more

Table [2] Filled in table for stakeholder identification

4.1.1 Tobias Sybesma Foundation

The Tobias Sybesma Foundation is represented by Reitse Sybesma. As a client, Reitse is included in the project and brings his own contribution and will have an influence on the decisions made for the final product. This makes this stakeholder have an important role in this project, so keeping in touch with this stakeholder is important. Besides being the client, he also belongs to the target group, the affected parents of children who are diagnosed with DIPG.

4.1.2 University of Twente

The University of Twente is represented by Richard Bults and Kasia Zalewska. They work as supervisors for this thesis and will have a voice in making the decisions. This makes the role of this stakeholder important for this project, and makes it important to keep in contact with this stakeholder.

4.1.3 Affected parents

As mentioned in 4.1.1., Tobias Sybesma Foundation, Reitse Sybesma also takes on the role of the user. This stakeholder is the target group of this project, so they play an important role. However, this stakeholder is not included in the decision making, but the requirements given by this stakeholder are taken into consideration when designing the concepts and eventually the final product.

4.1.4 Stakeholder Categorization

In this project there are a total of three different stakeholders which are divided into one of these four categories, shown in figure [18].

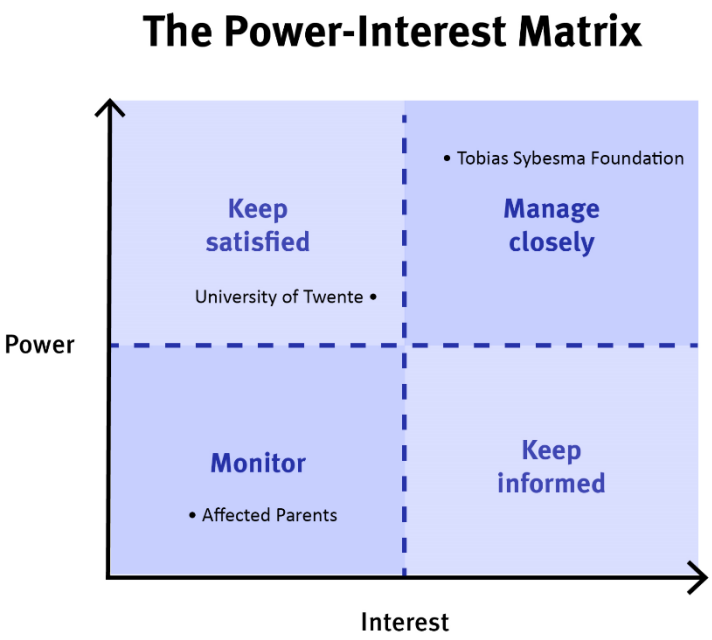


Figure [18] Power-Interest Matrix to define the importance of every stakeholder

The University of Twente is located in the high power - low interest category, since they have a big influence on the product, however they have less interest in the product than the client, the Tobias Sybesma Foundation. The client is categorized in the high power - high interest category. Their feedback has a big influence on the project, and they also show a high level of interest in the product. The last stakeholder, the affected parents, are categorized in the low power - low interest category. They don't have that much influence on the project and also do not have that much interest in the product.

This matrix shows that the client, the Tobias Sybesma Foundation is the most important stakeholder which indicates that close contact is a necessity. The supervisors help with actively consulting about the project, which makes them also important to keep in touch with. The users, the affected parents, are the stakeholders where it is needed to monitor them.

4.2 Requirements elicitation

4.2.1 Interviews

A way to understand what kind of requirements would be of good use for the product, interviews are conducted with the stakeholders which are the client, the supervisors and the users. Stakeholder interviews are useful research techniques for getting the design process started. They concentrate on gathering data from three key aspects of design:

- User requirements. What role will the design have in the users' experience?
- Business objectives. What role will the design play in achieving the company's goals?
- Technical restrictions. What are the technological challenges that must be overcome?

A total of two interviews were conducted with parents whose children suffered and had passed away from DIPG. Which resulted in them presenting a few topics that would be helpful for affected parents with a child who is diagnosed with DIPG. One of the parents was asked which topics he would have liked to know more about when he experienced his child being diagnosed. They expressed that they would have liked to know more about different hospitals in Europe or in the world, know more about the pros and cons about taking biopsy, which treatments are possible with DIPG, possible popular search terms on the internet about DIPG and know more about the medication used with the treatment. Besides looking into the medication, they suggested also to give information about how these medications operate and possible side effects of taking this medication.

The interview with the client, who is also a parent who had a child who suffered and passed away from DIPG, provided preliminary requirements. The client indicated that he wanted the product to have a clean and business-like feeling, while still being simple. Besides this, he preferred a product that has a possibility to give it to someone in person instead the product only being accessible on the internet or as a document. The last requirement that he pointed out was that the product includes simple minimal information that is being told in a way everyone can understand. This requirement was important since he experienced a hard time understanding difficult terms in the period he was understanding what DIPG included.

4.2.2 Brainstorm (mind map)

After listing the preliminary requirements, a brainstorm session was held with the supervisors to get an idea of what kind of product will be created.

First a mind map is created to see what kind of different options there are. The mind map made for this project concludes in a total of four different directions: an online paper, a video, a commercial or an app, shown in figure [19]. These categories are also divided into different categories to be more specific what kind of product would be a good fit.

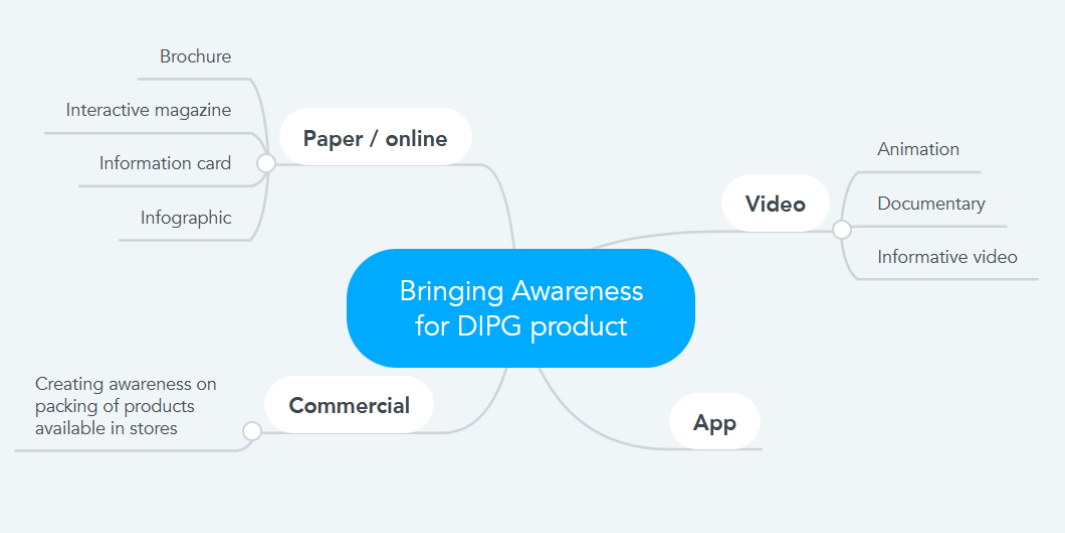


Figure [19] Mind Map to figure what product to use for bringing awareness for DIPG

After conducting this mind map, another meeting was planned to share these options with the supervisors. In this meeting, different ideas of the categories were made. Figure [20] shows an example of an elaborated idea of an interactive infographic as a concept.

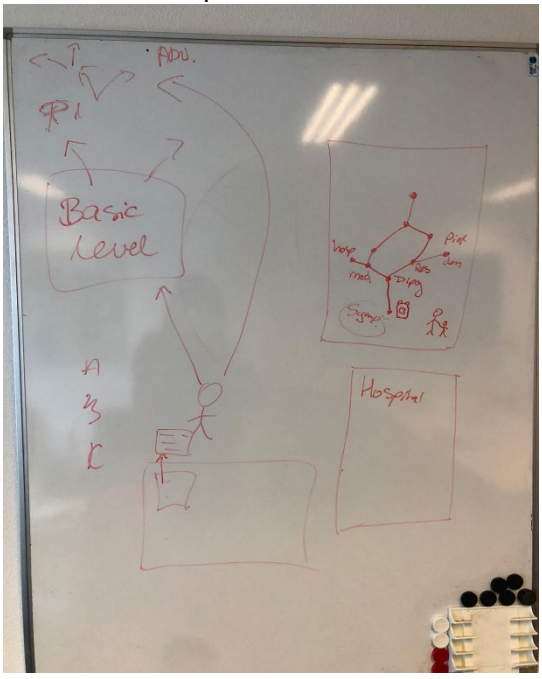


Figure [20] Brainstorming on what product to make

4.2.3 The requirements MoSCoW technique

To get an idea of the requirements needed for the product, there will be made use of the MOSCOW technique. This technique is to paint a picture of all the requirements needed for the product. It includes requirements you must have, should have, could have and requirements that you won't have in the product.

After conducting the interviews with the client, with another father who lost his child to DIPG and after several meetings with supervisors Kasia Zalewska and Richard Bults, different requirements for the product have been collected. These requirements are divided into two different groups: functional requirements and non-functional requirements. Functional requirements are any requirements which specify *what the system should do*, while the non-functional requirements are requirements that specify *how* the system performs a certain function [85]. The results of the preliminary requirements are composed in table [3].

MoSCoW method	**Preliminary requirements**
Must Have	**Functional** 1. Infographic should have dimension 2. Allow user to use the product with ease 3. Provide information relating on the context of the topic on DIPG 4. Include links of the websites used for the provided information **Non-functional** 1. Give the user a calm and secure feeling while using the product 2. Let the user feel they can choose for themselves what they want to know and what not 3. Must be appealing for the user to use 4. Bring awareness for DIPG 5. Give the user information about DIPG, possible treatments, medication, biopsy, progress of disease course and DIPG-hospitals around the world
Should Have	**Non-functional** 1. Be appealing enough for the user to have the tendency to share the product
Could Have	**Functional** 1. Tell about the effects and side effects of medicine 2. Most common search terms **Non-functional** 1. Make user donate to cancer research
Won't Have	**Functional** 1. Distracting things like animations or sounds **Non-functional** 1. User feeling overwhelmed by the amount of information 2. Focus on giving the user as much as possible information on DIPG

Table [3] Functional requirements

4.3 Preliminary concepts

4.3.1 (Interactive) Card

The first concept is a card to give to parents. It is a quick and easy way to explain the general information of what DIPG is. The stakeholder had indicated that it is nice to have something to hold in hand, instead of being given a website or anything other electronic. The card includes the most important information for the parents to know. The parents are also able to give the card to others, when they are asked what DIPG is and if they rather not explain it.

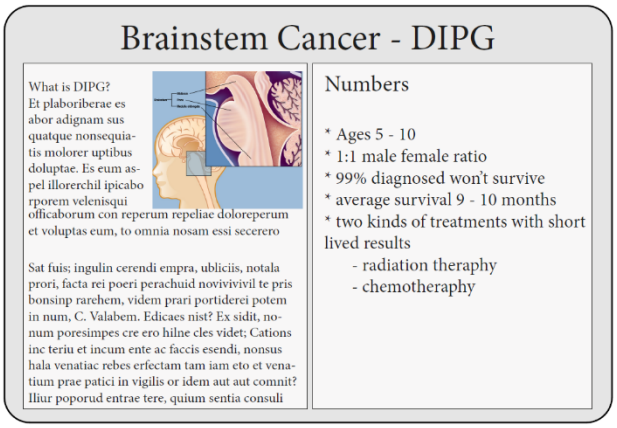


Figure [21] Card DIPG

4.3.2 (Interactive) Brochure

To give the parents a bigger picture of DIPG, instead of a card, a brochure can be made. This concept can include more information on DIPG but is also an object to hold and to give to others.

The front of the brochure will contain general information about who is affected by DIPG, information about what happens in the brain of a child who is diagnosed with DIPG, and information about the disease progression, so the parents can have an idea what to expect for the future. An example of this is given in figure [22] .

Figure [22] Front Brochure DIPG

On the back of the brochure, some tips and information where to find more information about DIPG is given, as well as the contact information for the Tobias Sybesma Foundation. The back can also tell the story of Tobias and Tijn, who both had DIPG. This way the parents might have some hope for their child that their child can still do a lot of things, and that the child can live the best quality of life possible. An example of this layout is seen in figure [23] The brochure can also have a QR-code, which takes the parents to a website where they can get more information.

Figure [23] Back Brochure DIPG

4.3.3 (Interactive) Infographic

The third concept is a bigger worked out brochure, which is an infographic. The idea is to make a total of two or three infographics who share the same theme. Examples of different topics for the infographics can be; What is DIPG, why is there no cure yet, and the disease progression. These infographics can be realised by the use of, for example, Adobe Photoshop.

A way to connect the different infographics is by using the same style, so it is easy to see that the infographics are connected to each other. However, there will be different colours used for the infographics, so the parents can easily see that the different colours stand for different subjects. The idea is to make this concept in real life, as well as an online version for the parents to view. This way there is also an easy possibility to share the information given by the infographics and to have the information close to hand. The online version can also include extra information and/or added features.

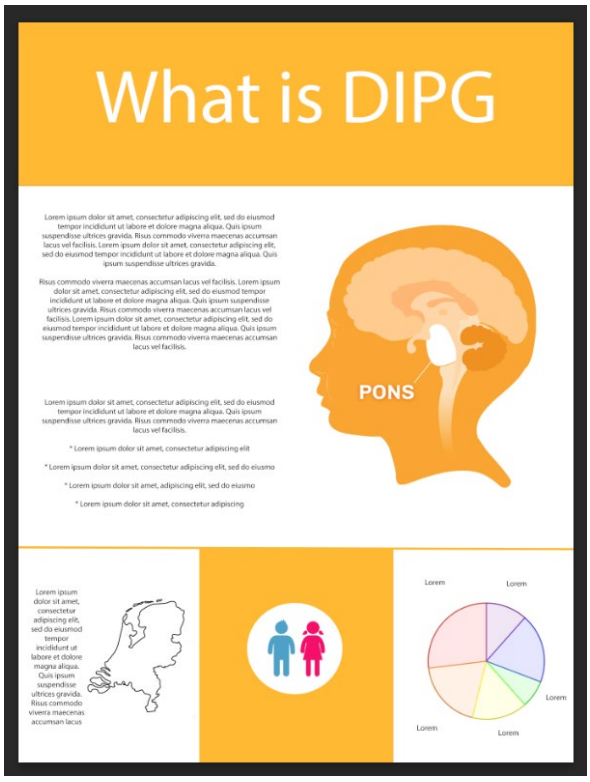


Figure [24] Example interactive infographic

4.3.4 Animation

In the sub-chapter [2.2.3.1 Different types of visual communication], it is explained that animation can have a benefit for educational purposes. Ghostproductions.com [86] also states that animation is an often used strategy in the healthcare industry, which makes it an effective tool to communicate DIPG to affected parents. By the use of images, the parents are able to understand the information given more quickly, which is discussed in the sub-chapter [2.2.3.3, Advantages and disadvantages]. In figure [25], an example is given for what could be discussed in the animation, which is an explanation of which part of the brain is affected by DIPG, and what the consequences of this will be in the body.

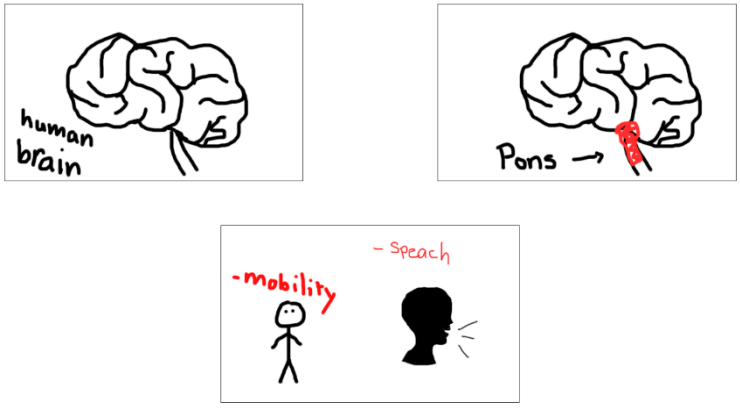


Figure [25] Idea Animation explaining DIPG

4.3.5 (Interactive) Magazine

The last idea for the concepts is the use of a magazine. An example of how the magazine would like is shown in figure [26] . The magazine can be used to give all the needed information for the parents affected, with some extra. An example of this is by giving a voice to children who are diagnosed with DIPG, or children who sadly have passed away from it. This way, affected parents who are new to the term DIPG can get a bit of hope that their children still can have a good quality of life. An example of this is given in figure [27]

Besides giving the children a voice, the magazine can also include articles about the experiences of parents who lost their child because of DIPG, or parents who are in the middle of the journey. This way, new affected parents might get some hope and feel more supported and understood. The magazine, just like with the infographic, can be a real-life product, but might also be implemented online. When being implemented online, there can possibly be features added to the magazine, to get the best out of the possibilities of online products.

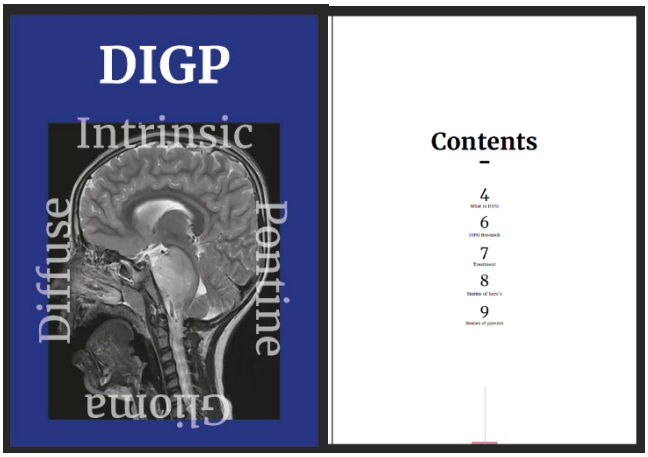


Figure [26] Example front of magazine and contents page

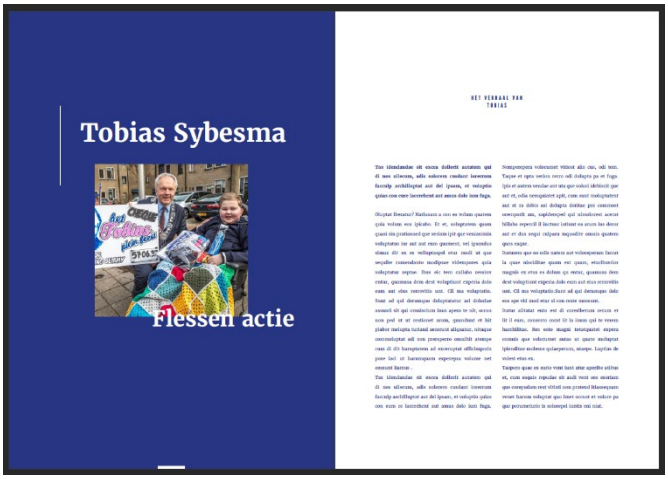


Figure [27] Example article story of a child who is or was diagnosed with DIPG

4.4 Final concept

After discussing the different concepts with the different stakeholders, the decision was made that the final concept will be an interactive infographic. The preference was first in the interactive magazine, however that would not have been enough of a challenge and it would not so much fit into the guidelines of a graduation project of Creative Technology.

The interactive infographic will be a big poster which includes different animations for the user to click through to uncover more information hidden in the poster. The idea is to have the possibility to print out the infographic so the client has the possibility to hand out the product, since this was one of the preliminary requirements they stated for the product. However, since the infographic will contain different pages which only show when interacted with, the product can still turn into a magazine, once printed out. The infographic can be the front of the magazine, and the other pages from the interactive infographic can be included as different pages. However this idea is an aspect of future works. So the focus of the final concept will only be on the interactive infographic itself.

From the preliminary concepts given in chapter 4.4, a final concept is chosen. The final concept will be an interactive infographic. In figure [28], a Lo-Fi prototype is shown.

Figure [28] Lo-Fi prototype of interactive infographic by the use of existing images

In figure [29], a sketch is shown of the infographic including the home screen and a very simple sketch of a topic page. The idea is to make an infographic including a route for the user to follow, as if they are going on a journey which links back to the mental and physical journey the parents and their child will go through once diagnosed with DIPG.

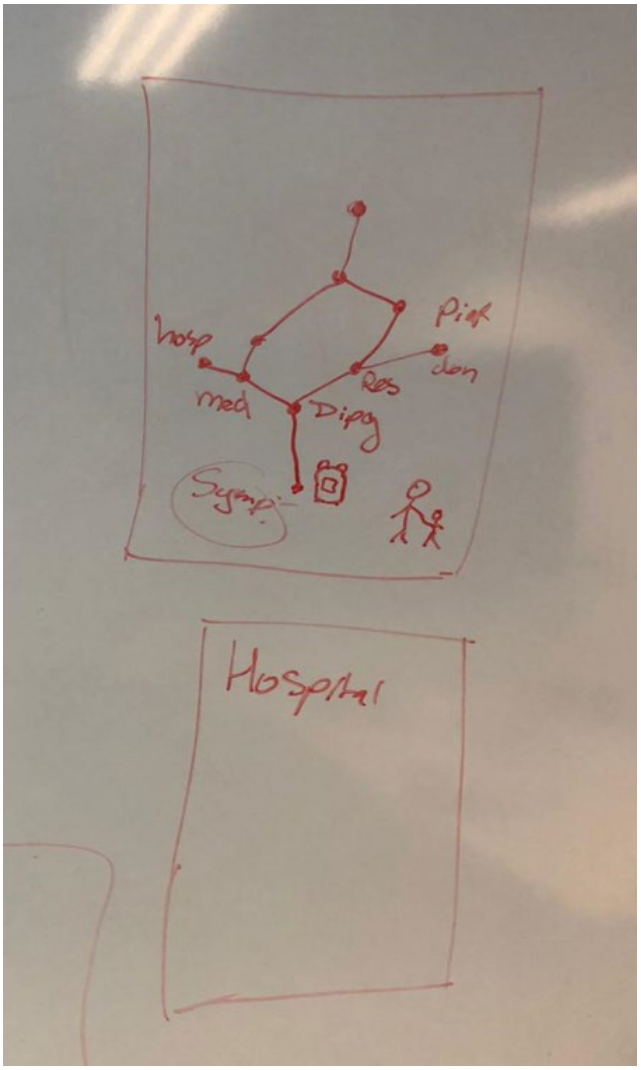


Figure [29] Sketch Final concept Interactive Infographic

The infographic will include a route with different waypoints which the user can follow. Each waypoint stand for a topic related about DIPG. The user can also choose to diverge from the standard route to choose to only read the topics that they are interested in. The topics will be visualised with the use of a white text block with comfortable and understandable text to read and the topic might also include an image regarding the topic.

The theme of the infographic will be a kind of camping route to give the infographic a bit of a comfortable and calm feeling, since camping can be seen as a fun activity to do with the family. Besides the route, the infographic will include different illustrations like trees, clouds, houses, mountains and tents to fit the camping concept.

5. Specification

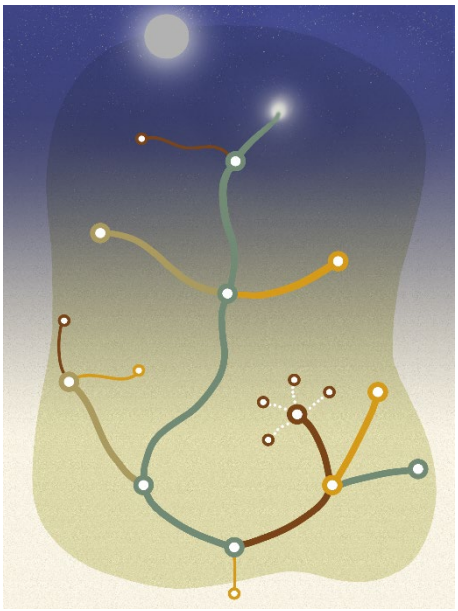
In this chapter, the different preliminary concepts developed in the ideation phase are looked into and specified, which results in developing the final idea. This chapter is divided into five different sub-chapters. These sub-chapters include the design specifications of the final product, a scenario how the product would be used, a storyboard to visualise the scenario, a lo-fi prototype to visualize the idea of the final product and a list of the final requirements for the product are set up. These final requirements will be used as a guide in the realisation of the final product.

5.1 Design Specification

5.1.1 Colour scheme

Since the time the parents have to go through can be very hectic and mentally exhausting, it is of importance to let the infographic radiate calmness without any distractions. A way to do so is by using warm colours and using simple figures to visualise the infographic. The colour scheme that will be used for the product is shown in figure [30]. The implementation of this colour scheme is shown in figure [31]

Figure [30] Colour scheme that will be used for the product



The colours have the following hex-codes:

= #728a76
= #ad9960
= #d29d17
= #88582d
= #dedaab
= #fbf5e4
= #404581

Figure [31] Colour Scheme implemented in the infographic

5.1.2 Topics

The infographic will contain different categories which provide information about DIPG-related topics. These topics will be connected to the different points seen in figure [32]. After the brainstorm session with the supervisors, the following topics were set up:

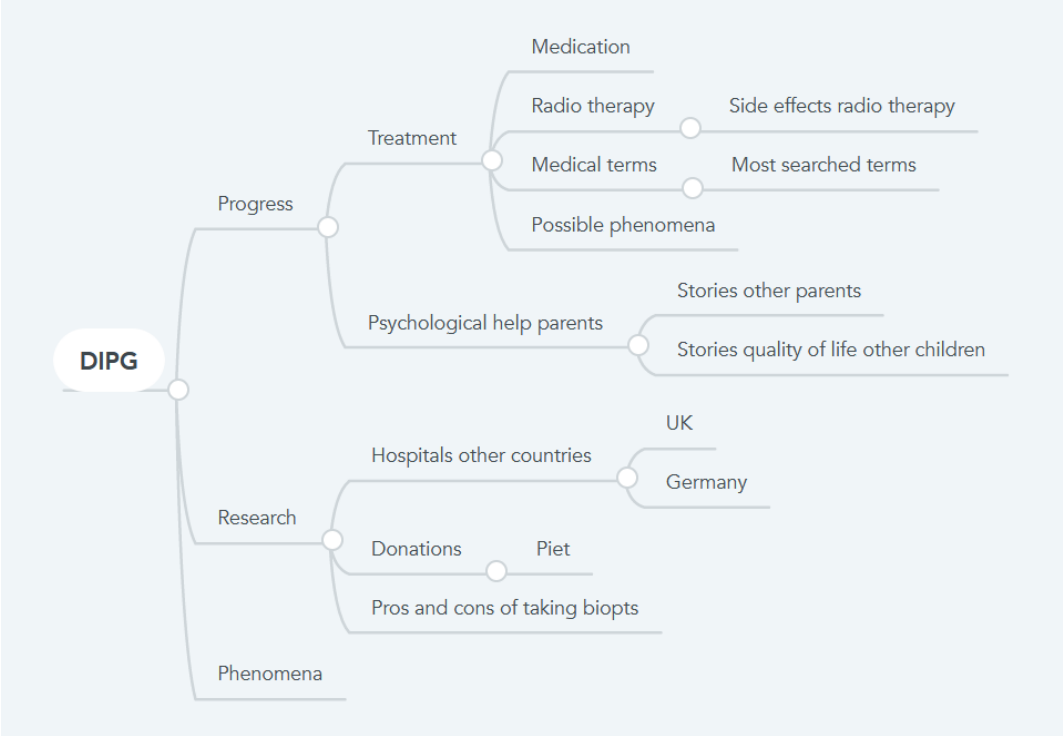


Figure [32] Example of different categories which can be shown as destination points on the infographic

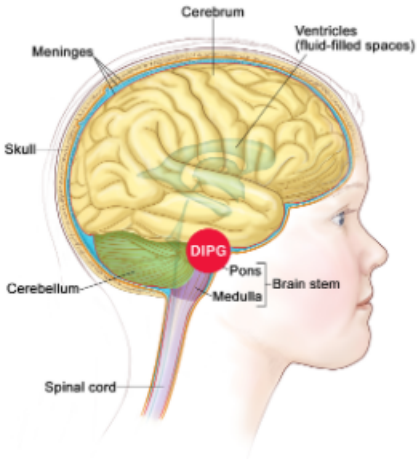
Figure [32] displays the infographic's very first start, which is the topic 'DIPG.' This topic is divided into three subtopics, which are further divided, and so on. The several subjects diverging from the 'DIPG' section show three different paths to take. The 'progress' route focuses on the various subjects encountered when dealing with DIPG, whereas the research' road focuses on the various types of hospitals throughout Europe and digs further into the research side of DIPG.

The topic that will be used for the product will be researched first to ensure that the information provided is accurate. Following that, the facts must be transformed into a flowing story that includes terms that are understandable to everyone. Next , the information will be placed in a text block on the topic for the user to read. Figure [33] illustrates an example of a clear and flowing block of text for the topic DIPG.

DIPG

DIPG, short for Diffuse Intrinsic Pontine Gliomas and better known as Brain Stem Cancer, is a rare terminal disease which affects only a handful of children every year in the Netherlands of the age around 8 and 11. Brainstem cancer is quite a rare and aggressive type of cancer which has no effective treatment and has a median survival time under a year.

The parts that are affected by DIPG are the
- midbrain
- pons
- medulla



These parts are located in the brain stem and are responsible for functions like regulation of the cardiac, the central nervous systems which includes consciousness and the sleep cycle, and respiratory.

DIPG is hard to treat and it is also hard to recover from. This is because the tumor is not that defined, and it spreads among the healthy cells in the brain stem.

Causes

Gliomas are caused by a developmental error in one of the progenitor cells of the supporting cells. Probably something is damaged in the chromosomes or in the DNA of this cell. It is unclear as to what exactly causes gliomas. Sometimes they are caused by a genetic disorder, causing the frequent occurrence of (brain) tumors in a family.

Figure [33] Text made for the topic "DIPG"(left)

The letter type used for the text will be in the style "Qanelas", with a few differences in the font weight to emphasize titles and important information. This particular font was chosen since it has a neutral and clean style. The font size will be 200, since this will fit the artboards and this size will be big and comfortable for the user to read.

5.1.3 Illustrations

As stated in 2.2.3: "*The main focus of an infographic is to inform, engage and summarize. [39]*", the use of an infographic can have a big impact on how the user understands the information and remembers it.

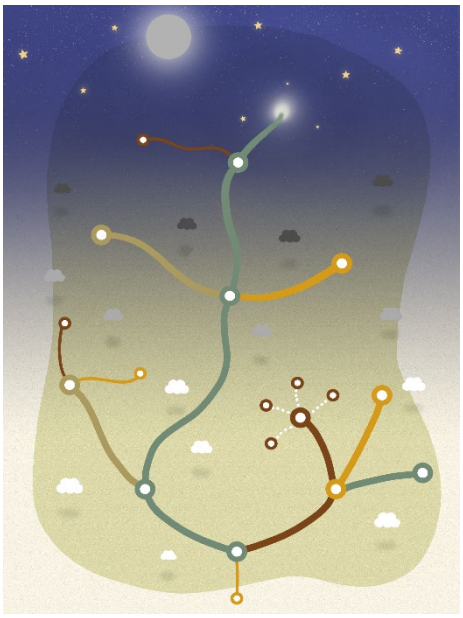


Figure [34] Infographic including the colour palette, roads, a moon, clouds and stars

In figure [34], the infographic is shown including the roads and little additions like stars and clouds. Something that stands out is the blue colour at the top of the infographic, since it is the only cool-coloured toned used in this infographic. This ombre of warm colours to a dark blue tone at the top is to indicate that the higher you go into the topics, the more night it becomes, which indicates the end of the journey. That is also why the top of the infographic includes a moon and the stars.

The last point of the original road, which is the road which is continuously a green/blue colour, is the end point of the treatment. This end of the treatment indicates it would be the end of the life of the child who battles DIPG. This end point, which is at the very top of the infographic, is a vague white spot. This is a conscious design choice, since it is a very general way of showing the end of someone's life. Since the users can have different ideas of what happens when someone dies because of their religion, this point is quite vague and shows some kind of a white door. This way the user can interpret this last point how they would like.

Another design choice is its choice in colours of clouds the more you go up. The further you are in the process of treatment of DIPG, the more serious, sad and terrifying it can become. That is why the clouds become darker the further you are in the process, which is visualised in the infographic as the further you go up, since darker clouds often means bad weather.

An interactive infographic is a big illustration in itself. Besides the road, the stars and the clouds, there will also be illustrations in the form of houses or clouds to give the infographic a bit more of a child-like feeling to distract the user a bit from the seriousness of DIPG. This child-like design is by making the illustrations simple yet still recognisable for the user to know what they are meant to represent. An example of this is an illustration of a house which is located beside the hospital-topic, see figure [35] as a reference. The user can see that it is a house since it is a square with a roof, but since it is besides the hospital-topic they might assume that the house should represent a hospital.

Figure [35] Example of an illustration of a house

As seen in figure [35], the house is not made in 2D but in 3D, this is to give the infographic a bit more dimension and to make the infographic more appealing to the eye. The house also has two roofs instead of one, this choice is made to indicate that the building is quite big. Normal houses would often be drawn with one roof, but the user might understand that the two roofs indicate a bigger building, and in this case, represents a hospital.

Another way of visualizing a topic is by making a sort of camping site. The idea behind the figure is that there are people camping in the tents, which indicates a topic related to humans. In figure [36] an example of an illustration of a tent is shown in the colours of the colour palette. Just like with the illustration of the house or hospital, the shapes used are quite simple and also made in a 3D kind of way to give the illustration a bit more dimension.

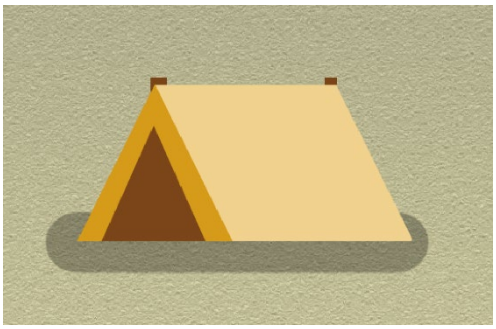


Figure [36] Example of an illustration of a house

An example of a topic that can fit this illustration, is something in the direction of psychology.

Since the infographic visualises a journey, and the further you go up, the more serious the topics become. To emphasise the challenge of this journey, small mountains are designed and added to the infographic. This indicates a harder time that you have to get through, which resonates with having to put in more effort when walking up a mountain.

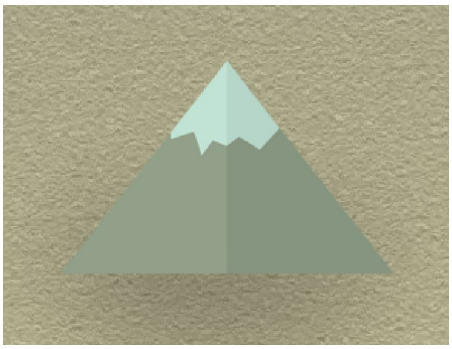


Figure [37] Example of a mountain

An example of where a mountain would fit on the infographic, is close to more rough things that a child has to go through, like radiotherapy.

Figure [38] displays a picture of a bear designed to show the viewer that a specific topic has a bad side to it. This bear has a dangerous and scary side, which could be appropriate for a topic such as informing the user about the side effects of particular treatments.

Figure [38] Example of an illustration of a house

There bear also has a connection to the mountains, since it has the connection that bears can live in areas with mountains, which makes them more likely to run into when walking there. An example of a connection the bear could have with the mountains on the infographic, would be a topic about radiation therapy where the mountains are located, and a connection to the side effects of this treatment, which is where the bear is located.

As seen on the figures [35] [36] [37] and [38], all the illustrations are provided with shadows. This is again to make the illustrations a bit more 3D and to give the infographic more dimension and appeal to the user.

Lastly, the illustrations shown in figure [39] are buttons which will be used in the infographic. The blue/green house symbol indicates the home screen. This button can be used to go back to the full size of the infographic, if someone wants to return. The yellow question mark is an indication to an explanation page for the user to read if they do not understand how to use the infographic. Once the user opens the web-application, they also will be welcomed with this explanation screen. However, they can choose to skip this part, but with the question-mark button, they have a possibility to come back to this page. Lastly, the red/brown book symbol stands for the library. Once opened, the infographic will include a page where all the links used for the information are stored so the user has the possibility to visit these links themselves.

Figure [39] Iteration of the storyline about using the product, shown in a storyboard

5.2 Scenario

Jacob and Lana are both 35 years old, and have a 7-year-old daughter named Emma and a 4 year old son named Charles. Both Jacob and Lana are working parents and the four of them live in Enschede, close to the school of Emma.

After a fun day at the park in the summer vacation, Lana notices that Emma acts a bit strange. Her reaction is a bit slow, and she is a bit absent. It does not feel right for Lana, so she discusses it with Jacob. Together they make the decision to visit their general practitioner to discuss Emma's situation. When arriving at the general practitioner, Jacob and Lana hear that Emma needs to go to the hospital to visit a specialist, who decides the need to have an MRI-scan done.

While the MRI-scan is analysed by a specialist, Jacob and Lana are waiting for the results. Jacob tries to calm down Lana and tries to be optimistic, while Lana feels like something is horribly wrong. After a long wait, Jacob and Lana are invited into the specialist's office, where they hear that their daughter is unfortunately diagnosed with an aggressive type of cancer, which is called DIPG, and are being told that the type of cancer is treatable, but there is no cure. Jacob and Lana are in complete shock, and are having trouble comprehending the information that the specialist is providing them about DIPG.

The specialist understands the shock of the parents, and understands they have trouble realizing what has just been said. To give Jacob and Lana the possibility to retrieve DIPG information, the specialist gives them an interactive infographic. In this infographic, parents of DIPG diagnosed children find needed information to understand the consequences and treatment of DIPG. The infographic gives parents the possibility to read as much information as they want, and with a scheme they can see where the information is relevant in the process of their child's prognosis of DIPG.

Jacob wants to know everything about the disease and wants to use the product provided by the specialist. When opening the website, he sees a welcome screen which explains how to use the product. Jacob reads everything so he can easily use the application. After finishing reading the explanation he clicks on start, which zooms into a section with a point called 'DIPG'. Jacob understands from the explanation that he can click the coloured circles with white circles in them, so he clicks on the topic 'DIPG' to see what it includes. The infographic zooms in a little bit more on the topic and Jacob sees a text block appearing. This text block includes all the general information about DIPG. He has the possibility to scroll down to access more information, and at the bottom he has an option to click on a button which directs him to the library. This library has all the links which have been used to collect all the information, so if he would like to know more about what has been mentioned, he can visit the websites himself.

After reading all the information provided about DIPG, Jacob scrolls back to the top and clicks on the return button to go back to the DIPG area of the infographic. Now, he has the option to go left or right on the infographic, or zoom out and see the overview of the infographic by clicking the home button in the top right corner. Jacob is curious about all the topics so he clicks on the home button, which makes him zoomed out of a particular area and lets him see the overview of the infographic. Here he sees the icon for the library and an icon to read the explanation again how to use the product. He can now make the decision for himself which topic he would like to know more about, or he can choose to follow the path indicated by the infographic itself, which indicates the points of the disease that they will experience in the future. After Jacob is content with the information he now knows

about DIPG, he calls Lana over to sit next to him. Jacob tells Lana that he decided to follow the order provided by the infographic, however Lana wants to choose for herself what to read and what not. She opens the web-application, but in contrast to Jacob, she only chooses to read information about DIPG, the medical terms, medication used, and the possible treatment. She does not want to know what might happen to her child further on in the process, and she is also not interested in the stories of other parents and what their children went through. By using the overview of the infographic, she is in control of how much information she would like to be exposed to .

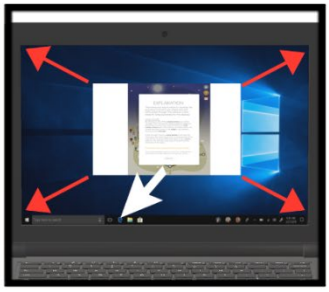
5.3 Storyboard

A storyboard is a document that is used to plan out a project. It is generated before the development of the final product and is used to illustrate a tale or depict scene changes. This will most likely be determined by a timeline, although it might also be determined by the user's selection or navigation choices [87].

A storyboard is created to visualize the scenario mentioned in chapter 5.2 called “Scenario”. The storyboard is made from the perspective of Jacob, who is the father of the DIPG diagnosed Emma. The images are in order.

Jacob walks up to his laptop to use the interactive infographic to understand more about DIPG, since his daughter Emma has been diagnosed with the disease.

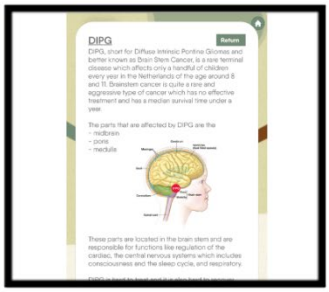
Jacob sits on his chair and turns his laptop on



He opens the interactive infographic on his web-browser by clicking the icon on his desktop and visiting the website.

The first screen Jacob sees is an explanation screen which explains how to use the product. He reads it carefully and after finishing he clicks on “START”

After clicking on “START”, he is zoomed into the DIPG section, here he can choose if he would like to know more about DIPG, or if he wants to know about a different topic. He wants to know more about DIPG, so he clicks on the blue/green circle called “DIPG”



After clicking the DIPG topic, a white screen pops up which contains information about DIPG. Jacob also notices a return and a home button in the top right which was mentioned in the explanation, so he knows how he can get back.

Jacob reads the information carefully by scrolling down. At the bottom, he notices a link which brings him to the library, which is a page with all the links used to collect the information for the product, which was also explained in the explanation-page. He chooses to click on the return button.

After clicking the return button, he is send back to the zoomed in section of DIPG. He is curious about all the topics of the map, so he clicks on the home-button on the top right to go to the overview of the map.

The zoomed in section is zoomed out back to the overview of the map. Here Jacob can see the different topics and he has the choice to click on every topic he would like to know more about. He chooses to follow the road, but Lana makes use of having her own choice of topic to click on.

Figure [40] Iteration of the storyline about using the product, shown in a storyboard

5.4 Final Requirements

In the ideation phase, a set of preliminary requirements was developed with the use of the MoSCoW technique to serve as a filter. By doing so, the number of ideas was reduced to a total of five early concepts. After choosing the final concept, the mentioned preliminary requirements were refined into a list of final requirements needed for the final product. This final set of requirements was used to specify the final design choices, and by the evaluation of the final product. The table shown in 4.2.3 of the MoSCoW technique is divided into functional and non-functional requirements.

Functional requirements

Functional requirements include the features of the product and the requirements of the user, so *what* the system should do for the final product.

MoSCoW method	Requirements
Must Have	1. Home button clicked; direct to the home screen 2. Option button clicked; direct to a white text block 3. Book button clicked; direct to a library text block 4. In home screen, waypoint clicked; zoom in 100% and centre selected waypoint in waypoint screen 5. In waypoint zoom screen, waypoint clicked; zoom in another 20% and display specific waypoint text block 6. In text block, return button clicked; zoom out 20% and return to waypoint zoom screen 7. Previous step button clicked; navigate to previous waypoint and centre selected waypoint in waypoint screen 8. In DIPG waypoint zoom screen, change “previous step” to label of left waypoint and “next step” to label of right waypoint
Should Have	1. User should be allowed to visit the websites used to provide the topics with information 2. Include clean animations of zooming into a particular section of a topic once that topic on the map is clicked 3. Text blocks can’t be longer than 2.5 pages
Could Have	1. Option to move between areas of the map 2. Return option in the right top of the text block in the topics
Won’t Have	3. Option to drag between the different sections of the map

Table [4] Final functional requirements

Non-functional requirements

The non-functional requirements include the properties of the product and the expectations of the users, so *how* the system should do it.

MoSCoW method	Requirements
Must Have	1. Every topic is provided with accurate medical information on DIPG, the progress of DIPG, psychological help for parents and children, research on DIPG, pros and cons of taking biopsy, medical hospitals, information on the Tobias Sybesma foundation, radio therapy, medical terms, possible side effects, palliative treatment and the medication used for treating DIPG 2. Easy interaction for affected parents
Should Have	1. Make the parents feel informed enough to feel more prepared to handle the process of their child having DIPG 2. Appeal to affected parents aesthetically 3. Be accessible by computer
Could Have	1. Encourage the user to donate to the Tobias Sybesma foundation by having a donate button in the topic "donations" 2. Be accessible by phone 3. Topic providing popular search terms used for DIPG
Won't Have	1. Animations or sounds

Table [5] Final non-functional requirements

6. Realisation

In this chapter, the realisation of the interactive infographic is described. This includes the software used to create the end product. This chapter also describes the process of how the product was made.

6.1 Tools

To realise the product, different software was used. The software needed to realise the product needed to have the possibility to create a map, and make it interactive. The first software chosen for this project were Adobe Photoshop to create the map, and Adobe Animate to create the animations. After trying to animate the map in Adobe Animate, the choice was made to switch to the software Adobe XD since this software would create a better prototype.

6.1.1 Adobe Photoshop

For the interactive infographic, a background is needed. This background consists of a map with different destinations points. To make this artwork, the software Adobe Photoshop 2021 [88] is used. Adobe Photoshop is the world's most advanced digital imaging software, used by photographers, designers, web professionals, and video professionals [89]. This software is chosen for this project since this is an often used software for creating images. Besides this, the creator of the product already has some sort of knowledge of this program, which makes it the best choice to choose. The final product of the map is shown in figure [41]

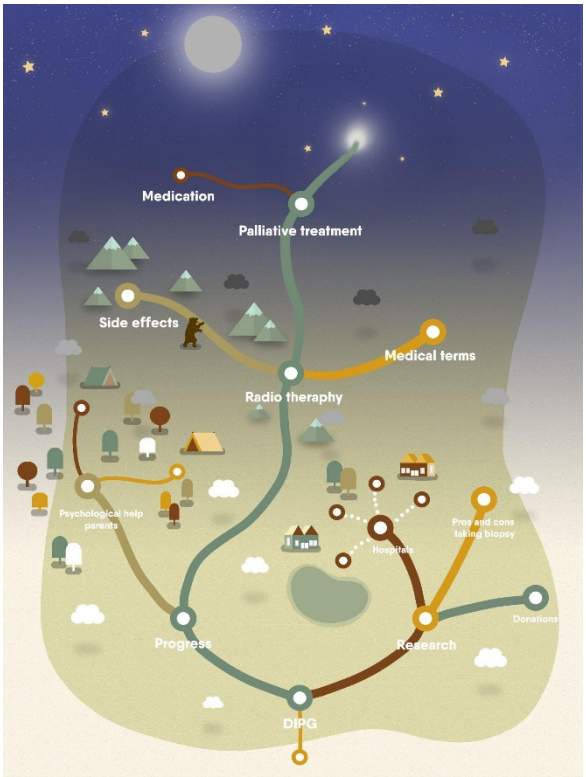


Figure [41] Lo-Fi prototype of interactive infographic by the use of existing images

Since the creator already had some knowledge about the use of Adobe Photoshop, the creation of the map and the illustrations went very smoothly.

6.1.2 Adobe XD

To make the map an interactive infographic, the program Adobe XD is used. Adobe XD is a software which is a vector-based user experience design tool, often used for web apps and mobile apps [90]. This program gives the user the possibility to make animations and clickable prototypes. Since Adobe XD together with Adobe Photoshop are part of the Adobe Creative Cloud, it makes it more accessible and easy to implement the illustrations made in Photoshop in Adobe XD.

After completing the design of the map in Adobe Photoshop, the map was imported into Adobe Animate, which is a software often used for animated web banners, games or mobile apps [91]. After watching tutorials about how to use the software and starting to animate the infographic, there were quite a few struggles. There was first a bit of a struggle to let the user click a certain point and that a text block would pop up, but after figuring that out, it only worked until the third waypoint. The different animations were played in the wrong order, which resulted in quite some frustration. After multiple attempts to make the animations work, the supervisors suggested using Adobe XD instead of Adobe Animate. So the Adobe Animate file was scraped and the map was newly imported into Adobe XD.

This software was eventually a better fit to make this prototype. The program was easier to run and was more convenient for the desired interactive infographic. Adobe XD provided the possibility to work very structured and without losing sight of the overview, which happened when using Adobe Animate. However a small disadvantage which could have a negative impact on the product, is that there is no possibility to add a link which is clickable for the user to be directed to a website. Since the final prototype includes multiple links for the user to visit, it makes visiting the website less attractive if they have to search for it themselves. This can be seen as an aspect for future work to resolve.

Another thing that was a bit of a hassle, was giving a page a small animation without having to create another page for it. An example of this is that it would have been better to give the user the impression that there is a possibility to click the different waypoints, shown in figure [42], without having to read the explanation page. A way that could have solved this problem would have been to make the white circles light up by flickering to indicate that they are clickable. After trying to accomplish this small animation, it started to conflict with other pages, since a lot of pages were connected to each other which is shown in figure [45]. Because of this, the decision was made to not add the small animations to all the waypoints in the map, but this could also be an improvement for future work.

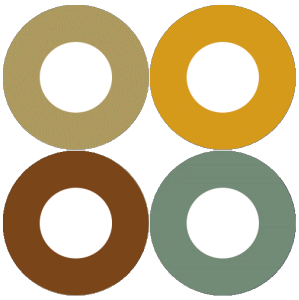


Figure [42] Waypoints used in the map

6.2 User interface

There are several components to the user interface. The first are the screens themselves, which include the start screen, different areas, pop-up topics and the menu-, explanation- and library popups. Secondly, there are the application's animations and navigation flows which are made in Adobe XD. These will be discussed down below.

6.2.1 Screens

The interactive infographic includes different screens which the user can visit. The very first one is a screen which contains an explanation of how the product works. After this the user can choose for themselves which area or topic of the map they would like to discover. A few examples of the many screens are shown in figure [43] and figure [44].

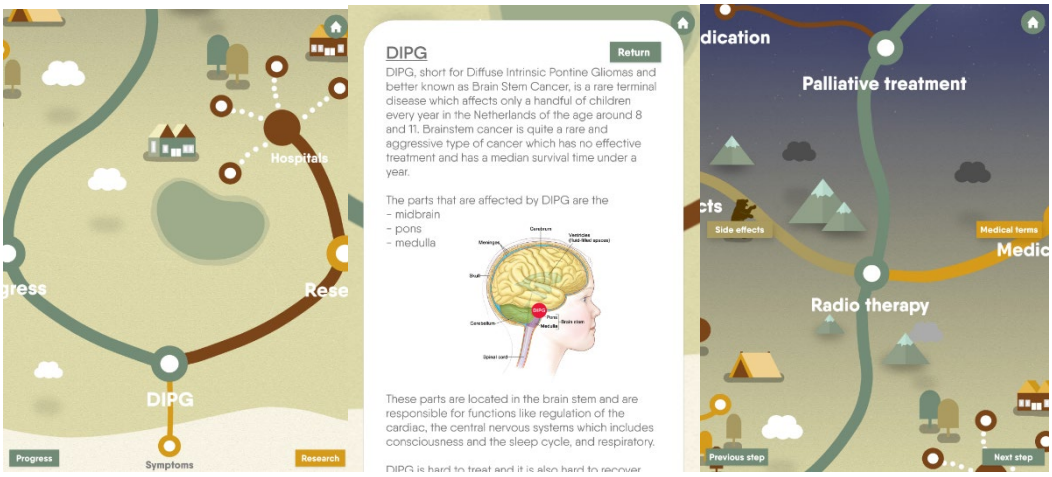


Figure [43] Examples visiting area 'DIPG', 'radiotherapy' and the topic DIPG

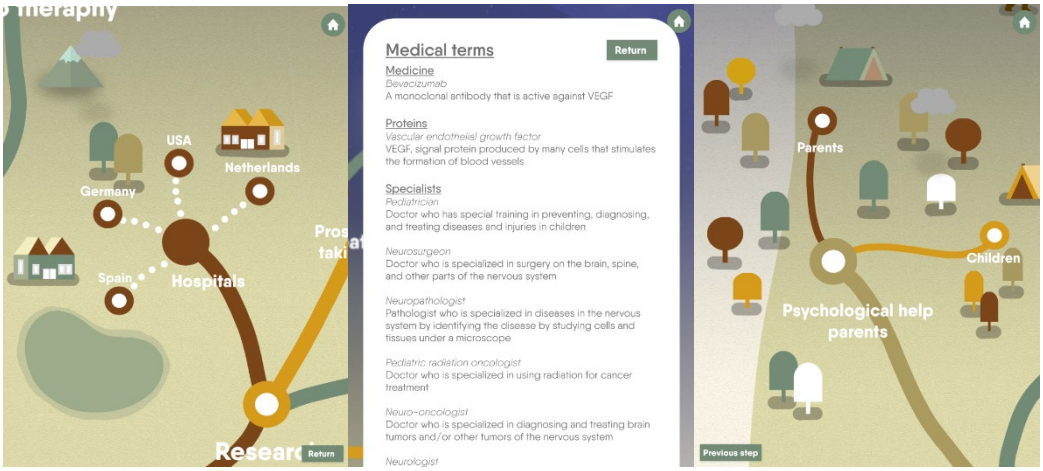


Figure [44] Examples visiting area 'hospitals', 'psychological help parents' and topic 'medical terms'

It was decided that the user would first be zoomed into a section before having the choice to click on a particular topic to read. This was done so the viewer would not be overwhelmed by the different topics if only shown the overview of the map. However a downside of this could be that the user does not really know how to visit one area when visiting another without using the map overview, which could be confusing.

6.2.2 Navigation flow

The product includes a lot of navigation flow. Unfortunately not everything can fit in one picture since the artboards used are way too big. When the file of the map made in Adobe Photoshop was imported, the file was very big but this was only noticed far into the project. When trying to make it smaller, the text and the symbols made in Adobe XD did not easily scale down, which resulted in keeping the big art boards which can be seen in figure [45].

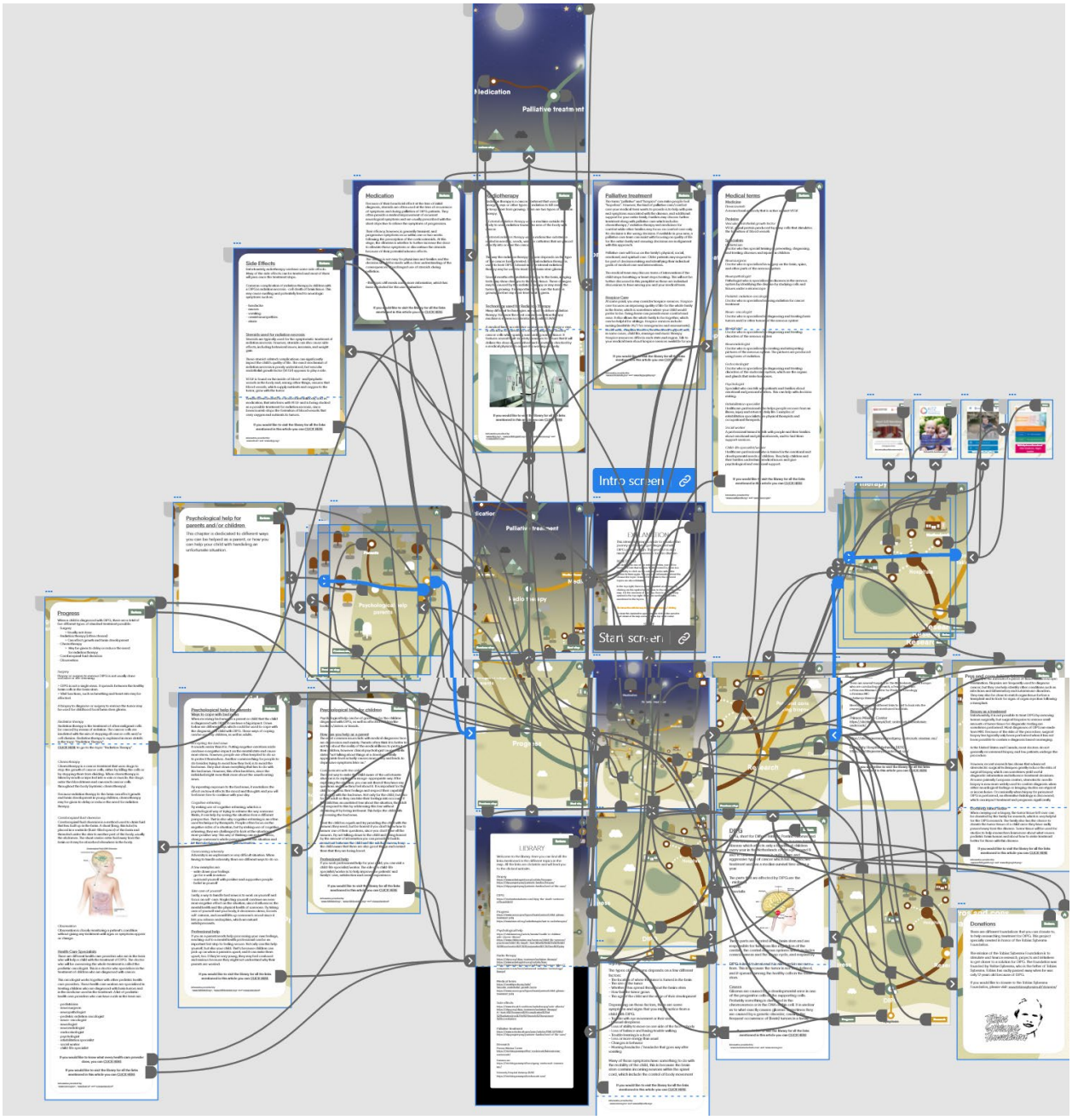


Figure [45] Navigation between the many artboards used for the product

To achieve a nice and smooth navigation flow, different types of animations were edited to connect the different artboards. All the connections shown in figure [43] are all the animations added to connect the different pages with each other. The only trigger the user can choose to set off the animations, is by tapping the different areas and buttons. By tapping, the animation type “auto-animate” will play, which consists of an ‘ease in-out’ animation to make the transition more smooth. The duration of these transitions are set at 1.5 seconds.

After trying multiple options for the animation, the auto-animate ease-in-out option was the best one, since it makes the transition play more smoothly than the other options. One of the options was not using the ease-in-out option. This included that once clicking on a topic, the text block with the information about the particular topic would pop up immediately. These types of transitions were very quick, unappealing and it just felt that an animation was forgotten to be added.

7. Evaluation

The prototype that was created during the realisation phase is assessed in this chapter. The purpose of the evaluation phase is to see if the user experience is satisfactory and if the functional and non-functional requirements established during the specification phase are satisfied.

7.1 Questionnaire set up

The questionnaire was made to ask users questions about the prototype to understand the way the user uses the product and to see possible improvements. The ideal target group for this questionnaire and product are parents between the ages of twenty and forty. The age was the most important aspect of the target audience, but if they had children or not could differ.

The questionnaire consisted of two types: statements and questions which are answerable by using a linear scale with a scale from one to five or open questions. The answer the participants could choose from differed. In table [6], an example is shown of the options of answers to choose from.

Question / statements	**Available answers**
Question What kind of emotion generates the design of the product?	1 – hectic 2 – little hectic 3 – neutral 4 – little calmness 5 – calmness
Question What is your overall impression of the product?	1 – dissatisfied 2 – a bit dissatisfied 3 – neutral 4 – a bit satisfied 5 – satisfied
All statements	1 – strongly disagree 2 – disagree 3 – neutral 4 – agree 5 – strongly agree

Table [6] Available answers for questions and statements questionnaire

For the open questions, the following three questions were lined up:

1. Are there things you especially liked about the product?
2. Are there things that you did not like about the product?
3. Are there things you would change about the product?

The open questions are mostly to understand what the user thinks about the product and have the possibility to view the product from a different perspective.

7.2 Questionnaire results

A total of eleven people have been able to test the product and fill in the questionnaire. The ages range from twenty to forty years old with a majority for the twenty to twenty-five group. From the responsive, a total of four of the users are parents. The different questions and statements are appointed as 'Q' for question and 'S' for statement. The exact data collected for this questionnaire is shown in Appendix E: Questionnaire results. In table [7], all the statements and closed questions are shown, including the results.

Question / statement	**Results**
What kind of emotion generates the design of the product?	The majority of the test subjects choose between neutral and agreeing. They are quite neutral about the product but some do tend to think of the product being calm.
The design of the product is appealing	Three persons were neutral about this statement, another three persons agreed and a total of five participants strongly agreed, which shows the majority thinks that the design of the product is appealing.
The design looks inviting to use	Most of the participants chose that they agreed with this statement, which shows they agree with this statement and shows that the design is indeed inviting to use.
I understand how to use the product	The opinions were divided between agreeing or stringy agreeing, which shows that the product is good to understand.
The product is easy to navigate	With this statement, the opinions were divided. One person disagreed, and two other people were neutral. This shows that some people do have some trouble with the navigation of the product, which could be improved in the future.
I have problems understanding how to use the product	One person indicated that they strongly agreed with this statement, however after looking into the answers of this person, it looked like they were very enthusiastic with the product and filled in "strongly agree" everywhere, without knowing this statement has a bit more of a negative approach. Besides this answer, the majority disagreed with this statement, which shows they don't agree that they are having problems. However there could still be some misunderstanding how to use the product, since they did not fully disagree.

The information in the product is understandable	The majority indicated that they agree that the product is understandable. However one of the users indicated that they did not agree with this statement, which shows a possibility for improvement of the product.
The product includes complicated words/phrases that I don't understand	With this statement, the opinions were divided. However the majority were neutral, which is understandable since the product tackles difficult subjects. People could also have been lost in translation.
What is your overall impression of the product?	Nearly everyone stated that they are quite satisfied with the product.
I would recommend this product to a parent who have a child with DIPG	All the test subjects chose to agree or strongly agree, with only one person stating that they did not agree with this statement. This test subject did not really state why they would not recommend the product in the open questions.
The product has taught me more about DIPG	Everyone agreed that they have learned more about DIPG.
I feel properly informed about DIPG	Same with the previous statement, however the opinions were more sided to being neutral about this statement.

Table [7] Results of statements and questions questionnaire

The open questions were focused on looking into the good points of the product and to understand what things could be improved. Overall the test subjects were satisfied with the design of the product. Looking into the things that they did not like, the comments were about sometimes not understanding the navigation and someone also indicated that they were not a fan of beginning at a certain point when clicking start, instead of starting at the overview of the map.

7.3 Requirements evaluation

For this last sub-chapter of chapter 7, the requirements list created during the specification process was assessed. The functional and non-functional criteria, as well as whether they were satisfied (✓), partially met (✓/✕), or not met (✕), are shown in table [8] and [9].

Functional requirements

MoSCoW method	Requirements	Met
Must Have	1. Home button clicked; direct to the home screen	✓
	2. Option button clicked; direct to a white text block	✓
	3. Book button clicked; direct to a library text block	✓
	4. In home screen, waypoint clicked; zoom in 100% and centre selected waypoint in waypoint screen	✓
	5. In waypoint zoom screen, waypoint clicked; zoom in another 20% and display specific waypoint text block	✓
	6. In text block, return button clicked; zoom out 20% and return to waypoint zoom screen	✓
	7. Previous step button clicked; navigate to previous waypoint and centre selected waypoint in waypoint screen	✓
	8. In DIPG waypoint zoom screen, change “previous step” to label of left waypoint and “next step” to label of right waypoint	✓
Should Have	1. User should be allowed to visit the websites used to provide the topics with information	✕
	2. Include clean animations of zooming into a particular section of a topic once that topic on the map is clicked	✓
	3. Text blocks can’t be longer than 2.5 pages	✓
Could Have	1. Option to move between areas of the map	✕
	2. Return option in the right top of the text block in the topics	✓
Won’t Have	1. Option to drag between the different sections of the map	✓

Table [8] Final functional requirements are met or not met

Non-functional requirements

MoSCoW method	Requirements	Met
Must Have	1. Every topic is provided with accurate medical information on DIPG, the progress of DIPG, psychological help for parents and children, research on DIPG, pros and cons of taking biopsy, medical hospitals, information on the Tobias Sybesma foundation, radio therapy, medical terms, possible side effects, palliative treatment and the medication used for treating DIPG 2. Easy interaction for affected parents	✓/✕ ✓/✕
Should Have	1. Make the parents feel informed enough to feel more prepared to handle the process of their child having DIPG 2. Appeal to affected parents aesthetically 3. Be accessible by computer	✓/✕ ✓ ✓
Could Have	1. Encourage the user to donate to the Tobias Sybesma Foundation by having a donate button in the topic “donations” 2. Be accessible by phone 3. Topic providing popular search terms used for DIPG	✕ ✓/✕ ✕
Won’t Have	1. Animations or sounds	✓

Table [9] Final non-functional requirements are met or not met

The answers has shown that the majority of the respondents felt they were sufficiently informed, that they find the information understandable to read and that they sufficiently could navigate through the product. However some of the respondents did still have some trouble with the navigation, which could be something to improve.

Regarding the requirements, some of the requirements were only partly met.

- The information in the infographic were unfortunately not checked by an oncologist. Because of this, it can not be said with certainty that the medical information is completely accurate.
- When it comes to the interaction, the majority of the respondents indicated that they could sufficiently interact with the product, however some of the respondents still had some trouble with this.
- The majority of the respondents indicated that they felt sufficiently informed about DIPG because of the product, however there were a few who felt that they needed more information to feel informed enough
- The product is accessible by phone, however since the user can't swipe around the map and can only click around, there is a possibility the user can see the navigation of the web-application inconvenient to use.

Besides the requirement which were partly met, there were also some requirements which are not met.

- The user was unfortunately not given the possibility to visit the links provided, since the software did not have this possibility.
- The user could not move around like you could do with Google Maps, which also came back in the answers what the user would have liked in the product.
- A topic about popular search terms regarding DIPG was missing, since there were enough topics which were more important than this one
- The users were not consciously encouraged to donate to the Tobias Sybesma Foundation. However it cannot be said with certainty that the users were not encouraged to donate, since this question was not asked in the questionnaire.

The respondents also had the opportunity to fill in suggestions what could be improved in the interactive infographic. One of the suggestions was to add an animation to make it more clear for the user that the different topics are clickable, without having to read the explanation on how to use the map. Another suggestion was to make the infographic swipe-able like how you would swipe in Google Maps. These suggestions can be used for the improvement of the infographic.

8. Conclusion, Limitations and Future Work

8.1 Conclusions

After creating an interactive infographic to bring awareness for DIPG to families affected, this chapter serves as a reflection on the work done so far, evaluating if it can answer the research question posed in chapter 1.3 Research Questions. The conclusion of this research and evaluation will be written as a response to the following research question:

How to effectively communicate the terminal disease DIPG to families affected?

For this thesis, an interactive infographic is made which contains information about topics regarding DIPG, explained in a non-scientific way for affected families to understand. The infographic portrays a journey that the affected family can follow while learning about many aspects relevant to DIPG such as possible therapy, medication, research done, and more. By clicking on a topic, the user can determine for themselves which topics they want to learn more about.

The client, the Tobias Sybesma foundation, has indicated that they are satisfied with the interactive product. Besides the client, the product was also positively perceived by the participants in the user evaluation. The user evaluation has shown that the product is appealing, includes understandable and sufficient information, and that the user can sufficiently navigate through the product. Some of the participants still had some trouble with the navigation and understanding particular information. But besides this and the medical information not being checked by an oncologist, the majority of the participants has indicated that the information is clear and comfortable for the user to read.

Thus, this research has shown that the use of an interactive infographic *can* indeed be an effective technique to communicate DIPG.

8.2 Limitations and Future work

The product is far from flawless, and there is still much potential for development. The first change that might be made is to make the product printable, as this was one of the client's requirements that was not addressed. The map's navigation should also be improved so that you can swipe the map in the same way that you can search for locations on Google Maps. One of the most important enhancements that could be made is the ability for the user to click on the links provided in the library; this could not be done in the prototype due to technical restrictions in Adobe XD. A final enhancement that might be implemented is to add minor animations to the various waypoints to signal that the waypoints are clickable, so the user knows how to use the product without having to read the explanation page.

The information provided in each topic is unfortunately not checked by a specialist to be sure that the topics are provided with accurate medical information since the specialists were too busy with work. If the prototype would be elaborated into a real product, it is of importance to make sure all the information is completely accurate. Besides this, the target group for the user evaluation was not perfect, the perfect age group would have been between the ages of 20 and 40 with young children. However the respondents differed from this target group.

When developing the final product into a real-type product, it is best to continue with further evaluations of the prototype. The perfect target group for these new evaluations would be parents who have a child who is diagnosed or passed away because of DIPG.

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Appendix A: Interview Reitse Sybesma as User (summary)

Interviewee: Reitse Sybesma
Interviewer: Quirine Vafi
Location: MS Teams
List of Acronyms: Q = question
Reason for the interview: to understand more about the target audience, to know where there is a problem for them and to get an idea of what kind of product is needed

Q: Hoe voelde je je toen je te horen kreeg van Tobias dat hij zich niet zo lekker voelde?

- Hij was op vakantie met z'n opa en oma, samen met z'n zusje
- Reitse in Spanje, moeder (Evelien) in Nederland (eigen winkel)
- Kon het zich niet voorstellen dat iemand zo ziek kan zijn, een tumor dat alles verwoest
- Reed van zuid Frankrijk naar Zwolle, maar de eerste keer toen Reitse Tobias zag, zag hij al dat er uitval was in zijn gezicht
- Je bent dan nog niet bewust van hoeveel impact die ziekte kan hebben, je weet niet wat je te wachten staat
- Je merkt alleen dat Tobias wat anders reageert
- Je denkt niet meteen het allerergste, maar dat was het helaas wel
- Dacht dat het bloedarmoede of pfeiffer was
- Moeilijke realisatie dat Tobias hersenstam kanker had, was Reitse totaal niet mee bezig, maar ze waren wel erg verdrietig

Q: Hoe kon je je eigen gevoelens de ruimte geven en er alsnog zijn voor Tobias

- Eigen gevoelens zet je aan de kant
- Alles ging heel snel, dus daar had je ook geen tijd voor
- Reitse was verbijsterd dat elke dag het erger kon met hoe de situatie eruit zag
    - Infuus, controle kwijt, vallen
    - Elke dag wel door een ondergrens
    - Rollercoaster aan emotie, je cijfert jezelf weg, focus op Tobias, grootste crisis waar je in kan zitten
- Reitse heeft ook moeite om alles goed uit te leggen hoe dat voelt
    - "Wat ik gevoeld heb dat kan ik niet eens overbrengen zodat jij weet hoe het voelt"
- Zaten in een crisis
- Professionals, artsen, onderzoekers, medische mensen nemen het over, als ouder kijk je ernaar

Q: Had jij momenten dat je je emotie aan Tobias liet zien?

- Bij Tobias was alles open
- Tobias was bij elk gesprek aanwezig
- Als Reitse iets niet zou snappen, dan zou hij dat Tobias ook niet kunnen uitleggen, dus daarom was Tobias bij elk gesprek met een arts aanwezig
- Als hij erbij zit, dat moeten de artsen hem ook alles uitleggen
- Erg tevreden met deze keuze, advies voor andere ouders om het kind erbij te hebben
- Emoties niet onder stoelen of banken gestopt
- Zeiden wat ze dachten
- Hoe opener het is – hoe beter het moment van kwaliteit van leven is
- Ook na zijn overlijden, Reitse erg ziek geweest van de rouw, maar houdt zijn emotie niet tegen, hoefde niets weg te stoppen, erg opgelucht en opgeruimd gevoel
- Nergens spijt van, Reitse zou precies hetzelfde opnieuw doen op die manier hoe ze alles hebben aangepakt

Q: Waren er momenten dat je jezelf moed moest inpraten om door te gaan?

- Nee, als hij nu zou leven had ik het ook gedaan
- Als ouder laat je alles achter je
- Als ouder heb je heel lang hoop
- Tot aan de dood vast gehouden “waarom zou het niet kunnen?”

Q: Waren er dingen van andere mensen waar je je aan kon ergeren? Of dat je bepaalde jaloezie had naar andere ouders? (bijv. waarom is nou mijn kind ziek)

- Nee, we hebben nog een waarom gekregen, daar komt geen antwoord op
- Niet druk mee gehouden
- Tobias zelf had er wel moeite mee wanneer een kennis hem gedrag zei en hem vroeg of alles goed was, aangezien het een erg slechte vraag is om te stellen aan een kind met DIPG
- Reitse heeft niemand iets kwalijk genomen als diegene zo’n vraag stelde, aangezien het ook een bepaalde ongemak is voor die kennis, niet wetende wat je kan zeggen of vragen
- Als ouder moet je ook na het overlijden van je kind een olifantenhuid hebben, met opmerkingen als “gelukkig heb je nog een dochter”. Maar als ouder snap je ook dat het moeilijk is voor andere om de juiste dingen te zeggen
- Opmerkingen als “ik heb aan je gedacht” komen veel beter aan
- Impact zusje als klasgenoten met het woord kanker schelden, maar die hebben niet door wat voor impact het kan hebben
- Maar het doet gewoon zeer, en het wordt ook zoveel gebruikt

Q: Had je momenten dat je de ziekte graag had overgenomen van Tobias? Hoe ben je met machteloosheid omgegaan?

- Reitse heeft nooit gezegd dat hij de ziekte graag zou willen overnemen, want het is niet zo, misschien helpt het even qua gevoel maar het lost niets op, dus hield zich daar niet mee bezig
- Tobias zelf was ook er realistisch

Q: Waren er momenten dat je graag wou dat Tobias uit z'n lijden werd verlost?

- Alles ging heel snel, en in zo'n korte periode hou je hoop houden
- Tobias dacht zelf wel eens dat het klaar was, wat het toen eigenlijk niet was
- Tobias heeft ook een tijd in coma gelegen, maar Reitse bleef zich toen afvragen of Tobias wel een bepaalde ondergrens weer zou bereiken (je blijft hoop houden) "vertel mij dat het niet kan"
- Tobias leed ook niet dus daar werd niet aan gedacht, maar uit een gesprek met Reitse en zijn dochter concludeerde zij wel dat het wel beter is, dat Tobias was overleden. Aangezien hij anders mogelijk meer had geleden
- "het is goed zo, want hij was niet te redden"

Q: Waren er momenten dat jij je blijer voelde als Tobias zich beter ging voelen?

- De emoties gaan in zo'n crisis alle kanten op, het raakt alle extremen aan
- Hij begint weer mobiliteit terug te krijgen

- Manier van verwerken -> foundation opstellen, paar dagen na zijn overlijden opgericht
- Manieren van verwerken tussen Reitse en Evelien erg verschillend, Reitse helpt mee met geld ophalen voor DIPG en aan de foundation werken, maar dat is oke
- Evelien had eerder een eigen winkel, maar daar is ze mee gestopt aangezien klanten bleven vragen hoe het ging, en zo kwam ze niet in haar ritme, dus heeft ze die winkel verkocht
- Ze zoekt naar rust en kijkt Netflix voor rust en relax
- Je rouwt zoals je bent, regel in huis van Reitse -> je neemt je eigen ruimte, en geef andere de ruimte als het nodig is

Appendix B: Interview Requirements Client

Interviewee: Reitse Sybesma
Interviewer: Quirine Vafi
Location: MS Teams

After a brief meeting with the client, he had the following wishes:

- Verplichtingen Reitse:
    - clean, zakelijk, volledig, lekker simpel,
    - magazine waar kaartje voorpagina is(?)
    - eerste wat je ziet is het meest minimale informatie over de ziekte in simpele taal dat iedereen het begrijpt
    - groot fan ook van het kaartje, want dat is clean en simpel en vertelt meteen de informatie dat men wil weten
    - gaat om de simpele informatie

Appendix C: Interview Requirements User

Interviewee: Affected parent
Interviewer: Quirine Vafi
Location: MS Teams
List of Acronyms: Q = question
Reason for the interview: expert opinion parent

Q: toen u te horen kreeg dat uw kind ziek was, was er iets wat u graag zou hebben gekregen om meteen duidelijk te hebben wat de ziekte inhield?

- november 2019 te horen mri scan, tumor hersenstam, niet te opereren, bestraling beperkt (in dit gesprek gehoord), chemo komt er eigenlijk niet goed bij
- dat er geen kans is op overleving
- maxima centrum
- informatievoorziening in nederland is oke
- overzicht thermlogie
    - moeilijke termen
- informatie loop van de ziekte -> alle kinderen anders
- je komt informatie tegen wat je nog niet wil weten
- er zijn verschillende mutaties
    - hangt dan de behandel richting af
- in gesprek blijven met behandelaars

Q: Is er bepaalde informatie over DIPG wat u nu weet maar graag al vanaf het begin had geweten?

- nee, je wil het eigenlijk niet weten, je zit nog in de ontkenning
- iedere situatie is heel uniek

Q: Wat voor specificaties zou jij behoefte aan hebben gehad als je toegang had tot een product?

- welke behandelingen zijn er allemaal beschikbaar
- voor en nadelen van biopten nemen
    - verzamelen van weefsel is noodzakelijk
- Wijs naar ziekenhuizen in andere landen, aangeven waar de plekken zijn waar veel kennis aanwezig is
    - of bijv over actuele info vinden
    - meest voorkomende zoektermen
    - veel gebruikte medicatie (korte uitleg) bijv de werking en bijwerkingen
- Geen geluiden of afleidingen in het product, de situatie is al hectisch genoeg

Appendix D: Interview Doctor Vafi

Interviewee: Dr. Vafi
Interviewer: Quirine Vafi
List of Acronyms: Q = question
Reason for the interview: expert opinion doctor

Q: Hoe werd het vroeger aangeleerd hoe je een slecht nieuws gesprek moest houden?

- niet, focus lag alleen op de informatie van het doctor zijn, geen aandacht aan hoe je slecht nieuws verteld aan patiënten, dat leer je pas in het vak zelf

Q: Hoe heb je het geoefend?

- door middel van in de praktijk

Q: Heb je wel eens iemand slecht nieuws moeten vertellen?

- Het kwam niet zo veel voor als vaatchirurg, maar er zal vast een paar keer zijn geweest dat ik slecht nieuws heb moeten brengen

Q: Had je in het begin moeite met slecht nieuws brengen?

- Ik kan het me niet zo goed herinneren maar volgens mij ging het vrij vloeiend, daarnaast leer je het ook stukje bij beetje elke keer als je het moet doen

Q: Waar hield je rekening mee bij patiënten?

- Als doctor ga je meestal van de worst case scenario uit. Dan kan het alleen maar meevallen voor de patiënt

Q: Wat voor impact had slecht nieuws brengen op jou?

- Naast dat het natuurlijk erg vervelend is om slecht nieuws te horen, het heeft ook best een impact als doctor zijnde. Als ik op een dag slecht nieuws moest brengen, was ik voor de hand altijd wel lichtelijk nerveus, maar achteraf voel je je toch nog een tijdje rot dat je dat persoon hebt moeten zijn die het slechte nieuws moest brengen. Je doet het natuurlijk gewoon liever niet.

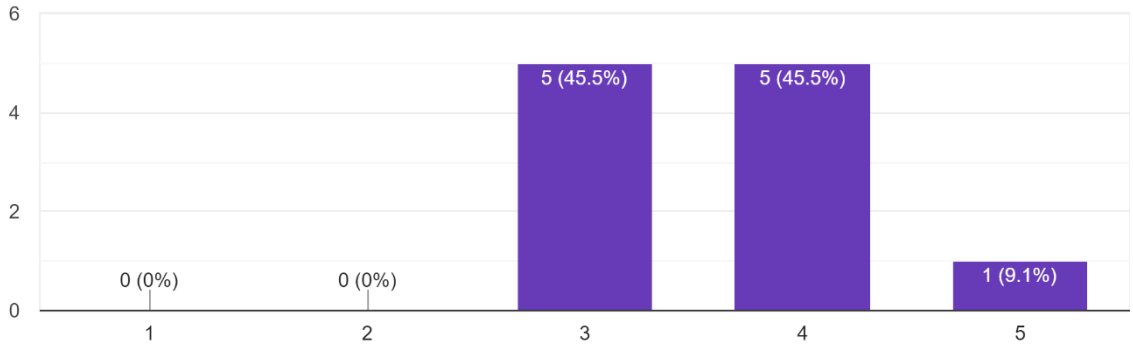
Q: Hoe was dit voor andere collega's?

- Het werd natuurlijk als iets lastigs gezien, het is niet de makkelijkste taak om iemand of de familie te vertellen dat de patiënt niet lang meer te leven heeft. Dus het was zeg maar niet de meest favoriete taak op de afdeling. Mensen keken er vaak vrij tegenop, ook al waren er ook genoeg collega's met de mentaliteit "het is eenmaal zo", en dat klopt ook. Het hoort eenmaal bij het beroep.

Appendix E: Questionnaire results

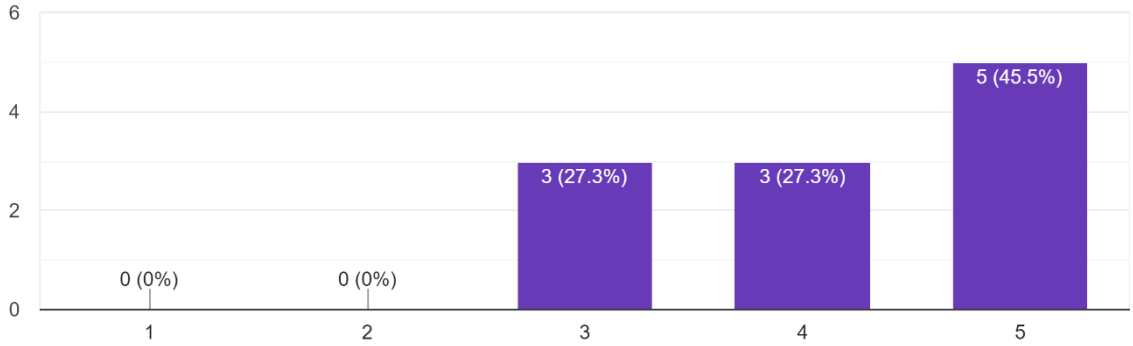
What kind of emotion generates the design of the product?

11 responses



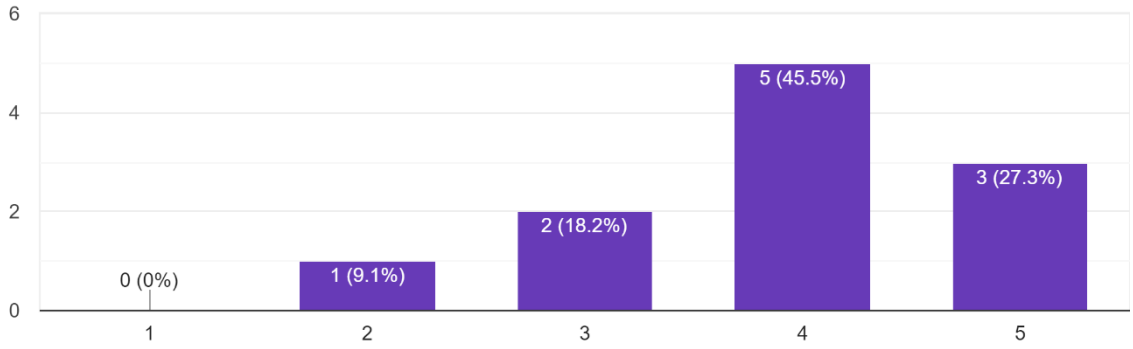
The design of the product is appealing

11 responses



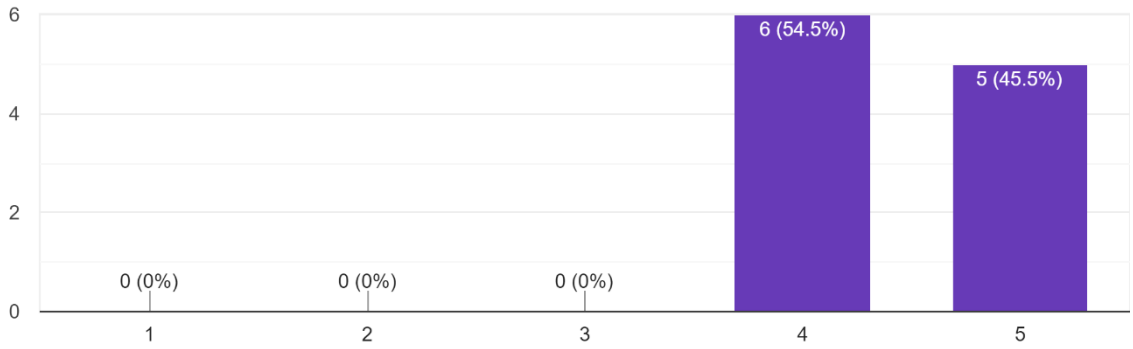
The design looks inviting to use

11 responses



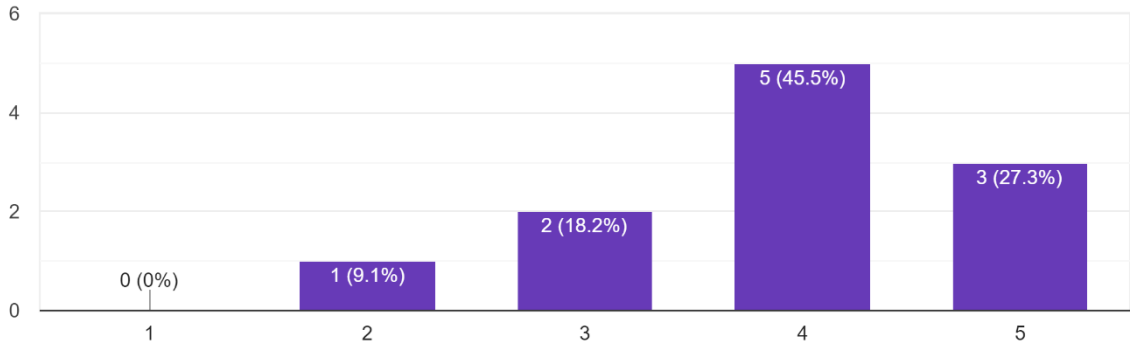
I understand how to use the product

11 responses



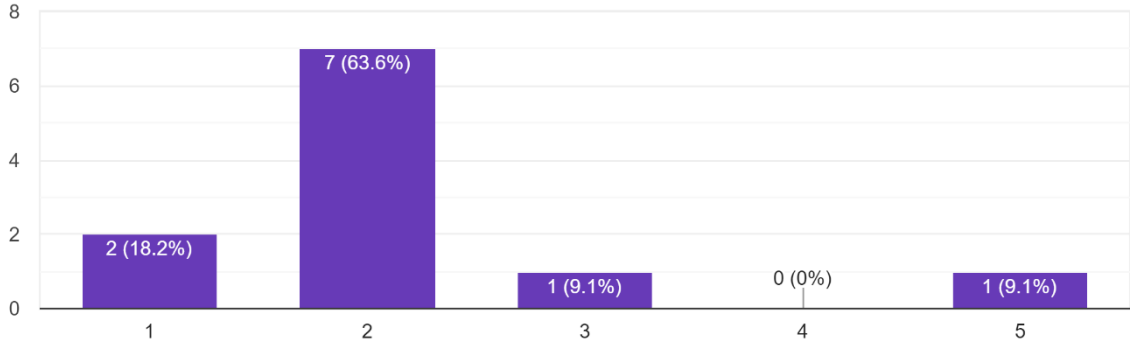
The product is easy to navigate

11 responses



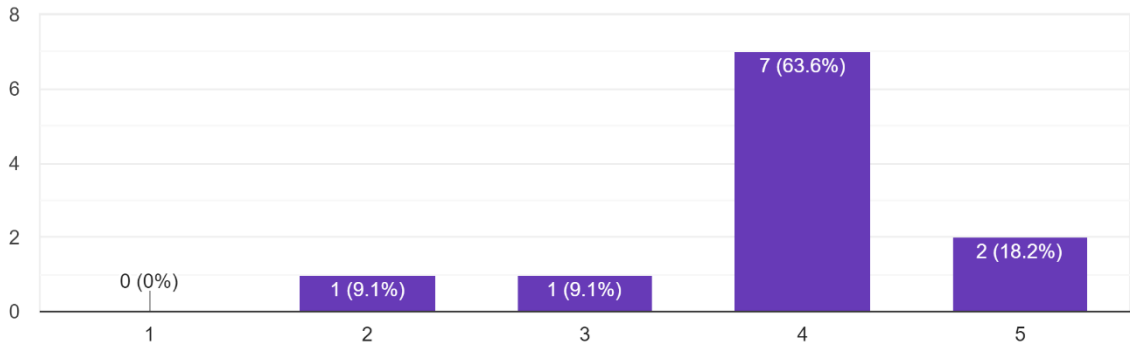
I have problems understanding how to use the product

11 responses



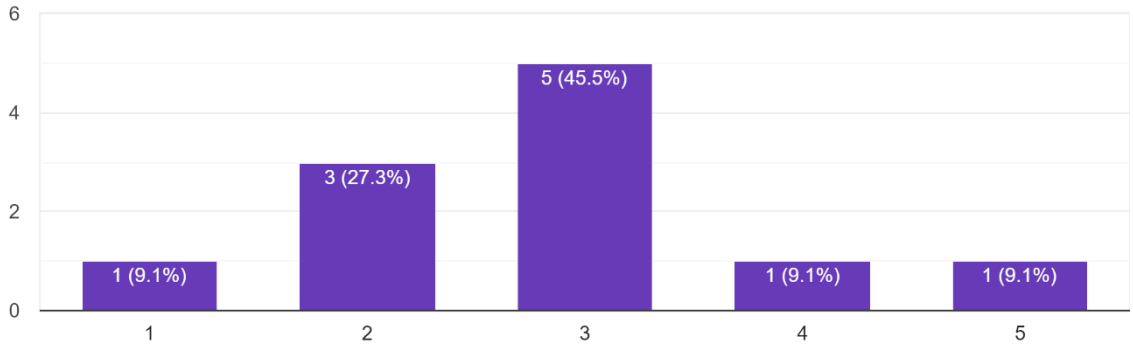
The information in the product is understandable

11 responses



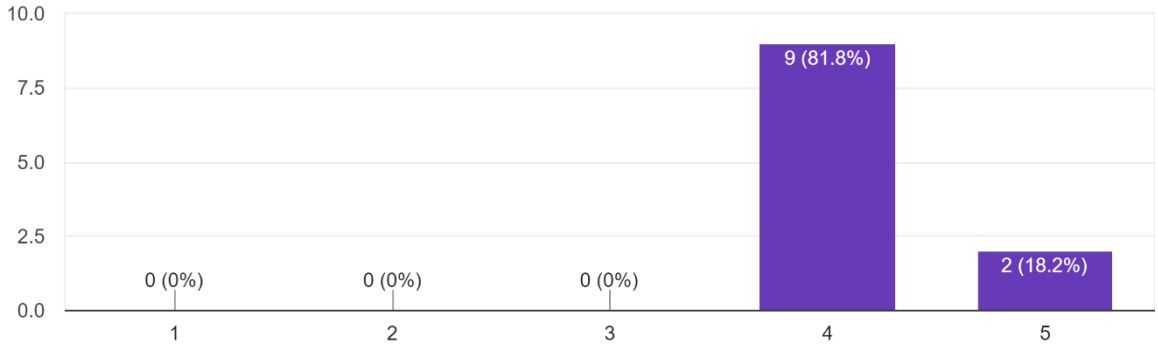
The product includes complicated words/phrases that I don't understand

11 responses



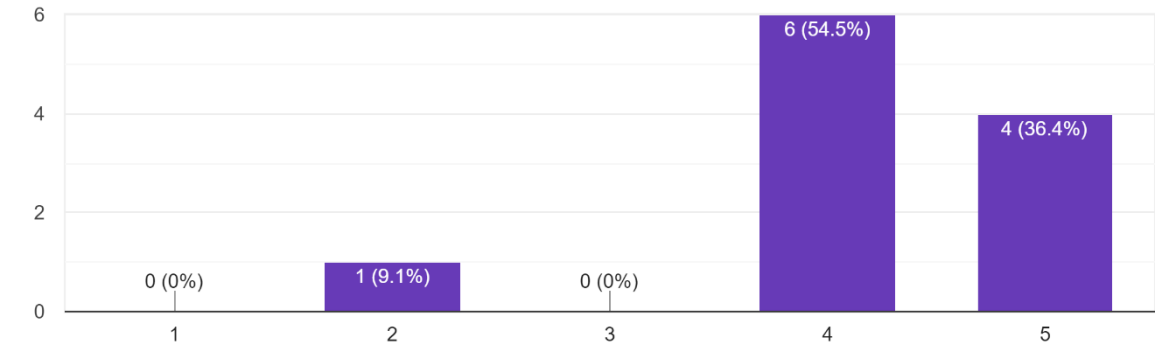
What is your overall impression of the product?

11 responses



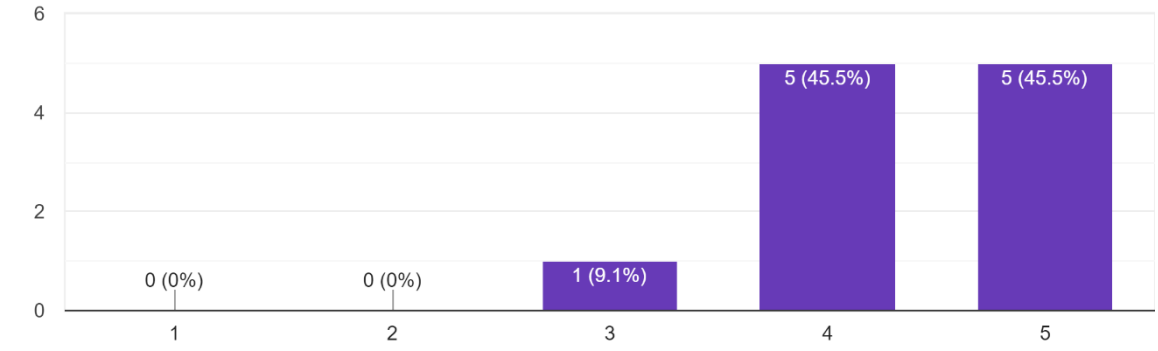
I would recommend this product to a parent who have a child with DIPG

11 responses



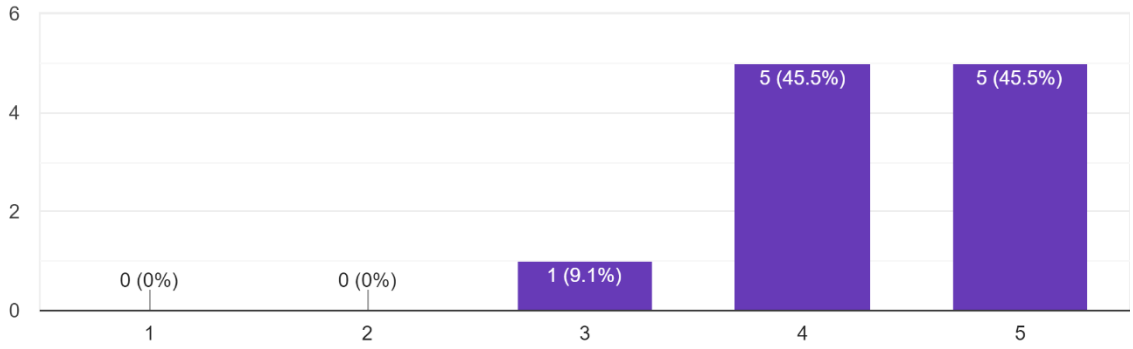
The product has taught me more about DIPG

11 responses



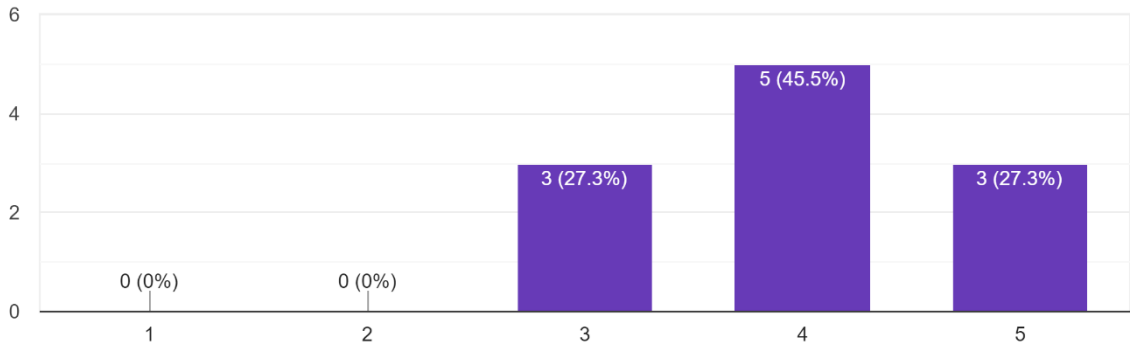
The product has taught me more about DIPG

11 responses



I feel properly informed about DIPG

11 responses



Open questions

Are there things you especially liked about the product?

8 responses

- The layout
- The map really looks beautiful and well done.
- The design is very welcoming, and the way the route is plotted is interesting aswell.
- the condensed information with the links where information comes from shows that the information is really legit and trustworthy
- It's not just informative and helps understand the different steps, but also looks appealing to children. The parent could look at it together with the child.
- Erg mooi ontwerp
- Erg mooi product! Ik vind het idee erg leuk dat het een soort kaart is, het geeft ook een rustig gevoel voor zo'n zwaar onderwerp
- I liked the idea of the road map with different roads each time you choose a new step.

Are there things that you did not like about the product?

8 responses

- There is a lot of text in the help menu and overall information when you tap on the circles.
- Some buttons are missing, in some cases you can only click on next or previous step, eventhough there is an other way to go. An example of this is when you go to progress. From there, there is no option to go to psychological help parents. But this is really just finetuning. The rest looks very nice!
- see improvements
- At first I had to look twice how to navigate, but it didn't take me long to understand.
- Misschien in het Nederlands om beter te kunnen begrijpen
- Ik merkte soms dat ik wat moeite had met het klikken van verschillende punten, ook dacht ik dat ik bij het punt progress naar links zou gaan als ik next step zou kiezen, maar de weg ging naar rechts, maar dat was niet zo'n groot probleem aangezien ik het eerst gewoon even niet begreep
- However, I would have like to have when you press start the complete overview instead of only the first step, it makes it confusing for the first seconds and by doing an overview to start it is clear what you can do.

Are there things you would change about the product?

8 responses

lets van een pointer na dat de user op start heeft geklikt zodat ook zonder de gebruiksaanwijzing te lezen de app kan gebruiken

I get the sense you want to visualize this disease with the map, but there is a lack of visualisation in the text boxes of the circles. There is an inconsistency between the amount of visualisation in the map and the content of the circles.

Another thing that bugs me, why cant I change my position in the map with scrolling/swiping, like in Google Maps? I cant do this on my mobile phone in your app. Only using the previous and next buttons really bugs me, because the buttons do not really visualize in which direction I'm going on the map if I would tap the buttons. Especially going from Progress to Radio Therapy on the map.

-

In the beginning you have the button progress and research, I however thought these were different from the circles, maybe you can zoom out a bit so that you can see the following circles more clearly then you do not need these buttons.

Maybe being able to swipe around the map instead of clicking

Not really. Maybe, if you'd really develop this and people would start using it, it could be nice to have a version that's easier to understand for children. But that's something for the future and not your goal right now, so that's not a form of criticism but just an idea.

Misschien wat natuur geluiden toevoegen? De kaart is erg stil, misschien maakt wat geluiden de kaart wat levendiger

Wat ik hier boven zeg