'Samen Sterk'

The design choices for a tool that represents non-numeric information for patients after an open heart surgery

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Abstract

The problem

This thesis contributes to a solution for two problems: *a design problem* and *a case problem*. By developing a solution for the case problem, insights were obtained regarding the design problem. The design problem concerns the visualisation of non-numeric information such as short texts describing people's experiences. Such texts are nuanced and full of details, but this information is hard to retrieve without reading everything, which can take much time and cognitive effort. There is no overview that shows trends or correlations. How to represent such non-numeric information in a way that is *clear and nuanced*? This question is explored by developing a solution for such an information representation problem in practice: the case problem. This case concerns the expression of worries that open heart surgery patients experience during their recovery period. Currently, they can't estimate to what extent their hindrances, such as severe headaches, are a normal part of recovery. As a result, they develop worries that are bad for their recovery and wellbeing. Patients could feel a barrier to contact the doctor and they can have difficulties with expressing these worries.

The contribution

Regarding *the case contribution*, a concept application was developed that essentially answers the question 'Is this normal?' about hindrances that patients experience while recovering. In the app, patients can indicate what hindrances they have and share their experiences with short text messages. Then they see how many others have similar hindrances and they can read experiences of others. Seeing that other patients have similar issues can reassure their worries. It can also give them incentive to contact the doctor, and information to explain their worries with, when issues appear rare. All submitted experiences related to a specific hindrance were visualised as a cluster of simple shapes. This way, a clear and nuanced information visualisation was designed, that meant to evoke a reassuring feeling of solidarity among the patients. This concept can also be applied more generally to other groups of people who experience a similar process over time. Regarding *the design contribution*, 26 design questions were found and investigated during the case's design process. A card set, the Info Fish, was made with each question and its possible answers. These cards could be useful for other designers that want to visualise non-numeric data in a clear and nuanced way in other cases. They help to reveal the design space for non-numeric data visualisations. Throughout the thesis, all 26 questions are addressed within the case's context.

The approach

The thesis describes the case's design process as three cycles of *exploration* and *validation* activities. Each cycle treats some of the 26 design questions. Exploration activities were done to explore possible answers to the design questions. For example, literature and related work were studied to learn about the current post-operative patient experience. Mindmapping was done, and personas and scenarios of use were made, to explore different product concepts. Several visualisations were made with the aid of two UI and UX experts. Validation activities were done to validate design decisions in practice. For example, interviews were done with a heart specialist, with post-operative patients, and with a revalidation expert. Different concepts were proposed to patients during a concept test. A usability test was done with an interactive prototype of the app. The visualisation was tested with a prototype that resembled the imagined product.

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1. Introduction

1.1 The design problem

The healthcare sector is a broad sector in which many different people play a role. There are patients, but also nurses, doctors, caregivers and other healthcare professionals. All these different people communicate with each other, sometimes on a daily basis. For example, in the hospital patients talk every day with a nurse and regularly with their doctor. They discuss the treatment plan and how the patient is doing. Patients also indicate how much pain they feel on a 1 to 10 scale. Afterwards, the nurses and doctors write down all updates in the electronic patient register. This is a digital document containing all information about the patient's healing process. Nurses and doctors from the next shift read this document to be up-to-date about the patient's status [1]. A recurring problem that patients and healthcare professionals face is how to express non-numeric information such as the patient's healing process. Currently, this is expressed as either text or numbers. On the one hand, texts provide all nuances and details, but no overview, trends or correlations. Besides, it takes much time to read and discuss everything. On the other hand, if non-numeric information is 'reduced' to numbers (e.g. 'happy' on a 1 to 5 scale), essential nuances are lost which makes the insights superficial and useless. Lastly, verbal communication is ephemeral and error-prone [1]. In short, there is need for a 'middle way' solution that represents nuanced information about patients in a clear way.

Game Solutions Lab (GSL) is a company that develops playful interactive applications to improve people's well-being and happiness. Some of their apps for the healthcare sector collect and express non-numeric information such as short diary texts. They also experience this information representation problem. To solve the problem, the company is exploring the possibilities of visual data representations, also known as data visualisations. It may be possible to nuancedly yet clearly express subjective concepts by visualizing them. However, currently there are few guidelines available to achieve this. Thus, the design question that GSL poses is:

"What are guidelines for the design of data representations of non-numeric information that preserve the rich insights that this information may contain?"

To answer this design question, Game Solutions Lab suggested to identify a specific problem in the healthcare sector that could benefit from a nuanced yet clear data representation solution. The design process towards this solution could reveal useful guidelines and knowledge for other designers in other cases. Therefore, prior to this graduation project, a field study was done to identify a specific case in the healthcare sector in which the expression of non-numeric information currently poses problems. Semi-structured interviews were held with a variety of people who are involved in the healthcare sector, such as a nurse, caregivers, doctors and a university researcher who has experience with design for healthcare. This preliminary study is entirely described in [1]. A variety of problems was revealed in [1], among which the following problem (Section 1.2) that poly patients encounter. Poly patients are people who regularly go to the hospital for a consultation or a small treatment, without being hospitalized. They don't stay overnight in the hospital. Poly patients are people who are healthy enough to live at home. They don't require constant attention from medical staff. They could be e.g. people that are recovering from a surgery, or people with a chronic disease.

1.2 The case problem

Poly patients have a "normal" life with work, hobby, sport, family and friends. However, in addition to this, Klaassen et al. found that poly patients, specifically those with a chronic disease, also have to take into account the following [2]:

a. Self-management: taking care of yourself, e.g. taking your medicines in time
b. Personal experience with the disease: finding out how this self-management fits in daily life and what works for you, e.g. what exercises are effective?
c. Knowledge about the disease: keeping yourself up-to-date on facts about the disease

Not every poly patient has a chronic disease, but these three aspects are true to some extent for all patients at home.

Patients can have difficulties with managing their condition in daily life, because they have little knowledge about it or experience with it. *This can lead to all sorts of questions and worries.* Moreover, it is unknown to the patient whether a specific worry is legitimate. An issue or situation that creates worries, could in fact be part of the condition and not be troublesome. This way, the patient could develop 'unnecessary' worries. To find answers on these questions and worries, people tend to search on the internet and discuss issues with loved ones. The latter are often no experts either and can't help substantially. The internet provides many different answers, which can be confusing. All this can lead to even more worries, doubts or fears, which is bad for the person's well-being.

From the perspective of people who work in the healthcare sector, there is increasing focus on 'patient-centred care'. This approach to healthcare focuses on the patient's needs, desires and preferences. The patient is rather treated as a person than as a patient. Central questions are: what does this person need, to make him healthy and happy? What does this person like to do? What is this person still able to do? Healthcare professionals have several methods to get such information from patients. Essentially these methods let the patient fill in questionnaires to provide the doctor with information on how the patient feels and what he wants. Some questions of such a questionnaire can be seen in Figure 1. These three example questions are "Do people take you serious?", "Do you have friends?" and "Do you have people that can help you?". However, when filling in the questionnaire, *the patient can experience difficulties with expressing him/herself.* Exactly expressing feelings is difficult in general. Furthermore, questionnaires focused on physical health do not facilitate this either. There is often a limited multiple choice answer-space that does not allow nuanced answers. From the patients' perspective, there seems little to no benefit to fill in the questionnaire. They just provide information to the doctor and don't directly get anything in return.

		Nee	Een beetje	Ja	Hier wil ik over praten
30	Nemen andere mensen je serieus?	○	○	○	○
31	Heb je vrienden?	○	○	○	○
32	Heb je mensen die je kunnen helpen?	○	○	○	○

Figure 1 Part of a questionnaire for patients

Consequently, patients stop filling in questionnaires, do it badly, or do it only one day before the consultation. With little or no patient information from the questionnaire, it is harder for the doctor to prepare the consult well. As a result, the actual consult mostly focuses on what has happened until that point in time in terms of physical health. The patient has questions regarding his disease or condition, and possibly other worries or fears. There is however little time left to ask these, because most time was already spent on updating the doctor. Furthermore, some doctors have a distant attitude, which does not invite to ask personal questions in the first place. As a result of all this, the patient's worries are possibly not fully discussed. The patient doesn't get answers that he wants, and doesn't know whether his worries are legitimate. Of course it is good to discuss physical health, but this is not the patient's only concern. If his questions remain unanswered, it could lead to negative effects on his mental health and well-being. This could then negatively impact the patient's physical condition or disease. For example, if someone is worried, he sleeps worse. He becomes tired and could become physically less active. This could increase pain, which increases worries, and so on.

In short, poly-patients develop worries and questions about their disease or condition in daily life and don't know whether these are legitimate. The internet and loved ones can't provide satisfactory answers. The hospital's questionnaires don't allow for nuanced expression. During consult, there is little time, a focus on physical health, and the doctor can behave distantly. Ultimately, these possibly unnecessary worries persevere and negatively influence the patient's well-being and health. Thus, patients could use a tool that helps them to estimate the seriousness/legitimacy of their worries and to express them towards the doctor.

Within this context, Game Solutions Lab suggested to focus on poly patients that are recovering from an impactful surgery, such as an open heart surgery. Smits and Marteijn [3] point out that about 15 000 open heart surgeries are performed yearly in the Netherlands. This equals about 60 surgeries on a daily basis, excluding weekends. This group of patients could typically experience the issue described above. Being under narcosis and undergoing an open heart surgery has a large impact on the body. Even after leaving the hospital, the patient will spend weeks or months recovering from this at home. During this period of recovery, worries and questions are likely to haunt the person's mind. This leads to the following 'case question':

How to help patients to estimate the seriousness of their worries and to express them towards the doctor in the aftermath of an impactful open heart surgery?

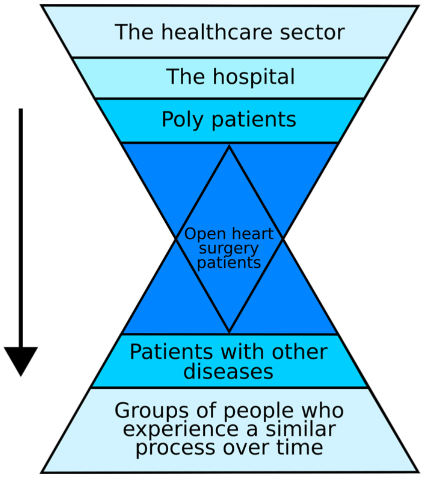


Figure 2 Case context specification and concept applicability

The context specification to specify a case problem that was just described is visualised in the upper half of Figure 2. As will be explained in Section 1.5, the designed solution for open heart surgery patients could also be applied in other contexts, see the lower half of Figure 2.

The relation between the design and case problem, the contributions of the thesis and the activities of the design process is visualised in Figure 3. In this Figure, the design problem in the top left is the starting point. As just described, this problem was translated to a concrete case problem. The process towards the case solution, i.e. contribution, is schematically visualised as links and nodes. The nodes represent the different design choices and possibilities that were explored in the case. The decisions made are represented by the green links. These decisions were then validated. Exploration and validation activities will be described in Section 1.4. All design choices and possibilities form the design contribution of the thesis, and thus the answer to the design problem.

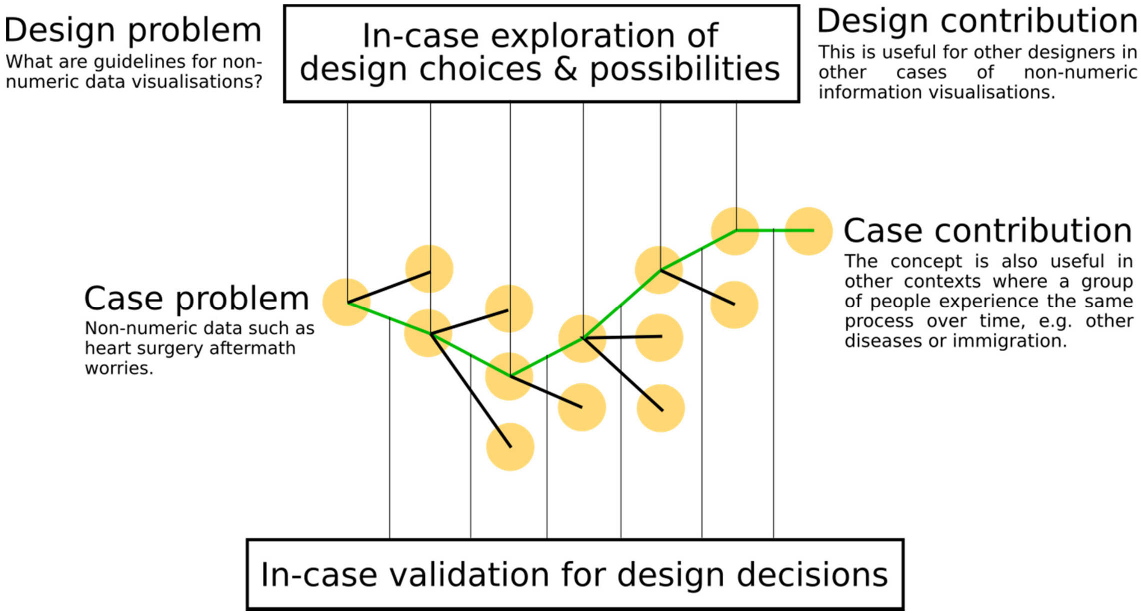


Figure 3 Relation between design and case problem and contribution

1.3 Research questions

Combining the case question with the earlier stated design question (*"What are guidelines for the design of data representations of non-numeric information that preserve the rich insights that this information may contain?")* results in the following main research question and sub-questions:

Main research question

What are design choices for a non-numeric information representation tool that helps patients to estimate the seriousness of their worries and to express them towards the doctor in the aftermath of an impactful open heart surgery?

Sub-question 1: current situation

What is the current situation regarding the patient's treatment before and after an open heart surgery?

- How do the patients experience this procedure and aftermath, what matters to them and what issues do they encounter regarding patient-doctor communication?
- What information about the patient do the doctors want to know before and after the surgery?
- What is existing work on worries in the aftermath of a surgery and what are solutions for this? What can be learned from it, and how can it be expanded?

Sub-question 2: information acquisition

How to express and obtain patient worries after an impactful surgery? (e.g. ‘anxiety’: in what terms can this be expressed, and how can this information be obtained?)

Sub-question 3: information representation

How to represent patient worries in order to estimate their seriousness and to facilitate their expression towards the doctor?

- How can this representation be used to also provide useful information for the doctor?

Sub-question 4: testing

How is the visualisation as part of the designed tool received and perceived by target users?

1.4 The approach

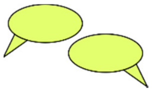
In the design process to go from the ‘case problem’ to the ‘case solution’, and thus to answer the research questions, the following steps were taken and repeated several times.

Design questions

A design question or choice and several possibilities to decide between were identified.

Exploration activities

These possibilities were explored through e.g. literature research, personas or sketches. Then a design decision was made.



Validation activities

This decision was then validated via activities such as expert interviews or tests with prototypes.

Information visualisation is often abbreviated as ‘InfoVis’. ‘Vis’ means ‘fish’ in Dutch. For this reason, design questions are represented as ‘Info fish’. These are fish that pose InfoVis questions.

Once a decision was made, new choices and questions were identified and the process was repeated. Some decisions were validated over the course of several activities, and not by a single explicit test.

A variety of such exploration and validation activities was carried out throughout the design process. Exploration activities include a literature study on the current post-operative patient experience, to further specify problems and solutions. In addition, existing design knowledge and solutions related to this domain were studied. In parallel, extensive brainstorming and mindmapping was done, to find solutions. This provided information for research sub-question 1 and 2. Personas and scenarios of use were made based on information acquired during interviews. These personas were used to explore primary design questions such as whether to use the patient’s live data, or to use a fixed data set. Next, when these primary questions were answered, different data visualisations and UIs were worked out in more detail. This was done by addressing secondary questions such as whether to use percentages or absolute numbers, or what visual parameters to use. This was done with advice from two UI and UX experts, and based on established UI design guidelines. All these activities provided information for research sub-question 3. A decision matrix was used to choose between two different data visualisations.

Validation activities include interviews with post-operative patients, and with a heart specialist. Additionally, a patient was accompanied during his pre-operative information session in the hospital. These activities allowed to confirm the identified problem in practice, and to answer research sub-question 1 and 2. Next, different data visualisation concepts were proposed and discussed with post-operative patients, to answer primary design questions. They were also proposed to a revalidation expert. The chosen visualisation was worked out as interactive prototype in the Invision tool. This prototype focused on the application as a whole, with all functionalities worked out to some extent. It was usability tested with colleagues from GSL to validate the designed UI and functionalities. Finally, to validate major design decisions regarding the visualisation, a prototype was made in PowerPoint. As opposed to Invision and other alternatives, this software allowed to create animations and develop a prototype that resembled more closely the imagined product. This prototype was tested with family members and friends from colleagues, who were used as stand-ins for the target user group (which was not accessible due to covid measures). These activities validated secondary questions and helped to answer research sub-questions 3 and 4.

An overview of the design process as three cycles of exploration and validation activities can be seen on Figure 4. The first half of each diamond, with diverging arrows, represents the exploration activities. The second half, with converging arrows, represents the validation activities. As will be explained in section 1.5, the design contribution consists of 26 questions that are categorized as data, interaction and representation questions. Figure 4 shows how the questions of these three categories are spread over the three cycles. Thus, note that e.g. among the secondary questions, some belong to the 'interaction' category and others to the 'representation' category.

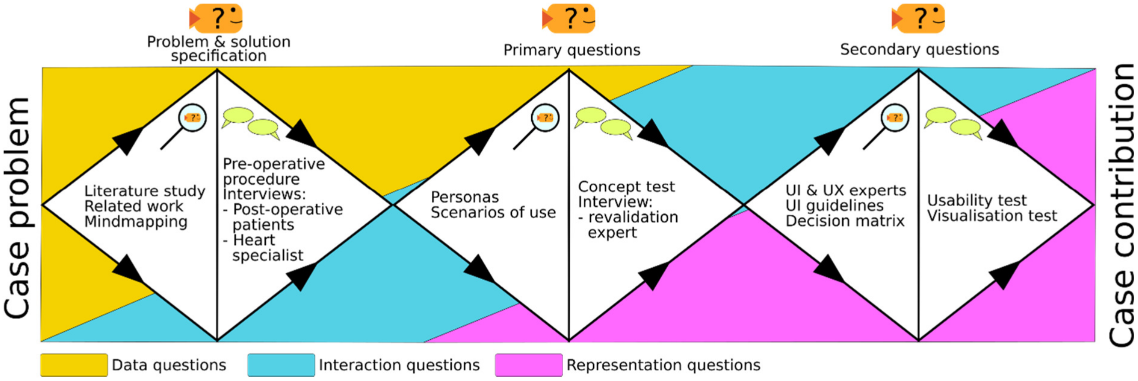


Figure 4 The design process as described in this Thesis

1.5 The design contribution and the case contribution

This project's key findings are twofold. Firstly, there is the 'case contribution'. This is the proposed data visualisation solution that has been developed for patients that are revalidating from an open heart surgery. The visualisation, as part of an app, intends to help patients to estimate the seriousness of their worries that they experience while recovering, and to express them towards the doctor. From a designer's perspective the goal was to clearly, yet nuancedly, visualize such non-numeric data. Secondly, there is the 'design contribution'. The design process has revealed a set of design questions that needed to be answered to advance from case problem to case solution. This list of questions, and possible answers, could be useful for other designers that want to visualise non-numeric data in a clear and nuanced way. The questions help to reveal the design space for non-numeric data visualisations. They should help designers to explicitly make decisions that would otherwise have been made implicitly. This may help to design better solutions for specific cases.

Regarding the case solution, an application was developed that essentially answers the question ‘is this normal?’, regarding hindrances that patients experience in daily life. Patients can indicate what hindrances they have, share their experiences, and read those of others. All hindrances and experiences together form a representation of the ‘normal’ revalidation process. In the first place, by viewing their experiences amidst those of others, patients can find reassurance in the fact that they are not alone having specific issues. This could sooth ‘unnecessary’ worries regarding issues that are shared by many and thus that appear to be normal to experience. Here the app helps to estimate the seriousness of the worries. In the second place patients have a good incentive to contact the doctor, in case their issues appear to be rare. Information from the application could be used to explain their worries with. Here the app helps to express worries towards the doctor.

This application was made with a focus on clear information visualisation that emits a feeling of solidarity among patients. It was found that the experiences, expressed as textual information, can be categorized in different types of hindrances that patients have. Visualising *the number of* experiences per hindrance can provide clear insights and overview, see Figure 5. When ‘zoomed out’, each experience forms a single data point in this way. Zooming in reveals the textual experiences that each data point represents, see Figure 6. This approach was found to be a middle-way solution that is clear as well as nuanced. It was also found that representing experiences as a cluster of simple shapes creates a feeling of solidarity and reassurance among people. The designed concept, the case solution, could also be useful in other cases in which a group of people share an experience over time. For example, this could be people who recover from other diseases, or people who are immigrating to another country, see Figure 2.

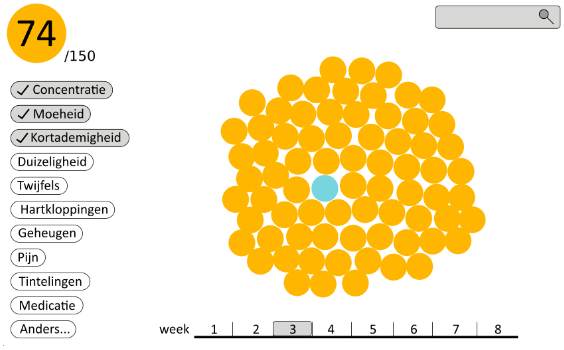


Figure 5 Final visualisation design, main screen


"Rustig aan de wat huishoudelijk werk weer oppakken, heel rustig." ~ Hugo

"Nog wat kortademig maar schijnt erbij te horen." ~ Gerard

"Vandaag ging beter dan laatst, conditie komt langzaam terug." ~ Joep

"Mijn concentratie is soms erg matig, bijv. als ik een spel wil spelen, zal wel weer over gaan. Ben ook moe..." ~ Marie

"Wandelen gaat steeds beter, alleen nog wat adem tekort en snel moe." ~ Loïs

Figure 6 Final visualisation design, zoom-in

Regarding the design contribution, 26 design questions were identified and investigated during the three cycles of the design process. See Figure 4 for the overview of the cycles and the questions. The questions were divided in three categories: ‘data’, ‘interaction’ and ‘representation’. ‘Data’ questions focus on identifying the problem that needs to be solved and what data will play what role in its solution. Most of these questions were addressed in the first cycle. ‘Interaction’ focuses on how the user interacts with the data and how he possibly adds new data. ‘Representation’ focuses on how the actual data is represented and how it communicates its message. Interaction and representation questions were mostly addressed in the second and third cycle. A card set was made with each question and its possible answers. This card set, the Info Fish, can be found in Appendix 5.

1.6 Thesis structure

The thesis' structure follows the three cycles of exploration and validation activities, as can be seen in Figure 4, and their respective design questions. Each time, first the design questions that were identified will be explained. Then the activities to explore possible answers will be described. Finally the activities to validate the decisions that were made will be described. Chapters 2, 3, 4 and 5 describe the first cycle. Chapters 7 and 8 describe the second cycle. Chapters 10, 11 and 12 describe the third cycle. Chapters 6, 9 and 13 provide a short summary of cycles 1, 2 and 3 respectively. Chapter 14 provides an overall overview of this project's results. All identified design questions and answers are listed, as well as in which chapter they are treated. Chapter 14 also includes some suggestions for the next iteration of the case product. Then the whole design process will be discussed and evaluated in chapter 15. Lastly, the thesis will be concluded and suggestions for future work will be given in chapter 16. The 'Info fish' design questions card set can be found in appendix 5.

Cycle 1

Design questions

This cycle focuses on formulating a more concrete problem statement, especially in terms of data. I.e. What data are we talking about? What do patients experience in the post-operative period? What are common issues in daily life after a surgery? What do these people find important while recovering? What exactly are problems in patient-doctor communication? Based on answers on these questions, some questions on the solution can also be answered, such as whether to develop a physical or a digital information representation.

Exploration activities

Chapter 2 describes a literature study in which the design questions were explored in literature. It ends with a summary of the current situation of post-operative patients and the problems they encounter.

Chapter 3 describes related design work on visualisations and expressing worries. This related work includes higher level design knowledge as well as products for specific cases. The insights that were obtained from the related work were mostly used as inspiration and starting points, or different perspectives, for ideation.

Chapter 4 describes the results of the ideation phase, i.e. of extensive brainstorming and mindmapping. These results include a better understanding of the patient's situation and the data involved, and two different ideas for a solution for problems that were identified in chapter 2.

Validation activities

Chapter 5 describes several field study activities that were done to validate the problems that were identified in chapter 2, and the ideas that were generated in chapter 4, in practice. These activities include following a patient during his pre-operative information session, and interviews with a heart specialist and with post-operative patients.

Chapter 6 briefly summarizes cycle 1 in terms of the design decisions that have been made in this cycle based on information that was obtained in the various activities.

2. Literature study

This chapter contains a literature study on the current situation regarding the post-operative period. The goal of this study was to identify specific problems, related to the expression of worries, that patients encounter during this period. First, the post-operative period is examined in terms of hindrances that patients experience, such as pain and depressivity. The effects of anaesthesia on these hindrances are studied in more detail, as well as current measures for quality of recovery and quality of care. This was done to get an impression of the patient's life post-operatively, and to learn what patients could be worried about. Second, patient values are studied, to learn what patients find important while recovering. Values related to the post-operative treatment, as well as more general values in life, are examined. Lastly, problems about patient-doctor communication are elaborated upon, to learn how these problems could be related to the problem of expressing worries.

2.1 The post-operative period from a patient's perspective

Recovering from an open heart surgery

An open heart surgery has a large impact on the body [4]. The breast bone is sawed in two, in order to reach the heart and perform the surgery. After the surgery, the two bone halves get stuck to each other, and need to grow against each other again. In the weeks and months after the surgery, the patient slowly recovers. This recovery mostly happens from home, since patients leave the hospital about one week after the surgery. In the first weeks, the whole upper body can be painful and sensitive. Besides, according to [4], it is normal to feel 'down' and exhausted and to have serious concentration problems as a consequence of anaesthesia. Even signs of depression can occur. Patients need to pick up their life again, starting with the most basic things such as eating, walking and sleeping. Gradually, within eight weeks, the situation should improve. However, cognitive and mental issues such as lack of concentration and feeling down can last for months. Furthermore, on the one hand it is important to stay active and e.g. walk daily. On the other hand, people should not lift heavy objects and intensively do sports too soon.

Anxiety and depression after a heart surgery

Research has been done on anxiety and depression of patients who underwent other, arguably less impactful, heart surgeries than an open heart surgery [5]. Insights about these related surgeries could also apply to open heart surgery. An example of such another surgery is percutaneous transluminal coronary angioplasty (PTCA). The goal of this less invasive operation is to widen narrowed blood vessels that disturb the blood flow. Narrowed vessels could cause heart infarctions which is deadly. This operation is less invasive because the breast bone does not need to be cut in two. Instead, a balloon is brought in the body via a vein. This balloon will be inflated to widen the vessel again [6].

Astin et al. studied anxiety and depression among PTCA patients in [5], and they stress the negative influence of these mental issues. First, they reduce quality of life. Second, they negatively influence recovery, because people are less likely to participate in cardiac rehabilitation, change behaviour, and return to work. Third, depression can increase cardiac mortality. Anxiety in this context is related to fear for e.g. sudden death, a heart infarction, or need for another surgery. Astin et al. state that PTCA patients are particularly vulnerable because they stay in the hospital for a relatively short time. Once at home, there is less contact with healthcare staff. Similar forms of anxiety and depression could also happen to open heart patients who only stay one week in the hospital as well. They may also have fear for e.g. sudden death or a heart infarction.

Astin et al. measured anxiety and depression levels of PTCA patients before (T1), six to eight weeks after (T2), and six to eight months after (T3) the operation. Their test included 117 participants. Their results show reduced anxiety and depression scores from T1 to T3, but, according to them, the numbers are worrying nonetheless. At T3, still 11% of men and 21% of women showed serious anxiety levels that could necessitate a psychological intervention. This is 14% and 10% respectively, for depression. In short, an important number of PTCA patients experience anxiety and/or depression, even several months after the surgery. This negatively influences their well-being, recovery, and life-expectancy. Other studies show similar results [7][8]. These insights could also apply to open heart surgery patients and demand attention.

The effects of anaesthesia

In [9], Royston and Cox discuss the patient's perspective on anaesthesia. Developments in technology, education and training have significantly increased the safety of anaesthesia. Nonetheless, patients keep reporting this as the most worrisome aspect of their surgery. Besides post-operative nausea and pain, people fear to never wake up again, or to wake up during the surgery. Furthermore, patients are concerned about mental impairment as a consequence of anaesthesia. Effectively, mental impairment, formally known as post-operative cognitive dysfunction (POCD), after anaesthesia has been reported by a multitude of studies. For example, in one study among 1218 patients older than 60, 10% would qualify as having POCD at three months after the surgery [10]. Complaints range from serious concentration problems to deliria. The risk of POCD increases with age. Royston and Cox point out that expectation management and comforting patients remain challenging for anaesthetist professionals. In short, anaesthesia is a source of worries, as well as of actual implications such as tiredness and concentration problems. Earlier described post-operative anxiety and depression may be related to worries about anaesthesia and its actual consequences.

Measuring quality of the post-operative period

In [11], Borrell-Vega et al. describe post-operative recovery as returning to the pre-surgery state or better. From a patient perspective, one could say: "*Going back to normal life.*" Borrell-Vega et al. distinguish three notions related to quality of the post-operative period. In the first place, there is quality of care, often used by healthcare professionals to evaluate a recovery process. This concerns evidence-based treatments and standards of care that should provide the optimal patient recovery experience. This is assessed with metrics such as survival rate, lack of symptoms and time spent in the hospital. In the second place, there is quality of recovery. This concerns, from a patient's perspective, the process of going back to normal, i.e. to the pre-operative state. This includes physical, but also, among others, psychological, emotional and social aspects of daily life. Thirdly, there is patient satisfaction. This is the degree to which the patient is satisfied with his recovery process. It is strongly dependent on the patient's expectations. These are highly subjective and personal and are influenced by factors such as past experiences, lifestyle and personal values.

Borrell-Vega et al. stress the difference between these three notions. Quality of care cannot simply replace quality of recovery, since the former does not include the patient's perspective. An absence of symptoms (thus high quality of care) is not the same as a normal life, including e.g. emotional and cognitive aspects. In recent years, the importance of taking the patient's perspective into account has become more recognized. However, well-defined and widely accepted metrics and definitions are lacking. This is the case with e.g. POCD. While cognitive function is an essential part of recovery, its evaluation is cumbersome and the topic of much debate. Besides, many recovery evaluation methods only look at the first month after the surgery. As said earlier, POCD could have effects that last for months. In other words, measuring quality of recovery, i.e. the patient's perspective, remains challenging. Post-operative recovery consists of many factors and it is difficult to precisely define and measure all of it. When there is too much focus on quality of care, less quantifiable issues, e.g. POCD, may not get the attention they need.

Summary of Section 2.1

A variety of issues impact the patient’s daily life while recovering. There are direct consequences of the surgery, and anaesthesia in particular, such as pain, tiredness and depressivity. Such issues are common. However, in addition to this, the patient can develop worries and fears related to lost trust in his body, and risks of new medical complications. These worries are bad for recovery and for the patient’s life expectancy because they can lead to depressivity and lack of motivation to recover. Thus, there are consequences of the surgery, and consequences of worries. It is hard to distinguish between these two and to tell which caused which. E.g. the patient could be depressive and tired as normal consequence of the surgery, but also as a result of worries. For healthcare professionals it is challenging to identify and measure such complicated and personal situations. As a result, these may not get the attention they need.

2.2 Patient values

Values in the perioperative period

In [11], Borrell-Vega et al. highlight several studies that investigated what is most important to patients in the period around the surgery, and anaesthesia in particular. In other words, what are major contributors to patient satisfaction? One study [12] concluded that clear information communication and attention for the patient (by e.g. visiting him and answering all his questions) significantly contributed to patient satisfaction. Another study by the same researchers added kindness of the caregivers and feelings of safety and good care to the list [13]. Another study highlighted that patients want to express their concerns and ask questions [14]. One study [15] also stressed the importance of empathy from the staff and clear information about the surgery procedure and possible side effects, also post-operative. Surprisingly, physical consequences such as pain and vomiting were rated low. Note that exactly such aspects are often emphasized in quality of care metrics. In other words, patients want to be well-informed and thus have a correct expectation of the perioperative period. They want to ask questions and express their concerns. A good patient-staff relationship based on empathy and safety is also important.

Values in everyday life

Berry et al. [16] performed a study on 54 patients with multiple chronic conditions (MCC) to identify what these people value in life. People’s personal priority regarding care and treatment is often based on what they value in life. However, their priority is often in conflict with the doctor’s vision of optimal care. Priorities of the doctor and the patient should better be aligned and communication should be facilitated, according to Berry et al. Identifying these personal values is a first step in facilitating their expression. They identified six categories of values:

1. Principles, such as independence or truth.
2. Relationships, such as with family or in communities
3. Emotions, such as happiness or serenity
4. Activities, such as playing board games or gardening
5. Abilities, such as mobility or vision
6. Possessions, such as a house or family heritage

These values and their categorization could also apply to heart patients. The values could be seen as goals that patients want to reach while recovering. Not being able to reach these goals could be the cause of worries. Expressing worries in terms of goals that patients can't reach could be promising because goals can be expressed in more concrete ways than worries, such as wanting to walk two kilometres three weeks after the surgery.

2.3 Patient-doctor communication

In [17], Rajabiyazdi et al. present the results of their extensive review of HCI as well as medical literature on patient-doctor communication problems. This concerns direct communication, such as during a poly-clinic consultation. They identified seven categories of problems.

1. Anxiety. Patients can experience stress while telling medical issues to the doctor. In the patient's opinion, this is caused by the lack of time, a feeling of hierarchy, and the physical setup of the room, i.e. the doctor who looks at a screen that the patient can't see. Doctors are aware of this anxiety and mostly point out its consequences, such as patients forgetting details, not knowing how to describe symptoms or sharing 'unnecessary' information. Doctors point out that they actually listen to patients when looking at their computer.
2. Facts & emotions. Patients seek emotional support and recognition from their doctor. They share negative, but also positive, moments. Doctors understand that this is important for patients and try to sympathize with them. However, they are mostly interested in facts and medical information and try to filter this from the patient's 'disorganized' story.
3. Differing expectations. Patients expect doctors to provide understandable information that fits their individual needs. They look for something that they know. Doctors say that some patients have too high expectations. Some patients expect easy solutions without having to manage the condition or change lifestyle.
4. Engagement. Patients want to be involved. They collect information on how their disease impacts their daily life. However, doctors would like patients to collect more medically relevant data, such as medication, symptoms and side effects.
5. Incomplete information. Patients want to have a normal everyday life. They share information that concerns reaching this goal and they may leave out information that they think is irrelevant. Doctors want the patient to have a healthier life. They think that patients are not fully aware of the problems they have. E.g. 'pain' could be a result of more serious problems, such as depression. Doctors want to find this out.
6. Information sources. Patients want to know how to deal with the condition in everyday life, and why they developed the condition and its symptoms. If this is not clear after the consultation, they will search for information on the internet. This is dangerous because the internet contains much irrelevant, complicated and wrong information. To make sure that patients understand the information, doctors mostly explain how the condition works.
7. Medical terms. Patients tend to use medical terms to impress doctors and show their knowledge. Doctors don't trust this. They suspect patients to misunderstand such terms and to misuse them. At the same time, doctors often talk fast and with many medical terms. Patients don't understand this and feel left out.

In short, during consultation patients share their emotions and everyday life experience. The doctor mostly filters out the medical information and based on this, he establishes the treatment plan. The patient has to implement this treatment into his daily life. To do this, he seeks understanding and tips on the internet. The internet provides complex and false information. This makes the patient confused and worried, and he will share this on the next consultation. Again, the doctor filters out the medical info, and so on. Essentially, the patient wants more focus on reaching a normal life and his personal values. The doctor wants more focus on a healthier life and a medically optimal treatment.

Rajabiyazdi et al. finish their inquiry by proposing some design directions to solve the above challenges [17]. First, they propose to re-imagine the consultation environment. The current setup with the doctor's screen creates anxiety. Technology should be used more seamlessly in the room, and be more accessible to all parties. Second, information and decision making should be more transparent. Visual or physical decision trees, that explain the doctor's thinking, are promising, as well as tools for collaborative information input and analysis. Finally, information could be expressed in new ways. Written or visual communication could be clearer than verbal communication. Furthermore, tools that facilitate the patient in collecting and expressing self-generated data are promising.

In [18], Lim et al. recognize the mismatch between patient priorities and doctor priorities for care. They argue that the patient's activities to manage his condition in everyday life, known as 'self-care', should align with his personal values. It should be clear how a self-care activity contributes to the realisation of his values. This could improve patient participation and motivation. However these personal values are often not discussed with the doctor. Moreover, it is possible that patients don't clearly know their values. Lim et al. argue that patients should reflect more, to identify their values and how self-care is related to them. Later, this could facilitate communication with the doctor and the alignment of priorities. Reflecting can be done in many ways. Lim et al. propose to write down values on cards and rate their importance, and to do the same for self-care activities. Relations between these value cards and self-care cards can then be found and discussed. It also stimulates sharing experiences from everyday life.

2.4 Summary

The patient has a complicated revalidation process and develops worries about it. Consequences of worries and consequences of the actual surgery are similar and hard to measure, thus hard to treat. Patients value clear communication and empathy from doctors. They try to address their worries during consultation, but this poses problems because the patient wants a normal life, and the doctor wants a healthier life for the patient. Patient's idea of what is 'normal' is related to their personal values. Worries could more concretely be expressed in terms of personal values that can't be achieved. Communication, in particular about personal values, can be facilitated in several ways. For example with reflection activities, tools to express personal data, or tools for shared decision making.

3. Related work

In the literature study (Chapter 2), it was found that worries can be expressed in terms of values that can't be fulfilled. When someone is unable to do something that he finds important, such as reading, it could make him worried. These worries could be expressed as not being able to fulfil this value. To design for the expression of such values and worries, related work on the expression of values and worries was studied. This included higher level design knowledge as well as products for specific cases. Regarding the design knowledge, dimensions for communication support and reflection were studied, as well as ways to design products that create pleasurable and meaningful experiences for users. The designers of the products for related cases used inspiring approaches, such as focusing on customization of the product and freedom of expression, or enhancing existing household products to design for existing habits. Lastly, theory of visualisations was studied, such as Gestalt principles and the influence of aesthetics. The insights that were obtained from the related work were mostly used as inspiration and starting points, or different perspectives, for ideation.

3.1 Design knowledge to facilitate expression of values and worries

<u>Design dimensions for communication support</u>

In [19], Berry et al. identify seven dimensions on which tools to support communication can differentiate. These dimensions could be used to systematically generate and classify ideas. They were obtained as a result of co-design sessions with 51 patients, doctors and nurses. These are the seven dimensions:

1. Explicitness: Communication is explicitly about values and their elicitation, or it is an indirect process in which values emerge more spontaneously. On the one hand, it can be unnatural to directly talk about values. On the other hand, more indirect approaches risk to be incomplete or misinterpreted.
2. Scale: The number and type of people who are involved in the conversation or interaction. On a small scale, the patient talks only with e.g. his doctor. On a larger scale, multiple doctors or family members are involved, or doctors talk among each other without the patient.
3. Synchrony: the degree to which the communication happens in one moment. Conversations are synchronous. Messaging and questionnaires are asynchronous. The latter could free up sparse consultation time, and allow the patient to think before answering.
4. Intimacy: The degree to which the values are shared in a personal and caring context. The doctor could show interest and compassion via e.g. body language and eye contact, and by knowing the person's personal interests.
5. Guidance: The level of support and direction on what to share, that is given to the patient. Doctors or digital media could e.g. suggest possible answers, and vary with the openness of their questions. They could also explain why these values are important for healthcare.
6. Effort: The degree of burden associated with value collection, sharing and reviewing. Low effort could be some passive monitoring via sensors. Questionnaires, or taking photos of your values, would require more effort.
7. Disclosure: The degree to which the patient controls what information is collected and shared and with whom. E.g. a monitoring system with sensors allows low disclosure, it just collects and sends everything. On the other hand, a conversation or questionnaire allows the patient to choose what to share.

During their co-design sessions, Berry et al. generated ideas with the participants. This gave some additional insights on the seven dimensions in practice and how some are related to each other. For example, regarding disclosure and explicitness, on the one hand people want control over what personal information they share. On the other hand, people don't want to explicitly think about this, and their values, while in the middle of valuable activities. Another example, if communication is asynchronous, such as via e-mail, it is often harder to express some form of compassion, related to the intimacy dimension.

Design for reflection

Lim et al. [18] performed reflection activities with 15 patients of multiple chronic conditions to elicit values and find relations with self-care activities. They found eight implications for the design of tools for reflection:

1. Tools should allow for sufficient time to reflect. It may take days for someone to think about an important issue or question. People could reflect on issues while doing other activities.
2. Tools should be portable and not be bound to a specific location or time. This allows for reflections whenever the person wants to, or whenever a person has something in mind.
3. It should be possible to get an overview of all the material that is reflected on, e.g. to see relations and to keep track of changes in the process.
4. Tools should allow for modifications, for when perspectives or opinions evolve.
5. Tools should allow, or challenge, people to think about habits in different ways, e.g. by assigning ratings of importance or by spatially arranging them. Evaluating habits may reveal assumptions or illogical decisions in daily life.
6. Tools should allow to externalize abstract notions such as values. By simply pronouncing them, or by making e.g. physical representations, people could get awareness or make discoveries about their daily routines and assumptions.
7. Reflecting together with another person may yield richer or different insights. Having someone who actively listens to, or discusses with, the patient could change the dynamics of reflection, as compared to a solo activity. However, loved ones could also negatively influence reflection if they e.g. interfere or disagree with the reflection outcomes.
8. Tools should be flexible and allow different usages. Not everyone reflects in the same way.

Taking all these implications into account for a single reflection activity may be difficult, but they should be kept in mind while evaluating ideas for tools or activities.

Design for an engaging user experience

In [20], O'Brien and Toms developed a conceptual framework of user engagement, including all factors that contribute to it. They did a literature review and they interviewed 17 people just after they had interacted with digital technologies, such as web shops and games, as part of the investigation. They argue that user engagement consists of four phases over time: the point of engagement, the period of engagement, disengagement, and possible reengagement. Each phase has several factors that lead to engagement. For the point of engagement, they highlight aesthetics, novelty and the potential it provides to users to reach a goal. During engagement, they highlight aesthetics, positive affect, challenge (not too much, and not too little), interactivity and control. Too much challenge, information overload or bad usability could lead to disengagement. For users to come back and reengage, they highlight ease of use, the user's need for information and novelty. Lastly, they point out that usability aspects such as efficiency and satisfaction with which users reach their goals with the product are strongly related to their identified factors of user engagement. A usable application is not necessarily engaging, but engaging applications inherently have good usability.

In [21], Kujala et al. argue that hedonic factors influence long-term user experience. Positive long-term user experience leads to more willingness to recommend the product to others, to more customer loyalty, and consequently to more product purchases. The hedonic factors that determine this user experience are therefore important for companies that want to design a positive long-term user experience. Examples of hedonic factors of a product are aesthetics, pleasure, innovativeness and status. In an experiment they led forty participants draw curves of their experienced attractiveness, ease of use, utility an degree of usage over time of two products that these participants had been using for years. They used ‘attractiveness’ as representative of the hedonic factors. They showed that hedonic factors had a larger influence on the long-term user experience than pragmatic factors such as ease of use. The latter were most determining for the user experience in the first periods of using a product.

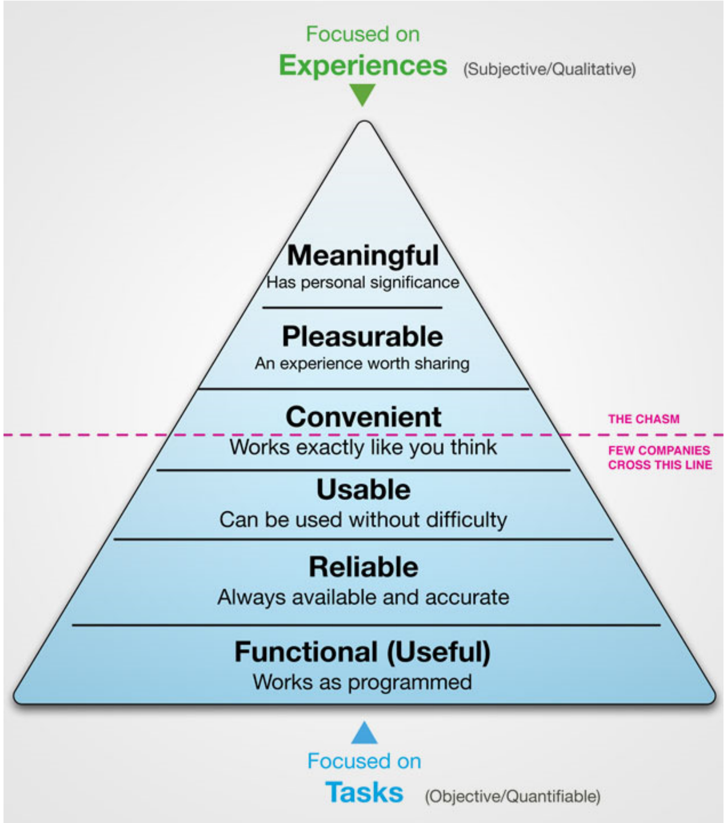


Figure 7 The user experience pyramid [25]

According to Hummels [22], Norman [23], and Jordan [24] a ‘well-designed’ product is not only functional and usable. It should also create a pleasurable experience that is meaningful for the user. This is in line with O’Brien and Toms’ [20] and with Kujala et al.’s [21] findings that hedonic factors contribute to a positive long-term user experience, and that user engagement does not only come from good usability. This is visualized in the user experience pyramid in Figure 7 [25]. It shows all aspects that contribute to a ‘good’ user experience. Hummels, Norman and Jordan have slightly different theories on *how to design* products that elicit such meaningful and pleasurable experiences. Hummels [22] explains this phenomenon as ‘resonance in interaction’. This occurs when there is a perfect interplay between a product and a person. It evokes positive emotions, a connection with the product, awareness of the product in the experience and more cognitive processing. She argues that this experience is personal. Not everyone resonates with the same products. It depends on e.g. someone's needs, personality, skills and culture. She also argues that resonance lasts after the moment of interaction. Thinking back about the product should still evoke positive memories and emotions. Over time, the user establishes a bond with the product.

Hummels investigated if it is possible to design for resonance [22]. She took specific personality types and designed products for them. Then 44 people assessed the products. The results suggested that personality types could be recognized in the designs, and therefore, people having these personalities could maybe feel resonance with these specific products. She did not succeed with all products, however. Besides this, Hummels investigated how to design for a feeling of pleasure that lasts after the interaction. She found that pleasure is achieved in exciting and/or clear interactions. Excitement and clarity can be achieved via e.g. surprise, novelty, intuitiveness, simplicity, customisability and rich feedback.

Norman argues that people should connect with a product on an emotional level to experience fun and pleasure [23]. Therefore products should evoke emotions. He distinguishes three different layers of design that evoke emotional connections with people. First, there is the visceral design layer. This addresses natural, intuitive and almost instinctive emotions. In terms of design, it concerns a product's perceptible qualities, the look and feel. For example bright colours capture people's attention, and people like symmetry in objects. Second, there is the behavioural design level. This addresses the pleasure of reaching a goal with the product, the ease with which a product can be used, and simply the joy of using the product. In terms of design, it is closely related to usability. For example a sharp knife with a comfortable grip makes the user feel fully in control while cutting food. Third, there is the reflective design level. In contrast to the visceral level, this addresses more conscious emotions and thoughts, a person's considerations to buy a product. It addresses the joy of expressing your your identity, your status to others around you via the product. For example wearing an expensive watch can contribute to an image of being wealthy.

Jordan [24] identifies four types of pleasures that products can evoke. He argues that these provide the user with an added experience, besides that of functionality and visual aesthetics. For a user they can be the reason to prefer one product over another. First, there is physio pleasure. This is about pleasure for the body and the senses. It includes e.g. touch and smell, but also sensual experiences. It could be addressed via e.g. the haptic qualities of a product, or its smell. Second, there is socio pleasure. This is about pleasure from the company of others. Products can facilitate social interaction and bring people together and create this pleasure in doing so. Third, there is psycho pleasure. It is pleasure from accomplishing a task. A product evokes this pleasure if it helps to reach a goal in a satisfying and efficient way. Fourth, there is ideo pleasure. This is about values. Products can embody values such as environmentally friendliness. Users can find pleasure in expressing their values through the products they use.

<u>Summary of Section 3.1</u>

For a product that facilitates the expression of patient worries or values, ideation could start from several perspectives. First, to ideate for communication facilitation, starting points could be the level of guidance the product provides to the user, how explicitly it address values, or how many people interact with it. Second, to ideate for personal reflection on values (in order to express these later on), a starting point could be the location where and the time when the user wants to reflect, or the challenge for the user to think about their habits in different ways, or the motivation of social interaction and reflection together with a partner. Furthermore, beyond being functional, the product should create a pleasurable experience that has meaning for the user. This is necessary to design a user experience that remains engaging over time. This personal and emotional connection can be realised in several ways, such as via the product's look and feel, the social interactions it facilitates, the ease with which the user reaches his goals by using the product, or the personal values that the user can express by using it.

3.2 Design solutions that could facilitate expression of values and worries

The designers of the following products all try to facilitate the expression of someone's values or worries with a different approach. Each of these approaches served as inspiration during ideation.

Personalisation

In [26], Ayobi et al. designed an app for multiple sclerosis patients to self-track personal information, such as mood of the day. In the app, the user can choose between several pictograms, such as a dinosaur or a flower. The pictogram is divided in areas that each represent e.g. a day. The user can color an area to indicate the mood of that day. The user can decide for himself what each color represents, see Figure 8. This way, the app allows for much personalisation and expression. Users expressed a sense of ownership, identity, self-awareness and control when using the app. With this work, Ayobi et al. demonstrate the importance of personalisation to foster mindful and meaningful engagement with health data.

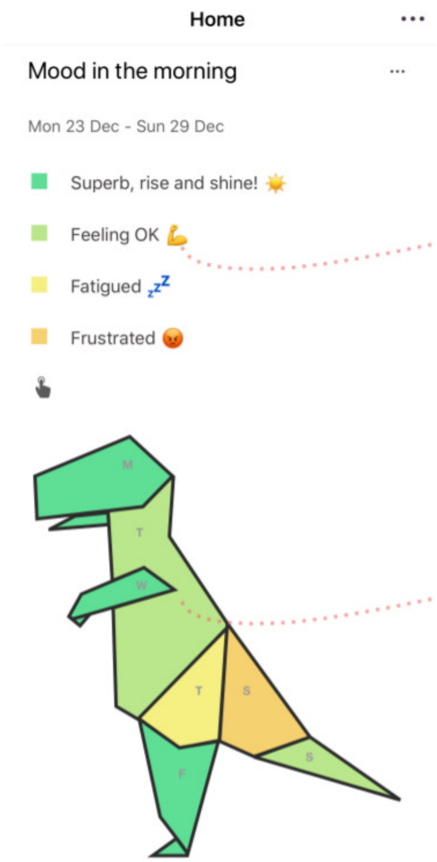


Figure 8 Trackly, customized self-tracking [26]

Family members

In [27], Olivo et al. designed two products for children with cancer that live at home. They highlight the importance of involving the whole family, instead of only the child, being the patient. The patient does not live in isolation. His situation changes the everyday life of everyone that lives with him. The child being sick could be seen as a social, physical and emotional challenge for the whole family. Therefore, a product for patients at home should be designed with the other family members and their needs in mind. Olivo et al. tried to solve two main problems. First, the reduced amount of quality time among family members during treatment, and second, the inability to talk about one's feelings and worries.

Regarding the former, they identified three important perspectives to take into account when designing for the whole family.

1. The presence of the artefact in the house
2. The way the artefact is shared and coordinated among family members
3. The way in which the artefact's usage blends with (family) routine. Their product suggested fun family activities, but if it did this at inconvenient moments, families would not do them. Blending into existing routines could be achieved when a product can be used in multiple ways, so people can fit it in their lives.

Regarding the latter problem, they learned that a product should not impose a problem on the user. Their product was made to facilitate communication but this suggested that the user currently had a problem with communicating. This can feel as an accusation and result in adverse effects towards the product.

Conversation support

In [28], Vos designed a tool for people with acquired brain injury (ABI). The effects of ABI are often cognitive and invisible. They are hard to recognize and to estimate by others, but also by the patient himself. It often happens that the patient is not aware of his own limitations and the consequences of his injury in daily life. In addition to this, old habits and task divisions within the family have to change and the patient needs to be cared for. Vos' tool, see Figure 9, supports communication in this new and complicated situation. The tool is used during the actual conversation, and therefore directly mediates it. Each person has to express what topics are important for them by placing tiles on a board. Differences and similarities get revealed and can be discussed.

Figure 9 Tool for conversation support [28]

Vos concludes that a tool should allow to indicate priorities among topics. This way a conversation can be more structured and prioritize the most important subjects. Furthermore, she found that people like to express issues in other ways than verbally, such as by placing tangibles relative to each other. This can be more accessible and convenient, especially regarding sensitive subjects. Additionally, the used symbols were ambiguous and did not impose one specific interpretation. They allowed users to put their own meaning in them and thus to express all sorts of topics. This resembles Ayobi et al.'s findings on customisation [26]. Lastly, Vos shows how a tool can be used *during* a conversation and directly influence it. Many other products focus on reflection *before* the conversation.

In [29], Van Bergeijk and Hengeveld developed a set of tangibles and a visualisation to facilitate child patients' participation during consultations. These fast and cognition-heavy conversations take mostly place between the doctor and the parent, and the child's perspective tends to be forgotten. In their concept, see Figure 10, topics are represented on tangibles (1). When the child wants to discuss something, he puts a tangible on the table-mat (3). The computer screen shows the sequence of topics (4). The color represents who initiated the topic. The size represents the time the topic is discussed. Afterwards, this visualisation is printed and it forms a physical reminder for the children on which they can also make annotations (5). This represents an informal health dossier for the child. The visualisations are also stored on a key chain (2). This concept is an interesting example of how topics can be categorized and represented as symbols that are available to all participants of a conversation. These can empower participants to express themselves about topics that are important for them. Furthermore, it shows how a complex conversation can be visualised and translated to tangibles, based on these same symbols.

Figure 10 Tool for conversation support for children during consultation [29]

Everyday objects and habits

In [30], Nicenboim et al. closely studied how elderly people use everyday objects in new ways to solve problems they face in daily life. For example, some elderly used a magnet to pick up small metallic items that they could not grasp anymore. Other people kept multiple versions of the same object to always have one at hand. One person communicated with her daughter via the daily newspaper. If she did not bring it to her, it meant that something was wrong. Furthermore, many elderly had daily routines, often to not forget something. E.g. turning on the radio, making breakfast, reading the newspaper. Then Nicenboim et al. proposed designs that can be seen as additional resources for this problem-solving behaviour. The products could be used in multiple ways, to afford personal usage and strategies. They did this by adding digital capabilities to familiar physical objects. For example they designed a bell that could be used to record messages. Moving the bell would play them back.

In [31], Giaccardi takes a similar approach. She also closely studied how objects are used in daily life. For example, she studied what people do while they are waiting for water to boil in the morning. This varies from doing push-ups to reading the newspaper. She also studied how a cup travels through the house during the day. She shows that it ends up in several places, such as in the sink or on a desk. She argues that objects do not exist in isolation. Even without internet, they are connected and part of habits and problem-solving strategies. In other words, there are many micro-level habits in which people show specific behaviour and use products in specific ways. These habits, such as the moment when someone is waiting for water to boil in the morning, are interesting opportunities for design. They take as starting point what people already do or want to achieve. As Nicemboim shows, one option to design for such moments is to enhance existing products with technology.

Information for empowerment

In [32], Shen and Yu use information visualisation to improve the well-being of college students. In their solution, first, the user indicates what his sources for stress are. Then, the visualisation shows an overview of the campus with all locations where the user can find social support for the indicated stress sources. By providing this resource to students, Shen and Yu want to empower them to actively work on their well-being. They see empowerment as a person believing to have the resources and competence to accomplish personally relevant goals. In their design process, they interviewed college students and eventually they identified twenty specific stress factors that they divided in four categories. Then they mapped all the available social services and help centres and for each of them, they indicated what stress factors the service or centre could help with. In this work, Shen and Yu show how categorizing information and presenting it clearly to users in an overview may empower them to take action and address personal difficulties.

Summary of Section 3.2

The most important insights that served as inspiration for ideation will briefly be summarized. First, customization is promising to let people express personally relevant information how they want it [26]. It gives flexible products that people can use as they want. This way, it has the potential to suit the individual needs of many different people. Besides, it highly stimulates user engagement. Second, a patient does often not live alone. Family members are influenced by the patient's condition. Their perspective should also be taken into account when designing [27]. Third, providing overview and categories, and rating the relative importance of subjects allows to more clearly express often complicated situations [28][32]. Lastly, it is promising to enhance products that people already use. This way, the design solution may more easily blend in existing habits [30][31]. On the other hand, it is also interesting to focus on the actual conversation during consultation, instead of on a person's home situation and on reflection. This may have a more direct impact on the problem of expressing worries towards the doctor [28][29].

3.3 Design knowledge of visualisations

In Section 3.1 it was pointed out that hedonic factors such as aesthetics and pleasure lead to user experiences that remain engaging on the long term. Aesthetics, as well as data visualisations, is often related to a visual experience. Therefore, designing a data visualisation with a focus on aesthetics seems promising to design an engaging and pleasant experience. In this section it is investigated what contributes to 'good' visualisations, what 'aesthetics' really means and how to design visualisations that are aesthetically pleasing. Gestalt principles will be discussed as a means to design for aesthetics. Visualisations based on these principles are generally intuitive to understand. As will be discussed, such intuitiveness is a form of aesthetics.

'Good' visualisations and aesthetics

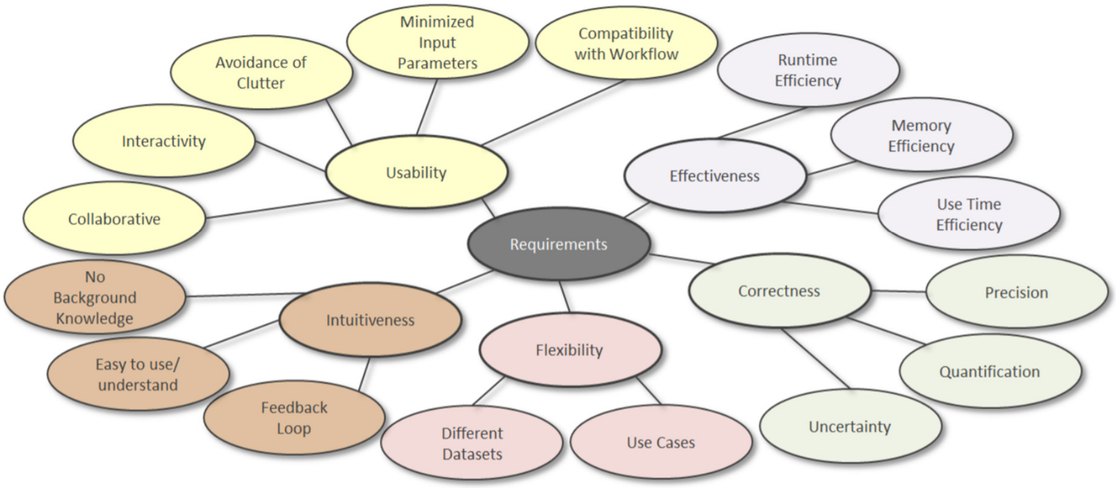


Figure 11 Overview of requirements for a successful information visualisation [33]

Research has been done on requirements for a successful information visualisation and the role of aesthetics in this [33 - 37]. Gillmann et al. [33] performed a literature study on requirements for a successful information visualisation and summarized their findings in a visual overview, see Figure 11. A variety of requirements was identified, but these were still rather abstract. For example, they found that a visualisation should be intuitive, by being easy to use for someone with little background knowledge. However, this does not explain how to actually design for such intuitiveness. Moreover, arguably not all these requirements are necessary in every design case. For example, they mention 'interactivity' as part of usability. However there are numerous examples of more image-like, non-interactive data visualisations that are widely recognized and clear, and thus arguably successful, such as bar graphs. Nonetheless, the overview also presents less abstract or ambiguous requirements, such as 'avoidance of clutter' and 'minimized input parameters'. Lastly, and maybe most surprisingly, the overview does not mention terms such as 'aesthetics' or 'emotional connection' while other literature, such as Norman [23], argues that such aspects are key in designing pleasant and effective experiences.

Lang investigated what 'aesthetics' means, how it relates to information visualisations, and what contributes to a 'good' visualisation [34]. He found that the definition of 'aesthetics' and how to measure it is a topic of debate. Nonetheless, in defining aesthetics, often recurring themes are beauty, subjectivity and multisensory pleasant experiences. Regarding a successful data visualisation, he found that such a visualisation facilitates understanding of a complex phenomenon by highlighting the most important features and relationships and minimizing distracting details. Arguably, this explanation strongly relates to the 'clarity' of a visualisation and the effectiveness with which it transmits information, which is related to several of Gillmann et al.'s [33] requirements such as avoidance of clutter and ease of use. Lastly, Lang explored the role of art in achieving successful as well as aesthetically pleasing visualisations. He concluded that aesthetic, artistic visualisations do not necessarily lead to clear and effective information transmission. Artistic visualisations can be appealing at first, but hard to understand when taking a closer look, which could decrease the initial pleasantness of the experience.

Quispel et al. interviewed ten professional data visualisation designers and reviewed literature to find out what designers find important when making visualisations, and what role aesthetics plays in this [35]. They found that the designers paid most attention to clarity and aesthetics. Regarding clarity, they wanted to objectively inform the public and not (unintendedly) deceive it. Although aesthetics was considered important, almost no characteristics of aesthetics were found in the literature, and the designers found it also hard to explain. Both literature and designers say that aesthetics plays an important role in information visualisation, but how to actually achieve aesthetics in visualisations was ill-defined.

Cawthon and Vande Moere investigated the effect of aesthetic on the usability of data visualisations in an experiment with 285 participants [36]. The participants rated eleven different visualisations of the same dataset on aesthetics, ranging between 'ugly' and 'beautiful'. The visualisations were ranked individually as well as relatively to each other. Then the participants performed information retrieval tasks with the visualisations. They had to answer multiple choice questions about this (effectiveness) and they had to do this as fast as possible (efficiency). Besides this, the researchers measured erroneous response latency, being the time someone spent before submitting a wrong answer, and task abandonment, being the number of participants that submit 'don't know' as answer to a question.

The results showed that the most aesthetically pleasing visualisation scored high on effectiveness and efficiency. In other words, participants were able to quickly find the correct answers on the data retrieval questions. Moreover, this visualisation scored low on task abandonment and high on erroneous response latency. Participants were thus encouraged and patient to find the correct answer. At the same time, the visualisation that scored among the lowest on aesthetics, received high scores on task abandonment and erroneous response latency. In other words, participants took a long time, answered wrongly or gave up on questions. Other aesthetically pleasing visualisations, that scored lower on effectiveness, had a high erroneous response latency. Thus, even though the visualisations were harder to use, participants were patient and eager to find the correct answer. In this research, Cawthon and Vande Moere pointed out that aesthetics positively influence usability of data visualisations. They argue that aesthetics should be taken into account in the design and evaluation of data visualisations. This corresponds with Norman's [23] statements that users are encouraged to think creatively and solve problems on a product if they feel a positive affection towards it.

Reber et al. investigated what contributes to an aesthetic experience [37]. They argue that aesthetics is strongly related to the concept of 'processing fluency'. Processing fluency is the ease with which a stimulus can be processed by a person. This is measured with terms such as speed and accuracy. Experiences with a high processing fluency evoke positive affective reactions and judgements from those who experience them. In other words, when an experience is easy to process, it is considered aesthetic. Reber et al. highlight a variety of characteristics of an experience that make it easy to process, thus aesthetic. First, the amount of information that is presented plays a role. If only the essential information is presented, people understand easier what they see and they judge this positively. In other words, redundant information and (visual) clutter make understanding of information harder and reduce the aesthetic value. Symmetry influences the amount of information that is presented. Symmetric objects present less information than asymmetric ones. These are thus easier to process and they contribute to aesthetics. Second, contrast and clarity play a role. It was found that images with high figure-ground contrast and clarity were more easily understood and rated as more aesthetic.

In addition to these characteristics, it was also found that people's history, or familiarity, with the stimulus played a role in processing fluency. Stimuli that people have experienced before, or that follow known rules such as words that follow grammar and spelling rules, were rated more positively. This can be explained in terms of processing fluency. Familiar stimuli are processed faster, with less effort and in a more organized way. People have already made sense of the stimulus before. Moreover, from an instinct perspective, new objects could be dangerous and demand caution. Familiar objects are rated 'safe' and don't require this extra attention. When a stimulus is unexpectedly familiar or simple, it especially evokes positive feelings. For example, this happens when you encounter a friend at a place where you did not expect to see him, or when a complex shape ends up to be easy to understand. Lastly, simplicity does not always imply ease of processing. Sometimes, oversimplifying e.g. a shape can make it harder to understand.

Gestalt principles

Todorovic provides a brief overview of Gestalt principles [38]. Everywhere where we look, humans perceive objects with details, positioned among other objects in front of some background, while the visual input to the eyes is just a distribution of individual colored points. Gestalt principles describe how humans naturally perceive objects and groups of objects based on visual input. Visualisations or user interfaces that are designed following these principles tend to be aesthetically pleasing, because users understand them with little effort. The most widely recognized principles will be described here. First of all, there is *the figure-ground articulation*. This principle can be described with Figure 12, showing a patch of one color surround by another color. This Figure can be divided in an infinite number of ways, such as the right and the left half, or all even pixels and all odd pixels. Nonetheless, humans automatically perceive a *figure* on a *ground*, which is the figure-ground articulation. These two components have some features. First, the figure is perceived as object and the ground as background. Second, the figure seems in front of the ground. Third, the border that separates the two seems part of the figure and irrelevant for the background.

Figure 12 Figure-ground articulation [38]

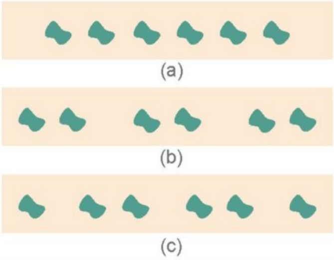


Figure 13 Proximity principle [38]

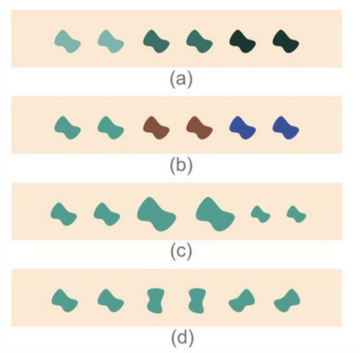


Figure 14 Similarity principle [38]

A second principle is *the Proximity principle*, which is apparent from Figure 13. Elements that are close to each other are perceived as groups. It is hard to see other groups of elements than the ones close to each other. This would require much cognitive effort. Figure 13 a shows one group of six elements, while Figure 13 b shows three groups of two elements, based on the proximity principle. In 13 a, it is harder to see these three groups than in 13 b. 13 c suggests yet other groupings. In 13 c, it is also hard to see the three groups from 13 b. Related to the proximity principle is the *common fate principle*. This principle states that elements are perceived as groups when they move together.

The similarity principle states that elements are perceived as groups if they are similar to each other, see Figure 14. Elements can be similar in lightness (14 a), color (14 b), size (14 c), orientation (14 d) or shape. When elements have multiple similarities, such as color and size, or when they are also spatially grouped together (proximity principle) the partition becomes even clearer.

Next, *the good gestalt principle* states that elements are grouped together if they are part of a pattern, which creates regularity and balance. Figure 15 a shows a curved saw tooth line and a line with square angles. This is stressed in Figure 15 b with the similarity principle. Figure 15 c presents another possible separation of two lines. Looking at 15 a, this separation is harder to see, because it violates the regularity of the good gestalt principle.

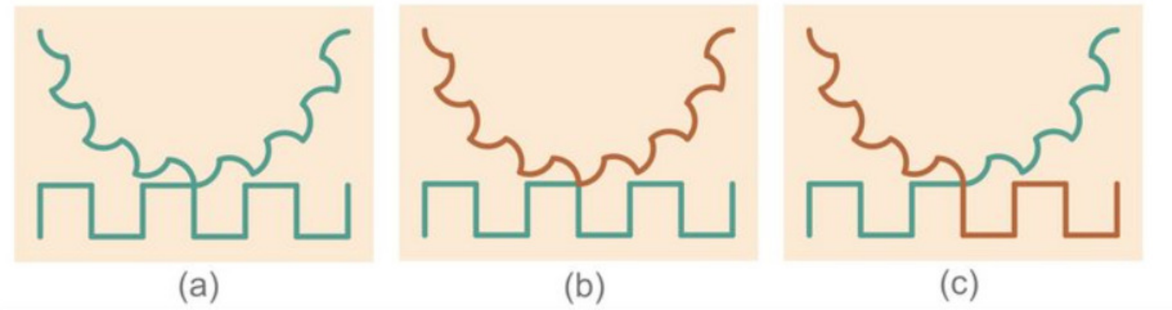


Figure 15 Good gestalt principle [38]

The past experience principle states that elements are grouped together if they were often together in past experiences of the observer. This is the case with letters in words, see Figure 16. Figure 16 a shows a word, and Figure 16 b and c show individual letters that many people also easily distinguish in Figure 16 a. Another separation such as shown in Figure 16 d would equally be possible, but this is very hard to see in Figure 16 a, because of the past experience principle.

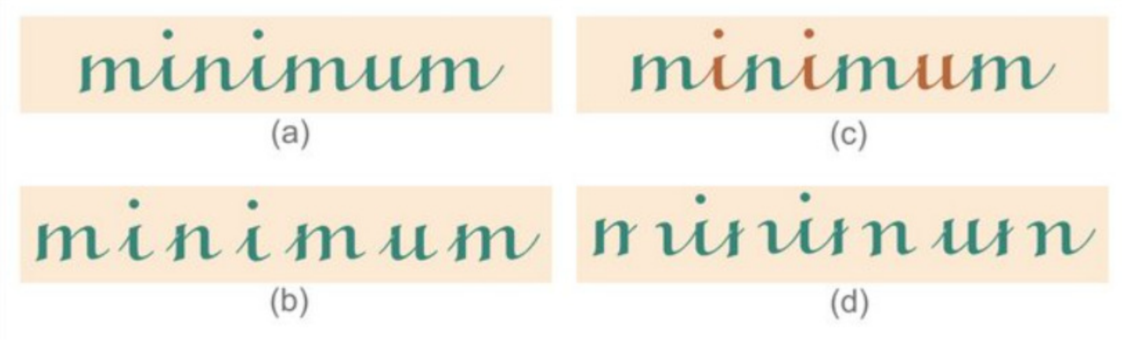


Figure 16 Past experience principle [38]

Lastly, there is *the common region principle*, shown in Figure 17. It states that elements are grouped together if they are placed in the same closed region. Figure 17 a actually shows the same groups of elements as Figure 13 c. However, because of the circles around the elements, they are nonetheless easily perceived as three groups of two elements. Figure 17 b demonstrates the *connectedness principle*, which states that elements that are connected to each other are grouped together.

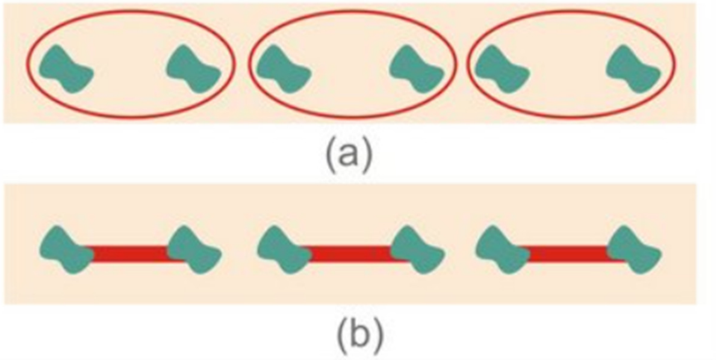


Figure 17 Common region principle [38]

A possible explanation for the Gestalt principles' origin is that they are derived from our experience with the external world. Objects in the world are usually located in front of a background (figure-ground articulation), they have a texture which is different from the background (similarity), they consist of parts that are close to each other (proximity), and they move as a whole (common fate).

<u>Summary of Section 3.3</u>

Aesthetics is related to a subjective, pleasant and multisensory experience of beauty. Aesthetics and clarity are major contributors to the success of an information visualisation. Aesthetics increases user engagement with, (perceived) usability of, and positive emotions about information visualisations. However, how to objectively design an aesthetic information visualisation remains a topic of debate. One approach is to focus on 'processing fluency', which is the ease with which a visualisation can be understood. Some factors lead to processing fluency, and thus to aesthetics, such as leaving away visual clutter and unnecessary details, using symmetric shapes, and using visuals that are familiar to the user. Using Gestalt principles is another way to design easy to process visuals. They are based on what we humans are familiar with from our experiences in the real world. Thus, an aesthetically pleasing visualisation can be made by making use of Gestalt principles and e.g. simple and symmetrical shapes, because these are easy to understand. So, while aesthetics and clarity separately lead to successful visualisations, they are not independent. Aesthetics can be achieved through clarity, in the form of an easy to understand visualisation. On the other hand, aesthetic works are not necessarily clear, as can be the case with artistic visualisations.

4. Ideation

This chapter describes the results of the ideation phase. Ideation consisted of elaborate brainstorming and mindmapping with insights and inspiration from the literature study and the related work as starting points. Such starting points included among others the patients' problems and metaphors to visualise these. Visualising worries in some metaphorical way could facilitate their expression towards the doctor. Another starting point for mindmapping were different everyday objects such as the coffee machine and ways to enhance these. By enhancing such products that people already use, the design solution may more easily blend in with existing habits and eventually be adopted. Another starting point for mindmapping were alternative and ambiguous ways of expression such as by movement. This way, patients could possibly express worries in a way that is logical or relevant for them.

In the first place, the ideation process led to a better understanding of the patient's situation and the data involved. This led to the development of the goal-hindrance-remedy framework, i.e. a simplified representation of patients' situation in which they have goals, related to values. These goals can't fully be achieved because of hindrances from the condition. The doctor proposes remedies against these hindrances. Most of the identified problems can be expressed and related to each other within this framework. Additionally, ideation led to two ideas, from now on referred to as the *Is this normal?* idea and the *recovery calendar* idea. The *Is this normal?* idea is a tool with which patients can see how many other people are having the same hindrance while reaching a certain goal in a certain week of the revalidation. The tool's goal is to create a feeling of reassurance regarding normal issues, and to provide vocabulary for talking to the doctor regarding abnormal issues. The *recovery calendar* idea is a physical tear-off calendar, functioning as a wheel of fortune, that asks one word questions to trigger reflection and in-household conversations, so that patients appear better prepared on the consultation. The framework and these two ideas will be described in this chapter.

4.1 The goal-hindrance-remedy framework

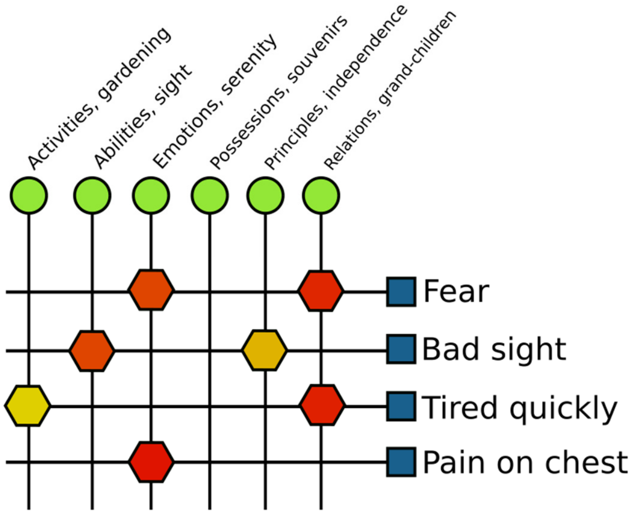


Figure 18 The goal-hindrance-remedy framework

The goal-hindrance-remedy framework that I developed can be seen in Figure 18. The green dots represent the patient's goals. These are based on the six value categories as identified by Berry et al. in [16], which was explained in Section 2.2. Each dot represents a value category, with an example goal written next to it. The blue squares represent the hindrances that the patient experiences during recovery. These are three examples based on the information provided by the website of the heart lung centre [4]. ‘Bad sight’ is a hindrance that is not related to open heart surgery in particular. Other hindrances are equally possible. Note that the framework thus proposes an inverse correlation between patients’ goals and patients’ hindrances, in which the hindrances prevent patients from achieving their goals. In other words, the more hindrances patients experiences, the fewer of their goals they are able to achieve.

Following this correlation, the hexagons show which hindrance conflicts with which goal. The color indicates the relative importance to the patient of each goal-hindrance couple. A yellow hexagon represents a hindrance that is relatively unimportant to the patient. A red hexagon represents a hindrance that is relatively important to the patient. This way, patients can show their doctor what they find most important. A doctor could then suggest remedies and self-care to specific goal-hindrance couples that are most relevant for the patient. The doctor’s role is to show where and how the self-care helps to achieve personal goals, to stimulate the patients to do the self-care. At the same time, patients can express to the doctor what they find most important. This way, selfcare and the patient’s personal goals should be better aligned. As was pointed out by Rajabiyazdi et al. [17] and by Lim et al. [18], explained in Section 2.3, this alignment is currently a major challenge in patient-doctor communication because patients want a normal life and doctors want them to have a healthier life. Lastly, patients track progress over time of their goals and hindrances, in order to discover trends in their recovery process, reflect on it, and find points of attention that should be shared during consultation. This information is also valuable for doctors, to have an overview of the patient’s recovery process and estimate how the patient has been doing.

Ideally, all information represented in the framework is known to the patient and the doctor. However in practice patients often can’t explicitly formulate their values [18]. Besides this, the revalidation period is complex. The source of certain issues is unclear. They can be a result of consequences from the surgery, but also of worries, as was explained in section 2.1 [9]. Thus, a tool should be designed that facilitates the discovery and expression of the information represented in the framework. However, the framework consists of much information that is probably hard to cover all in one tool. To scale down this overview to smaller problems, a stepwise procedure was defined, based on the framework. The to-be-designed tool should be a solution in at least one of these steps.

1. The patient formulates his values for each of the six categories of the framework
2. The patient sets concrete goals for each value
3. The patient identifies hindrances for each goal
4. The patient decides the relative importance of each goal-hindrance pair
5. The doctor suggests remedies to the most important goal-hindrance pairs
6. The patient tracks progress over time of his goals and hindrances

4.2 The *“Is this normal?”* idea

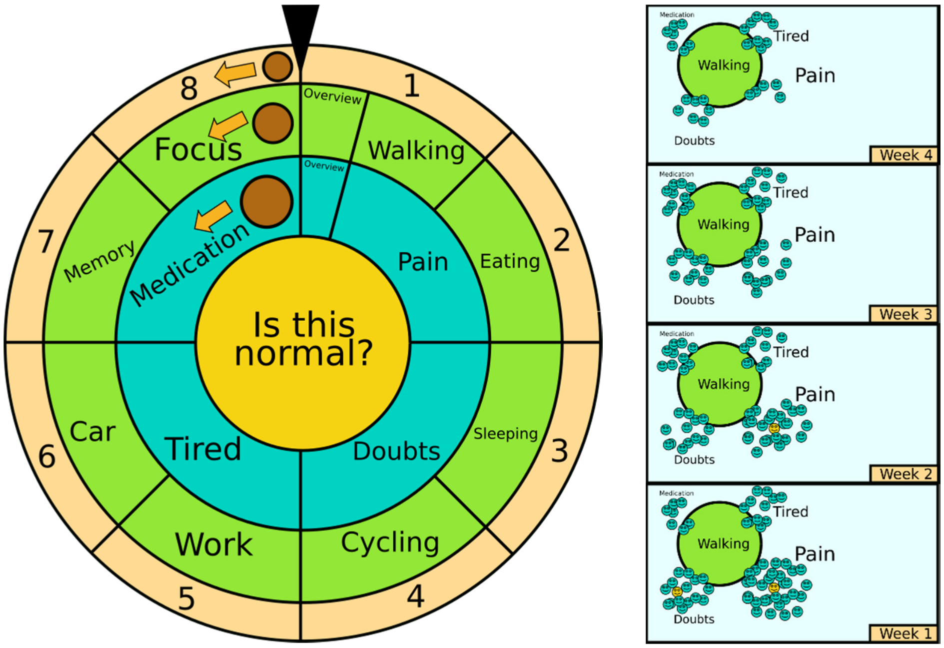


Figure 19 The 'Is this normal?' idea, early drawing

<u>Idea explanation</u>

The first idea is all about the question ‘Is this normal?’. It consists of a tangible user interface (TUI) and a web app, see Figure 19. The TUI consists of three rings that can be moved independently. The outer ring represents the week number after hospital release. The middle ring represents the goals that patients want to achieve. The inner ring represents hindrances that patients can experience while trying to reach the goals. A limited number of goals and hindrances is displayed in this conceptual picture. By moving the rings such that a category is located under the black arrow on top of the device, patients can indicate a certain week-goal-hindrance combination. Such a combination would correspond to the hexagons of Figure 18. Then, after pressing the middle yellow button, the result for the indicated combination is displayed on the web app. In other words, the web app shows per week, per goal, how many others experience a hindrance. It is also possible to get an overview of e.g. all hindrances that are experienced for one goal, as can be seen in Figure 19. Here, all hindrances for the ‘walking’ goal are displayed. By moving the week wheel, the development throughout the weeks of hindrances can be seen. Figure 19 shows actually four screens, i.e. weeks. In the product, only one of them is visible at the same time.

This product allows patients to estimate whether the issue that they have is normal, by comparing their issues to those of others. If many patients experience something, it is probably a normal part of the revalidation period. In that case, the tool provides a feeling of reassurance and it could take away unnecessary worries. When an issue appears to be less normal, patients could use this insight during consultation as an argument for their worries. In either way, the tool should provide a feeling of reassurance, by showing that the patient is not alone having issues. Reber et al. [37] show that unexpectedly familiar experiences evoke positive emotions. The ‘Is this normal?’ idea possibly also evokes such positive emotions, by showing users that other people experience similar, and familiar issues, as they do, while they were not aware of this.

On the web app, each person that experiences a hindrance is represented by a blue smiley face. All individuals together form a cluster of such smileys. The Gestalt principles of proximity and similarity, see section 3.3, were used in this visualisation. The blue smileys are identical and grouped together. This way, the fact that these people have something in common is highlighted. When the user pushes the yellow button, he is added to the cluster of the target goal-hindrance as a yellow smiley. By doing this, this information is added to the dataset. The users who use the app and submit their goal-hindrances build up the normal representation that is visualised in the app, in this way. In other words, the visualised ‘normal’ is the accumulation of all goal-hindrance pairs over the weeks that are submitted by the app’s users. The user sees himself among other people that share the same issue and, at the same time, the data set grows. The same smiley is used for the user, but displayed in a different color, to show the presence of the user among the others. There should be an option for users to turn off that they are added to the dataset, in case they just want to explore certain combinations that they do not have themselves. In the final design, this is solved in a different way, see Sections 11.1 and 12.1. Users are added to the dataset at most once a day.

In terms of the steps of the goal-hindrance-remedy framework, this idea mostly addresses step 4. It allows patients to estimate what issues are most important and require most attention, by distinguishing the normal ones from the rarer ones. To a lesser extent, this idea addresses step 6. The tool allows patients to explore the development of hindrances over the course of eight weeks after hospital release. Regarding the weeks that are ahead of the patient, he can estimate what is to come. For example, if someone is in week three and experiences pain while walking, he could look in weeks four, five, six etc. to see how this hindrance develops over time for other patients. This is an indication of how this issue may develop for him in the coming weeks. The tool allows patients to set an expectation of how their situation may develop. At the same time, patients can look back to past weeks, and reflect on their progress.

Insights that led to this idea

Issues during recovery can be divided in two groups. The first group consists of issues that are a direct, and normal, consequence of the surgery. This could be e.g. concentration problems, pain or depressivity. The second group consists of issues that arise when the patient has difficulties with coping with his situation. This could be e.g. worries, but also depressivity. As part of recovery, issues of the first group will naturally reduce over time. However, the second group is problematic, since these issues can harm the patient’s mental and physical health. For example, patients can experience pain as a normal consequence of the surgery. Nonetheless, they can develop worries about this, if they don’t know that this pain is normal to have and experienced by many. These worries could increase the pain. Increased pain leads to even more worries, and so on. To break this circle, a tool should point out what issues are normal. In other words, by being clear on the normal issues, the unnecessary worries can be reduced.

A possible indicator for whether an issue is normal or not, could be the number of patients that experience this at a given point in time during recovery. Having headaches in week 2 may be experienced by many and be normal, while having these same headaches in week 4 may be rare and require attention. Thus, a tool should show the number of people that have an issue at a certain point in time. This way, people can compare their situation to that of others, learn that their issues are normal, and feel reassured.

This idea is mostly based on problems that were identified in the literature study. In the first place, as just explained, the tool should take away unnecessary worries and their consequences, described in section 2.1. In the second place, it allows patients to prioritize issues that they have. Issues that appear to be normal probably require less attention during consultation. This leaves more time for remarkable issues. Additionally, it provides patients with information that they can show to express their worries with, when talking to the doctor. A low number of people that have a specific issue is a concrete argument to be worried. As explained in section 2.3, the expression of worries currently poses problems because people mostly share daily life stories that are hard to translate to a treatment plan, for the doctor. Prioritizing worries and having concrete arguments for them could solve this problem. Categorizing information and presenting it in a clear overview to facilitate expression is based on Shen and Yu's, and on Van Bergeijk and Hengeveld's, design for empowerment [32] [29].

Furthermore, while using the product throughout the period of recovery, the user generates information about his recovery's progress. Each time that the user uses it, he submits the hindrances that he experiences. It shows what issues the patient faces, or has faced, and how this developed since release. This information could be valuable for the doctor during the consultation. He or she can identify abnormalities in the patient's recovery process and address this during the consultation. Thus, this product addresses the problem concerning questionnaires that are not being filled in and the lack of information for the doctor as a result of that, as was explained in Section 1.2, and in [1].

From the perspective of pleasure and motivation to use the product, it mostly addresses Jordan's socio and psycho pleasure [24]. The tool makes users feel connected to other people who are facing the same challenges, by explicitly showing them as a cluster of smileys. It makes people feel less alone. This is socio pleasure. Besides this, the user may have questions such as '*Is this normal?', 'Am I the only one with this issue?'* and *'When does this end?'*. The tool provides answers to such questions, and thus understanding to the user. Therefore it gives users psycho pleasure of reaching a goal, of providing them the answers that they seek.

Lastly, this idea can be explained in terms of the design dimensions for communication support that were identified by Berry et al. [19], explained in Section 3.1. This idea would be *explicit*. Communication is explicitly about worries. The idea is *small-scale*. It facilitates communication between the patient and the doctor, and possibly between the patient and their partner. There are no larger groups involved. The idea is *partly synchronous and partly asynchronous.* The consultation with the doctor is synchronous, but if patients share their data with the doctor beforehand, this is asynchronous. The idea does not focus on *intimacy*. Although the doctor can be compassionate and the patient might share his personal interests, it is not the idea's main goal to facilitate this. The idea provides *guidance.* It suggests categories of hindrances that the patient can choose from. The idea requires average *effort*. Patients need to submit their information actively, but this is a small quantity. Furthermore, patients get answers to their questions in return, so they get something in return for their effort. Lastly, the idea is careful with *disclosure*. Patients can decide what information they want to share with the doctor. This is not shared automatically.

4.3 The recovery calendar idea

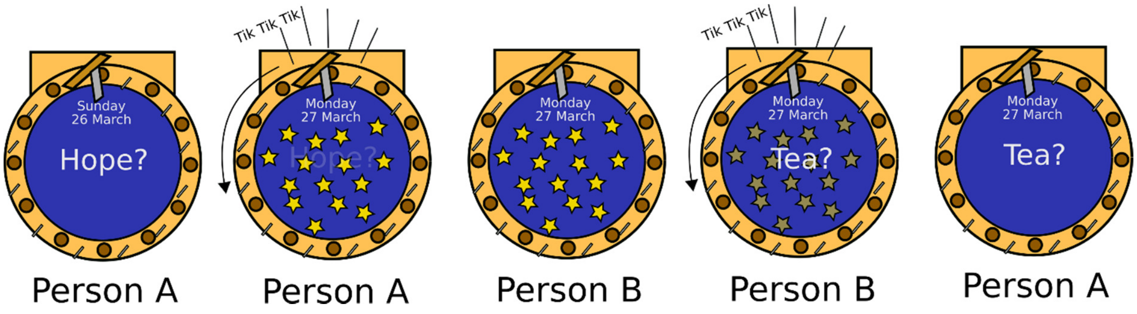


Figure 20 The recovery calendar idea, early drawing

<u>Idea explanation</u>

The second idea is a physical tear-off calendar that functions as a wheel of fortune, see Figure 20. It consists of a wheel with a screen in the middle. The screen displays the day, and a one-word question, such as 'Hope?'. Instead of tearing off a paper to go to the next day, the user can spin the wheel. By doing this, the date advances one day, the question disappears and the user answers the question in terms of stars. The harder the user spins, the more stars appear on the screen. Whether many stars are good or bad, is undefined. The meaning stays ambiguous. When the next person sees the calendar, he sees the number of stars, but he does not know to which question this answer belongs, because the question disappeared. If he is curious about this, he could ask the previous person about it and start a conversation. The person can also spin the wheel again. When doing this, the stars disappear and a new question pops up. He could answer this question himself, by spinning the wheel again, or leave this question for the next person. Now he knows the question. The next time he sees a number of stars, it could be someone's answer to his question. This creates moments of mutual understanding ("onder-onsjes"), because only few people know both the question and its answer. Lastly, people can also personalise the calendar by adding and removing their own questions to the list of possibilities.

By posing questions this product's goal is to trigger reflection in users on their values, their goals, and more generally on their revalidation process. Moreover, these questions and answers could facilitate conversations among members of the household and further enhance reflection. Unexpected questions or answers may lead to new or deeper conversations. This way, patients may appear better prepared on the consultation. At the same time, less serious topics, such as 'Hungry?' or 'Movie night?' could create funny moments or even quality time. In terms of the steps of the goal-hindrance-remedy framework, this idea mostly addresses steps 1 and 3. It helps patients to identify values and hindrances.

<u>Insights that led to this idea</u>

First of all, this idea is inspired on Nicemboim et al.'s and Giaccardi's work to use everyday objects that people are already familiar with [30][31]. In this case, the tear-off calendar is used. People interact daily with this object to advance the date. This habit is an interesting opportunity for the design of something that should be done regularly, i.e. reflection. In addition to this, the idea is based on Olivo et al. who design for the entire household, instead of only for the patient [27]. The product aims to facilitate conversations and create quality time, which are two important contributors to patient well-being, according to Olivo et al. [27]. Furthermore, the product can be personalised by adding and removing questions. Personalisation was highlighted by Ayobi et al. in the design of Trackly [26]. It fosters among others a sense of ownership and control. Moreover, the expressivity, i.e. the number of stars, is ambiguous, and it happens through motion. Expressive freedom and alternative ways of expression were highlighted by numerous authors such as by Vos [28], Olivo et al. [27] and Hummels [22]. It allows users to communicate meaning in new and subtle ways. This could facilitate the expression of difficult topics. Lastly, this playful and tangible interaction is pleasurable. People can spin the wheel, ask questions and express themselves. They connect with it on a personal level, especially via the personalisation and expressive freedom. The importance of pleasure and meaning in interaction was pointed out by Norman [23].

4.4 Summary

Elaborate brainstorming and mindmapping has led to three results. In the first place, this led to a better understanding of the patient's situation and the data involved. This led to the development of the goal-hindrance-remedy framework, i.e. a simplified representation of patients' situation in which they have goals, related to values. These goals can't fully be achieved because of hindrances from the condition. The doctor proposes remedies against these hindrances. Most of the identified problems, see Chapter 2, can be expressed and related to each other within this framework. Additionally, ideation led to two ideas. The *Is this normal?* idea is a tool with which patients can see how many other people are having the same hindrance while reaching a certain goal in a certain week of the revalidation. The tool's goal is to create a feeling of reassurance regarding normal issues, and to provide vocabulary for talking to the doctor regarding abnormal issues. The *recovery calendar* idea is a physical tear-off calendar, functioning as a wheel of fortune, that asks one word questions to trigger reflection and in-household conversations, so that patients appear better prepared on the consultation.

5. Field study part 1

Insights from the literature study and the related work, and the two ideas that were based on these insights, were validated in practice. In collaboration with a hospital in the Netherlands, several field study activities were done. First, one patient was followed during his pre-operative information session with the specialists that would execute his surgery, such as the surgeon and the anaesthetist. The goal of this activity was to observe what information was shared with the patient pre-operatively, and how his expectation on the post-operative period was set. Besides this, a heart specialist was interviewed. The goal of this interview was to validate the identified problems from the literature study and the mind map activities. Then, five post-operative patients were interviewed. The goal of these interviews was to learn their personal stories from the post-operative period. In other words, what did these people actually experience? Which problems did they face? Ethical approval to hold interviews and to discuss ideas with patients and healthcare staff was obtained from the university's ethical committee, as well as from the hospital's own ethical committee.

5.1 Observation: the pre-operative procedure

The involved doctors were informed beforehand about my visit and they verbally agreed to this. The patient was informed before the start of the conversations and also agreed verbally. I tried to disturb the procedure as little as possible. I sat on a chair, slightly away from the doctor and the patient. I only observed and took notes on my laptop. The patient was together with his partner. They had three conversations. First they spoke with his cardiologist. Then they spoke with the surgeon who was going to execute the surgery. Lastly they spoke to the anaesthetist who would be in charge of the narcosis.

Conversation with the cardiologist

The conversation was rather casual. The specialist asked some informal questions, and she asked what is important for the patient. Additionally, she comforted him and his partner by saying that he is a relatively healthy and young man, and by saying that this operation is performed often. It is thus not specifically challenging for the surgeon. Then, with the aid of an image of the heart, the specialist explained how the heart works, what the problem is, and how this will be solved during the surgery. Apart from this explanation, all communication happened verbally. The specialist also addressed the period after the surgery: *"After the operation you can expect to have a wound on the chest as well as on the leg. The latter will feel as a broken leg. You will also feel the chest bone while coughing. The first days will be painful."* She also advised to walk daily, and to not cycle, drive, or lift heavy objects in the first six weeks after the surgery. Besides this, she explained what the revalidation trajectory consists of. She stressed that only these activities are not enough and that the patient should do additional exercises to improve recovery. Furthermore, the specialist explained what the patient should not do in this period before the surgery. For example he should avoid intensive physical exercise. Lastly, the patient has diabetes. The specialist explained how this will influence the recovery of the wounds, and how the patient will periodically have to change his medication. These medicines had complex names, but the patient's partner knew them all.

Especially the patient's partner asked several questions and showed the most concerns. She verified information that she had heard during previous consultations, or that she had read online. For example she asked for the chance on reoccurrence of implications. The specialist answered all her questions. She also stressed that the partner could always call the hospital in the days around the surgery, to get reassurance and an update. The partner showed relief that the patient will probably already be released less than a week after the surgery. The procedure goes much faster than she expected. At the end of the conversation, the patient received a 'personal information folder'. This booklet generally explains the surgery, as well as the pre- and post-operative period. In contrast to what the name suggests, it does not contain 'personal' information. For example, it mentions the effects of diabetes on recovery, but there are no details on the patient's personal case. The folder could be used e.g. to read back topics that were just discussed.

Conversation with the surgeon

This conversation was shorter and more technically oriented than the first one. Again, almost all communication happened verbally. The surgeon explained certain decisions that he would need to make during the surgery. For example whether or not he would have to use the heart-lung machine. The machine can take over the heart's function during the surgery in case the heart has to be stopped. However this is not always needed. The patient's partner verified some information that she had just heard from the cardiologist. Again, the surgeon reassured the patient that he is a young and relatively healthy patient. Lastly, he said that the revalidation would take "a month or two".

Conversation with the anaesthetist

The anaesthetist first verified information about the patient such as his allergies and his medication. She reassured the patient that narcosis techniques have improved a lot in the last decades and have become safer. Then she provided a detailed and stepwise description of the narcosis procedure, i.e. the preparation, all tubes that would need to be placed and removed, and how he would wake up afterwards. There was enough time to ask questions. Again, she reassured the patient that he is relatively young and healthy and that this is positive for recovery. The anaesthetist explained very little about the weeks after the surgery and the possible longer-term consequences of narcosis.

Summary of Section 5.1

The specialists did not behave 'distantly', as opposed to what was reported in some cases in the literature [17]. In contrast, they reassured the patient, and especially the partner, in several ways. Reassurance and asking questions were a key part of all three conversations. The period before the surgery, the surgery itself, and the days in the hospital after the surgery were discussed clearly and step-wise. Each specialist did this from their own perspective. However, there was much less attention for the weeks and months after the hospital release. This was barely discussed. Also mental consequences of the surgery and the narcosis were barely discussed. In other words, the pre-operative session only seems to set a vague expectation of this recovery period at home. The patient is not, or barely, informed about possible (mental) consequences that are not unlikely to happen according to literature [9]. This may be done on purpose, however. Royston and Cox [9] report that providing extra information to patients pre-operatively can lead to adverse effects such as more worries and questions. Lastly, most communication took place verbally, and quite some difficult terms were used. It is unlikely that the patient and his partner clearly remembered all this afterwards. General information can be found back in the personal information folder, but more personal details may be forgotten.

5.2 Interview: heart specialist

An interview was held with a heart specialist. The goal of this interview was to validate the identified problems from the literature study and the mind map activities. Four problems were formulated in advance and each of them was discussed with the specialist. First, each problem will briefly be described. Then, the interview results will be described.

Problem 1

People don't know if their recovery process develops as it should be, as normal. All issues seem problematic while some of them are perfectly normal, as pointed out by healthcare specialists [4], Astin et al. [5] and Royston and Cox [9], which is explained in Section 2.1. As a result, the consultation does not focus on the issues that require most attention, as these are not easily noticed among all the other issues. Patients should be reassured on normal issues and rare issues should be filtered, such that the latter can be expressed towards the doctor. This problem is addressed by idea 1 *'Is this normal?'.* Within the goal-hindrance-remedy framework, it addresses steps 4 and 6.

Problem 2

Patients don't reflect enough on their goals and hindrances, as pointed out by Lim et al. [18] and explained in section 2.3. Furthermore, they don't express these in terms that the doctor can work with. During consultation, much time is lost on clarifying values and hindrances, and on translating these to a treatment plan. This problem is addressed by idea 2, the recovery calendar. Within the goal-hindrance-remedy framework, it addresses steps 1 and 3.

Problem 3

People's actual recovery process is different than what they expected, as was pointed out by Royston and Cox [9], explained in section 2.1. They experience setbacks and as a result, they develop worries and lose motivation for recovery exercises. There is not enough expectation management of the recovery process. The patient's worries should be expressed in terms of expectation versus reality. Within the goal-hindrance-remedy framework, this addresses steps 2 and 6.

Problem 4

People don't see how the doctor's advice contributes to achieving their personal goals, as pointed out by Rajabiyazdi et al. [17] and by Lim et al. [18], explained in section 2.3. The advice concerns short-term basic exercises, while the patient's goals are long-term, such as living independently. Consequently, people have little motivation to follow the doctor's advice. Within the goal-hindrance-remedy framework, this addresses steps 5 and 6.

The interview

The heart specialist mostly recognized problems 1 and 3. He confirmed that patients' expectations should be managed better. This could be done based on the 'normal' recovery (problem 1), or based on their own expectation versus reality (problem 3). Post-operatively, the revalidation trajectory for which patients can sign up only starts six weeks after the surgery. This is late, in the specialist's opinion. Directly after the surgery, patients seem to have a period of six weeks during which there is very little support from the hospital and in which worries could accumulate.

Regarding problem 1, the specialist added that data on the normal recovery trajectory, i.e. the development of hindrances over the weeks, is not available. Such data would have to be collected first, if it were to be used in e.g. the 'Is this normal?' idea. Besides this, the specialist said that problem 3 occurred mostly for relatively young patients. Post-operatively they are the least satisfied because, as opposed to what they expect, their physical strength and endurance can stay worse than pre-operatively. Additionally, they have to start taking medication for the rest of their lives from then on. In contrast, older patients' pre-operative situation is often worse and more problematic. Their strength and endurance decrease less, or even improves post-operatively. They are often already used to taking medication for other conditions.

The specialist rejected problem 2. In his experience, patients don't tell vague stories. Instead, they often address concrete problems. If not, doctors are experienced and know what questions to ask to get the information that they need. Not much time is lost in this process. Regarding problem 4, the specialist said that this was mostly a matter of lifestyle. Patients don't follow the doctor's advice because they have unhealthy habits such exercising little and they are not willing to improve this for revalidation. In other words, not following the doctor's advice seems to be the healthier life versus normal life problem, as was described in Section 2.3, rather than a mismatch between short-term exercises and long-term goals.

Remarks

Obviously, the specialist's statements are from his point of view and experience. Patients could have another opinion about these problems. For example, regarding the specialist's rejection of problem 2, he thinks that he understands the patient's situation, but it does not mean that he actually does. Even though the specialist rejected it, this does not guarantee that the problem does indeed not exist. This is equally true for the other problems. Patients could have another opinion on them.

Summary of Section 5.2

Four problems that were identified in literature were proposed to a heart specialist, to verify whether he recognized them in practice. Both problem 1 and 3 were recognized in practice by this specialist and these two are similar. They both come forth from poor expectation management. Problem 2 and 4 were not supported in their current formulation. These insights validate the opportunities for the 'Is this normal?' idea and reject those for the 'recovery calendar' idea. In the specialist's opinion, patients seem to have a period of six weeks during which there is very little support from the hospital and in which worries could accumulate.

5.3 Interview: post-operative patients

Five post-operative patients were interviewed. The interviews were semi-structured. The patients had come to the hospital for their post-operative consultation with the heart surgeon that had done their surgery. There, they were asked if they had time for a short conversation with me afterwards and if I could join the consultation. All five, as well as the two surgeons involved, gave permission verbally. The interviews were held on two different days, as a result of the consultations being on two days. Two were held on the first with one surgeon, and three on the second with the other surgeon. During the consultation, as during the pre-operative sessions, I observed the conversation from a distance without disturbing it. I took notes on my laptop. The interview took place in another room without the specialist. In most cases, the patient was together with his or her partner. The consultation was joined most notably to learn what these post-operative consultations involve in practice. They were also joined to get familiar with the patient's personal story and current state, to have some context for the interviews, to know what is referred to when the patient would mention something during the interview. Lastly, the 'Is this normal?' idea was briefly introduced to the patients, to estimate their first reaction on the idea. The recovery calendar idea was not proposed, because the problem it solved had been rejected by the heart specialist, see Section 5.2. A short summary of each consultation and interview will be given, followed by concluding remarks. The interview questions can be found in appendix 1.

In addition to the semi-structured interviews, I proposed a list with hindrances and goals to the patients. This list was based on information found in [4]. I asked whether this list was complete in their opinion. They were free to add hindrances and goals that were missing, according to their experience.

This way, I wanted to obtain an overview of all possible goals and hindrances that open heart surgery patients could experience or have during recovery. The hindrances that were obtained in this way were implemented in prototypes as hindrance categories that users can choose from, see Sections 11.1 and 12.1.

Consultation and interview 1

This was the first time that the patient saw her surgeon again after the surgery. The surgeon asked how she was doing, if she was satisfied and what she was able to do again. Additionally, he verified some medical information, e.g. regarding medication. He also shared medical information such as blood pressure, he showed scans of the heart to show that it looked good now, and he explained what had been done during the surgery, with the aid of an image. The patient emphasized that she had suffered severe headaches, especially in the first weeks after the surgery. She also sometimes felt heart rhythm disturbances. The surgeon reassured her that both these hindrances were normal and would diminish over time. In case of the headaches, these could reoccur until three to four months after the surgery.

In the interview, the patient said to have underestimated the recovery period. In addition to the severe headaches, she had also felt dizzy, experienced bad memory, and had difficulties with finding the right words in the first weeks. She had been worried about this, because she had not expected this. Three weeks after hospital release, she got called to start with the revalidation trajectory. During this call she expressed her worries and got finally reassured that her issues were normal. The revalidation activities had been a great relief for her. Here they told her that her issues were normal consequences of the surgery, and they gave her back some trust in her own body and capabilities. When worried, she did not look on the internet, but she liked to read the personal information folder. Regarding physical activities, in the first weeks she could do almost nothing, but this had improved over time.

Even though her situation in the first weeks had been difficult and she had been worried, she had not contacted her cardiologist. She felt too much of a barrier to call him and ask questions. She would have preferred someone to contact her instead, and to simply ask how she was doing. This (in her opinion, simple gesture) could have helped a lot for her to express her concerns and tell her story. She had experienced the cardiologist's role as 'formal'. 'Behind the scenes' he had organised a lot for the surgery and in case of complications after the surgery he was available, but other than that, she hadn't seen him. She had also expressed her worries to the general practitioner. However he had not been able to fully reassure her, because he was not a heart specialist. Lastly, the patient was positive towards the 'is this normal?' idea. She could imagine this to bring some reassurance and recognition of issues.

Consultation and interview 2

During the consultation the patient said he felt heart rhythm disturbances, he felt his heart beating more clearly, and he felt his heart beat resonating strangely in his jaw sometimes. The surgeon suggested to discuss this with the cardiologist and to make a new scan.

This patient's recovery had been faster and easier than he had expected. He hadn't experienced mental issues and the physical issues were not severe. He had felt few worries and fears. However, in his experience he felt a gap between the hospital and him (and his partner), in the first six weeks after release, before start of the revalidation activities. In this period, it was not easy to get in contact with the hospital and he received very little guidance for recovery, e.g. suggestions for exercises. He was told to walk and to stay active, but not how much and in what way. After release, he felt like his recovery was his own responsibility. He continued with the exercises that he had started in the hospital. Regarding the ‘is this normal?’ idea, he thought it would be very pleasant to be able to compare his situation to that of others.

Consultation and interview 3

The surgery had taken place ten weeks ago. This patient had already had a heart surgery before getting this one, so he has been operated twice. The consultation had an informal tone. The surgeon reassured that the surgery had been easy and that the patient was looking healthy. The surgeon showed scan results and explained what he had done during the surgery. The patient indicated that he felt much better now.

During the interview, the patient indicated that his recovery had gone well and that no unexpected issues had occurred. In his opinion, the pain on the chest that he felt with every movement he made was annoying in the beginning. He also slept worse because he had to sleep on his back. Besides this, he expected to feel better after the surgery, and that was the case. Because of his quick recovery, he would have liked to start earlier with the revalidation activities. Even though he felt good, he had some questions in the weeks after the surgery. He most notably wondered what weights he was allowed to lift exactly. The hospital stayed vague about this, but he understood that this was hard to estimate, as it would be different for each patient. In addition to this, although he was hopeful, he had worried whether he would get back his normal life from before the surgery. He was positive about the role of the cardiologist, especially because of his effort to plan the surgery from a to z. This patient had consulted the personal information folder only before the surgery. Because this had been his second surgery, he was already more informed.

Regarding the ‘is this normal?’ idea, the patient was positive. In his opinion, it would be helpful especially in the weeks between the surgery and the revalidation activities. It reminded him of a forum to share experiences, and that would be useful. With such a tool, he would know that he called the doctor for a good reason. He also suggested some factors that patients should be distinguished on: age, having a job or not, and the effort that exercises require.

Consultation and interview 4

The surgery had taken place six weeks ago. This patient was relatively old for this impactful surgery. During the consultation the patient expressed worries about noise that he perceived in his heartbeat. The surgeon reassured him that this would probably diminish over time. The surgeon behaved in an informal manner. Again the surgeon explained the surgery and showed scans of the heart. The patient said that he had recovered quickly, although in the beginning he had suffered much pain in his shoulders. He went for a walk almost daily and had not yet started the revalidation activities.

During the interview, the patient said that he had had the same type of surgery sixteen years ago. Then recovery went worse than now, so this time recovery went better than expected. The patient hadn’t had questions or big worries. Now some types of physical exercises were still difficult, such as cycling. Besides this, he slept worse because he had to lie down on his back. He was positive about the cardiologist, who was social, positive and gave reassurance. He had regularly consulted the personal information folder for information on hospital release and medication. Regarding the ‘Is this normal?’ idea, it did not appeal to him. He would not use such a tool, because his recovery was going well.

Consultation and interview 5
This patient had his surgery sixteen months ago and now he came back because of irritations on the wires around the chest bone. After the surgery these are placed to make the two bone halves grow together again.

This relatively young patient had had cancer seven years ago. This came unexpectedly. Also his heart problems and the surgery came unexpectedly. As a result, he had lost trust in his body. He had many doubts whether he would be able to take up his socially and physically active life again. Only now, sixteen months later, he is convinced to be fully recovered. His worries diminished as his life became more and more active. The patient's recovery had gone a little different than he expected. It took longer than expected before he could take up physical activities again, such as cycling or grocery shopping. He had had much pain in his shoulders and felt the chest wound with every movement. He felt useless in the first weeks. He had received much support from his family and his neighbours. In the first weeks, he had called weekly with the cardiologist and he had used psychological aid that was offered to him. He was satisfied about this. He had repeatedly consulted the personal information folder. Regarding the 'Is this normal?' idea, he thought that it is a good idea. He would be interested to compare his recovery process to that of others. However he also showed concerns that some people could get more worried upon reading stories of others.

Remarks
The consultations had a pleasant and informal ambiance and the surgeons did not behave distantly, as opposed to what was found in the literature [17]. However, the surgeons were often looking at their screen, also when the patient was talking. Besides this, they spoke rather quickly and used difficult medical terms. These observations agree with the literature [17]. Furthermore, scan images were used by the surgeon to show the current state of the patient's heart. On the scans, certain areas were marked with a color, and the rest was in greyscale. In my opinion, these scans seemed very hard to interpret for an ordinary person. The surgeon's fast talking and medical terms did not help with this either. Therefore, it might be that communication with the surgeon was not always clear and satisfactory, from the patient's perspective. Lastly, patients expressed their worries in terms of hindrances they encountered with 'basic' activities such as sleeping and walking. This is in contrast to what was found in literature by Berry et al. [16] and by Lim et al. [18], see Sections 2.2 and 2.3. These researchers argued that patients express themselves in terms of higher values such as independence and gardening. This was thus not validated in practice in the interviews that I held.

Summary of Section 5.3
In the period of recovery after hospital release, patients need to get comfortable again with the most basic daily activities such as sleeping, eating and walking. In this process, they can experience a large variety of issues, such as pain, tiredness, forgetfulness or heart rhythm disturbances. Many patients have some worries or questions because the recovery process is different than expected. Worries could concern e.g. whether patients will fully recover, what activities they can take up again, or the severity of issues such as pain. This is also true for those who have rather mild issues during recovery. There is little initiative from e.g. the cardiologist to contact patients and to ask how patients are doing. Consequently, some patients feel a barrier to take the initiative themselves and to contact the specialist, to address their worries or questions. This is equally true for their partners. As a result, patient worries and questions remain unexpressed towards the specialist. In addition to this, the hospital advises patients to get physically active by walking and exercising regularly. However, concrete training schedules or advice are not provided. It is the patient's own responsibility to find exercises and to do them regularly. Only six weeks after the hospital release, the revalidation

trajectory starts. This is an important moment of relief for patients, because here they can ask their questions and they regain trust in their body.

There are large differences in how patients experience the recovery period. Some simply encounter less severe issues than others, possibly because their surgery was in fact less impactful. However, the experience is probably also impacted by patients' expectation. If an issue was expected to happen, it may be perceived as less severe than when this same issue was encountered unexpectedly, or for a longer duration. Patients' expectation is influenced by a variety of variables such as by a patient's medical history. Someone who has had a heart surgery before, may have more realistic expectations when he gets operated a second time.

The first post-operative consultation takes place six weeks after hospital release. The consultations have an informal tone. Although specialists try to reassure patients, they tend to talk fast and use difficult medical words. Patients express their worries in terms of issues that they encounter. For example, regularly having severe headaches for weeks after the surgery. Patients' opinions on the cardiologist's role are different. Some are happy with the cardiologist because he/she organizes the surgery well. Others aren't because they expect more emotional support. At home, many patients read the personal information folder for information. Some look on the internet as well. Lastly, four out of five people reacted positively on the 'Is this normal?' idea. They would be interested to compare themselves to others and to see whether issues are common or not.

6. Cycle 1 design decisions

This chapter summarizes cycle 1, i.e. Chapters 2, 3, 4 and 5, in terms of the design decisions that have been made in this cycle based on information that was obtained in the various exploration and validation activities that were described in these chapters. This cycle focused on formulating a more concrete problem statement, especially in terms of data. Based on this problem statement, some decisions have been made regarding the solution, such as whether to develop a physical or a digital representation, and what would be the main goal of the representation.

What problem do you want to solve?

Patients are at home recovering from the open heart surgery. Often this process goes differently than expected. It was found that pre-operatively, there is little attention for post-operative expectation setting. During post-operative patient interviews it was found that patients can experience other issues, more severe issues, or issues that last longer than expected. They can't estimate the seriousness of these issues because of this bad expectation setting. As a result, patients develop worries and have questions. According to literature, such worries can be bad for the patient's recovery and wellbeing. During interviews with post-operative patients and a heart specialist, it was found that there is little contact between the hospital and the patient in the weeks after the surgery. Some patients feel a barrier to contact the hospital. As a result, these worries and questions remain unexpressed until the consultation. Before then, they could be harmful and hinder recovery. Simply providing more information pre-operatively is not the solution however, as literature shows that this could have adverse effects, i.e. cause more worries [9].

As opposed to what was found in the literature, patients express their worries in terms of hindrances that they experience, and not in terms of their personal values or goals. These hindrances are often clear, and don't need to be identified. This was observed during the post-operative consultations that I joined as part of the semi-structured interviews that I held, see Section 5.3. Thus, problems with value and hindrance identification were not validated in practice. At the same time, expectation management and the estimation of the seriousness of worries were. Therefore, it was decided to proceed with the 'Is this normal?' idea, that addresses the latter, and to reject the 'recovery calendar', that addresses the former, see Chapter 4.

In short, as a result of vague expectations, patients can't estimate the seriousness of hindrances that they experience while recovering and they get worried because of their hindrances. These worries are bad for recovery. Additionally, patients have difficulties with expressing these worries towards the doctor because there is little contact with the hospital in the weeks after hospital release and they can be hesitant to contact the hospital themselves.

What is your data and what are the relations within it that you want to communicate?

Patients could use a tool that facilitates the estimation of the seriousness of their issues and expression of those issues. This could be achieved by showing whether an issue is normal or not, which may be expressed in terms of the number of other patients that also experience the specific issue. Therefore, the data consists of hindrances, and the number of people who experience each hindrance. In addition to this, time is an important factor. Feeling tired in week two may be normal, while feeling tired in week five may be rare. Thus, the number of weeks after hospital release should also be taken into account. Besides this, patients have many characteristics, such as age, medical profile and being athletic or not. Such factors could equally influence the recovery process, and might therefore be important to take into account.

In short, the tool communicates per week, per hindrance, the number of patients that experience that hindrance and that are similar people to the user in terms of age.

What do you want to achieve with the data representation?

The tool should allow users to get an overview of the ‘normal’ recovery process as well as of their own process, to discover and analyse trends. This should allow users to compare their recovery process to that of others. In doing so, the tool should bring about *reassurance* that certain issues are normal, and it should provide arguments to contact the doctor and to explain worries with, regarding less normal issues.

Will you make a physical or a digital information representation?

Physical and digital information representations both have their advantages and disadvantages. Game Solutions Lab would like a product that can easily be spread among users and that has low production costs. Digital tools, such as apps, are easy to share and don’t require as much production facilities as physical tools do. Furthermore digital tools can more easily be modified for e.g. other user groups, or receive updates. Physical tools have advantages as well. They allow for richer multimodal interactions that better exploit human motor skills, and they facilitate cognition [39]. However, in this case these advantages don’t weigh up against the advantages of a digital tool. From a business perspective, the advantages of the latter are more valuable. Furthermore, the continuous presence of a physical object in the house could be a disadvantage. The object could remind users of their surgery and its consequences at moments when they don’t want to be reminded of this.

Does the visualisation require active attention, or does it reside in the background?

The user actively seeks answers to his questions whether specific hindrances are normal. It therefore makes sense to design a tool that clearly provides these. The user directly interacts with the tool and pays active attention to this interaction.

How often and how do you capture the user’s attention?

Users should regularly interact with the product, because information of their recovery is stored each time they interact. This information is useful for doctors to estimate the patient’s recovery process, but this is only insightful with a certain minimum number of entries. It is expected that users will use the app regularly because it answers their recurring questions during the weeks of the recovery process. O’Brien and Toms found that providing information that users want is a major contributor to user reengagement [20], see Section 3.1. Besides this, the tool should provide a pleasant feeling of reassurance that certain issues are normal. This pleasure and connection with others could make users connect on a more emotional level with the product and make them come back, as Norman [23] explained, see Section 3.1. Thus, the user should use the app at least once a week. Users’ attention is captured by providing answers to questions that they have, and by providing a pleasant feeling of connection with other patients. However, in the end no long-term user studies were done so this is not validated in practice.

Cycle 2

Design questions

In cycle 1 a problem was identified as well as the data that is involved, and the goal for the information representation. This resulted in new questions that were answered in cycle 2. *These questions address how the data is obtained and how this data should be presented to users to reassure their worries.* For example, do users submit their own data and is this live data represented, or is it better to use a fixed data set that represents the normal? Additionally, the tool should bring about reassurance when users compare themselves to others and see that their issues are normal. How will this feeling of reassurance be evoked? Can this be done with clarity and hard data such as percentages, or rather with solidarity and soft data, such as texts that describe people's experiences? Is reassurance achieved by showing many people that are somewhat similar to the user (e.g. only sharing a hindrance), or by showing few people that are very similar (e.g. sharing a hindrance, age, medical profile)?

Exploration activities

Chapter 7 describes the personas and the scenarios of use that were written. These were written to translate cycle 2's design questions to concrete implications for the product. Personas helped to evaluate design decisions from the user's perspective. Scenarios of use were used to imagine different product concepts, each concept being a combination of answers to the design questions.

Validation activities

Chapter 8 describes field study activities that were done to validate the concepts that were developed with the aid of personas and scenarios of use in chapter 7. A concept test was done, and an interview with a revalidation expert was held. The goal was to get an impression of what information patients would like to see or know and how they would like this to be visualised.

Chapter 9 briefly summarizes cycle 2 in terms of the design decisions that have been made in this cycle based on information that was obtained in the various activities.

7. Personas & scenarios of use

To translate cycle 2's design questions to concrete implications for the product, personas and scenarios of use were written. The personas helped to consider design decisions from the user's perspective, the user being a person that is recovering from an open heart surgery, with his own goals and frustrations. The personas were based on the information that was gathered during the field study activities of cycle 1. Most notably the post-operative patient interviews formed a rich source of information for the personas. Scenarios of use were used to imagine different product concepts, each concept being a combination of answers to the design questions that were just described. For example, one product could focus on information submission in the form of texts and on showing this as live data for patients who have similar profiles. Another product could focus on the exploration of a representative dataset of the normal, being percentages of people that have a hindrance at a point in time.

7.1 The personas

Four different personas were written. Several characteristics that may influence a patient's recovery progress were identified based on the cycle 1 field study activities. Each persona represented a different combination of these characteristics, see table 1.

	Age	**Weeks after hospital release**	**Athletic**	**Partner**	**Hindrances**	**Medical profile**
Gerda	56 (young)	5 (average)	no	yes	Headaches, memory	Smoker, overweight
Barrie	70 (old)	3 (short)	yes	no	Lost trust in body	-
Japie	65 (average)	8 (long)	yes	yes	Variety of problems	2nd heart surgery
Truus	62 (average)	2 (short)	yes	yes	Pain, dizzy	diabetes

Table 1 Overview of the personas

The description of the first persona, Gerda, is provided here. The other three can be found in appendix 2.

Persona 1: Gerda

Occupation: German teacher

Gerda is relatively young to have had an open heart surgery, but she needed it because of several problems on and around her heart. Gerda has been smoking for years and she barely does any sports. She is also a bit overweight. She used to walk the dog before the surgery, however. Now, after the surgery, she tries to pick this activity up again, but this is hard. Her partner has the same lifestyle. Gerda shows little initiative to do revalidation exercises. After all, she did not do such things before the surgery either. Her husband does all the household tasks at the moment. Before the surgery, this was more equally divided. Gerda sleeps badly because she has to lie on her back as a result of the surgery. Normally she does not do this. According to her, this is the main reason why she is so tired during the day. The wound on her chest heals well, but she is still in bad shape. Going to the toilet is already tiring. Gerda is worried about the severe headaches that she experiences regularly. She does not understand why this happens. After all, it was a heart surgery and not a head surgery. While watching TV, she often feels sudden and severe headaches. Because her memory is also worse than before, she suspects to have suffered brain damage. Emotionally she receives much support from her husband, but he is not a medical expert so he cannot fully reassure her.

Goal

Gerda would like to know whether it is normal to be so forgetful and to have such frequent headaches as a result of the heart surgery, while already being home for weeks.

Frustrations

- She does not dare to call the cardiologist, because he will be very busy. The GP says it is normal, but she does not fully trust this.
- There is much information available on the Internet, but she is never sure whether these people have had the exact same surgery as she had, and these people are often older.
- She has many questions, but she forgets these as well.

7.2 The scenarios of use

A variety of product concepts, representing different combinations of design decisions, were worked out as scenarios of use. The Gerda persona was taken as the patient in these scenarios. A total of eight different scenarios/product concepts were created. The three scenarios that describe the concepts that were used in the concept test, are provided here. These three concepts were selected for the concept test, which will be described in Section 8.1, because they represent clearly distinguishable combinations of design decisions. This would make it possible to estimate what designs, and thus decisions, are appreciated the most by patients.

It was decided to imagine the concepts as tablet apps in landscape mode. Regarding the final product, it was estimated that the target group would possess either a tablet, a laptop or a personal computer and that the final app could run on these devices. This way, the app would probably be available to most people of the target group. Interaction on these three devices is not similar and the tablet versions as designed in this thesis, e.g. see Section 11.1 and 12.1, would need adjustments to optimize them for laptop or PC usage. For example, laptop and PC users have a mouse and can hover over elements. This hover action could trigger a pop-up message. In the tablet version, this would work differently. It was estimated that tablets would become more popular compared to laptops or PCs among this target group in the near future. Therefore, the tablet was taken as default device in the thesis.

Concept 1 – Clarity & hard data

This concept focuses on showing hard data, percentages, of people who have a certain hindrance, for each week after hospital release. Users select a hindrance, and then the app shows the percentages of people per week in a clear and simple way, i.e. with a bar graph. As explained in Section 4.2, when people select a hindrance while being in a certain week after hospital release, this information is added to the dataset. This way information is collected and the 'normal' is created. The app uses data from people that use the app now, and those who used the app up to one year ago. Showing hard data in a clear way could reassure worries. A simple conceptual drawing of this concept can be seen in Figure 21 in Chapter 8.

Scenario 1 – Clarity & hard data

Gerda is watching TV with her husband in the evening when she suddenly feels a severe headache. She is fed up with it. She takes her tablet and opens the 'recovery compass' app. She logs in, after having looked up her log in information. She sees that the surgery has been five weeks ago. The screen shows several buttons. Each button represents a hindrance. Gerda clicks on 'pain'. Then she sees a bar graph of the percentage per week of patients of her age group that also experience pain. She sees that few people of her age are feeling pain in week 5 after the surgery. This makes her worried, and she will call the cardiologist tomorrow. She also quickly checks the other categories, such as memory. Here she sees that many people are having problems with their memory. This reassures her a bit that she might not have a brain injury after all. She is happy to see that many people suffer from breathlessness, while she has no problems with this herself.

Concept 2 – Solidarity & hard data

This concept uses the same data as concept 1. The percentage of people in the user's age range that experience a selected hindrance are shown. However, in contrast to concept 1, this concept only shows the percentage of one week at a time, and this quantity is visualised as a cluster of smiley faces. Each smiley represents one percent of the app's user base in the user's age range that use the app now or that used the app up to one year ago. This visualisation is less clear, but the cluster of smileys should evoke a feeling of solidarity among the users, which could reassure worries. The quantity as percentage is shown next to the cluster. A simple conceptual drawing of this concept can be seen in Figure 22 in Chapter 8.

Scenario 2 – Solidarity & hard data

Again, Gerda is watching TV while she feels severe headaches. She takes the tablet and logs in to the ‘recovery compass’ app. On her screen, a hundred blue smiley faces appear in week 5. A pop-up notification tells her that these smileys represent all patients that used the app that have had an open heart surgery at the same hospital as she has. Each smiley represents 1 percent of the patients. At ‘I am hindered by…’, she says ‘memory’. At that moment, about half of the smileys group together and one smiley turns yellow. Now Gerda knows that many people, more than 50%, are hindered by their memory in week 5. In her opinion, her memory problem is still annoying, but less troublesome. She goes from ‘memory’ to ‘pain’, and again she sees the smileys coming together, this time a bit less than half of them. She feels a little reassured. The GP probably was right that these hindrances are normal.

Concept 3 – Solidarity & soft data

This concept focuses on sharing soft data, i.e. people’s experiences of their recovery process. When using the app for the first time, users need to submit some more information than in concept 1 and 2, in order to make a more detailed user profile that e.g. also mentions whether you often do sports or not. Users can write a short message on how they are doing that day. After submitting the message, users see a group of avatar images of other users who wrote a message containing similar words as theirs. They are also users who have a similar profile as the user. By clicking on the avatars, users can read these user’s messages and see their profiles. Exchanging experiences with users who are similar to the user and who are represented as a cluster of avatar images could reassure worries. A simple conceptual drawing of this concept can be seen in Figure 23 in Chapter 8.

Scenario 3 – Solidarity & soft data

Again, Gerda is watching TV on the couch and she feels severe headaches. She takes the tablet, opens the app and logs in. A question pops up, “How are you doing today?”, as well as a text cloud in which she can type an answer with a maximum of a hundred characters. She fills in: “I have slept badly and my head hurts incredibly.” She presses OK. Now a space appears on the screen. In this space she sees an avatar of herself surrounded by avatars of others. She reads “All these people are experiencing something similar as you today.” She presses on some of the avatars, to read what messages these people have written and what they are experiencing. In addition, she sees that these people are similar to her. They are more or less from the same age, share the same medical profile, and they are in the same week of recovery as she is. She reads that some of these similar people are doing even worse than she is doing, which reassures her. It can be worse, apparently. However, she is still a little worried whether her issues are normal.

In short, concept 1 is the closest representation of hard data that is represented in a clear way, with bar graphs. Concept 2 involves the same hard data as concept 1, but now the visualisation focuses on solidarity between the patients, instead of clarity of the visualisation. Patients are represented as a cluster of smileys. Concept 3 focuses on sharing experiences and displaying patients with similar profiles to evoke a feeling of solidarity in this way.

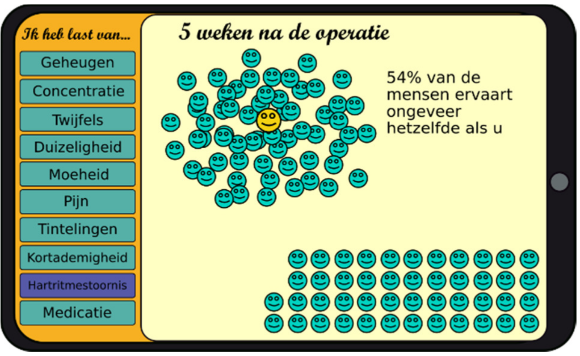
8. Field study part 2

This chapter describes a concept test that was done and an interview that was held with a revalidation expert. The goal of the concept test was to evaluate the concepts that were developed with the aid of personas and scenarios of use, see Chapter 7, being combinations of design decisions, and by doing so, to get an impression of what information patients would like to see or know and how they would like this to be visualised.

A revalidation expert is someone who guides post-operative patients with doing revalidation exercises on a daily basis. The goal of the interview was to get a more general impression of post-operative patients' questions and worries that she hears during her work, in contrast to the individual experiences that were obtained from the post-operative patient interviews (Chapter 5). This could validate cycle 1's decisions again. In terms of the design, the goal was to learn what information patients actually want to see or know, what information the design should provide. Also the three concepts were explained to the expert, with the aid of the drawings from the concept test. Her opinion about them was asked. This interview took place digitally, in the form of a video call. The concept test questions and the expert interview questions can be found in appendix 3.

8.1 The concept test

The concept test was done with two patients. One patient was together with his partner. The other patient was together with his son. Similar to the post-operative patient interviews, these patients had come to the hospital for a consultation. Before the consultation, I asked them permission if I could join the consultation and if I could ask them some additional questions afterwards. Both patients and the surgeon leading the consultation agreed verbally. The consultation was joined to get some background information of the patient, most notably about his recovery experiences, to be able to put their responses during the concept test in perspective. During the consultation, I was seated on a chair slightly removed from the doctor and the patient and I took some notes on my laptop. Simple drawings of each of the three concepts had been made in Inkscape. These can be seen in Figures 21, 22 and 23. During the concept test, first the three concepts were explained with aid of these drawings. Then, they were discussed in a semi-structured way. Some questions were prepared as guideline for the interview and these were addressed during the discussion.



54% van de mensen ervaart ongeveer hetzelfde als u

Figure 21 Concept 1

Figure 22 Concept 2

Ik heb erg slecht geslapen en ik heb nogal veel hoofdpijn, snap niet waarom...

Operatie: 3 weken geleden
Leeftijd: 61 jaar
Sportief: een beetje
Beroep: vooral fysiek actief
Medisch: roker

Ik blijf maar last hebben van de pijn in mijn schouders en op m'n borst 21 april 2021

Vandaag gaat het een stukje beter, heb weer een eind gewandeld! 22 april 2021

Ik heb toch weer last van mijn hoofd, en daardoor slaap ik echt slecht... 23 april 2021

Operatie: 3 weken geleden
Leeftijd: 63 jaar
Sportief: een beetje
Beroep: mentaal actief
Medisch: ---

Vandaag gaat het wel goed! Beetje oppervlakkig geslapen, maar ach 14 april 2021

De hoofdpijn lijkt weer terug te komen, hoort dat? 20 april 2021

Beetje futloos, maar wel gewandeld. 17 april 2021

Heb veel tijd in bed moeten doorbrengen... 22 april 2021

Ik begin steeds meer last te krijgen van vergeetachtigheid! 19 april 2021

Ik heb erg slecht geslapen en ik heb nogal veel hoofdpijn, snap niet waarom... 23 april 2021

Figure 23 Concept 3

Concept test 1

This patient had his surgery six weeks ago and has not yet started his revalidation trajectory. Until now recovery has been troublesome and worrisome. After release, he has been hospitalised again. In the past weeks the patient has had much fears and he has slept very badly. As a result he is tired during the days. He has received help after contacting the hospital and now the situation is improving, even though he still has some issues such as dizziness. His partner was, and still is, worried.

The patient would be interested to use such an app (either of the three). He experienced the first days and weeks after release as a sort of vacuum. He had several issues, did not know where they were coming from, and lost trust in his body. In this period, he and his partner would have wanted to talk to someone. They highlighted the advantage that the app provides information directly. You don't need to e.g. wait for someone to reply. For certain issues they wondered whether these were normal. Seeing someone that experienced the same would give them rest, they indicated. This was most clearly realised in concept 3.

Among these concepts, the patient preferred concept 2. This concept would reassure him the most, especially because of the clear information in the form of a percentage, in combination with the smiley faces. He also expressed interest in concept 3 but couldn't specify what exactly attracted him. His partner preferred concept 3. She liked the personal and human side of sharing messages with each other. She thought that this concept would suit her partner better.

Concept test 2

Being aged above 80, this patient was relatively old for an open heart surgery. His surgery has been three months ago. In the beginning he has had some complications. He recovers slowly, and expected it to go faster. Especially his muscle strength and endurance are still worse than before. Besides this he still has some other issues, such as breathlessness and bruises on his body.

This patient was not really interested to use such an app. Most notably, he did not want to learn how to use it. His son, who accompanied him, was more positive however. He liked the fact that you can quickly estimate your situation without much effort. Among the concepts, concept 1 appealed the most to both of them. It seemed the most straightforward and easy to use. You say what hinders you, and directly you get your answer in a clear way. The son thought that concept 3 was the most promising, but also visually the messiest in its current state. He said that concept 3 would be great, but expressed concerns regarding its usability for elderly people. Ideally, he would want concept 3 with the clarity of concept 1.

<u>Insights</u>

Hard data such percentages and soft data such as experiences are both appreciated. Hard data provide clear and simple to interpret information that can be reassuring. At the same time, reading that other people experience the same as you do, can also be reassuring. In other words, a middle-way solution of these concepts can be promising in which personal experiences are visualised in a clear and simple way. In addition to this, the patients liked that reassuring information can be obtained quickly and with little effort, especially in concepts 1 and 2.

8.2 Interview: revalidation expert

A revalidation expert was interviewed digitally in a semi-structured way. Also the three concepts from the concept test were proposed to and discussed with her.

<u>The interview</u>

According to this revalidation expert, patients ask the most questions about what physical activities they can do again. E.g. how much weight they should lift or how far they should walk. Patients have lost trust in their bodies and they are quickly worried when for example they feel pain after a walk. Then she reassures them that feeling pain is a normal part of recovery, and it is not troublesome. She helps them with regaining trust in their body. Patients also often ask whether certain issues are normal or not. For example some people become much more emotional during recovery. She tells them that such things are normal. Additionally, many patients develop worries because their recovery process takes longer than expected.

In her opinion, what patients miss the most when recovering at home is contact with other patients. Often people have a tendency to think that they are alone having certain issues, while this is not the case. Also the patient's partner should receive much more attention. From the hospital, there is little contact with and support for the partners while they are often at least as worried as the patient. In addition to this, in her opinion, people should receive support to adopt a better lifestyle. The risks of smoking and being overweight should be shown more explicitly.

The expert gave several variables that could influence a person's recovery process or how someone experiences it:

- Age
- Medical profile / history
- Being athletic or not
- Lifestyle
- Life attitude (being a positive or negative person)
- Receiving support from a partner and/or other close social relations
- Being a man or a woman
- Culture
- The time between the diagnosis and the surgery

Regarding the concepts, concept 1 and 3 appealed the most to her. Concept 1 because of the clear overview over time of the data. Concept 3 because it is much more personal and it allows to compare experiences from similar people.

Insights

This interview confirmed the possible added value of the 'Is this normal?' idea. According to the expert, many patients are worried whether issues are normal, and how long issues normally persist. Moreover, they believe they are the only ones having specific issues and they are not connected to others. Also the partner's worries should be taken into account. The 'Is this normal?' idea could contribute to solving these issues by giving insight in the recovery process of others. However, the expert also revealed a major other problem that is less explicitly addressed by the 'Is this normal?' idea. Patients don't know what their body is capable of at what point in time during recovery. The 'Is this normal?' idea does not explicitly provide users with information about this. Nonetheless, showing what hindrances people experience at what point in time could indicate what these people are thus not able to do yet, regarding physical activities.

The provided variables that influence a recovery process could be important to incorporate in the tool, to group together patients that could have a similar recovery process. Lastly, the expert seems to confirm the concept test's insight that showing personal experiences in a clear way is a promising direction for the tool.

9. Cycle 2 design decisions

This chapter summarizes cycle 2, i.e. Chapters 7 and 8, in terms of the design decisions that have been made in this cycle based on information that was obtained in the various exploration and validation activities that were described in these chapters. This cycle focused on how the data will be obtained and how this data should be presented to users to reassure their worries.

The concept test, see Section 8.1, was done with only two patients. Insights that were derived from them and from the revalidation expert interview, see Section 8.2, suggested the design decisions that will be described here, but they couldn't fully be confirmed yet because of this low number of participants. Cycle 3 validation activities were used to validate these decisions more thoroughly.

Does the user submit his own data?

The results from the concept test and the revalidation expert interview suggest that people appreciate personal experiences. One patient said that seeing someone that experienced the same would reassure him. Before you can show personal experiences, they have to be collected. It was therefore decided that patients submit their own data in the app. Moreover, the heart specialist, see Section 5.2, indicated that currently there simply is no data available on what hindrances patients face at what point during recovery. So, to use this data, it will first need to be obtained. This could be done by letting users submit data as part of the tool. Lastly, data on patients' recovery process could be insightful for the doctor to prepare the consultation. Currently, questionnaires are often not sufficiently filled in [1]. The tool makes people submit data more regularly. First people submit their data, then the app shows them the 'normal'. The reason for this is that the user might not fill in anything at all, if he has access to the data he wants before filling in his own data.

It is logical to first show the number of people that have *the same hindrance* as the user. He is probably interested in this. The exploration of other hindrances is allowed afterwards. This is a good middle way solution between making sure users submit data, and allowing them to explore other data. The app asks the user to submit data at most on a daily basis. If he logs in multiple times per day, he would not need to give his hindrances each time.

Will you use live data or a fixed data set?

Patients indicated that they appreciated personal experiences from people that are recovering at the same moment as they are. The app displays these experiences, but it also displays experiences from people who recovered at an earlier moment. This is done to guarantee a sufficiently large dataset that represents a 'normal' recovery trajectory. All entries from the past year are incorporated. Entries that are older than one year from people that don't use the app anymore will be removed. Otherwise the dataset will never stop growing, and people's data will be stored for an unnecessarily long time. Moreover, the 'normal' recovery may change over time. Old entries could therefore lead to an inaccurate representation of the normal. Messages contain a date on which they were submitted, to maintain data transparency. The used prototypes in Chapters 11 and 12 don't show these dates yet because this decision was made later on.

Is the information that you want to represent being categorized in subsets by a computer or by the user itself?

The use of algorithms to categorize the hindrances of users seems unnecessary. The app provides an overview of all possible hindrance categories and people can choose the right category for what they experience. In the concept test, the participants expressed that it was convenient to select a hindrance from a list.

Is the visualisation’s interpretation ambiguous or one-sided?

In ambiguous visualisations, notions such as happiness are not linked to pre-defined elements. For example green is not necessarily better than red. Users can decide for themselves how to interpret, or what to express with, these elements. For one-sided visualisations, the opposite is the case. Following conventions, red is bad, happiness is a smiley face.

The post-operative patients that were interviewed and the patients that participated in the concept test all had a different recovery process. The revalidation expert stressed that each person’s recovery process is personal and different. Therefore, even for a certain age group or medical profile, it is hard to define an absolute ‘normal’ recovery and it is thus impossible to judge for patients whether they are normal or not. The tool provides patients insights in the recovery process of others, but patients themselves should judge whether they trust a certain situation or not. For example, even though 90% of the patients suffer pain in week 1, a patient could still be worried about his pain, think that it is not normal, and contact the doctor. In other words, the tool does not make a value judgement whether a situation is normal or not, it only provides more information to patients for them to make a better estimation.

How does your visualisation evoke a specific feeling or message?

The tool should evoke a feeling of reassurance when an issue appears to be experienced by many. During the concept test it was found that showing other patients’ experiences creates a feeling of solidarity, which would reassure people. At the same time, during the concept test, patients indicated to appreciate clear and simple information such as percentages. Thus, a middle way solution is promising in which experiences are represented in a clear way that evokes a feeling of solidarity. The group of avatar images from concept 3 was reported to be visually too messy. A representation with simpler shapes, such as concept 2’s smileys or concept 1’s bar graph was preferred, see Chapter 8. However, such a visualisation should represent experiences, instead of a dataset that only consists of numbers. Sections 10.1 and 12.1 describe in more detail how the visualisation is designed to evoke a feeling of solidarity among patients with the use of animations, colours, the relative arrangement of the data elements, and a metaphor.

On what data level does the user identify himself with others?

During the concept test, patients preferred the simplicity and the clarity of concepts 1 and 2. What contributed to this simplicity and clarity was the fact that few variables were involved in the tool. Only the patient’s age and week after hospital release were used and patients didn’t need to submit any more details or make choices. Both participants of the concept test highlighted the speed with which their questions got answered in this way. Additionally, this way the tool can show absolute numbers of a larger group of people that share somewhat the same experience. If people are matched based on more information such as medical profile, naturally there will be less similar cases even though issues are normal, which may reassure less. In other words, if people are matched ‘behind the scenes’ (so people get automatically matched to a few very similar cases) it seems as if few people share the same issues when represented in absolute numbers. If people have much choice about variables, they have to put in more effort. Thus, showing absolute numbers of many roughly similar patients (who only share age and week after hospital release) has advantages over matching patients closely in this case.

In short, the results from the concept test and the revalidation expert interview suggest that patients’ worries can be reassured by providing solidarity among patients. This solidarity is achieved when patients share experiences, and when the tool represents these experiences in a clear way. Avatars are visually too messy. Simple shapes are preferred, but they should represent experiences instead of an impersonal data set. This clarity and solidarity are also achieved by matching patients only globally, such that large numbers of patients share somewhat the same hindrances, and such that the tool remains simple without many variables and choices. A preference for simple and symmetrical shapes is in line with Reber et al.’s [37] findings that such shapes increase processing fluency and perceived aesthetics, as explained in section 3.3. Additionally, it is in line with Lang’s argument that visualisations should bring forward the most important relations in the data and minimize distracting details [34], see section 3.3.

Cycle 3

Design questions

In cycle 2 it was found that patients show solidarity with other patients when reading similar experiences from them. This takes away worries. These experiences should be visualized in a clear way that is easy to understand. Cycle 3 focuses on the design of this visualisation, and the design of the app in which this visualisation is embedded. In this process, several questions are addressed. For example, could this clarity and solidarity be achieved by using a metaphor? Does the user want to see his own data in the visualisation? Does the interaction start with an overview of all data, or is more specific information shown at first? How does the user interact with the data? Are the visualisation's elements themselves interactive, or are there buttons outside the visualisation?

Exploration activities

Chapter 10 describes the design process of the information visualisation. Two approaches were considered. The first focused on visualising categories of hindrances. The second focused on visualising the content of messages that people wrote. During the design process of the visualisations, a UX expert was consulted several times. A decision matrix was used to choose one of the two visualisations.

Validation activities

Chapter 11 describes the design process of, and the usability test with, an interactive prototype of the app that incorporated the visualisation as designed in chapter 10. All different functionalities of the app are explained in this chapter. The goal of the usability test was to validate design decisions of the visualisation and the app, by e.g. testing whether participants understand the app's navigation, and the visualisation's meaning. A UI expert was consulted several times. Her ideas and feedback were taken into account while designing.

Chapter 12 describes the design process of, and the test with, an interactive prototype of the app's main functionality as envisioned in the final product. This main functionality consists of sharing your hindrances and seeing how many other patients experience something similar. Feedback from the usability test was incorporated and animations were worked out. The goal of the test was to obtain insights on whether this functionality and visualisation indeed evoked reassurance.

Chapter 13 briefly summarizes cycle 3 in terms of the design decisions that have been made in this cycle based on information that was obtained in the various activities.

10. Data navigation and visualisations

In cycle 2 it was found that people find reassurance in sharing experiences with each other and in seeing clear information such as percentages. Therefore it was decided to continue with data consisting of hindrance categories and short messages in which people can describe their experience. The number of people that have a hindrance could be shown, to provide clear information. At the same time, short messages would allow to share personal experiences. The data is visualised schematically in Figure 24. First users select the hindrances that they experience. For example, the total list could consist of 12 different hindrances, and among these, the users could select three of them. Then, users write a message in which they describe what they experience. This way, data is obtained that consists of a text message that is labelled as one or more hindrances.

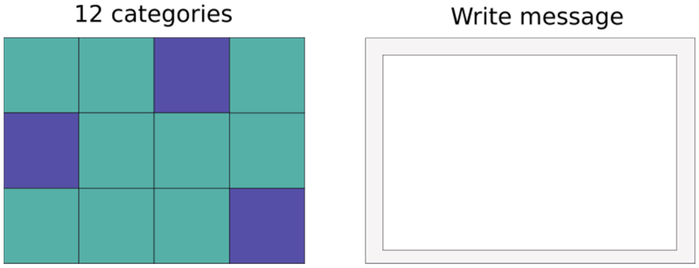


Figure 24 Schematic representation of the data

Different visualisations were explored to find out how to communicate this data in a clear way that evokes a feeling of solidarity. Two approaches were considered. The first focused on data navigation and visualisation based on the hindrance categories. Showing all people that experience the same hindrance as the user could create reassurance. This approach could lead to simple overviews and the development over time of the number of messages from people in each hindrance category. The second approach focused on data navigation and visualisation based on the content of messages that people wrote. By visualising the words that people used, the visualisation could be a more nuanced overview that shows how a hindrance is experienced by the patients. These two approaches refer to the question whether to visualise the actual data, being the user’s text messages, or metadata, being the hindrance categories to which these messages belong.

During the design process of the visualisations, a UX expert was consulted several times. He explained advantages and disadvantages of design options and he gave feedback on design decisions that had been made. His input will be mentioned throughout the chapter.

10.1 Hindrance category visualisation

While designing a visualisation that focuses on the hindrance categories, several questions came up. The design process will be described here in terms of these questions and their choices. Muiser et al. [40] also visualised metadata (such as categories to which texts belong). By visualising metadata of tens of thousands of Dutch folktales, they aimed to make this large dataset more accessible to casual users, and they aimed to facilitate trend analyses and comparisons by expert users. Although they have much more metadata, they designed inspiring visualisations.

The level of overview

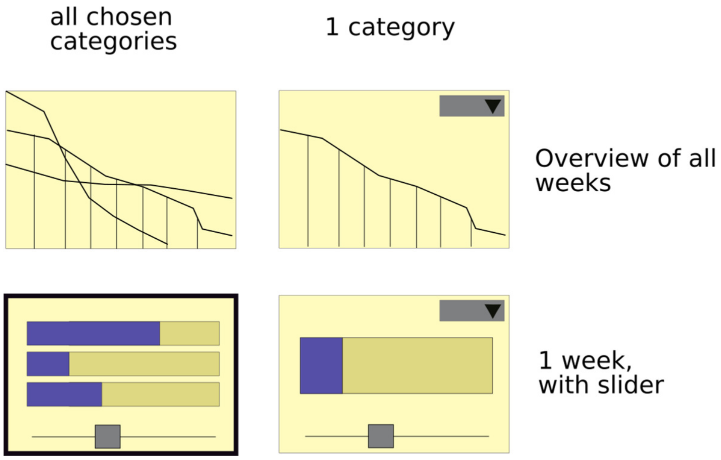


Figure 25 Different levels of overview of the data that could be visualised

After submitting their hindrances, users should see how many others experience these same hindrances. In other words, the data visualisation should be presented. The data can be shown at different levels of overview. A schematic representation of the options can be seen in Figure 25. Given that the user has selected more than one hindrance, e.g. three, the number of other people that experience these hindrances over the weeks could be shown all together, see Figure 25 top left. All three hindrances in all weeks are visible at once. This way, users would have an overview of the data and they would be able to select specific weeks and/or hindrances from here. However, showing much data can become messy, especially if users choose even more than three hindrances. Presenting less data would be clearer.

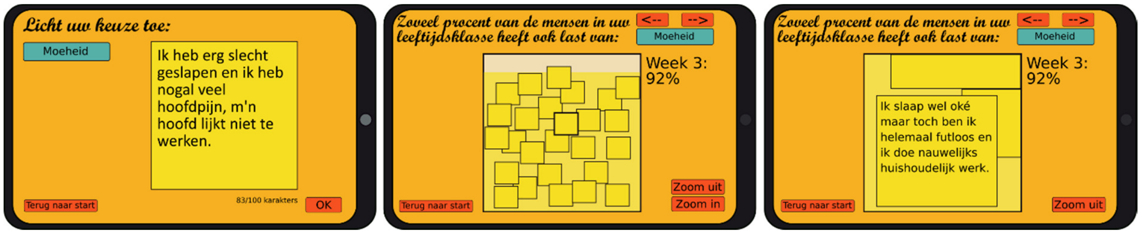
Only one category and its development over the weeks could be shown at a time, see Figure 25 top right. Other hindrances can be chosen with a drop-down menu. Another option would be to show all chosen hindrances, but only for one week at a time. Other weeks can be accessed with a slider, see Figure 25 bottom left. These options are more concentrated on a subset of the data. Arguably, this visualisation is clearer readable than when everything is visible (top left), but it provides less overview of the whole dataset. It may be harder for users to discover trends, or compare different hindrances. Lastly, Figure 25 bottom right shows one hindrance in one week. This provides no overview, but it gives a very clear representation of this one hindrance in one week.

One visualisation was not estimated to be objectively better or worse than the other. *What data to show, depends on what the tool should communicate, what the user wants to know.* Patients want clarity and solidarity. They want to know how many others experience the same hindrance as they do, preferably at that moment in time, as explained in Section 8.1 and in Chapter 9. It was therefore decided to continue with a visualisation of all chosen hindrances in one week, i.e. the week after release in which the patient currently is, with a slider to go to other weeks. This is Figure 25 bottom left. This way, users see all people that share a hindrance with them at that moment.

Overview – details structure

In [41], Benyon explains that data visualisations are generally built up following an ‘overview-details’ data structure. The visualisation first shows an overview of the data. In this overview, users can select subsets of the data and, in doing so, see more detailed data of this subset. For example, first a visualisation shows a world map with all countries and their capitals. When users select one country, the visualisation zooms in on this country and does not only show the capital, but all major cities and the number of habitants per city.

In the tool, the hindrances and the text messages could also be organised following this structure. Navigation is based on the hindrances. People select hindrances and the week that is relevant to them. Once there, other users' experiences should be accessible to read. A possibly intuitive way to realise this, is to make each text message a data point. When zoomed out, all messages together represent the total number of people having that hindrance in a week. When zooming in, the messages become readable. See Figure 26 from left to right, first the user writes a message for a selected hindrance on a post-it note. Then he sees the number of other people that also experience that hindrance. This quantity is visualised as a cluster of all post-it notes together. If the user wants more details, i.e. read the messages, he can zoom in on the cluster and the text becomes clear. This would be similar to zooming in on Google Maps. The more a user zooms in, the more details of the map become visible.



Licht uw keuze toe:

Ik heb erg slecht geslapen en ik heb nogal veel hoofdpijn, m'n hoofd lijkt niet te werken.

Zoveel procent van de mensen in uw leeftijdsklasse heeft ook last van:

Week 3: 92%

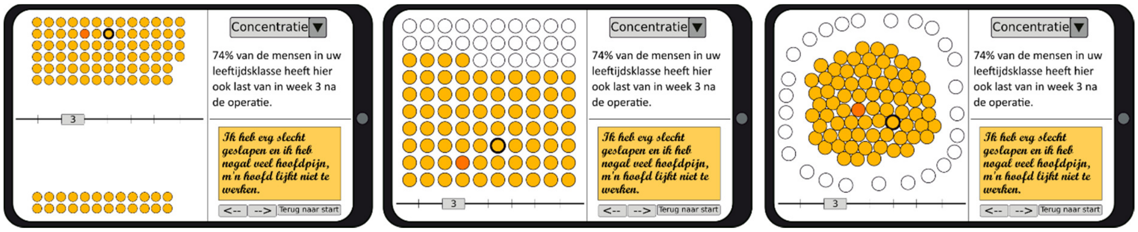
Zoveel procent van de mensen in uw leeftijdsklasse heeft ook last van:

Week 3: 92%

Ik slaap wel oké maar toch ben ik helemaal futloos en ik doe nauwelijks huishoudelijk werk.

Figure 26 Overview-details structure exploration

<u>Clarity and solidarity</u>



74% van de mensen in uw leeftijdsklasse heeft hier ook last van in week 3 na de operatie.

Ik heb erg slecht geslapen en ik heb nogal veel hoofdpijn, m'n hoofd lijkt niet te werken.

74% van de mensen in uw leeftijdsklasse heeft hier ook last van in week 3 na de operatie.

Ik heb erg slecht geslapen en ik heb nogal veel hoofdpijn, m'n hoofd lijkt niet te werken.

74% van de mensen in uw leeftijdsklasse heeft hier ook last van in week 3 na de operatie.

Ik heb erg slecht geslapen en ik heb nogal veel hoofdpijn, m'n hoofd lijkt niet te werken.

Figure 27 Visualisations with different levels of clarity and solidarity

Designs were made to explore different levels of clarity and solidarity that the visualisation emits, see Figure 27. In all cases, simple shapes were used because using these received positive reactions in the concept test, see Section 8.1. Moreover, literature shows that simple and symmetrical shapes are easy to process and aesthetically pleasing, especially when there is high contrast with the background, see Section 3.3 [37]. The left and middle designs were intended to be clear, while the right design was intended to make patients show more solidarity with other patients. Clarity in this case would be the extent to which the number of people that have a hindrance is readable from the visualisation. Arguably, the fact that *74%* of all patients experience concentration problems in week 3 after release is better readable in the left and middle designs, than in the right one. Each ball represents one percentage, and the balls are visualised in a structured way. Therefore, they can more easily be counted than in the cluster of the right design, which is messier. However, the right design possibly emits more solidarity. The simple shapes are visualised more metaphorically, i.e. as a group of people that stand together. As explained earlier in Section 4.2, grouping similar elements together would stress the fact that the individual elements have something in common, according to Gestalt principles. The visualisation takes on more the role of an image, representing a group of people. The exact quantity, 74%, is hard to read in this image. However, this number is displayed next to the visualisation and it should therefore still be clear to users. Note that percentages were replaced by absolute numbers in later versions of the design, which will be explained later in this Section.

In short, a clear visualisation would focus on communicating an exact quantity. An image-like visualisation would use a metaphor to evoke a feeling of solidarity. The exact quantity is communicated via a number.

The right, most image-like, design was chosen. This design possibly best communicated a feeling of not being alone, dealing with a difficult situation. This feeling was found to be important, as a result from the concept test and the revalidation expert interview. Only showing the percentage could already be enough to clearly communicate the quantity. In other words, while still being clear, this design could emit the most solidarity. The UX expert also preferred this visualisation.

The number of variables

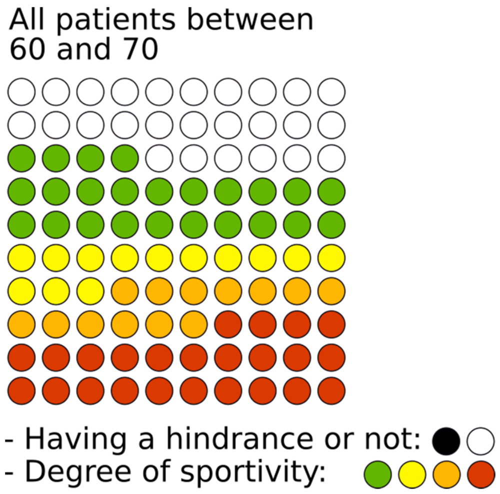


Figure 28 Visualisation of multiple variables

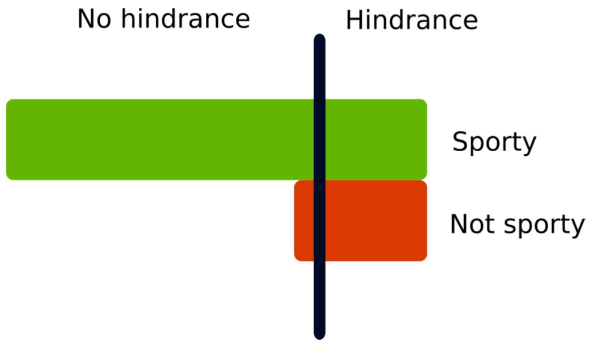
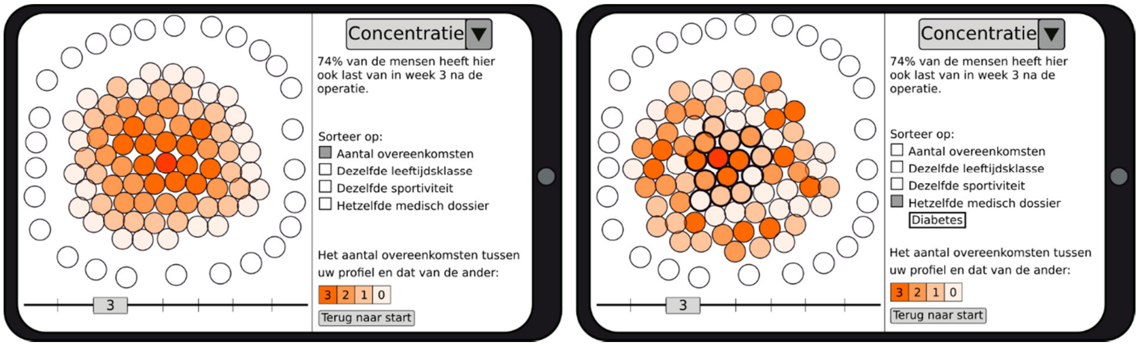


Figure 29 Visualisation of the actual data of Figure 28

Several designs were made to explore the possibilities of showing more information. For example, Figure 28 shows not only whether patients in a certain age group have a hindrance or not, it also shows the degree of athleticism of these patients (given that this information was provided). The red balls represent the percentage of these people that are not athletic. The green balls represent the percentage that is athletic. Yellow and orange represent intermediate levels of athleticism. However, it was found that providing more information can easily become misleading. Figure 28 shows that an equal number of people who do sports (green) and people who don't do sports (red) have this hindrance. It therefore suggests that doing sports or not has no influence on this hindrance. However this is not necessarily true. From all people that don't do sports, possibly most of them suffer from this hindrance. From all people that do sports, only a small part could suffer from this hindrance. Therefore doing sports does have an impact, even though the two groups having the hindrance make an equal part within all people having the hindrance. This is clarified in Figure 29.



74% van de mensen heeft hier ook last van in week 3 na de operatie.

Sorteer op:
☒ Aantal overeenkomsten
☐ Dezelfde leeftijdsklasse
☐ Dezelfde sportiviteit
☐ Hetzelfde medisch dossier

Het aantal overeenkomsten tussen uw profiel en dat van de ander:

74% van de mensen heeft hier ook last van in week 3 na de operatie.

Sorteer op:
☐ Aantal overeenkomsten
☐ Dezelfde leeftijdsklasse
☐ Dezelfde sportiviteit
☒ Hetzelfde medisch dossier
Diabetes

Het aantal overeenkomsten tussen uw profiel en dat van de ander:

Figure 30 Another visualisation with multiple variables

Another example of showing more information can be seen in Figure 30. Among the patients that share a hindrance, the visualisation shows how many characteristics these patients share with the user. Characteristics would be based on the list that was provided by the revalidation expert, see section 8.2. The higher the opacity, the more characteristics people have in common. Those with the most characteristics in common, could be put closest to the user, being represented by the central ball, see Figure 30 left. Given this information, it would also be possible to show patients that have a specific characteristic in common, such as having diabetes or not. The balls representing these people could be indicated with a thicker border and moved towards the centre, see Figure 30 right.

Although this information can be insightful, it also adds complexity, according to the UX expert. As with the first example, the visualisation consists of more different colours and thus could easily look messier. Moreover, users have more choices to make, and they will also have to submit more information initially. Literature points out that effective visualisations highlight the most important relations while leaving out other details [34], see Section 3.3. At the same time, an information overload could lead to user disengagement [20], see Section 3.1. Besides this, providing more information may reduce the feeling of solidarity that the user gets. For example, when dividing all patients based on their athleticism, a user might only identify himself with those that do sports as much as he does, instead of with everyone. By showing more different shapes, the Gestalt principle of similarity (section 3.3) suggests more different groups of people, instead of one big cluster of people that have something in common. The focus of the visualisation might switch from *identifying with others* to *comparing to others* who also have the hindrance but e.g. do less sports. This deviates from this tool's goal to evoke solidarity with a clear visualisation.

Because of risk on misinterpretations, increased complexity and reduced solidarity, it was chosen to use a minimal number of key variables that highly influence patients' recovery, i.e. patients' age and how long they have been released from the hospital. However, a search function was added to look for specific words that people used in their messages. This way, users would still be able to look in a little more detail for people with specific experiences.

Percentages or absolute numbers

The number of people who have a hindrance could be visualised as a percentage of the total number of patients, or as an absolute number. For example, when 75 of 150 patients in a certain age group that use(d) the app experience(d) pain in week 3, this could be represented as 50%, thus 50 of the 100 balls, or it could be represented as 75 balls. The advantage of using percentages is that large quantities can easily be visualised. Even if 750 of 1500 patients experience a hindrance, it could still be expressed as 50 of the 100 balls. However, balls visualising percentages can be confusing in combination with the messages that these balls also represent. As was explained earlier, to gain an overview-details data structure, the number of people that have a hindrance is expressed as a cluster of simple shapes. When zooming in, each simple shape contains one message. It would therefore be most logical to show the absolute number of people/messages, where each ball represents one entry.

The UX expert explained that combining percentages with absolute numbers in the visualisation would lead to confusion. For example, there could be an absolute number of 10 out of 20 patients that have a hindrance, thus there would be 10 messages in total. If this quantity is represented as 50 out of a 100 balls and each ball should lead to one message, 40 from the 50 balls would not have a message to show when zooming in. At the same time, having e.g. 75 out of 150 patients that have a hindrance that are represented as 50 out of a 100 balls, 25 of the 75 messages could not be displayed. Another problem arises when the absolute quantity is visualised, accompanied by a percentage. Showing 2 out of 3 people that have a hindrance would give 67%. Showing 50 out of 75 people would also correspond to 67%. In other words, the same percentage is shown, but the quantities are different. This is confusing.

Therefore, it was decided to abandon percentages and to work with absolute numbers to maintain clarity. The problem of dealing with large quantities of data will be discussed in Section 10.2.

Color blindness

The UX expert stressed that people with color blindness should be taken into account when choosing colours for the visualisation. According to the national eye institute, red-green color blindness is the most common form. Within this form, there are different types and degrees. Deuteranomaly is the most common type. It makes green look redder. Protanomaly is also common. It makes red look greener and less bright [42]. A color blindness simulator was used to verify what colours would also be clear for people with these common types of color blindness [43]. Figure 31 shows the visualisation with the colours that were chosen in the end. The left Figure is the ‘normal’ visualisation. The middle Figure is how a person with deuteranomaly would see it. The right Figure is how a person with protanomaly would see it. Blue and orange were chosen, because these two colours can be distinguished in all cases. The difference between normal orange and darker orange becomes less clear for color blinded people, but this was compensated with thick borders on the dark orange balls.

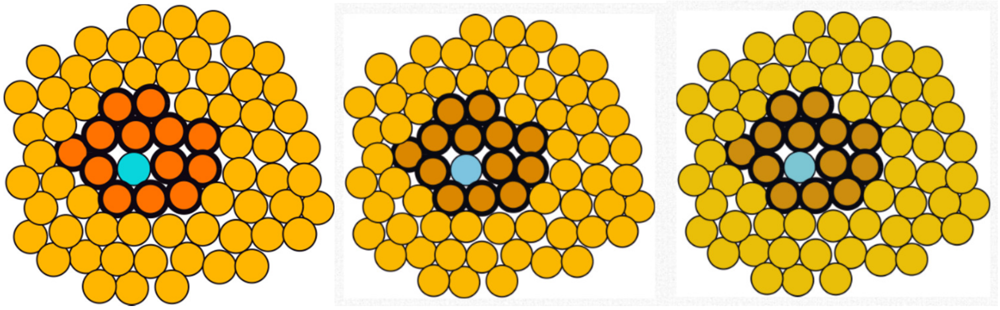


Figure 31 The visualisation, as seen normally (left), with deuteranomaly (middle) and with protanomaly (right)

Showing patients’ own data in the visualisation

It was decided to show the user’s own data in the visualisation as a blue dot among orange dots, see Figure 32. To make sure users feel part of the group even though their ball has a different colour, the blue ball was put in the middle of the cluster, following the Gestalt principle of proximity. Logically, when users submit data, they become part of the dataset, and they should therefore be included in the visualisation of this dataset. Besides this, users can explicitly see themselves among all others that have the same issues. This could enforce the feeling of solidarity that the user gets from seeing the visualisation. Lastly, showing users' input is a form of feedback to them that their input has been received by the system.

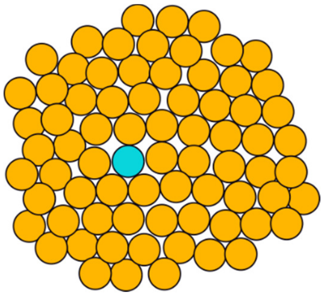


Figure 32 The user as blue ball among other users as orange balls

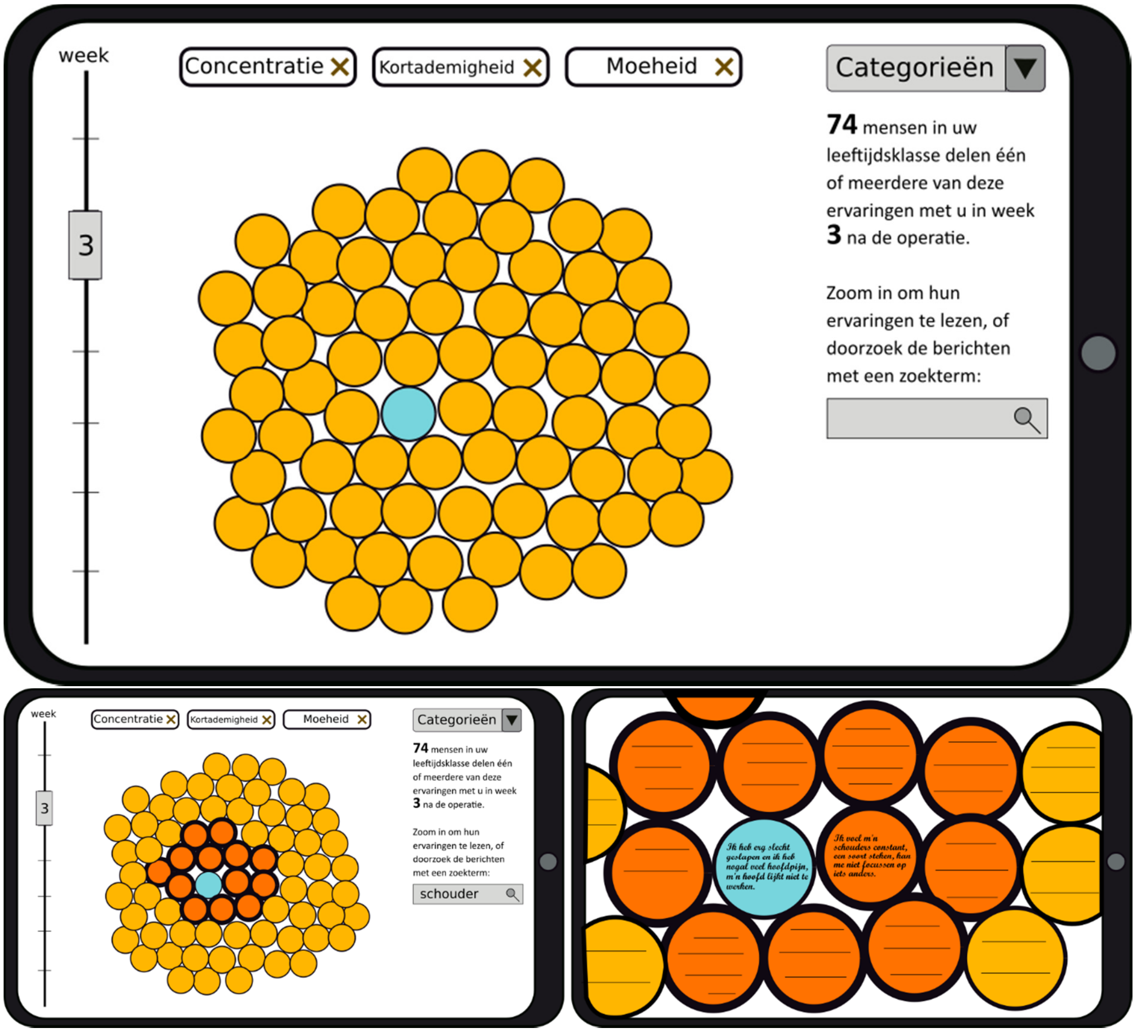
Text input

The participants from the concept test and the revalidation expert appreciated text messages of other patients. Messages are personal, they make users feel connected to actual people. Besides this, they allow users to express their experience with a little more nuance, compared to only selecting a hindrance category. These advantages could weigh up against the additional effort it takes to write a message, compared to simply selecting a hindrance. It was decided to limit the text messages' size to a hundred characters. This would reduce the length of stories that users write and the risk that users spread information that is not true. Lengthy stories are not necessarily bad, but in these, users could express their experience in much detail. This would stress the fact that every experience is different, which reduces solidarity. By guarding a more general level of information in short messages, people might identify with more others. Besides this, people might quickly get tired of reading long stories. Moreover, if the app creates the expectation that users should write long stories, people might stop using the app because they don't want to put in this effort.

Ik heb erg slecht geslapen en ik heb nogal veel hoofdpijn, m'n hoofd lijkt niet te werken.

Figure 33 The user's text input

The design: hindrance categories



74 mensen in uw leeftijdsklasse delen één of meerdere van deze ervaringen met u in week **3** na de operatie.

Zoom in om hun ervaringen te lezen, of doorzoek de berichten met een zoekterm:

Ik heb erg slecht geslapen en ik heb nogal veel hoofdpijn, m'n hoofd lijkt niet te werken.

Ik voel m'n schouders constant, een soort steken, kan me niet focussen op iets anders.

Figure 34 Intermediate version of the hindrance category visualisation and app

With the above design decisions made, the visualisation based on the hindrance categories looked as can be seen in Figure 34. This design formed the basis for further iterations and improvements, see Sections 11.1 and 12.1. After having submitted hindrances and a text message, users see the visualisation. This is a cluster of balls that represent the user and all other people within the same age group that have the same hindrances as the user in that week after hospital release. This visualisation is meant to evoke a feeling of solidarity among the patients. The exact number of balls, thus of people, is shown on the right, together with a short explanation of what the visualisation shows. To read the experiences, users can zoom in on the balls to reveal the text messages. Users can explore other hindrance categories by selecting these in the drop-down menu in the top right. Users can explore other weeks by using the slider on the left. Users can search through the messages for specific key-words with the search bar on the right. All messages that contain the key-word, e.g. 'shoulder', turn dark orange, get a thick border, and are placed around the user's blue dot. This way a subgroup is formed within the total cluster, based on the Gestalt principles of proximity and similarity (section 3.3). The possible hindrance categories that users can choose from are based on the list of possible hindrances that was collected during post-operative patient interviews, see Section 5.3.

10.2 Message visualisation

As said, the data consisted of short text messages that are labelled as one or more hindrances. The visualisation that was described in section 10.1 focused on visualising these hindrances. Another approach would be to visualise the text messages themselves. This visualisation could be a more nuanced overview that shows how a hindrance is experienced by the patients. This could be reassuring. Trends, key-words and subtleties could easily be revealed in this way. Several design questions were found while designing this visualisation. The design process will be described in terms of these questions.

Visualising relations in the data

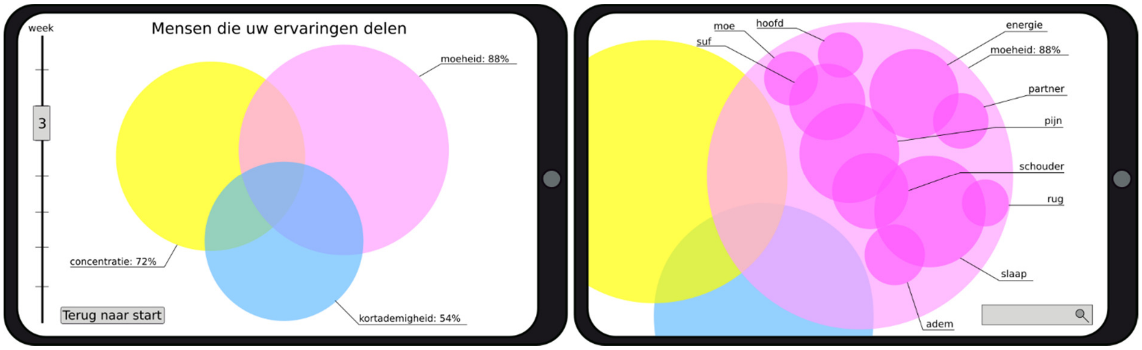


Figure 35 Visualisation of used words in messages per category

Several designs were made to explore how to show relations among the text messages, and to explore how users could navigate to messages based on this. One design is shown in Figure 35. Each of the selected hindrances, three in this case, is represented by a ball. The size of the ball indicates how many people experience the hindrance. The overlapping region of two balls represent messages that were labelled as both these hindrances. When zooming in on a ball, smaller balls would appear that each represent a word. The larger this ball, the more messages from that hindrance contain that word. When two or more of these balls overlap, it means that messages contain all these words. When zooming in even more, the messages could become readable. Messages are visually grouped together according to the Gestalt principle of common region, see Section 3.3. Groups of messages that share e.g. a word, are placed in the same ball. This way, users would be able to search the messages based on (combinations of) words that they are interested in. Visualising relations among messages in this way was discouraged by the UX expert, because in practice many combinations of words could be used in the messages, and therefore most balls will overlap. This would result in a messy visualisation that is hard to navigate. Showing only the most common relations would be clearer, but not transparent because it would hide less common but possibly interesting relations.

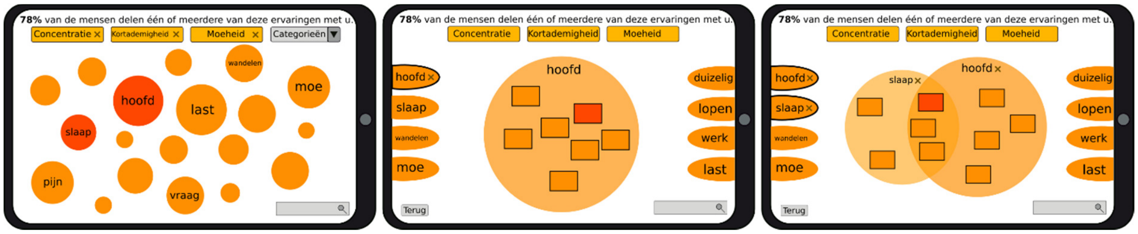


Figure 36 Another visualisation of used words in messages per category

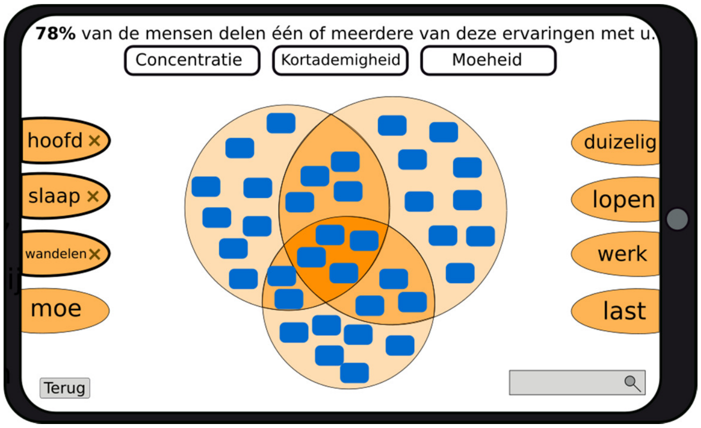
Figure 36 shows a design in which less relations are visualised. The left visualisation shows which words were used the most in text messages of a certain selection of hindrances. Note that it does not show which words were used together in a message, in contrast to the previous design. When users click on a ball, the visualisation zooms in and all messages that contained that word show up, see the middle visualisation. Tabs on the sides allow users to select another word. This shows messages with either one or both words, see the right visualisation. It gives less overview of *all* relations among the words, but it should focus on the ones that are most relevant to the user. In case specific words are not shown at first, because they are not often used in messages, users could use the search bar.

In other words, there can be many relations among elements in a data set. By focusing on what information users most likely want to know, the visualisation can be kept simple by leaving out other relations. In this case, patients might be more interested in reading messages, than in seeing the relations between these messages. Therefore, messages should be accessible in the first place, and relations can be explored based on these messages.

Nonetheless, visualising text introduces natural language processing challenges. For example, users could use a slightly different word for the same notion. Such differences should be grouped in the same visual element of the visualisation. Otherwise, relevant messages will not be shown to users.

<u>Large quantities of data</u>

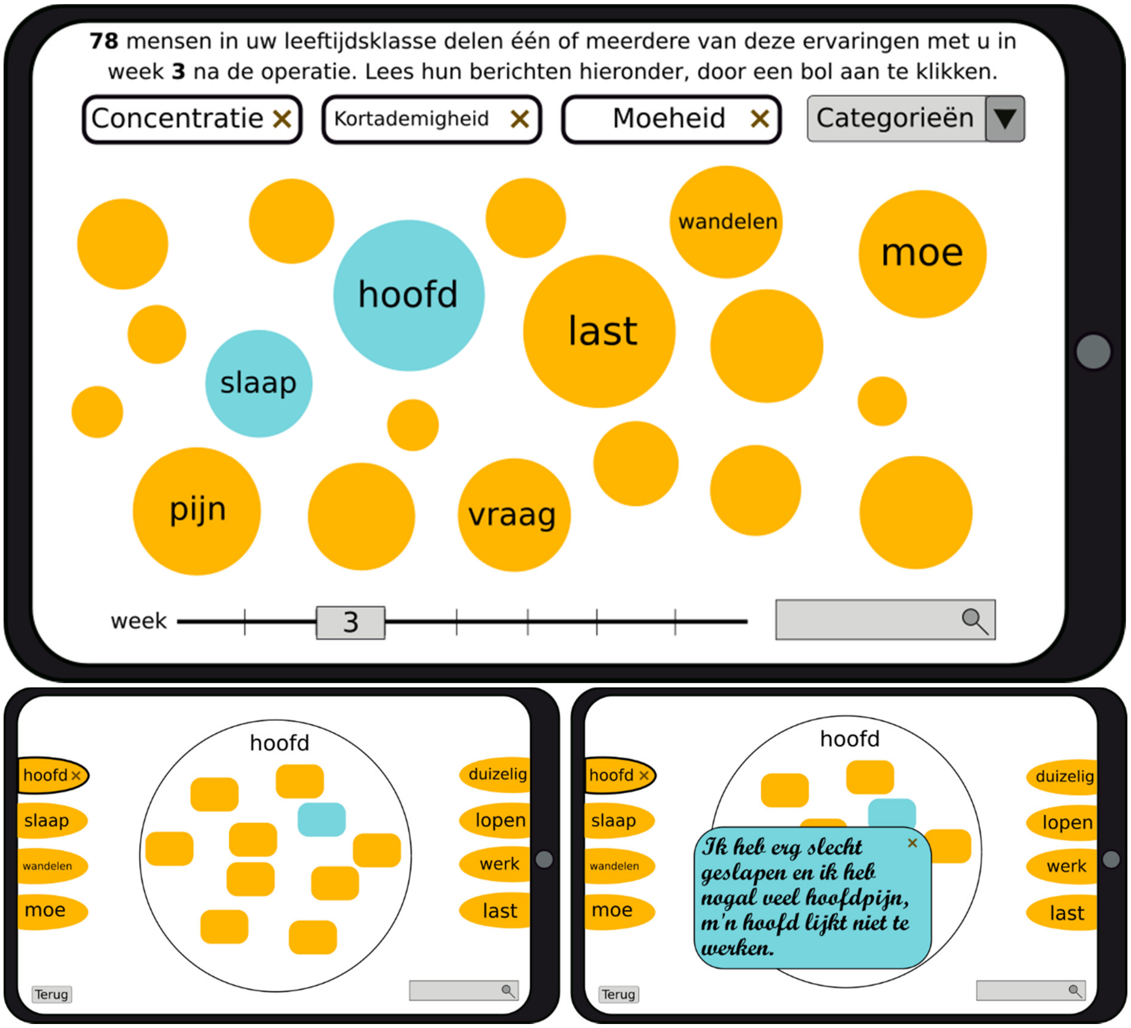
As was mentioned in section 10.1, large quantities of data can pose problems for visualisations when they are visualised in absolute numbers. E.g. how to visualise a hundred, or even more, messages in a clear way? Figure 37 shows that this problem occurs quickly. Relatively few messages already fill up the circles. Several solutions were considered, proposed by the UX expert. One option would be to cluster messages together when zoomed out. Zooming in would reveal all individual messages. Another option would be to only show a subset of the messages, with an option to display others that are not visible at first. In both cases, the absolute quantity could be displayed as a number. This way the quantity is always clear, even when the quantity is hard to read from the visualisation.



78% van de mensen delen één of meerdere van deze ervaringen met u.

Figure 37 Exploration of what to do with larger quantities of messages

The design: messages


78 mensen in uw leeftijdsklasse delen één of meerdere van deze ervaringen met u in week **3** na de operatie. Lees hun berichten hieronder, door een bol aan te klikken.

Ik heb erg slecht geslapen en ik heb nogal veel hoofdpijn, m'n hoofd lijkt niet te werken.

Figure 38 Messages visualisation and app

Taking the above design decisions into account, the visualisation that focuses on the messages' content looked as can be seen in Figure 38. The functionalities, i.e. selecting hindrances with a drop-down menu, sliding to other weeks, a search bar, and a short explanation of the visualisation, are the same as for the visualisation of categories that was shown at the end of Section 10.1, see Figure 34. Also the same colours were used, because these would be clear for color blind people. The main difference is that the visualisation and navigation is based on the words that people have used in their text messages. In the upper Figure, the size of the balls indicates how many messages contain the word that the ball represents. Users can click on a word/ball to see all messages that contain that word. With the tabs, users can switch to other words. The UX expert's advice was followed to use round shapes when possible, to get a calmer design.

10.3 Decision matrix

To decide between the category visualisation and the message visualisation, see the end of Sections 10.1 and 10.2, a decision matrix was used, see table 2 visualisation 1 and 2 respectively. Selecting criteria and giving these weights and scores was done together with the UX expert. The chosen criteria were listed and they were given a subjective weight. The first two criteria relate to the goal of the visualisation, i.e. being clear and evoking a feeling of solidarity. They were given a high weight. The other criteria were related to usability, and were given a medium weight, to make a difference with the first two criteria. Each of the two visualisations were given a subjective 1 to 5 score for each criterion. The total score for each visualisation was calculated by multiplying the score with the weight for each criterion, and adding this up.

As can be seen in table 2, visualisation 1 received the highest total score. Especially on the most important criteria it scored higher than visualisation 2. The cluster of balls was estimated to emit more solidarity than the word cloud. It focuses on connection among the people, instead of on connection among the words. Visualisation 1 scored higher on clarity and showing all relevant messages. This visualisation shows all messages, one message being one ball. There is a low risk of missing out on messages. Visualisation 2 shows all messages less explicitly. Moreover, some messages could go unnoticed in the visualisation if users use uncommon words, given that the most frequently used words are shown primarily. Clarity, accuracy and effectiveness of information transmission were reported to be a key aspect of successful visualisations by several researchers [33][34][35], see Section 3.3. Visualisation 2 was estimated to be calmer and more easily scalable. Visualisation 1's large cluster of balls could appear visually messy. Additionally it scales worse. Large quantities of balls would no longer fit on the screen, and they should e.g. be grouped together or made very small, which reduces overview of the total quantity. Visualisation 2's balls are scaled relative to each other, which handles large quantities better.

Based on this matrix, it was decided to continue with visualisation 1, the category visualisation.

Criterion	**Weight**	**Vis. 1 score**	**Vis. 2 score**
1. Feeling of solidarity	5	5 (25)	3 (15)
2. Clear navigation / visualisation	4	4 (16)	3 (12)
3. All relevant messages are shown	3	5 (15)	4 (12)
4. Overview as well as accessibility to details	3	4 (12)	4 (12)
5. Pleasant and calm app / visualisation	3	3 (9)	4 (12)
6. Intuitive / needs least explanation	3	4 (12)	3 (9)
7. Scalability	2	3 (6)	4 (8)
Total		95	80

Table 2 Decision matrix

11. The usability test

A qualitative moderated usability test was performed with an interactive prototype of the tool that incorporated the visualisation as described at the end of Section 10.1, see Figure 34. The goal of the test was to gain usability related insights on the tool, such as if people are able to accomplish basic tasks the first time they use the app, if the interface and app navigation are intuitive and what actions users do differently than intended. Besides this, several questions were asked to each participant after the test. The goal of these questions was to learn if the participants understood the visualisation, what effect it had on them and what functionalities they preferred.

The usability test was performed with eight colleagues from Game Solutions Lab who had not been involved in the design of the prototype app, described in Section 11.1. According to Nielsen and Norman, testing with about five people is enough to reveal the most important points for improvement in the design [44]. The participants had a varying age and expertise, such as design, management and video & audio. Ideally, post-operative patients would have been recruited for the test, but this was discouraged due to covid-19 measures at that time. For this test, using other participants than the target group was acceptable, because whether the tool and its UI are understandable or not in this early stage can be estimated based on a non-patient's behaviour as well.

11.1 The prototype

An interactive prototype of a landscape tablet app (see Section 7.2) was made of the visualisation and the tool with all its envisioned functionalities. Images of the app were designed in Inkscape. These images were linked to each other in Invision. In other words, Invision made sure that buttons that were drawn in the image, would indeed lead to another image when users clicked on them. This way, a working prototype was mimicked and the app could be evaluated in a way that resembled more the envisioned product, compared to only showing images. All different functionalities of the prototype app will be explained in this section.

Similarly as with the design of the visualisations, a UI expert was consulted several times. Her ideas and feedback were taken into account while designing, and this will be described as well throughout the section. In general, the UI expert's advice was followed to make an app that has a consistent design. First of all, the same font and a limited number of font sizes was used. Besides this, all components, such as the buttons or pieces of text, were placed with consistent margins from each other and from the screen's border. Also all corners, of e.g. buttons, were made slightly round. This is more calm and pleasant. Conventional icons were used for e.g. 'additional information' and the loop in the search bar.

Submitting information

Welkom bij Samen Sterk

Wat is uw voornaam?
Joep

Wat is uw leeftijd?
Tussen 61 en 70

Wanneer bent u ontslagen uit het ziekenhuis?
02/04/2021

23 april 2021

Joep, waar heeft u last van?
- Geheugen ☐
- Concentratie ☒
- Twijfels ☐
- Duizeligheid ☐
- Moeheid ☒
- Pijn ☐
- Tintelingen ☐
- Kortademigheid ☒
- Hartkloppingen ☐
- Medicatie ☐
- Anders... ☐

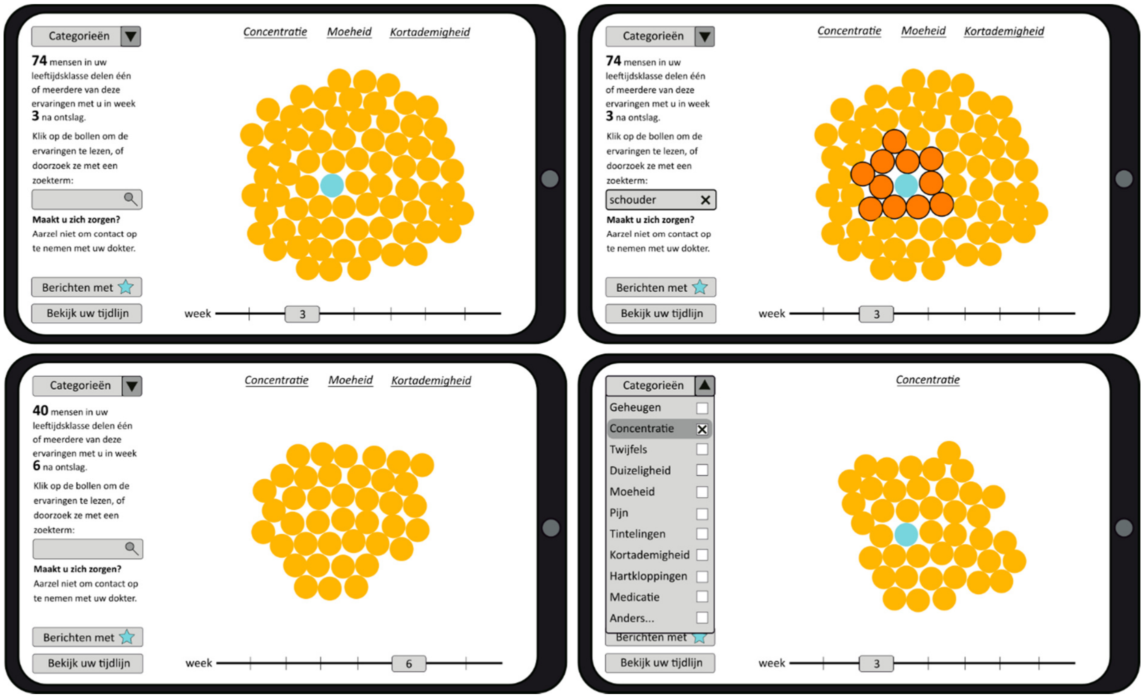
Licht uw keuze toe:
Ik heb erg slecht geslapen en ik heb nogal veel hoofdpijn, m'n hoofd lijkt niet te werken.
~Joep

83/100 karakters

Figure 39 The app's start screen and information submission screens

Figure 39 shows from left to right the first screens that users see. The left screen displays the tool's logo, name and slogan. The logo represents the visualisation, i.e. one ball that is surrounded by other balls, which represents a group of patients who show solidarity with each other. The name and the slogan enforce this feeling of not being alone while recovering. Users only see the middle screen when using the app for the first time. The app asks users to provide the information that is used in the app, i.e. the first name, the age group and the date of hospital release. The information button in the bottom left shows a text box that explains how this data is used in the app, when users click on it. In the screen on the right, users indicate their hindrances and they write the text message with their experience. Following the expert's advice, the list with hindrances was designed following design conventions, as can be seen in [45]. Each option is followed by a check box. When an option is selected, it turns dark grey and the check box is marked. The possible hindrance categories that users can choose from are based on the list of possible hindrances that was collected during post-operative patient interviews, see Section 5.3.

The visualisation



74 mensen in uw leeftijdsklasse delen één of meerdere van deze ervaringen met u in week **3** na ontslag.

Klik op de bollen om de ervaringen te lezen, of doorzoek ze met een zoekterm:

Maakt u zich zorgen? Aarzel niet om contact op te nemen met uw dokter.

74 mensen in uw leeftijdsklasse delen één of meerdere van deze ervaringen met u in week **3** na ontslag.

Klik op de bollen om de ervaringen te lezen, of doorzoek ze met een zoekterm:

schouder

Maakt u zich zorgen? Aarzel niet om contact op te nemen met uw dokter.

40 mensen in uw leeftijdsklasse delen één of meerdere van deze ervaringen met u in week **6** na ontslag.

Klik op de bollen om de ervaringen te lezen, of doorzoek ze met een zoekterm:

Maakt u zich zorgen? Aarzel niet om contact op te nemen met uw dokter.

Categorieën
Geheugen ☐
Concentratie ☒
Twijfels ☐
Duizeligheid ☐
Moeheid ☐
Pijn ☐
Tintelingen ☐
Kortademigheid ☐
Hartkloppingen ☐
Medicatie ☐
Anders... ☐

Figure 40 Different possible data subsets and the according visualisations

Figure 40 shows the visualisation and some possible modifications. Given that the user is currently in week three having concentration problems, tiredness and breathlessness, the top left visualisation would be shown. From this screen, users can modify what data is shown, and they have access to other functionalities. The UI expert pointed out that users read screens following an 'F' shape. They start looking in the top left, and go to the right, then they go down to the left, again to the right, and they go down again, and so on. In other words, the top left information will most likely be read, and the bottom right information most unlikely. Therefore, the most important information should be placed to the top and to the left. Thus, it was decided to move the UI elements from the right to the left, compared to the former design of Figure 34. To get a more understandable and calm design, the expert advised to put the week slider horizontally instead of vertically, and to remove the balls' borders. A vertical slider could be confused with a progress bar, that is conventionally often put vertically. Lastly, a short text was added to stress that the user should contact the doctor when worried. This may be useful for edge-case users that are particularly reticent to contact the doctor.

Figure 40 bottom left shows how the visualisation could change when the user slides to another week. Note that the user himself is not visible anymore as blue ball, because he has not yet submitted messages in week six. Also note that the numbers in the explanatory text on the left are updated. The top right Figure shows the visualisation when the search bar is used. As explained earlier, the messages that contain the searched word are placed in the centre around the user. These are marked dark orange and get a thicker border, which is also distinguishable for color blind users. Lastly, Figure 40 bottom right shows how the visualisation changes when other or less hindrances are selected. Logically, the number of balls reduces when only one hindrance is selected.

<u>Reading messages</u>


"Bewegen blijft lastig, vooral m'n schouders zijn nogal stijf en slap." ~ Eddy

"Mijn schouders zijn nog erg stijf en pijnlijk, waardoor ik nog niet zwaar kan tillen." ~ Sabine

"Ik heb erg slecht geslapen en ik heb nogal veel hoofdpijn, m'n hoofd lijkt niet te werken." ~ Joep

"Ik voel m'n schouders constant, een soort steken, kan me niet focussen op iets anders." ~ Peter

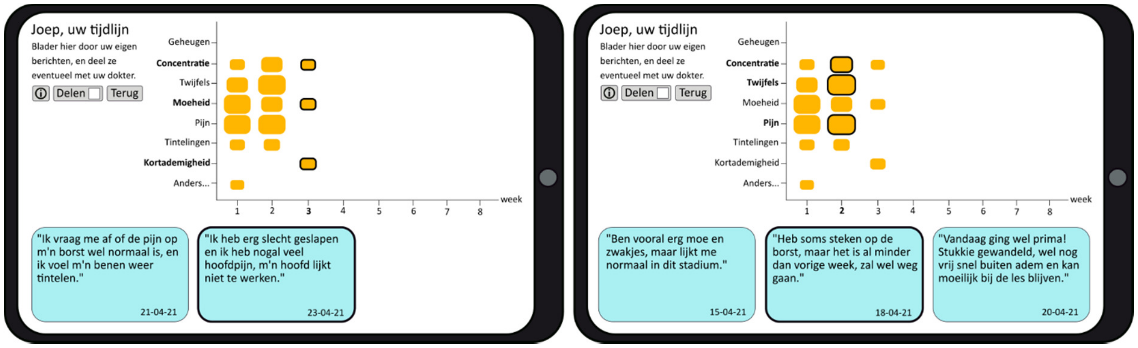
"Ik slaap nog steeds matig, maar m'n schouders voel ik niet echt meer." ~ Sjoerd

Figure 41 Zoom in on the visualisation to read the patients' messages

Users can zoom in on the visualisation by clicking on it. If the user clicks on his own ball while the search bar is active, he sees the screen as shown in Figure 41. Some balls contain horizontal lines. These are placeholders for messages. Once zoomed in, users can zoom out or stay zoomed in and move to other parts of the visualisation by dragging it. To enhance the feeling of reading personal messages, the users' first names are displayed with them. However the expert pointed out some risks of doing this. Although hard, it is not impossible to trace back people based on only their first name. This could happen when someone has a rare name, or when someone accidentally filled in his full name instead, for example. The viability of showing names should be tested in practice. Showing initials may be an alternative, but this is probably less personal.

Each ball represents *one person* that indicated to have a hindrance in a week. It can happen that one person submits multiple messages labelled as the same hindrance in one week. To read these other messages, a small button was added in the ball if this was the case. This button indicates the number of messages this person has submitted in the week, and what message of these is shown. Pressing it would show the next message, see Figure 41. Lastly, as will be explained later, messages can be saved by marking them. This can be done by pressing the grey star that is in the top of each ball.

Timeline



Joep, uw tijdlijn

Blader hier door uw eigen berichten, en deel ze eventueel met uw dokter.

"Ik vraag me af of de pijn op m'n borst wel normaal is, en ik voel m'n benen weer tintelen."
21-04-21

"Ik heb erg slecht geslapen en ik heb nogal veel hoofdpijn, m'n hoofd lijkt niet te werken."
23-04-21

Joep, uw tijdlijn

Blader hier door uw eigen berichten, en deel ze eventueel met uw dokter.

"Ben vooral erg moe en zwakjes, maar lijkt me normaal in dit stadium."
15-04-21

"Heb soms steken op de borst, maar het is al minder dan vorige week, zal wel weg gaan."
18-04-21

"Vandaag ging wel prima! Stukkie gewandeld, wel nog vrij snel buiten adem en kan moeilijk bij de les blijven."
20-04-21

Figure 42 Overview and visualisation of the patient's personal messages

In Figure 40, if the user presses the button 'watch your timeline' in the bottom right, the tool would show the messages that the user has submitted himself, see Figure 42. The bottom part shows the messages, starting with the most recent one. Swiping to the right shows older messages, see Figure 42 right. The upper half of the screen shows an overview of the hindrances to which the user's messages belong. For example, Figure 42 left shows that the most recent message was submitted in week three, and that it was labelled as concentration, tiredness, and breathlessness. Figure 42 right shows that the selected message was submitted in week 2 and was labelled as concentration, doubts and pain. In the overview, the larger the orange dot, the more messages in that week were labelled as that hindrance. The smallest dot represents one message. The middle-sized dot represents two messages, and the largest dot represents three or more messages. For example, Figure 42 shows that in week 1, only one message was labelled as 'concentration', while three or more were labelled as 'pain'.

As was found by Lim et al. [18], explained in section 3.1, tools for reflection should provide overview, for users to see relations and changes over time. Besides, they should externalize abstract notions such as doubts. This visualisation provides a clear overview of the patient's recovery process in terms of what hindrances were experienced in what week. It may thus facilitate users in reflecting on their recovery process, although this is not the main goal of the tool. Moreover, this information can be useful for doctors to prepare the consultation. With the overview, they can quickly get an impression of the patient's recovery, and possibly notice abnormalities that should be discussed. Therefore, the app gives users the possibility to share their personal messages and the overview with the doctor, see Figure 42 top left. The share button is accompanied by an information button that explains what exactly will be shared and why this could be useful for patients and for doctors.

Messages with a star

Joep, uw berichten met ster

Blader hier door de berichten die u gemarkeerd heeft met een ster.
Klik op een bericht voor meer informatie over dat bericht.

"Vandaag ben ik weeste wandelen, viel nog niet mee om het vol te houden."
~ Marie

"Het herstel gaat erg voorspoedig eigenlijk, alleen wat moe af en toe vandaag."
~ Geert

"Voor het eerst sinds dagen weer echt goed geslapen."
~ André

"Gisteren ging prima maar vandaag voel ik m'n schouders weer!"
~ Evie

"Smiddags een dutje doen doet wonderen tegen de moeheid in de avond."
~ Henk-Jan

"Heb veel last van pijn vandaag, eigenlijk overal wel, en m'n conditie is ver weg."
~ Pedro

Figure 43 Overview of all messages that the user has 'starred'

Lastly, as said earlier, users can mark messages with a star. All ‘starred’ messages can be found in one overview, see Figure 43, when the user presses the button ‘messages with star’ in Figure 40. Specific messages could be particularly reassuring, informative or in another way important to users. Users may want to reread such messages. However among all the messages in the app it may be hard to find them back. For this reason, messages can be starred, so they can be found back easily. If users press on a starred message in Figure 43, the message’s week of submission and hindrance labels are displayed, as well as the option to show the message in the main visualisation.

11.2 Test description and results

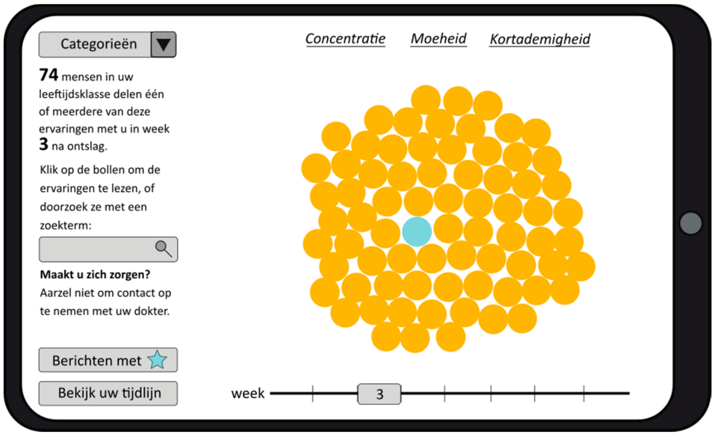
Test procedure

To put the participants in the shoes of a post-operative patient, a short scenario was written in which a fictional post-operative patient and his current situation during recovery were described, see Appendix 4. Participants were intended to act as if they were this person. Then a list was made of all goals a user should be able to achieve with the app. Based on these goals, seven tasks were written that test participants would have to accomplish. For writing the scenario and the tasks, tips from the Nielsen and Norman group were followed [46]. For example, they stress that tasks should not tell users what to do, be too elaborate, resemble an advertisement or be formulated as a question. The tasks were shared one by one with the participants, the goals weren't. These were the goals and their respective tasks:

- Goal: Find out how many others have the same hindrances as I have in this week.
  Task 1: You are tired, quickly out of breath and you have problems concentrating. Find out how many others also experience these hindrances in week 3 after hospital release.
- Goal: Read other people's experiences.
- Goal: Specify search with a search word.
  Task 2: Today you are having pain in your shoulders. Find and read experiences of others who also have pain in their shoulders.
- Goal: Read back your own messages.
  Task 3: You would like to read your messages from last week, to see what hindrances you experienced then. Go to your messages from week 2.
- Goal: Look in different categories.
  Task 4: You are especially worried about your persisting concentration problems. Find out how many other people also experience this in week 3 after hospital release.
- Goal: Explore what happens over the weeks.
  Task 5: Find out if your hindrances (concentration, tiredness, breathlessness) will diminish over time in the coming weeks, or not.
- Goal: Mark messages as 'starred' and read them back.
  Task 6: A while ago you read a message from someone who talked about afternoon naps. You can't remember where you found this message back then, but you did save it. Retrieve this message.
- Goal: Share your data with the doctor.
  Task 7: Tomorrow you have a consultation with your doctor. You would like to share your messages from this app with him and discuss them. Share your messages with the doctor.

The tests were held digitally on a computer, using the Google Meet video call tool. First the participant was informed about the test procedure, i.e. pretending to be the patient from the scenario, executing tasks, and answering some last questions. Some practical information was provided as well. It was explained that the tool was still a prototype, thus some interactions worked differently than intended, and some buttons did not work yet. For example, all interactions took place by clicking, instead of e.g. by sliding. This was done partially because the test took place on a computer and partially because of limitations of the Invision tool. Invision allows the swipe interaction, but for a slider that should be slid, this is at least as unintuitive as moving it by clicking on the next case in the bar. Then the scenario was shared with, and read by, the participant via the Google Meet chat. Next, the link to the prototype was shared. Then participants were asked to share their screen, so that I could see how they would interact with the prototype. Then, the first task was shared and the participant executed it. When finished, the next task was shared, and so on. Lastly, the questions were asked and answered in interview style. Finally, participants were thanked for their participation and the video call was ended.

Test results: improvements regarding clarity



74 mensen in uw leeftijdsklasse delen één of meerdere van deze ervaringen met u in week **3** na ontslag.

Klik op de bollen om de ervaringen te lezen, of doorzoek ze met een zoekterm:

Maakt u zich zorgen? Aarzel niet om contact op te nemen met uw dokter.

Figure 44 The app's main screen

While discussing the results, components of the app will be mentioned repeatedly. For convenience, the main screen of the app as used in the prototype is shown in Figure 44. The participants were positive about the app's idea, and some parts of the UI were well understood, such as the week slider. At the same time, several improvement points were found. First of all, the number in the top left was not always linked to the number of balls in the visualisation. This is important because this number and explanatory text should contribute to understanding the visualisation. This misunderstanding was enforced by the dropdown menu that hides this number when it is unfolded. Consequently, people did not see the number changing when selecting e.g. less hindrances.

Secondly, the search bar and the categories were confused. In task 2, people were intended to use the search bar and search for 'shoulders', however several participants first tried to find 'shoulders' via the category drop down menu. The word 'category' is probably too vague and meaningless here. 'Hindrances' could be better. Third, the button 'your timeline' was not directly linked to the user's own messages. Consequently, in task 3 almost all participants first went to week 2 in the visualisation, using the slider, and wanted to click on their own ball. This approach would give the correct results, but users were intended to go to their timeline. Fourth, the timeline visualisation posed two problems. First, people wanted to click in the visualisation, e.g. to go to week 2's messages. While not possible now, this is a logical interaction that should be made possible. Second, it was unclear that users could go to other messages than the ones currently visible. There was no arrow that indicated this. Fifth, the visualisation's meaning was not always clear immediately. For example, what people are exactly represented by these balls? What is the highest possible number of balls? What exactly changes when going to another week, what balls are added and removed? Such things should be made clearer. Lastly, some participants found the main screen, see Figure 44, a bit crowded. In their opinion, there were too many elements, such as buttons or text, visible at the same time.

Test results: participants' suggestions

During the test, participants suggested a variety of changes and additions for the app. The ones that were most often repeated, or were estimated most promising, are described here.

First, the app should use pop-up messages to explain its functionalities, especially when using the app for the first time. This way it may be clearer how to use the app from the beginning. It also helps to make the interface calmer. E.g. the explanatory text that is now always visible in the top left could be put in a pop-up message. The user can remove it when the message is clear and this empties the screen and thus makes it calmer. To make clearer the number that displays the balls count, it should be made bigger and put more centrally. Besides, it should be put in a large orange ball, such that it is more easily linked to the visualisation.

Secondly, users should be notified when other users appreciate their message(s), to enhance social connection. By sending a ‘like’, someone can show his support or appreciation towards the other. This like, or the total number of likes on a message, should be invisible to others, to prevent openly rating experiences and resulting competition, which happens on social media platforms. This feature could be combined with the ‘starring’ messages functionality. By starring a message, you would send a notification to that message’s owner. Furthermore, users may want to get in contact with each other, via chat or with e-mail. Some people’s experiences may be particularly similar or inspiring for someone. It would be interesting to allow users to contact each other if they want to exchange experiences more closely. People could indicate in the ‘options’ whether they want to be contacted or not by other users.

Thirdly, users should be motivated to write a message. One or different starting phrases can be suggested. Moreover, messages should be more positive and contain tips. People should be motivated to share e.g. their solutions to inconveniences, inspiring messages, or what activities they are able to do again. Currently, there may be too much focus on complaining and the negative side of the recovery process. Users should be able to help and inspire each other and together go forward.

Fourthly, participants suggested more transparency and freedom in sharing messages with the doctor. It should be clear with which doctor the messages are shared exactly. It should be possible to decide what selection of messages you want to share. Currently, users can only share all messages at once. Lastly, users should be able to edit messages later on. Currently, messages can’t be edited once submitted in the app and this feels too definitive.

Test results: question answers

Do you understand the visualisation? Can you explain what you see?

Six of the eight participants immediately understood that they were represented as the blue ball and other users sharing the same hindrances were represented as the orange balls. This was confirmed when they started modifying the visualisation with e.g. the slider, or when they zoomed in and read their message and those of others.

How do you feel seeing that others experience similar hindrances as you?

All participants felt positive about this. They said that as user you see that you are not alone and that your issues are normal. This is reassuring and it can take away fears. Especially the possibility to look ahead in time with the slider was mentioned several times as being reassuring. It can show a hopeful future and set an expectation for the coming period. Although someone also said that it can work adversely, if you see that a hindrance can last for weeks to come.

Would this app influence your conversations with your doctor? If yes, how?

Several participants thought they would less quickly contact the doctor if the app showed them that their hindrances were normal. The app would already reassure them. At the same time, participants said that they would be able to ask more specific questions and go to the doctor earlier when hindrances appeared to be abnormal. Two participants would only use the app for themselves to find confirmation and recognition, but they would not share this with the doctor. Another participant mentioned that the doctor would have more information about the patient's recovery process before the consultation, if the patient shared his messages with the doctor. It would then facilitate the conversation.

How do you experience navigating through the app?
As said earlier, many participants gave points for improvement regarding navigation and clarity, such as using pop-up explanations, changing the words on buttons, or using animations.

Which functionality would you use the most?
Most participants would use the app's main functionality the most, that is, exploring how many other patients experience hindrances throughout the weeks. They would compare this to their own recovery process. Within this functionality, some participants indicated to be most interested in the quantity, thus the *number* of people having a hindrance, the size of the visualisation. Others indicated to be most interested in reading the messages. Two participants would be most interested in their personal timeline and messages, for reflection and progression tracking.

Are you worried about the information that you share with others?
Most participants indicated to be not worried about sharing information. Two participants were a little more hesitant, especially given the recent attention in the news on data leakages in major companies. For them it would help if it was absolutely clear with whom the data was shared, and if they only needed to submit data that would be strictly necessary for the app to work. Some participants thought that people from the actual user group would be more hesitant towards sharing personal data with other users and with the hospital.

12. The visualisation test

The prototype from the usability test contained all envisaged functionalities. However, as appeared from the usability test, the prototype's user experience was not optimal. As explained in section 11.2, several points for improvement were identified to improve the app's navigation and clarity. For example, the highest possible number of balls was not shown. Whether 74/150 or 74/1500 patients have an issue, makes a big difference for how normal something is. Moreover, the way in which the prototype was built, i.e. a network of images that can be clicked through, did not allow to implement representative interactions and animations. The images were static and only mouse click interactions were possible, while the imagined product would contain more modern interactions and animations. Arguably, the prototype's sub-optimal user experience hindered the test participants to have a pleasant and meaningful experience. Figure 45 shows the user experience pyramid [25]. The usability prototype did not fully reach the 'pleasurable' and 'meaningful' layer because the lower layers were not well achieved. As a result, the validation of the concept evoking reassurance, being something pleasurable and meaningful, was still weak.

Additionally, some key design decisions regarding the visualisation were not yet well validated, most notably the decision to visualise all patients having a hindrance as a cluster of balls, instead of as something else. It was assumed that this visualisation would evoke the most reassurance. The visualisation, being a metaphor of people surrounding the user, took the role of an image and rather supported the quantity of people having a hindrance, than clearly communicating this by itself. The exact quantity was now communicated by displaying the number. A visualisation in which users can read the quantity of balls in the visualisation may be clearer and more reassuring. This way, the visualisation itself would communicate the quantity, instead of supporting it.

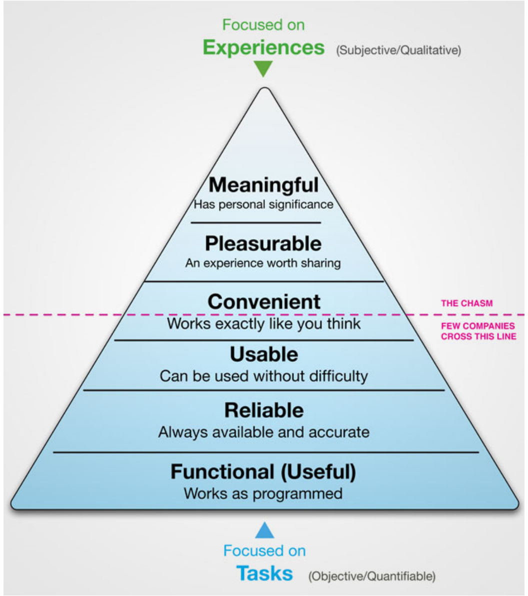


Figure 45 The user experience pyramid [25]

A prototype was developed in Microsoft PowerPoint. This prototype was limited to the tool's main functionality. That is, the user submits his hindrances and a short message, and then sees how many others experience the same hindrances. This functionality was worked out in such a way that it closely resembled the imagined product. Feedback from the usability test was incorporated and animations were added. Microsoft PowerPoint was used because it made it possible to prototype these animations as they were imagined in the final product. Additionally, a second version of this prototype was made that was identical, except for the visualisation. In the first version, the same visualisation was used as in the usability test. This will be referred to as the ‘cluster’ version. In the second version, the same orange balls were used but these were well aligned, such that the quantity could be read more easily from it. This will be referred to as the ‘formation’ version. The prototype and its two versions will be described in more detail in the following section.

A within subjects test with these two prototypes was done with eight participants. These people were friends and family from Game Solutions Lab colleagues. They were not open heart surgery patients, but they were of the same age as most open heart surgery patients are, i.e. between 55 and 75. Additionally, as opposed to the GSL colleagues who participated in the usability test, these people were no experts on e.g. design or management. For these two reasons, these people would be a close representation of the the actual target group. The goal of the test was twofold. In the first place, by testing with a close representation of the core functionality of the imagined product, more accurate insights could be obtained on whether this functionality indeed evoked reassurance. By well working out the lower layers of the UX pyramid for this one functionality, also the higher layers of pleasure and meaning could be experienced and thus validated, see Figure 45. In the second place, testing two different versions of the visualisation made it possible to validate one of the key design decisions within this core functionality, i.e. evoking reassurance by visualising a group of people having the same hindrance as a cluster of balls.

12.1 The final prototype

The prototype will be explained, focusing on the differences with respect to the prototype that was used in the usability test. Overall, animations were the largest difference. As said, the usability prototype was a network of static images. Clicking from one image to the other did not show transitions. If an element was intended to move gradually from A to B, the first image would show it on A, and the next image on B, without transition. As a result, it could be unclear that this element was the same and that it had only changed places. It might have looked as two different elements. In other words, the continuity of the UI elements was lost. This may have contributed to usability test participants not immediately understanding the visualisation, or e.g. linking the displayed number to the number of orange balls on the screen.

Starting the app

23 april 2021

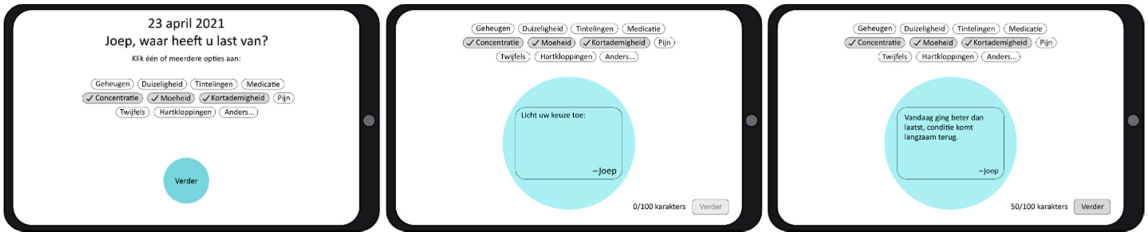
Joep, waar heeft u last van?

Klik één of meerdere opties aan:

Figure 46 The final app design, start and category submission screenshots

On the starting screen, the user is asked to press the blue ball, see Figure 46 left. Then, with an animation, the orange balls fade away and the name and slogan move downwards out of the screen, see Figure 46 centre. The blue ball moves downwards, and the date, a question and the hindrances move in the screen from the top, see Figure 46 right. Note the phrase *“Click on one or multiple options.”* that makes clear to users that they can choose more than one option. A usability test participant suggested this, for extra clarity. Based on Google material design guidelines, the hindrances were shown as filter chips [47]. According to [47], chips should be used to let users, among others, make selections and filter content. They are a group of multiple interactive elements. Filter chips represent filters for a collection. In this case, all hindrances together represent the full dataset. By selecting hindrances, users filter the data. Although drop down menus are also well-known and suitable in this situation, filter chips fit better in the app's centralized design because they don't need to be displayed in a vertical list. Additionally, chips, being individual components, are more suitable to move to other locations on the screen with an animation, as will be shown later in this section. The possible hindrance categories that users can choose from are based on the list of possible hindrances that was collected during post-operative patient interviews, see Section 5.3.

Data submission


23 april 2021
Joep, waar heeft u last van?
Klik één of meerdere opties aan:

Licht uw keuze toe:

Vandaag ging beter dan laatst, conditie komt langzaam terug.
—Joep

Figure 47 The final app design, writing a message, screenshots

Users select the hindrances that they experience, see Figure 47 left. Following [47], selected chips are marked grey and a checkmark precedes them. 'Continue' appears on the blue ball and an impulsion animation shows the user to click on it. This animation is not visible in Figure 47. The blue ball expands gradually into an area where users can type their message, see Figure 47 centre. When something is typed, the 'continue' button lights up, see Figure 47 right, again with an impulsion animation. Note that the logo on the start screen already suggests the visualisation and the blue ball's central role in it, the continued presence of this blue ball in the next screens, and how users clearly write their message in it. This is done to make clear that users and their messages are represented by the blue ball. It should create familiarity of the visualisation to the user. Reber et al. [37] found that familiar objects are easy to understand and contribute to an aesthetic experience.

The visualisation animation

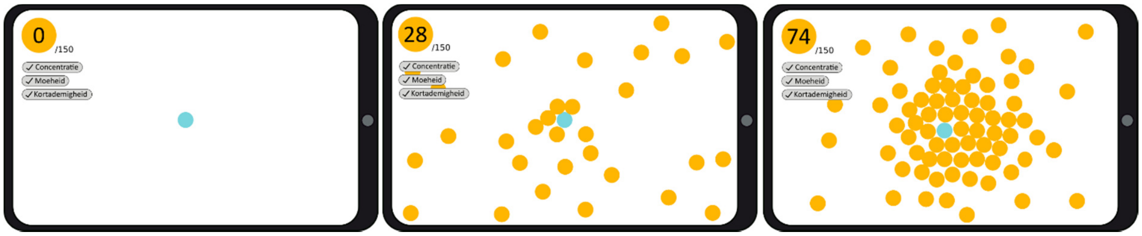
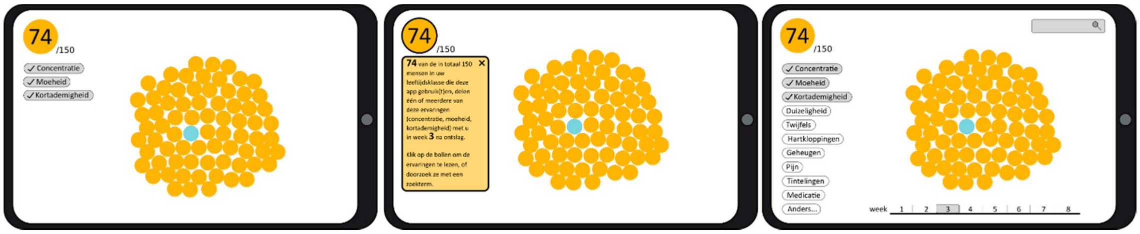


Figure 48 The final app design, the animation that builds up the visualisation

When the user presses 'continue' from Figure 48 right, the blue ball minimizes gradually, the selected hindrance chips move to the left side of the screen and a large orange ball appears with the number 0 in it, see Figure 48 left. '/150' tells the highest possible number of orange balls, this will be explained in the next paragraph. Then, orange balls move into the screen from all directions and surround the blue ball, see Figure 48 centre and right. The number in the top left equals the number of orange balls that are visible in the screen and counts up as more and more balls enter. As was suggested in the usability test, enlarging the number and putting it in an orange ball in this way could more clearly show what it represented, and contribute to users' understanding of the visualisation. Because the orange balls enter the screen from all directions, the fact that each ball represents an individual person is stressed. According to the Gestalt principle of common fate (section 3.3), elements are grouped if they move together. Thus, by letting each ball move individually, they are not yet seen as one group during the animation.

<u>The main screen</u>



74 van de in totaal 150 mensen in uw leeftijdsklasse die deze app gebruik(t)en, delen één of meerdere van deze ervaringen (concentratie, moeheid, kortademigheid) met u in week **3** na ontslag.

Klik op de bollen om de ervaringen te lezen, of doorzoek ze met een zoekterm.

Figure 49 The final app design, the main screen and visualisation

Figure 49 left shows the finished visualisation after the animation. Then a pop up shows up that explains the visualisation, see Figure 49 centre. It clearly says what these orange balls represent, i.e. the number of the in total 150 other patients in the user's age range that use(d) the app who also had the selected hindrances in that week after hospital release. Especially the addition of the total number of these patients, e.g. 150, should help users in understanding what the visualisation shows and in estimating how serious their hindrances are. After all, 74 out of 150 could mean that a hindrance is normal, while 74 out of 1500 would make a hindrance rare. Displaying this number is thus essential in order to estimate the seriousness of hindrances. From the usability test it appeared that the visualisation was not always fully understood. These changes should improve this.

Then options to explore the dataset, i.e. the search bar, the week slider and all categories enter the screen one after the other, each accompanied with a similar pop up explanation as shown in Figure 49 centre. After having clicked away these pop ups, the main screen would look as shown in Figure 49 right. From here, it was possible to click on the blue ball. This would show a zoomed in image similar to the one that was used in the usability test, i.e. Figure 41. In the final product, pop ups should always be shown when users use the app for the first time, to explain the app. Showing tool tips on later usages might be optional, with exception of the pop up from Figure 49 centre. This could be shown each time, or when the user presses on the large orange ball. As suggested in the usability test, pop ups were used to clearly explain the app, and to remove fixed texts from the screen to make its appearance calmer.

The formation version of the prototype was identical, except for the visualisation in which the balls are displayed in a well-organized formation, as can be seen in Figure 50. The balls in this shape are better aligned and together they make a symmetrical square shape. Symmetry is perceived as aesthetically pleasing, according to Reber et al. [37]. Thus, it could be that users prefer this shape over the cluster, that is a bit messier. This may also help to retrieve the number of balls that are displayed.

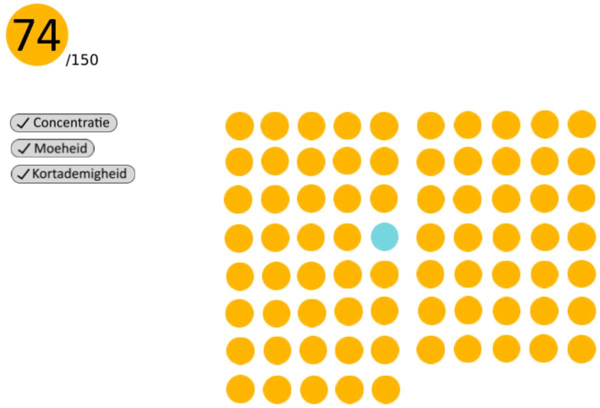


Figure 50 The formation version of the visualisation

12.2 Test description and results

<u>The procedure</u>

For this test, a similar procedure was used as for the usability test. Instead of Google Meet, Skype was used this time, because documents can be shared with the latter. This was necessary to share the PowerPoint prototype with the participants. First a short introduction was given, pointing out that participants would use a prototype with limited functionalities. Then the same scenario was shared as during the usability test, i.e. Joep being a patient who is recovering, see Appendix 4. Then one of the two versions of the prototype was shared. Four out of eight participants interacted with the 'cluster' version, and the other four interacted with the 'formation' version. I asked participants to share their screen, so that I could see how they would interact with the prototype. Participants only executed two tasks, one before the other, being:

1. You are tired, having breathlessness and concentration problems. Find out how many others experience these issues three weeks after hospital release.
2. Read back your message, and that of some other users.

Afterwards, a variety of questions was asked. Questions focused on understanding and impact of the visualisation and clarity of the navigation. Besides this, some questions were asked to gain more insights on specific design choices, such as whether the participants wanted to get in closer contact with other users, which was suggested in the usability test. After these questions, participants indicated to what extent they agreed with four statements on their understanding of the visualisation, its appeal, its solidarity and its contribution to put worries into perspective. Next, participants were shown the other prototype version than the one they interacted with. For this version they also responded to the same four statements. Participants were also asked to explain their responses to statements. Then the test ended. Some participants had difficulties with the video call software, or could not open the PowerPoint prototype they were intended to use. To solve this, I shared my screen and showed the prototype. The participants then gave instructions of what they would do, where they would click, and I followed these.

There were thus two types of results: the answers to the questions, and the answers to the statements and their comparison. The question answers were used to validate the concept as a whole, thus the user seeing that he is not alone with his issues which should reassure him and which allows him to estimate their seriousness. The statement comparison was used to see differences between the two visualisations.

The results: question answers

Do you understand the visualisation? Can you explain what you see?

7 of the 8 participants understood the visualisation. They said they were the blue ball in the middle and that the orange balls are others experiencing the same hindrance. They also understood that you have to click on these balls to read their experiences. The explanatory text was also clear and helpful in this, although often not essential to understand the visualisation. One person did not link the large number in the left to the number of balls visible in the visualisation.

What would change in the visualisation if you use the slider to go from week 3 to 4? (to verify if people understand that balls not only disappear, but also (re)appear, if someone suddenly has a hindrance in week 4 that he did not have in week 3)

6 of the 8 participants would expect the number of balls to reduce when going from week 3 to 4. When I explained them that ‘new’ balls could also appear, they found this logical, but they did not mention this themselves. Only one participant did this explicitly. Some did mention that the number could increase instead of going down, which is true.

How do you feel with the idea that others experience the same hindrances as you?

7 of the 8 participants expressed positive reactions, one was rather neutral. This one person was not the person who did not understand the visualisation. They said that it would be reassuring to see that you are not alone. It would be a recognition of your issues that they are a normal part of recovery.

Would this app influence your conversations with your specialist? How?

All participants answered yes, or ‘probably’. They thought they would ask more specific questions, address certain issues earlier, or would not ask something if the app already reassured them. They said they could compare themselves to others and use this as argument. In general, the app provides more information for the consultation.

How do you experience navigating through the app?

6 of the 8 said that it was clear and simple. 2 said they could not estimate this, given the limited functionalities of the prototype.

If you were Joep (the persona), how often would you use this app? (to verify app usage, how to capture the user’s attention)

7 of the 8 participants thought they would use the app at least once a week. Some thought they would use the app more often in the beginning of recovery (when they were still having many hindrances), or in general when having some new or worrisome issue. Some mentioned to not use the app anymore once the issues diminished. However, it might be that people continue to use the app for a longer time if the app focusses more on tips and positive messages. This was not verified.

If you were Joep, would you want to get in touch with other users based on their messages that you read in this app?

3 of the 8 participants thought they would want to get in contact with others, such as with a chat, just to ask a question maybe. Two people who did not want it, could imagine others to want it.

Would you prefer to first see the whole visualisation and then submit your own data? (now you first submit your own data and then you see the data. Doing this the other way around may influence what people e.g. tell in their message)

6 of the 8 participants preferred the current order. They wanted to look to themselves, their own experience, and not be influenced by others when writing a message. The other two participants would like to see messages of others before posting something themselves *when using the app for the first time*. On first usage, they would be hesitant to write something and not know what happens afterwards with it.

The results: visualisation comparison

Cluster	Clear	Appealing	Solidarity	Put worries into perspective	Sum (max. score is 20)	Average participant score
Participant 1	5	4	4	5	18	
Participant 2	5	5	5	5	20	
Participant 3	4	4	4	3	15	
Participant 4	5	4	5	4	18	
Participant 5	5	4	5	4	18	
Participant 6	3	2	2	5	12	
Participant 7	4	5	5	3	17	
Participant 8	3	3	4	4	14	**16,5**
Sum (max. score is 40)	34	31	34	33		

Table 3 The visualisation test results for the cluster version of the visualisation

Formation	Clear	Appealing	Solidarity	Put worries into perspective	Sum (max. score is 20)	Average participant score
Participant 1	5	2	2	3	12	
Participant 2	5	5	5	4	19	
Participant 3	4	3	3	3	13	
Participant 4	5	4	5	4	18	
Participant 5	5	2	2	4	13	
Participant 6	3	4	4	4	15	
Participant 7	5	4	4	3	16	
Participant 8	4	4	4	4	16	**15,25**
Sum (max. score is 40)	36	28	29	29		

Table 4 The visualisation test results for the formation version of the visualisation

Tables 3 and 4 show the scores that the participants gave to the four statements (in the columns). 1 being ‘fully disagree’, and 5 being ‘fully agree’. The summations under each column show that the formation visualisation scored slightly better on clarity, while the cluster visualisation scored higher on the other statements. Participants gave the cluster an average score of 16,5 / 20 (20 being a 5-rating on all 4 statements), and the formation an average score of 15,25 / 20.

Due to the low number of participants, I did not try to proof that these scores are significant, but they suggest that the cluster visualisation is more appealing, better against worries, and evoking a feeling of solidarity, while only minimally being less clear. Participants commented that the cluster was more playful and happier. This puts the seriousness of the situation into perspective. The balls being so close to each other creates more of a connection with the other patients than in the formation visualisation. Because the number of balls is shown so clearly, it doesn't matter that the visualisation is less readable, some said. However, participants that disliked the cluster indicated that the balls were too close to each other and sometimes slightly overlapped. This was messier in their opinion. Making these distances a little larger would make them like it more.

13. Cycle 3 design decisions

This chapter summarizes cycle 3, i.e. Chapters 10, 11 and 12, in terms of the design decisions that have been made in this cycle based on information that was obtained in the various exploration and validation activities that were described in these chapters. Cycle 3 focused on the design of the visual representation of patients' worries in a clear way that evokes a feeling of solidarity among the patients. Cycle 3 also focused on the design of the app in which this visualisation is embedded.

Do you visualize actual data or metadata?

Metadata, i.e. the hindrance categories to which text messages belong, was visualised. This results in a simple and clear visualisation. It focuses on what experience people have in common instead of on each experience's uniqueness. It thus stresses a feeling of solidarity. Almost all participants of both tests found the visualisation clear and reassuring and/or evoking a feeling of solidarity.

Does your visualisation use metaphors?

All people sharing a hindrance were visualised as simple shapes that stand close to each other, supporting each other while dealing with the same situation. Simple shapes were used to minimize visual details and clutter in the screen, while preserving the metaphorical message. The concept test showed that using e.g. avatars would be visually too messy and detailed. Additionally, the animation in which the balls enter the screen and come together enforces this supportive message of solidarity and connection with others. The visualisation comparison in the last test showed that, besides the cluster evoking more a feeling of solidarity, participants felt more positive towards it than towards a structured formation of balls. It was reported to be playful and happy.

Does the visualisation *communicate* the message or *support* the message?

The visualisation supports the message. Because the balls are clustered, the exact number of balls is not easily readable. This quantity is communicated with a large number next to the visualisation. The visualisation is used to evoke a feeling of solidarity. Participants from both tests indicated that the message was clear in this way.

How is the visualisation interactive?

The visualisation is interactive inside as well as outside the visualisation. From the outside, users can interact with a week slider, select different categories and use a search bar. Within the visualisation itself, users can zoom in to read other users' experiences and 'star' messages. The usability test showed that pop ups should be used to explain all possible interactions, and their differences. Some participants understood the functionalities right away, others preferred more explanation.

Do you have an « overview -> details » information structure?

The cluster shows an overview of all people having a hindrance. The messages, describing people's experiences, are more detailed information. When zooming in on the cluster, the user goes from overview to details. The usability and visualisation tests showed that this was intuitive. However, the interaction as imagined was not exactly tested. It would use a ‘zoom in’ gesture, which was impossible to mimic with the used prototype tools. Clicking worked less intuitively.

What (visual) parameters do you use in your visualisation?

The visualisation is a cluster of balls. Each ball represents one user of the app. To distinguish the user from all other users/patients, he is coloured blue, while the others are orange. Test participants understood this. These two colours are also distinguishable by most color blind people. The search results of the search bar are displayed around the user, and marked dark orange and with a thick border. Here, location is used to communicate relevance of messages. No other visual parameters, such as the size, or shape of objects were used to communicate extra data. As was shown in Figures 28, 29 and 30 in Section 10.1, showing more data quickly makes the visualisation more complex, while users prefer clarity.

Is your visualisation static or dynamic?

The visualisation is static. Its elements don’t move continuously. A dynamic visualisation that constantly shows different relations in the data could be aesthetically pleasant. However, given the target user group of age, it was decided to focus on simplicity when possible.

How free is the user, regarding text input?

The user can write a message with a maximum length of a hundred characters. Already during the concept test, participants said that reading messages of others would be more personal and reassuring than standard answers. It was not yet tested what sort of messages people would actually write. It could turn out that this hundred character limit is too narrow. On the other hand, only allowing a small message could lower the barrier that users feel to write anything. People might feel obliged to reach the limit, which would take more effort with a large limit. During the two tests, several participants mentioned that they expected to find tips among the messages of others. It may therefore be promising to steer users more in writing tips or other positive messages. The current freedom could result in too much complaining and negative messages.

On what level in the data does the user start the interaction?

Users see all others that have the same hindrances as they have in their current week. In other words, users only see the hindrance categories they just submitted themselves in their current week of recovery, which is probably the data they are most interested in at that moment. Other weeks or hindrances are accessible, but they are not shown immediately. This way, users start with what they most likely want to know, and they can explore the dataset afterwards.

Does the user explicitly see his own data in the dataset?

Yes, users see themselves among all others that have the same issues. During the usability and visualisation tests, many participants reported this as clear and reassuring. It stresses a feeling of solidarity of all others with the patient.

Does the user compare to, or identify with, others?

Users of the app identify themselves with others who have similar issues to evoke solidarity. Differences between users are not stressed because this would reduce the feeling of solidarity.

Do you use percentages or absolute numbers?

Absolute numbers are used to show transparent data. It is easier to estimate the seriousness of issues with absolute numbers than with percentages. For example, 50% could be 1 out of 2, or 50 out of a 100, this is unclear. Showing absolute numbers right away removes this problem. Besides, it is more consistent to show absolute numbers because the messages are also shown in absolute numbers. Depending on the total, 2 messages could correspond to 67%, but also to 1%. Different percentages for the same number of messages could be unclear. During the two tests, these absolute numbers were well understood and linked to the visualisation.

How do you deal with large quantities of data?

The quantity is always displayed as a number, even when very large. Consequently, the quantity does not need to be clear in the visualisation at all times. When dealing with many messages, the most fitting option in this case would be to cluster messages together when zoomed out. Zooming in would reveal all individual messages. However, another option would be to only show a subset of the messages, with an option to display others that are not visible at first. This might decrease the feeling of solidarity that the visualisation emits. It is also promising to show the most relevant messages closest to the centre, so they are always well accessible. No definite decision was made yet.

In what ways can the user interact with the system's components and navigate through the data? What happens with each action?

Given the target user group's age, basic and generally well-known interactions are used, such as clicking, zooming and dragging. Most interactions were based on clicking, such as indicating what hindrances you have, or pressing buttons. With a zoom-in gesture, users can zoom in on the visualisation to read messages. However, this is also possible by clicking on the messages. The slider is controlled by dragging the slider along the bar. The tools in which the prototypes were made did not allow full freedom to design interactions. Therefore, the intended interactions could not be fully validated.

14. Project results overview

This chapter provides a brief overview of this project's results, i.e. the design contribution and the case contribution. In Section 14.1 in Table 5, all design questions that were identified are listed, as well as their possible answers and the answer that was chosen in the case. Furthermore, for each design question the corresponding chapters are listed in which this question's case answer is explained shortly, and the chapters in which this question was mostly explored and validated. Section 14.2 briefly discusses suggested design decisions for the next iteration of the case product which would build on the last iteration as described in Section 12.1. Someone who wants to continue this project, could start with these suggestions.

14.1 Design questions and decisions overview

Identified design question	**Question category**	**Identified possible answers & case answer (in bold)**	**Short explanation of case answer in…**	**Question mostly explored in…**	**Answer mostly validated in…**
What problem do you want to solve?	Data	**Patients can't estimate the seriousness of their issues and don't easily express them**	Chapter 6	Chapter 2	Chapter 5
What is your data and what are the relations within it that you want to communicate?	Data	**The number of patients in an age group who have a specific issue, per week during recovery**	Chapter 6	Chapter 4	Chapter 5
What do you want to achieve with the data representation?	Data	Conversation starter, reflection, **trend analysis**, behaviour change, aesthetics, **comparison**	Chapter 6	Chapter 4	Chapter 5
Will you make a physical or a digital information representation?	Representation	Physical, **digital**, hybrid	Chapter 6	Chapter 3	Chapter 5
Does the visualisation require active attention, or does it reside in the background?	Interaction	**Active attention**, background	Chapter 6	Chapter 3	Chapter 5
How often and how do you capture the user's attention?	Interaction	Once or a few times, **regularly**	Chapter 6	Chapter 4	Chapter 5
Is the information being categorized by a computer or by the user itself?	Interaction	Computer, **user**	Chapter 9	Chapter 3	Chapter 8

Identified design question	**Question category**	**Identified possible answers & case answer (in bold)**	**Short explanation of case answer in…**	**Question mostly explored in…**	**Answer mostly validated in…**
Will you use live data or a fixed data set?	Data	**Live data**, fixed data set	Chapter 9	Chapter 7	Chapter 8
On what data level does the user identify himself with others?	Representation	Detailed, **global**	Chapter 9	Chapter 7	Chapter 8
Does the user submit his own data?	Interaction	**Yes before seeing the data**, yes while seeing the data, no	Chapter 9	Chapter 7	Chapter 12
How does your visualisation evoke a specific feeling or message?	Representation	**Animations**, **shapes/colours**, **arrangement of elements**, **metaphor**, sounds and haptics.	Chapter 9	Chapters 7 & 10	Chapter 12
Is the visualisation's interpretation ambiguous or one-sided?	Representation	**Ambiguous**, one-sided	Chapter 9	Chapter 7	Chapter 12
Do you visualize actual data or metadata?	Representation	Actual data, **metadata**	Chapter 13	Chapter 10	Chapter 11
Do you have an « overview -> details » information structure?	Representation	**Yes**, no	Chapter 13	Chapter 10	Chapter 11
What (visual) parameters do you use in your visualisation?	Representation	An object's **location**, size, texture, **color**, shape, orientation, movement, sound	Chapter 13	Chapter 10	Chapter 12
Is your visualisation static or dynamic?	Representation	**Static**, dynamic	Chapter 13	Chapter 10	Chapter 11
How free is the user, regarding text input?	Interaction	Not free, add options, **free with limitations**, free	Chapter 13	Chapter 7	Chapter 11
On what level in the data does the user start the interaction?	Interaction	Full overview of all data, overview of one variable, **no overview**	Chapter 13	Chapter 10	Chapter 11
Does the user explicitly see his own data in the dataset?	Representation	**Yes**, no	Chapter 13	Chapter 10	Chapter 12
Does the user compare to, or identify with, others?	Representation	Compare to, **identify with**	Chapter 13	Chapter 10	Chapter 11
Do you use percentages or absolute numbers?	Representation	Percentages, **absolute numbers**	Chapter 13	Chapter 10	Chapter 12

Identified design question	**Question category**	**Identified possible answers & case answer (in bold)**	**Short explanation of case answer in…**	**Question mostly explored in…**	**Answer mostly validated in…**
How do you deal with large quantities of data?	Representation	**Zoom and clusters**, percentages, show data subsets	Chapter 13	Chapter 10	Chapter 11
In what ways can the user interact with the system's components and navigate through the data? What happens with each action?	Interaction	**Digital: click**, double click, swipe, **zoom**, **drag**, draw shape, and more. Physical: press, pull, move, voice input and more	Chapter 13	Chapter 10	Chapter 11
Does your visualisation use metaphors?	Representation	Yes in a concrete way, **yes in an abstract way**, no	Chapter 13	Chapter 7	Chapter 12
Does the visualisation *communicate* the message or *support* the message?	Representation	Communicate, **support**	Chapter 13	Chapter 10	Chapter 12
How is the visualisation interactive?	Interaction	**Inside the representation, outside the representation**, it is not.	Chapter 13	Chapter 10	Chapter 11

Table 5 Overview of this project's results: the identified design questions and answers

14.2 Next iteration suggestion

Results were collected during the usability test (Chapter 11) and the visualisation test (12). Several points for improvement were identified, and participants gave some suggestions to improve the prototypes. After Chapter 12's prototype and test, no next iteration based on these latest insights was made. Therefore, I made a selection of improvements, based on Chapters 11 and 12's insights, that I would do next in a new iteration after the iteration as explained in Section 12.1. This is described in this section. See Section 11.2 and 12.2 for all test results.

Most importantly, messages should be more positive and contain tips. People should be motivated to share e.g. their solutions to inconveniences, inspiring messages, or what activities they are able to do again. Currently, there may be too much focus on complaining and the negative side of the recovery process. Users should be able to help and inspire each other and together go forward. This way, users might be more motivated to write and read messages and to use the app longer. Several test participants said they wanted to read tips, and they expected to find these in the app. To achieve this, it could be good to introduce some 'tags'. When writing a message, users can tag their message e.g. as 'tip' or as 'progress'. Then people can search on these tags with the search bar. To motivate users to write a message, one or more starting phrases could be introduced.

Secondly, the application should be made more interactive. Now, users can only read messages of others, but they cannot interact with them. For some users this is what they want, so interactivity features should always be optional in the options menu. To achieve this interactivity, it could be good to ‘upgrade’ the starring feature. For example, users could get a notification when someone starred their message. By starring a message, you can let the message’s owner know that you found his or her message e.g. inspiring, or that you support him or her. Furthermore, some test participants indicated that they would want to get in contact with other users, e.g. if their messages are particularly inspiring or similar. Whether you want to contact, and be contacted by, others should also be an option.

Lastly, test participants suggested more transparency and freedom in sharing messages with the doctor. It should be clear with which doctor the messages are shared exactly. It should be possible to decide what selection of messages you want to share. Currently, users can only share all messages at once. Additionally, users should be able to edit messages later on. Currently, messages can’t be edited once submitted in the app and this feels too definitive.

15. Discussion

The case contribution

The designed visualisation and the app as a whole received many positive reactions during the usability test and the visualisation test. Earlier on, the concept received positive reactions from post-operative patients during semi-structured interviews. Test and interview participants said that it would be reassuring to see that you are not alone having issues and that your issues are normal. The visualisation of the user among other patients as a cluster of balls was reported to enhance this feeling of connection with others. The possibility to look ahead in time and to see how an issue could develop in the weeks to come can be hopeful and help to set an expectation. Participants also indicated that they would be able to ask more specific questions to the doctor, and contact him/her earlier when an issue appeared to be abnormal.

However, there are also some potential risks. The app could have a negative influence on users, instead of the intended positive one. For example, users can get more scared or depressed when seeing that they are behind on the 'normal' or when seeing how long the recovery will still take or when reading negative and scary experiences. This was also mentioned a couple of times by post-operative patients and usability test participants. Arguably this issue is hard to completely remove. There will always be people that interpret information negatively. Nonetheless, pop up messages should motivate users to contact the doctor when they are worried.

Furthermore, the app has a risk of spreading false information. People could share tips that actually have a negative influence on recovery, or false information they found on untrustworthy websites, for example. Even unintended, people can share false information. A possible solution is that some 'moderator' verifies each week all new messages of that week, and adjusts or removes the ones that are false or insulting. However this introduces a new issue, because this moderator could easily censure the app's information. Even though patients share a negative story that is not reassuring, it is part of the 'normal' representation. A moderator influencing messages, thus what users see as normal, should carefully distinguish false information from negative but true information.

Besides this, it is risky to match users that are different and represent them in the app as equals. Now people are matched based on week after hospital release and age, but this may be not specific enough. Within this group, people could have e.g. a whole different medical profile. If an athletic and healthy person suggests an exercise to someone that is totally not athletic and has diabetes, these exercises could maybe work adversely for the latter. For safety reasons, it could be wise to match people based on more information, even though this would display less people in the visualisation. It is also an option to show messages of the most similar people the closest to the user's central ball.

The number of app users might diminish drastically over the weeks. Many users might use it the first weeks and when they feel a bit better, they stop using it, even though they still experience some hindrances (to a lesser extent than before). Consequently, the app could have much less entries in the later weeks. Thus the difference in number of people who have a hindrance may become very big between the first and second month, bigger than it is in reality. Arguably, this behaviour is created due to design choices in the app. The app allows such behaviour (stop using the app at any moment). Thus, more generally, design choices influence what people see as normal in the app, what information they have at their disposal. Based on this information, they make decisions regarding their health. This is delicate because people can then make unwise, or even dangerous, decisions. There is thus great responsibility in the design of products about people's health, such as this app. Design choices could directly influence people's decision-making about their health. Especially for this user group that is of weak health, this is risky. Information transparency might help against these issues. Users should be aware that the information is coming from other patients, who are no experts. Their experiences can be hopeful or helpful, but should never replace a doctor's consultation. Showing more specific user profiles to estimate whether someone is really similar to you is also a form of information transparency.

In this project an app was developed, because I wanted to make something that could be used right now, instead of a technology-push product for 'in the near future'. Besides, from the company's perspective, apps are cheaper to produce and to spread than physical products. However, from a design perspective, it would be interesting to more thoroughly explore possibilities to develop tangible products for embodied interaction. This is a promising domain. Tangible products could create richer interactions with more senses and that more seamlessly fit in everyday life. The rejected idea, the recovery calendar idea, was more interesting in that sense, because it followed personal design ideologies. It was rejected because the problem it was intended to solve, appeared to be no problem. Nonetheless, the concept was interesting, using a physical product and interaction, freedom of expression and customisability. Other, more extraordinary ideas would also be interesting, such as dynamic visualisations that constantly move and display different information, or ambient information displays that display information passively and subtly in the background. It would be interesting to explore these possibilities for the 'Is this normal?' problem.

Lastly, the app was made for open heart surgery patients, but the concept of sharing experiences labelled as categories to identify with or compare to others could be applied to other cases as well, see Figure 2 in Section 1.2. It could equally be useful for patients of other impactful treatments and diseases, such as cancer, (long) covid-19 or chronic diseases. Outside healthcare, it could be used in other ways, such as to visualise questionnaire results. It may be a clear way to show people's questionnaire answers among those of others and to evoke solidarity with them. More generally, it could be useful to connect a group of people who experience a similar process over time, such as the period of pregnancy or the process of immigrating to a foreign country.

The design contribution

26 design questions were identified throughout the design process, as well as a variety of possible answers to each question. This proposed set of questions should be a useful base to start designing visualisations from in other design projects. The questions address issues that are generally encountered at the start, as well as issues that are encountered later in the process, such as 'What problem do you want to solve?' and 'How do you deal with large quantities of data?'. However, the list is not necessarily definite. Other design processes for other cases could reveal additional questions that can be added to this list. Besides, some possible answers were provided for each design question, but there could be other answers that were not yet found. This set of design questions is a continuous project and knowledge base that will expand with every project involving a visualisation.

The design research process

During the design research process, insights were derived from a variety of sources and activities with different people, such as a literature study, UX and UI designers, interviews with healthcare experts and patients, and a test with participants who resemble the target group. Many design choices have been identified, explored and validated with these activities. As a result, the final concept is a combination of well-considered design decisions. Furthermore, the list of identified design questions addresses a broad variety of issues that designers may encounter while designing non-numeric information representations. Nonetheless, some remarks should be made on the activities that were done and the design decisions that were made.

Firstly, the initial problem given by GSL was a design problem: how to visualise non-numeric data? However no practical context was given for this problem, other than 'the healthcare sector'. Consequently, much time was spent on finding and specifying a case problem. Ten weeks of preliminary research, preceding this project, were spent on this, with a literature study and interviews. Then in the graduation project a considerable period was spent on this as well. In other words, much time was spent on 'what' do we need to visualise in the first place, before I could start looking at 'how' to visualise it, while this 'how' was mostly of interest for the company. With a more specific case from the start, more time could have been spent on exploring different visualisations. However, it is also true that defining the problem is already half the work. If the problem is fully clear, decisions for the visualisation become more evident. Thus, if a design choice is hard to make, it could mean that the problem you want to solve is still vague.

Secondly, the recovery calendar idea was possibly rejected too easily. It was rejected because a heart specialist firmly denied the problem the product would solve. Next, only the 'is this normal?' idea was proposed to post-operative patients. It would have been better to show both ideas to the patients. After all, they are the target group and their opinion on the product could have been different than the specialist's opinion. Furthermore, not all possible design choices have been evaluated thoroughly throughout the project. Sometimes, a decision was made while alternatives were not proposed. Even though the made decision received positive feedback in validation activities, it is uncertain whether alternatives would have been received even better. For example, a static visualisation was made, but a dynamic one was not thoroughly explored or proposed. Making a static visualisation seemed evident given the target group's average understanding of digital technologies. Arguably, a static visualisation is simpler and corresponds better to what is expected than a dynamic one. However, unexplored dynamic visualisations could still be promising.

Thirdly, the project was done in collaboration with one hospital. All interviewed post-operative patients were operated and treated in this hospital, following the hospital's approach of recovery. However, other hospitals could use different approaches. This was confirmed by the revalidation expert. Especially the first six weeks after hospital release were problematic for patients from this hospital because the revalidation trajectory only started after six weeks. However, in other hospitals this could start earlier, for example after three weeks. This has two consequences. First, the app cannot simply mix users from different hospitals, because these people might have a different revalidation trajectory which influences their (perceived) hindrances and worries, and thus the resulting 'normal' that the app would show. Second, design decisions were made based on this hospital's situation, but patients from other hospitals might have other needs or problems to solve.

Lastly, several validation activities have been done, such as interviews, a concept test and a usability test. However all these activities only had a limited number of participants. Furthermore, due to covid-19 measures, some activities' participants were not exactly the target group. Most notably, the usability test was done with colleagues from the company, among whom some had an expertise in e.g. design or video and audio. These people were thus not exactly representative of the target group, and also not of the general Dutch population. Design decisions have been made based on these activities' results. If more participants, preferably from the target group, were recruited for these validation activities, the results could have been different, which might have led to different design decisions. Thus, more testing is required to fully validate the made decisions.

16. Conclusion & future work

16.1 Conclusion

Main research question

What are design choices for a non-numeric information representation tool that helps patients to estimate the seriousness of their worries and to express them towards the doctor in the aftermath of an impactful open heart surgery?

- ➔ A total set of 26 questions, i.e. choices to be made, was established while designing the tool. These questions can be divided in three categories: 'data', 'interaction' and 'representation'. 'Data' questions focus on identifying the problem that needs to be solved and what data will play what role in its solution. The design process starts with these questions. 'Interaction' focuses on how users interact with the data and how they possibly add new data. 'Representation' focuses on how the actual data is represented and how it communicates its message. In this project much time was spent on problem specification. If the problem is as clear as possible, decisions for the visualisation become more evident. A card set of the identified questions was made. Each single card shows one question and possible answers to this question. The card set can be found in Appendix 5. It could be useful for other designers that want to visualise non-numeric data in a clear and nuanced way in other cases. The design decisions taken in the case that was described in this thesis, being answers to the questions, can be found in Chapters 6, 9 and 13. A list of all questions and answers can be found in chapter 14.

Sub-question 1: current situation

What is the current situation regarding the patient's treatment before and after an open heart surgery?

- How do the patients experience this procedure and aftermath, what matters to them and what issues do they encounter regarding patient-doctor communication?
- ➔ Patients have a complicated revalidation process and develop worries about it. They have many hindrances and wonder whether these are normal or not, how long they should last and what activities they can do again at what point in time. Pre-operatively, there is little attention for post-operative expectation setting. This increases the risk of post-operative unexpected issues and hindrances, and worries about them. Consequences of these worries and consequences of the actual surgery are similar and hard to measure, thus hard to treat. Patients value clear communication and empathy from doctors. They address their daily life hindrances and worries during consultation. Doctors reassure patients and behave in an informal way. However, they can't always provide a treatment plan that patients want. Patients want a normal life, and the doctors want patients to have a healthier life. Moreover, patients have little contact with the specialists in the weeks after release and before the revalidation trajectory. Patients can feel a barrier to get in contact with their specialist when worried or having questions. As a result, these worries and questions remain unexpressed until the consultation or revalidation trajectory. Before then, they could be harmful and hinder recovery because they can lead to stress and feelings of depression, which is bad for mental and physical health.

- What information about the patient do the doctors want to know before and after the surgery?
- ➔ Before the surgery, doctors are mainly interested in patients' medical profile, i.e. if patients have medication, if they have had other major surgeries before, or if they have diseases such as diabetes. After the surgery, doctors mainly evaluate the surgery's success based on medical

information such as blood values and scans of the heart and chest. This information is shared with patients to tell if the surgery has been successful. However, such information might be hard to fully understand by patients, not being medical experts. Regarding the recovery process, doctors are interested in the recovery development *over time.* They would like to have information of how patients are doing in intervals, and not only from one moment, such as during consultation.

- What is existing work on worries in the aftermath of a surgery and what are solutions for this? What can be learned from it, and how can it be expanded?

➔ Existing work consists of higher level design knowledge as well as of solutions for specific cases. Regarding the design knowledge, Berry et al. [19] identified seven dimensions on which tools to support communication can differentiate. By facilitating patient-doctor communication, taking these dimensions into account, patients could more easily express their worries. Lim et al. [18] found eight implications for the design of tools for reflection. According to them, patients should reflect on their personal values before going to the consultation. This way, they could more easily express their worries and what they find important. Besides this, work was read on how to design pleasurable and meaningful experiences for users [22][23][24]. According to these authors, products should not only be usable, they should connect with the user on an emotional level.

Regarding the solutions for other cases, the designers used inspiring approaches, such as focusing on customization of the product and freedom of expression [26], enhancing existing household products to design for existing habits [30][31], or providing overviews of relevant information [32] [29]. The insights that were obtained from this related work were used as inspiration and starting points, or different perspectives, for ideation. This work was expanded in two ways. First, the design knowledge contribution consists of a set of questions that should help other designers to develop non-numeric data representations in other cases. Second, the designed tool is a possible solution to worries that patients develop while recovering. It allows them to estimate the seriousness of their post-operative worries and to express them towards the doctor by showing how many others have similar experiences. This solution could also be used in other contexts, such as for other conditions.

<u>Sub-question 2: information acquisition</u>

How to express and obtain patient worries after an impactful surgery? (e.g. 'anxiety': in what terms to express this, and how to obtain this information?)

➔ Patients express worries in terms of *hindrances* that they have at a given *moment in time* while recovering. Together with post-operative open heart surgery patients, a list was made of all hindrances that such patients can experience, such as pain, tiredness and breathlessness. Time is a crucial variable as well. Having headaches in week two may be normal, while having these same headaches in week five could be rare and worrisome. The tool asks patients about their current hindrances when opening it. Patients first submit their hindrances, then the app shows how many others also experience these hindrances. This way, patients' information is obtained, while patients receive answers to their questions.

Sub-question 3: information representation

How to represent patient worries in order to estimate their seriousness and to facilitate their expression towards the doctor?

- ➔ In the tool, patients submit their hindrances by choosing from a list and they describe their experience in a short text message. Then, the app shows how many others submitted one or more of the same hindrances at that certain week during recovery, now or in the past year. This number is visualised as a cluster of balls that is meant to evoke a feeling of solidarity and connection among the patients. The user is represented by the central ball, and all others, each individual represented as one ball, who submitted one or more of the same hindrances in that specific week after hospital release, appear around him. In the first place, by viewing themselves amidst others, patients can find reassurance in the fact that they are not alone having specific issues. This could sooth 'unnecessary' worries regarding issues that are shared by many and thus that appear to be normal to experience. Here the app helps to estimate the seriousness of the worries. In the second place patients have a good incentive to contact the doctor, in case their issues appear to be rare. Information from the application could be used to help explain their worries to the doctor.

  Additionally, in the tool patients can see how many others have a hindrance in later weeks after hospital release. This way they can estimate how this hindrance will probably develop over time and set an expectation for the weeks to come. Moreover patients can read the text messages of others, to learn in more detail what these people experience.

- How can this representation be used to also provide useful information for the doctor?
- ➔ By using the app, users regularly submit what hindrances they experience during their recovery period. This can be useful for the doctor. They can get an overview of the patient's recovery trajectory and notice any abnormalities. They could use this information to prepare the consultation with the patient. To guard privacy, patients' information is not shared with the doctor automatically. Patients can indicate in the app whether they want to share their hindrances and text messages with the doctor.

Sub-question 4: testing

How is the visualisation as part of the designed tool received and perceived by target users?

- ➔ People from the target group were only shown early concepts from the idea. Nonetheless, they were generally positive towards this. They would be interested in comparing themselves to others and in seeing whether issues are common or not. Participants from the usability and the visualisation tests who interacted with more representative prototypes were also mostly positive and said that it would be reassuring to see that others experience similar things as you do. It was found that visualising the user and all others as a cluster of balls contributes to the solidarity that users feel with the others. In most cases, participants from the usability and the visualisation tests understood the visualisation.

16.2 Future work

Regarding the case, it would be good to develop a working prototype that can be tested with real patients who are recovering. The changes to the design that were suggested in Chapter 14.2 should be considered when building a new prototype. Of course, during the test it has to be fully clear that it is a prototype and not a final product. Moreover it should be clear that the information in the app is from other patients and that they should not base major decisions on this. Such a test would mostly be useful to see how the product will be used in practice, i.e. how often per week will patients consult it? What messages will people actually share? How will the 'normal' look like? Will it actually be reassuring? What will the influence be on consultations? Such a test in practice would be essential to validate the design, because real patients in practice may behave differently than participants in tests. At the start of this test, there would not be any data yet (since data is collected by using the app). This could e.g. be solved by initially filling the app with place holder data that is generated in close collaboration with revalidation experts, or even with patients that have already recovered during the past year. Gradually, the real data that users submit could replace the place holders. This approach might only minimally influence the test participants' behaviour. Nonetheless, this problem remains delicate because solutions could easily influence test participants' behaviour and it should therefore be considered thoroughly while preparing the test.

Another interesting direction for future work is to follow design ideologies and to explore other approaches than apps, such as physical products, as was said in the discussion. Such products may be less conventional and they introduce scalability and logistical challenges that can be expensive to overcome. However, their advantages could be valuable. They allow for richer and seamless multimodal interactions that better exploit human motor skills, and that facilitate cognition [39].

Given the risks and the responsibilities that design for this case brings about, a study should be done on how to implement the product from an ethics, privacy, information transparency and responsibility perspective. Before that, it is irresponsible to launch the app because users might take dangerous decisions about their health, based on the app. This risk should first be reduced to the minimum.

Regarding the design contribution, the found design questions should be used in other cases to validate these questions themselves. In this project they are found, but it was not yet tested whether these questions really lead to successful visualisations in other cases.

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Appendix 1: post-operative patient questions (see Chapter 5)

1. Before the surgery, what was your expectation of the recovery process?
2. What were differences between your expectation and your actual recovery process? What was more positive or negative than expected?
3. What are questions that you ask yourself, or what is unclear or uncertain regarding the recovery process?
4. How do you experience the role of 'the hospital' (such as the cardiologist) in your recovery process? What does he/she do for you? What should he/she do for you?
5. What were your biggest worries regarding the recovery process?
6. To what extent have you consulted the personal information folder and for what information?
7. When are you the most hindered in your daily life, because of consequences of the surgery? And in what way?
8. Regarding the 'Is this normal?' idea, what could be improved about this, what do you like and dislike?

Appendix 2: personas (see Chapter 7)

Persona 2: Barrie

Occupation: accountant (retired)

Barrie is a widow. His wife unexpectedly died five years ago because of an aggressive form of breast cancer. He has struggled a lot with processing this tragic loss and he has started to do sports fanatically. Before his open heart surgery he walked at least two hours per day, and he boxed three times per week. Then he got a cardiac arrest and it appeared that an open heart surgery was needed. Now three weeks after the surgery he often goes for a walk again, and his children help him with the household tasks. He had not expected to be able to go for walks so quickly. This positive surprise gives him even more energy to revalidate and to start moving. However Barrie was very shocked and surprised by his cardiac arrest and he is afraid that this can happen again at any moment. He does not trust his body anymore and he does not dare to go for a walk alone. He does not want to be a burden for his neighbour and his children, who have to go walking with him all the time. After all, they already help him a lot with the household tasks. He is very uncertain about how much weight he is allowed to lift. It was told to him to "not lift heavy objects", but he does not know when exactly something is heavy.

Goal: Barrie would like to get rid of his uncertainties and doubts regarding his heart. He would like to do things independently without being scared that something bad happens to him.

Frustrations:

- He tries to convince himself that it will be alright, but severe pain make him doubt again.
- Because Barrie does not have a partner anymore, he sometimes has difficulties with expressing his worries.
- Barrie is a bit clumsy with computers and tablets.

Persona 3: Japie

Occupation: concierge on a primary school

Japie has had an open heart surgery for the second time and he is in his eighth week of recovery now. The first time, fifteen years ago, had gone very well. After three months he felt good again. He was relatively young back then. Now Japie is older and the recovery process is more complicated. He had expected that it would take longer, but not so much longer. Japie experiences all sorts of issues, such as shoulder pain, breathlessness, dizziness, and extreme tiredness. When resting it is okay, but as soon as he want to do something, he gets issues. His wife is very worried about him. She has looked on the Internet, but this did not make her happy. Since two weeks, Japie goes to the revalidation therapy. Because of his issues, he has difficulties with participating, and for this reason he does not really like it either. The revalidation expert says that his issues will diminish over time if he continues to move, but exactly this is the most painful. Pain is part of the process in this stadium, the expert says.

Goal: Japie would like to get rid of his pain and other issues. His wife wants to be reassured that Japie will be alright.

Frustrations:

- Japie is hopeful that his issues will disappear, but he has the impression that he has many issues this time, and that he has bad luck.
- Japie's wife is worried, even though the revalidation expert said it will be alright.
- Japie and his wife don't know anyone who has experienced the same. It is difficult to be understood by their family and friends, and to share experiences with them.

Persona 4: Truus

Occupation: control systems engineer

Truus has diabetes, and two weeks ago she has had an open heart surgery. During the pre-operative information session, the cardiologist already said that the healing process of the wound would take longer because of the diabetes. This would not take one, but two weeks. Now, after two weeks, she still experiences much pain around the chest. She is also often light in her head, but this will due to the narcosis. Because of the pain and the dizziness, Truus leaves most tasks for her husband. She tries to go for a walk every now and then, but she is very careful with this. Before the surgery, she walked a lot. She also used to swim, but she does not yet dare that. Despite the pre-operative information, she had not expected to be so limited in her daily life. Truus likes to consult the personal information folder that she received from the hospital. It is full of useful information about the recovery process, in her opinion. Besides this, she has good contact with her cardiologist. She has already called him once because of her worries about her pain on the chest. He reassured her that this was normal for diabetes patients. However, this conversation took place some days ago, and the pain remains. Truus thinks that it takes a long time, and she would like to start earlier with the revalidation. Unfortunately, this starts four weeks from now. She would like to start earlier to have more frequent contact with an expert and with other patients.

Goal: Truus would like to get rid of the pain on her chest, or receive more reassurance that it is normal that it takes so long to recover. She would like to know how exactly her diabetes influences her recovery process.

Frustrations:

- Truus likes to read the personal information folder, but it is not as personal as she wants it to be. The advice and guidelines are so general that she does not know whether they also apply to her as a diabetes patient.
- Truus sleeps very badly because of the pain.
- Despite her good contact with the cardiologist, she would like to have even more contact with him, but she thinks that this is not what people normally do.

Appendix 3: concept test and expert interview questions (see Chapter 8)

Concept test

After showing and explaining the three concepts

1. Would you use one or more of these apps? Why?
2. Which app is the most appealing to you, and which one the least?
3. Which app would reassure you the most if you had worries about whether certain issues are normal or not?
4. Can you mention two pros and cons for each app?

Revalidation expert interview

1. What are the core variables that influence someone's recovery process?
2. What information do patients really want to know when recovering?
3. What do patients tell you about their recovery process? What happens often in this period?
4. What are patients missing now, according to you?
5. When collecting patient data (as described in Section 4.2), when would you have collected enough to obtain a representative image of a 'normal' recovery process?

   After showing and explaining the three concepts

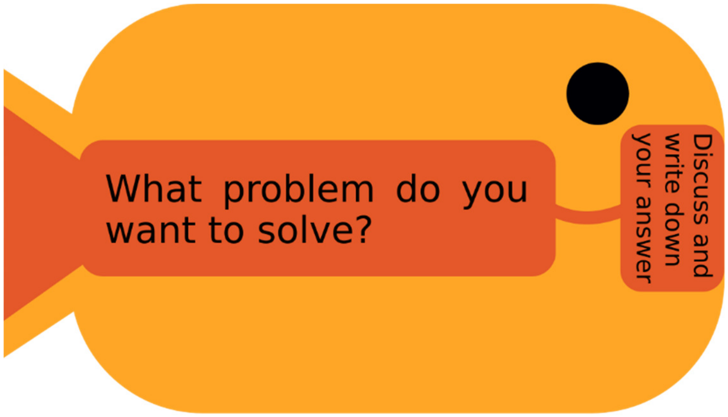
6. Which one of these concepts is the most appealing to you and why?

Appendix 4: usability & visualisation test scenario (see Chapter 11 & 12)

You are Joep, a 63-year-old man. Four weeks ago you have had an open heart surgery. Three weeks ago you have been released from the hospital. Now you are slowly picking up normal life at home again. The first weeks at home were heavy and insecure. The chest pain has diminished, but you still have severe headaches and you sleep badly. Besides this, your endurance is much worse than before and today you feel breathless. All these issues make you worried.

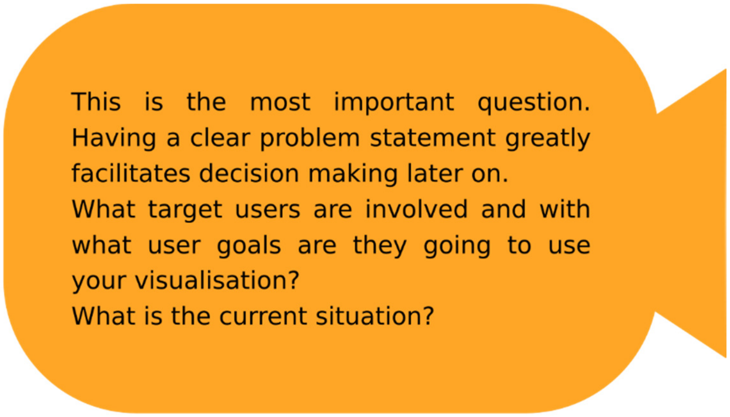
Is your recovery progressing as it should be, or should you be worried and contact the doctor? When should all these hindrances really disappear? This is all unclear to you. The Internet provides general or too specific answers. The hospital advised you to use the 'Together Strong' application. In this app you can share your experiences, and you can read those of other patients. You would like to try out this app.

Appendix 5: design questions card set, the Info Fish



What problem do you want to solve?

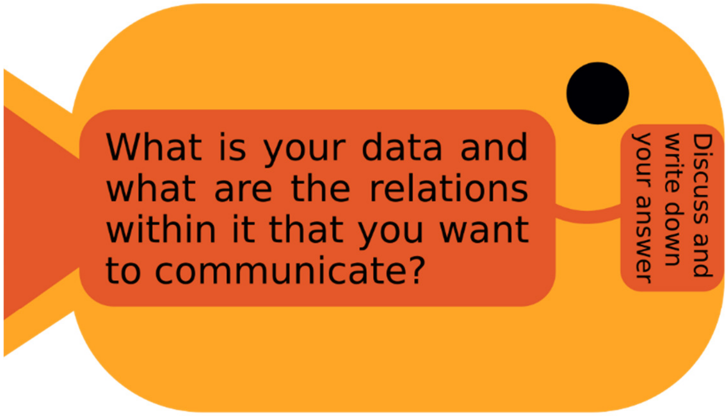
Discuss and write down your answer



This is the most important question. Having a clear problem statement greatly facilitates decision making later on.

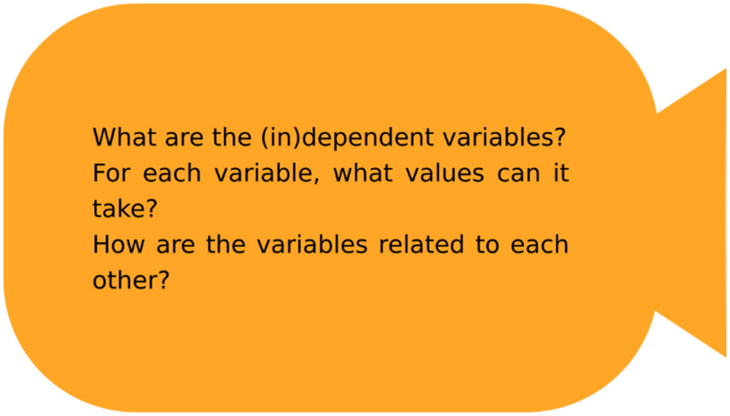
What target users are involved and with what user goals are they going to use your visualisation?

What is the current situation?



What is your data and what are the relations within it that you want to communicate?

Discuss and write down your answer

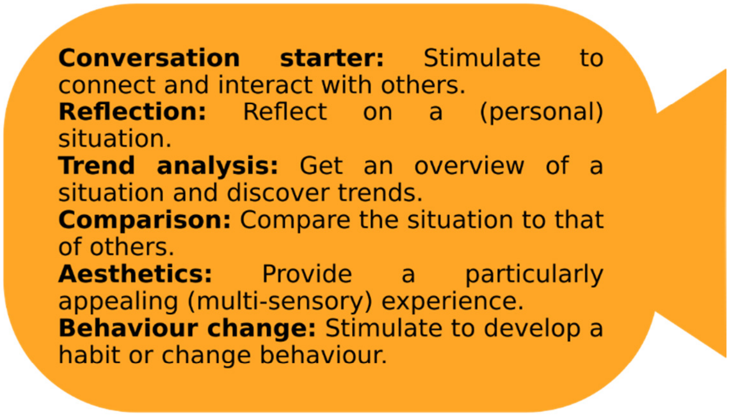


What are the (in)dependent variables?

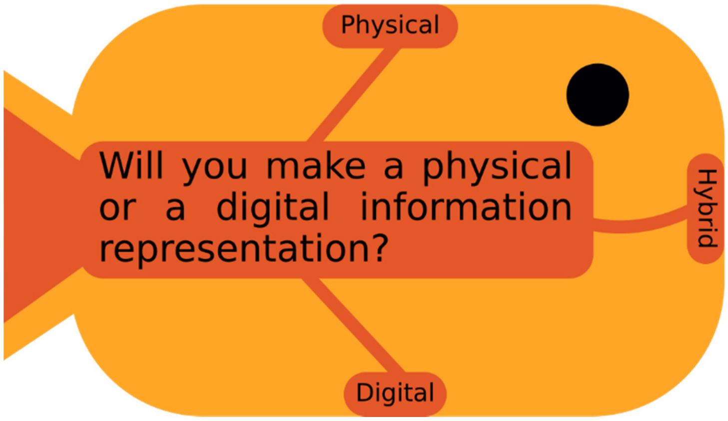
For each variable, what values can it take?

How are the variables related to each other?

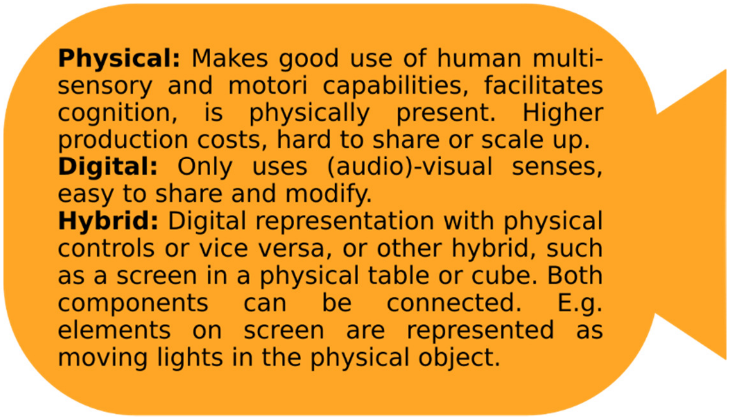
What do you primarily want to achieve with the data representation?



Conversation starter: Stimulate to connect and interact with others.
Reflection: Reflect on a (personal) situation.
Trend analysis: Get an overview of a situation and discover trends.
Comparison: Compare the situation to that of others.
Aesthetics: Provide a particularly appealing (multi-sensory) experience.
Behaviour change: Stimulate to develop a habit or change behaviour.



Will you make a physical or a digital information representation?



Physical: Makes good use of human multi-sensory and motori capabilities, facilitates cognition, is physically present. Higher production costs, hard to share or scale up.
Digital: Only uses (audio)-visual senses, easy to share and modify.
Hybrid: Digital representation with physical controls or vice versa, or other hybrid, such as a screen in a physical table or cube. Both components can be connected. E.g. elements on screen are represented as moving lights in the physical object.

With what actions can the user navigate through the data and what happens with each action?

Discuss and write down your answer

Digital actions: Click, double click, swipe, zoom, hold, hover, drag, draw a shape, sound/voice input, move/shake the device.

Physical actions: Press, pull, move an object, shake the device, sound/voice input, body movements, draw/create a shape.

Once, or a few times

How often and how do you capture the user's attention?

Regularly

Once (or a few times): E.g. installation in a museum or on a festival, or visualisation in a magazine. Draw attention e.g. with size, sounds, lights, movement, interactivity, or an interesting question.

Regularly: To make the user come back, e.g. incorporate the visualisation/object in an existing habit/pattern/device, use gamification principles, make the experience particularly pleasant, answer recurring user questions, help users to reach their goals, use pop-ups/notifications, make each interaction different or surprising.

Inside the representation

How is the information representation interactive?

It isn't

Outside the representation

It isn't: E.g. an image or a piece of art. The user can't control what is shown.

Outside the representation: E.g. buttons that are separated from the representation itself. All options for interaction are visible via the buttons. Interaction is straightforward, too many buttons can get messy.

Inside the representation: The representation's components themselves are interactive. May be intuitive for e.g. zooming or selecting subsets. Can be elegant and minimalistic, but make sure the interaction possibilities are clear.

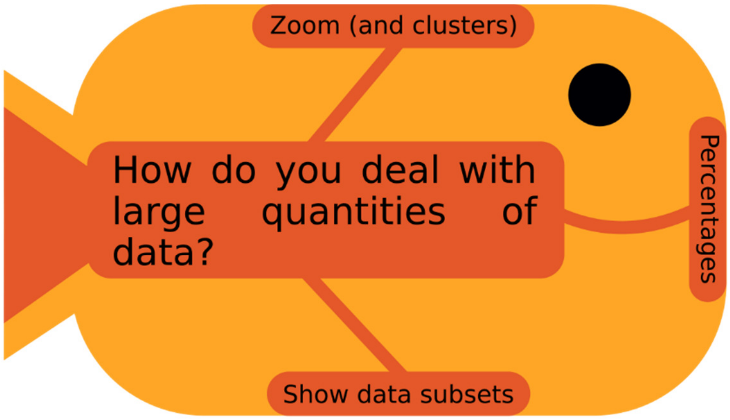
Dynamic

Is your representation static or dynamic?

Static

Static: Components don't move all the time. Possibly fits better to what people expect, because this is more standard.

Dynamic: Components move continuously. Constantly, different data relations or different levels of detail become visible. E.g. something is revealed when two components collide. Could be part of a chosen metaphor. Can get messy and uncontrollable. Can be aesthetically pleasing and an eye-catcher due to movement.



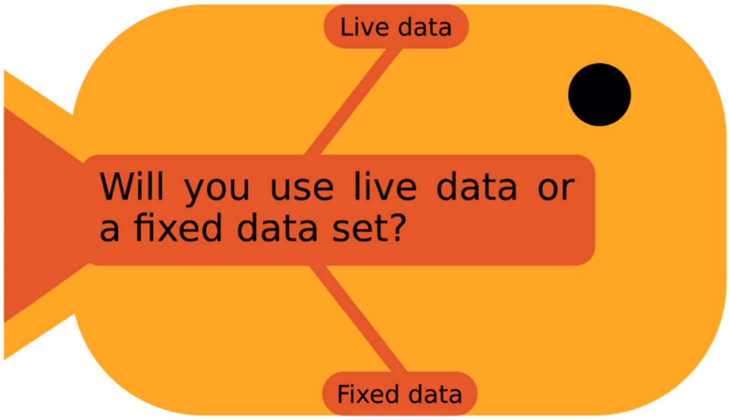
How do you deal with large quantities of data?

Zoom (and clusters)

Percentages

Show data subsets

Zoom (and clusters): Allow enough zoom-out and accept that details are not visible then. Cluster similar cases together when zooming out. Show the number next to the representation, so the quantity is still clear.
Show data subsets: Only show a subset of the total, plus option to see more.
Percentages: Represent percentages instead of absolute numbers.

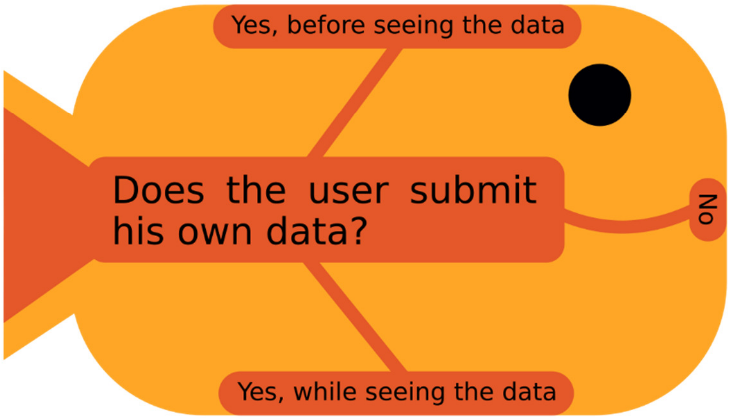


Will you use live data or a fixed data set?

Live data

Fixed data

Live data: Could be more personal, and could give a representation of the current users. Fits well with users submitting their own data. Could give skewed representations if temporarily one sub-set of users is overly present.
Fixed data: Can be more representative and stable, but less personal.



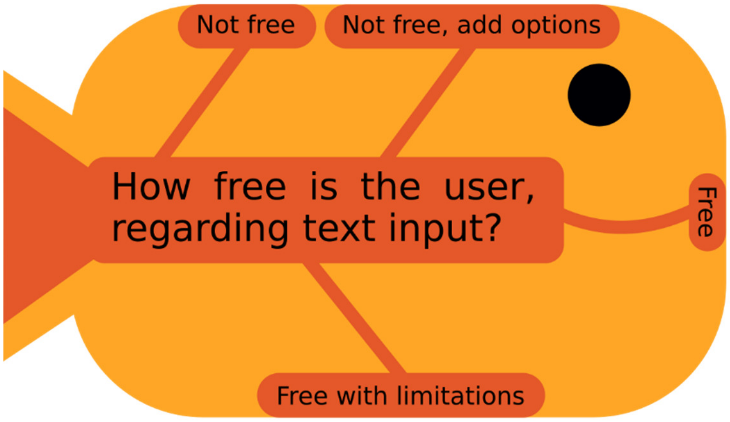
Does the user submit his own data?

Yes, before seeing the data

No

Yes, while seeing the data

No: The data can still be relevant for users. The user's data does not need to be collected. Less user effort.
Yes, before seeing the data: Submitting data could be a requirement to see the data representation. Users might give 'expected' answers, but they are not influenced by others. Fits well to representing live data.
Yes, while seeing the data: Users already see the information of others before submitting, and get reference points. Users could give more honest answers, but they could get influenced by the data of others.



How free is the user, regarding text input?

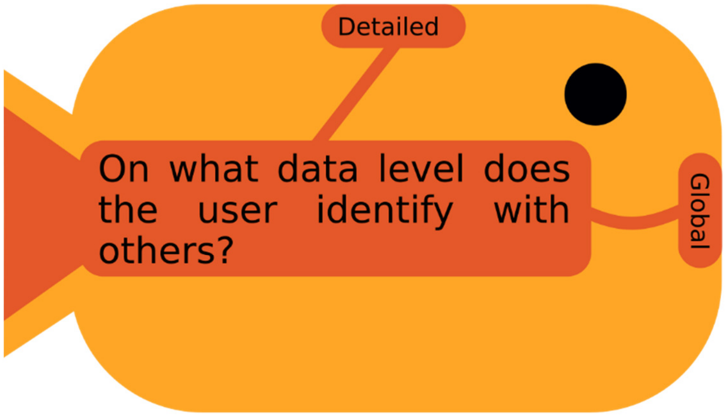
Not free

Not free, add options

Free

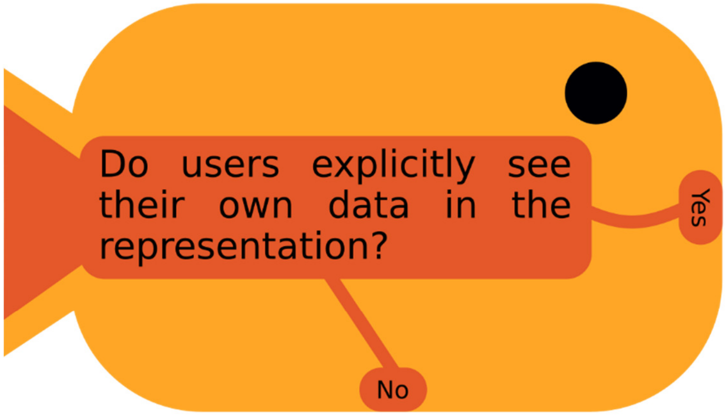
Free with limitations

Not free: The user can choose between pre-defined options. E.g. fill in gaps in a pre-made text, using dropdown menus.
Not free, add options: Next to pre-defined options, users can add their own options to the list.
Free, with limitations: Users can write their own text, but with a maximum length or other constraint.
Free: Users can write their own texts with no constraints. More freedom = harder automatic classification, harder to compare, higher risk of undesired behaviour, more user effort, more personal and human, more nuanced.



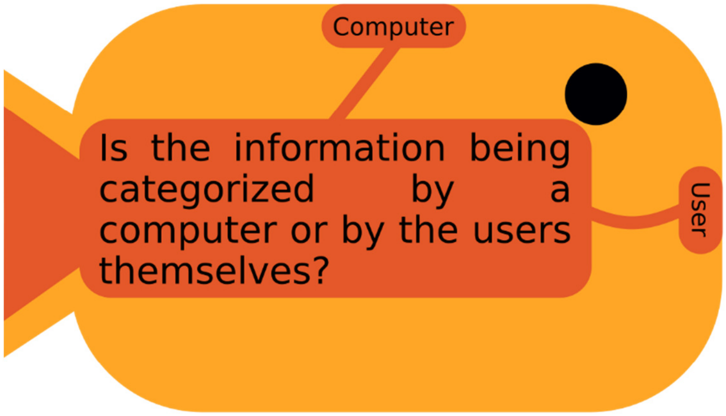
On what data level does the user identify with others?

Global: Users see many people who share one or few global characteristics, such as 'having pain' or 'eats fruit daily'. Shows many companions, quantity, creates solidarity among many people.
Detailed: Users see people who are very similar to them, having many characteristics in common. Creates solidarity among a few people, quality. Requires more information input from the user.



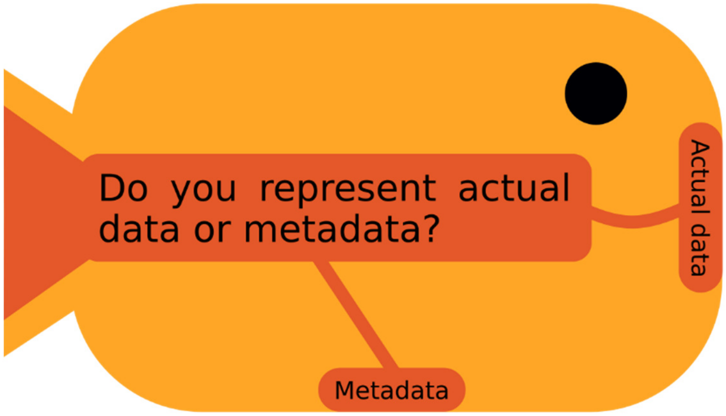
Do users explicitly see their own data in the representation?

Yes: Allows users to identify themselves among others and to put their situation into perspective. Makes clear that the user's input has been received.
No: Less personal. Data submission is maybe not needed at all. How do users know that their data has well been received?



Is the information being categorized by a computer or by the users themselves?

Computer: Technically more complex with e.g. textual information, risk of interpretation errors, everyone is treated equally.
User: Requires more user effort, stays true to the user's personal experience. Something that is in fact similar could be categorized differently by different users.



Do you represent actual data or metadata?

Actual data: Could give a close and nuanced representation of the data. Could be good to represent experiences and to keep the representation human and warm.
Metadata: Creates an overview of interesting properties, which is useful to compare and to see trends. Metadata are often related to numbers and quantities. They can be clear and simple.
Men might prefer numbers and quantities, while women might prefer exchanging experiences.

Communicate

Does the representation communicate the message or support the message?

Support

Communicate: The representation is the main channel to communicate the data/ message. The representation should thus be clear and easily readable.
Support: The representation supports another channel, such as a number or short text, in communicating the message/data. The representation can focus on evoking a feeling, and is rather taking the role of an image or interactive experience. There is less need for clear data communication via the representation, given the clear main channel.

Yes, in a concrete way

Does the representation use metaphors?

No

Yes, in an abstract way

Explanation: data relations are explained via relations in the metaphor that people are familiar with from everyday life. Don't create too much visual clutter. Metaphors can also evoke feelings.
No: Make sure the data relations are clear in other ways, e.g. by using conventional representations such as bar graphs.
Yes, in a concrete way: The metaphor is used as it is known in the real world. E.g. a cluster of penguins hiding from winter cold.
Yes, in an abstract way: The metaphor is used with abstract shapes. E.g. a cluster of balls, dealing with the same situation.

What (visual) parameters do you use to represent different variables and their values?

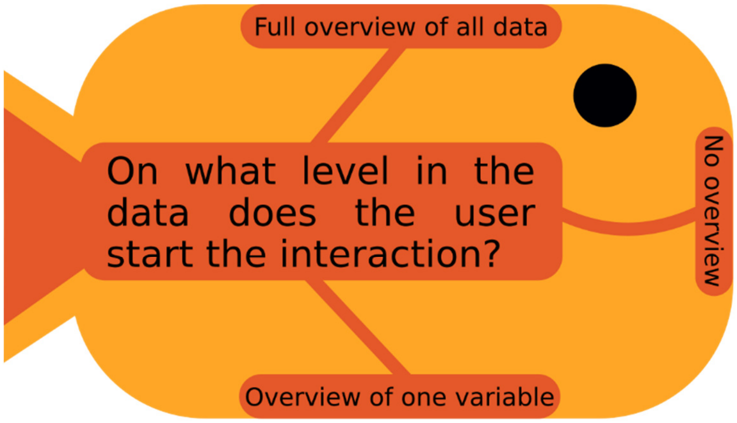
Discuss and write down your answer

For example: The location of an object on the surface, the size of an object, the texture of an object, the color of an object (take color blindness into account), the shape of an object, the orientation of an object, sounds, movements of objects.

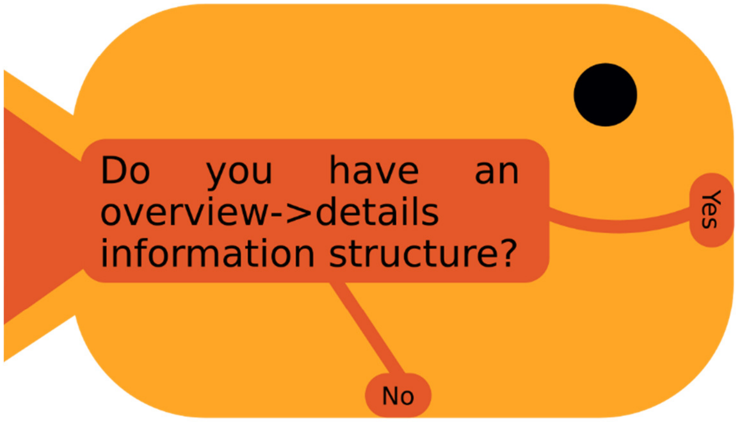
How does your representation evoke a specific feeling?

Discuss and write down your answer

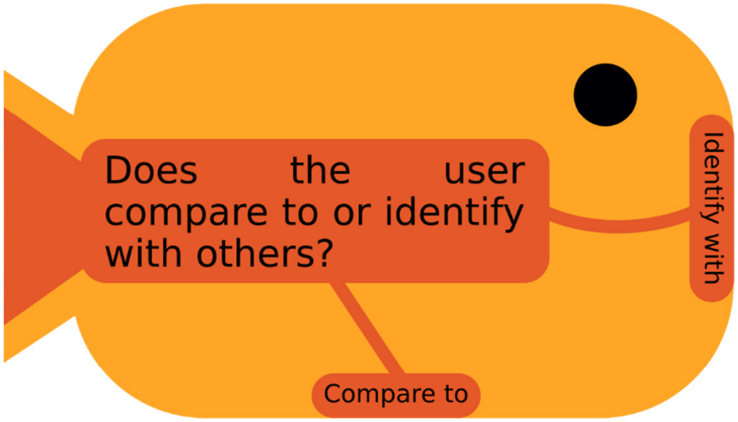
Animations and motions: E.g. rapid and decisive motions versus slow and gentle motions. Motions support the continuity of elements, unlike static displacements.
Shapes and colors: E.g. blue is cold, orange is warm. Round is soft, square is rigid.
Relative arrangement of elements: The arrangement of all single data elements together can form a shape of its own that emits a feeling or represents something.
Metaphor: Familiar events evoke feelings.
Sounds and haptics: E.g. environmental sounds set an ambiance. Rough versus smooth, wood versus plastic.


On what level in the data does the user start the interaction?

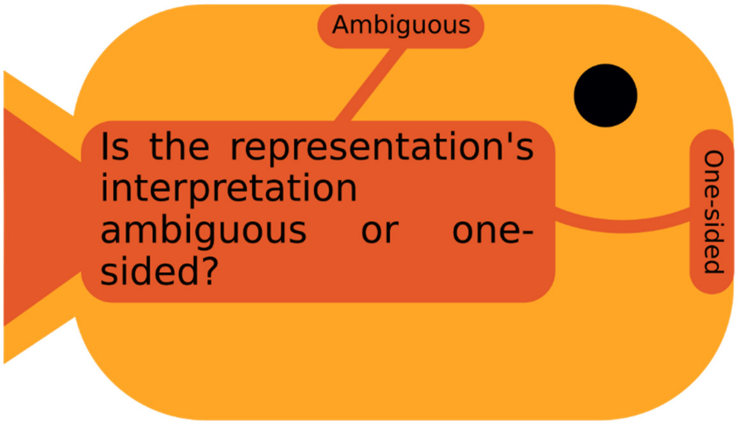
Full overview of all data: Is this relevant and not too messy? Can be a clear starting point for further navigation.
Overview of one variable: What variable is key and could be an intuitive starting point for more detailed data?
No overview: Focused and specific on one value, may lack overview, and create unclear navigation. Allow to explore other data as well.
In general: if the user submitted data, start by showing this first. This may be expected.


Do you have an overview->details information structure?

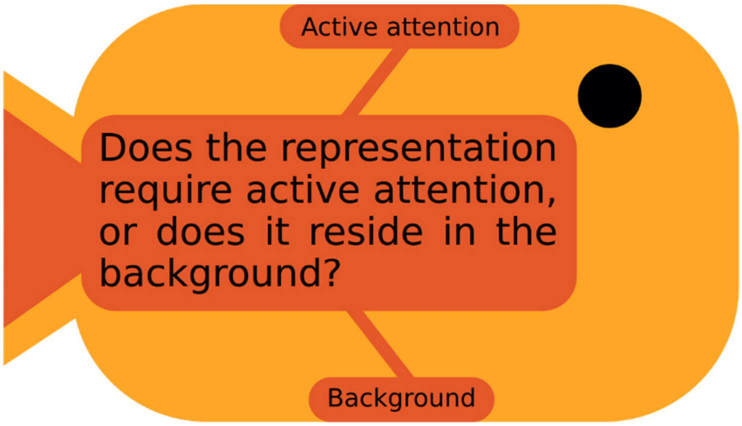
Explanation: Overview->details means that users first see an overview of available data. Then they can navigate to more detailed data of their interest.
Yes: Does the overview show the key insights? How do you navigate between overview and details?
No: Why not? This is an intuitive and well-known convention. Be sure to have a good reason for not following this convention.


Does the user compare to or identify with others?

Compare to: The group to which the user belongs is represented among groups of other users with other characteristics. Users see the influence of certain characteristics. They put their situation into perspective.
Identify with: Users only see the group to which they belong. They find companions and like-minded people.

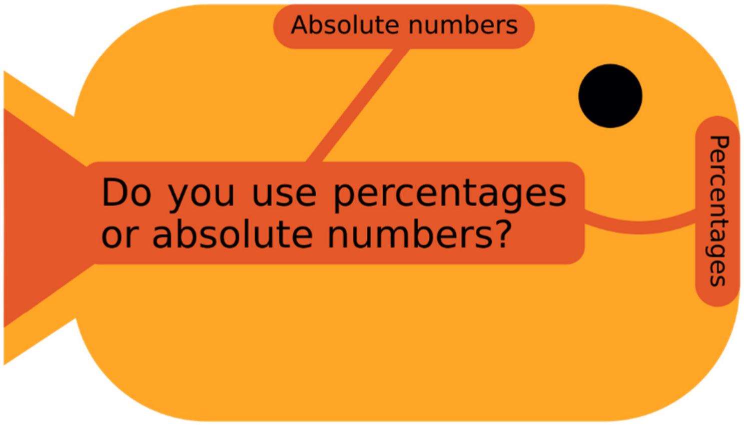

Is the representation's interpretation ambiguous or one-sided?

Ambiguous: Notions, such as happiness, are not linked to any pre-defined elements. Users can decide for themselves what to express with, or how to interpret, these elements. This meaning is not necessarily immediately clear to spectators. E.g. green is not better than red, many stars is not better than few stars. Allows for customization, personal storytelling and sense-making.
One-sided: Notions are linked to pre-defined elements, following conventions. E.g. red is bad, happiness is smiley, five stars is good. Easy to understand. Less free and creative.



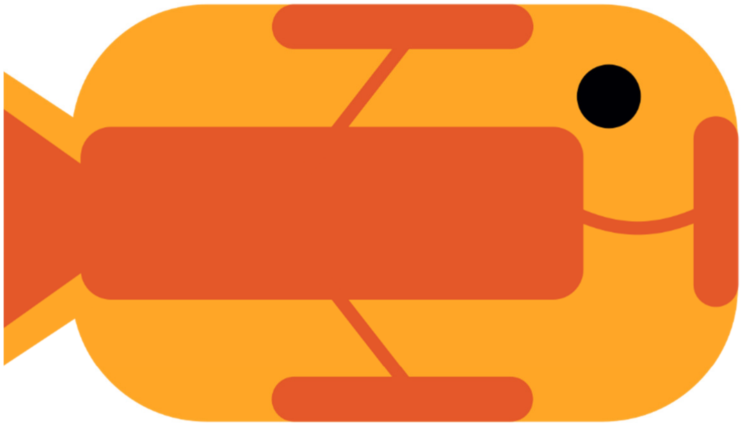
Does the representation require active attention, or does it reside in the background?

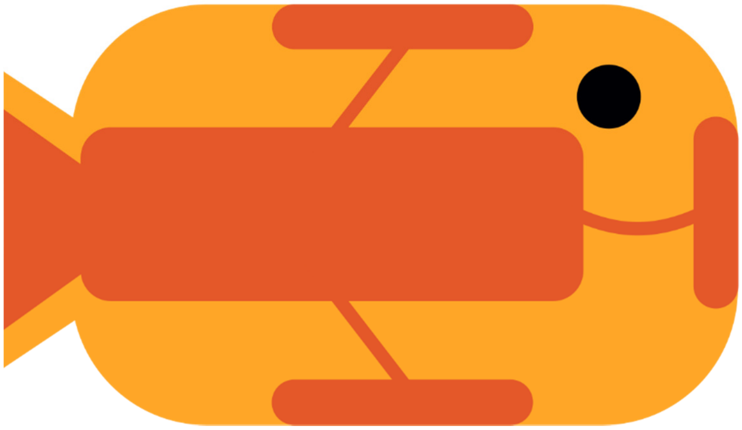
Active attention: The user pays attention to, and interacts consciously with, the information representation.
Background: Ambient representations. The user is often less aware, or unaware, that information is being communicated. Communication is subtle and blended in the environment. Works well with physical and/or artistic representations. E.g. patterns on (household) objects, or the varying size, color or location of objects, could be used to represent data.



Do you use percentages or absolute numbers?

Absolute numbers: Clear communication of quantities. The number stays true to the actual value that is represented. Harder to handle large quantities.
Percentages: Useful for comparisons with large quantities of data. Can be confusing about absolute quantities and significance of the data, e.g. 67% can be 2/3 but also 100/150. Be careful with representing absolute values and showing percentages, this can be misleading or confusing.





Instructies:
1. Schud de vissen en verdeel ze onder de deelnemers.
2. Doe steen-papier-vis om te bepalen wie begint.
3. De winnaar legt een vis uit zijn/haar hand op tafel. Tip: Speel de vis met de vraag die je het meest aanspreekt.
4. Bespreek de vraag met het team en kies één van de antwoorden. Op de achterkant van de vis staan de antwoorden uitgelegd.
5. z.o.z.

Instructies, vervolg:
5. De volgende speler legt een vis uit zijn/haar hand op tafel. Leg de vissen aan elkaar met de staart van de nieuwe tegen het antwoord dat jullie zojuist gekozen hebben van de voorgaande.
6. Bespreek de nieuwe vraag en kies wederom één antwoord.
7. De volgende speler sluit op dezelfde manier, zie (5), een vis aan, enzovoorts.
8. Alle aaneengelegde vissen vormen een handig overzicht van vragen en (voorlopige) antwoorden voor jullie project.

A physical version of the Info Fish card set was made for the company to work with, as well as a box to keep them all together. The cards were made from paper and the box was made with a laser cutter.

Does the representation require active attention, or does it reside in the background?

With what actions can the user navigate through the data and what happens with each action?

Will you make a physical or a digital information representation?