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Personal Visualization in a Citizen Science Portal

Sanne Bouman

Supervision and Examination:

Dr. Ria Wolkorte

Dr. Lieke Heesink

Dr. Ir. Monique Tabak

Abstract

The TOPTFIT Citizenlab is developing a digital portal for the practicing of citizen science in the healthcare sector. As part of this portal, citizens will be able to investigate their own personal data with the goal of gaining insight on their wellbeing. In this thesis it is investigated how a personal visualization tool should be designed for the Citizen Science Portal that supports citizens in the gaining of insight on their wellbeing. To do this, the Creative Technology Design Process was used. Previous work on the gaining of insight through data visualization was investigated, and six common themes influencing this insight gaining were identified. Through an online focus group (N=4) further needs of the target audience for this personal visualization tool were identified, and a prototype was created. This prototype was evaluated with the target audience (N=4). The results showed that the personal visualization tool allowed for the gaining of insight. Based on the evaluation, four guidelines for the further development of the personal visualization tool are suggested: no one visualization fits all, offer support for remembering relevant context, show something the user is familiar with, and keep it as simple as possible. Further research into the validity of these guidelines and the continued development of the personal visualization tool is necessary.

Acknowledgement

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Lastly, I would like to express my thanks towards all the people that have helped me with my research by participating in the co-creation session or in one of the evaluation sessions. Their opinions have been extremely valuable, and without them this research would not have been possible. Their perspective on design for healthcare has inspired me both during the writing of this thesis, and beyond that.

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Chapter 1 – Introduction

The TOPFIT Citizenlab [1] is a collaboration of knowledge institutions, healthcare organizations and companies in Twente working on establishing a citizen science methodology for and by citizens, that can be applied in practice in the healthcare sector. Citizen science is an increasingly discussed concept and is often defined as a science methodology that combines the scientific objectives of scientists with public engagement and outreach objectives [2]. The Citizenlab is fulfilling a desire from citizens to be more involved in health research and innovation. Multiple pilots are being set up to test and develop different ways in which this collaboration with citizens can help with identifying health problems as well as with the development of relevant and necessary new technologies. One of these pilots focuses on developing a digital Citizen Science Portal where cooperation between scientists and citizens can be facilitated. This Citizen Science Portal will be a website where citizens can go to participate in health-related research by sharing data. Not only can they participate in research, but the portal is creating an environment where the citizens will be actively involved in what topics will be researched. Where researchers are experts on how to perform scientific research and develop new technologies, it is the people who must live with a health condition that are experts on their own experiences, feelings, needs, and desires [3]. Providing a place for them to share data and knowledge of their disease with researchers will allow researchers to perform more relevant scientific research and development.

Next to this benefit for researchers, the Citizen Science Portal also gives the patients an opportunity to track and analyze data about their body, lives, and environment, and gain new insights into their wellbeing doing this this. Gaining these insights can help them to both understand their own condition better, and to find possible solutions that can increase their day-to-day wellbeing. However, most citizens are not experts in data analysis, so to find these insights the data must be presented in a way that is intuitive and easy to understand. This can be made possible by visualizing this data, rather than presenting this personal data as is.

The visual exploration of personal data is a process that in recent years, has already become more available to the public. An example of this is the use of visualization in activity tracking apps like Google Fit [4], which uses the internal sensors of a smartphone or smartwatch to show its users their daily activities. With the increase in interest for using data visualization to explore personal data, a new field of research has appeared - Personal Visualization and Personal Visual Analytics (PV & PVA). Personal visualization is defined as

the design of interactive visual data representation for use in a personal context [5]. How these visualizations should be designed so that they are appropriate for use in personal context by people with varying experience in data analysis and statistical knowledge, is the key question that PV & PVA is concerned with.

Goal of the research

The Citizenlab would like to incorporate a Personal Visualization tool into their Citizen Science Portal, which the users of the portal will be able to use for analyzing their personal data. This Personal Visualization tool, which will be referred to as the PV tool going further, will serve the important function of enabling citizens to gain new insights on their own wellbeing. In this thesis, the development of such a PV tool will be described. Huang et al. state in their article that before personal data can lead to insights, it must first be accessible, understandable, and interpretable [5]. As it is important for citizens using the PV tool to gain insight about their wellbeing through their personal data, it should be investigated how this data can be visualized in a way that makes it accessible, understandable, and interpretable.

Research Question

The research question this thesis attempts to answer is the following:

How can a personal visualization tool be designed for the Citizen Science Portal that supports citizens gaining insight on their wellbeing?

This research question will be answered with the use of several sub research questions, which will be discussed in the following chapters of this thesis.

Chapter 2 - State of the Art

- How can insight gained from personal visualizations be defined?
- What factors support people without data visualization experience in gaining insight from personal visualizations?

Chapter 5 - Specification

- What is important to people with Rheumatoid Arthritis when it comes to the design of a personal visualization tool?

Chapter 7 - Evaluation

- What impact does the addressing of the identified areas of concern and implementing the identified encouraging factors have on the ability of citizens to gain insight from personal visualizations?
- Does the designed personal visualization tool allow citizens to gain insight about their wellbeing?
- What other factors influencing the gaining of insight on wellbeing from a personal visualization are important to consider when designing a personal visualization tool for the Citizen Science Portal?

Target Audience

The first iteration of the Citizen Science Portal will be developed for people who have Rheumatoid Arthritis, a chronic disease that leads to the inflammation of the joints and surrounding tissue [6]. Rheumatoid Arthritis, like many chronic diseases, comes with a wide range of possible symptoms, and many different experiences from each who has to live with it. During previously conducted research with this audience by the Citizenlab [7], it became apparent that people with Arthritis want to be more involved with research on their condition. Preferably, this involvement could happen close to home. This was why the decision was made to develop the Citizen Science Portal for them. Through follow-up interviews and a survey under people with Arthritis, it was further investigated if such a portal would be of use to them, and what they would use it for. This inspired the design of a larger research project about what the Citizen Science Portal would have to be, of which research into how a PV tool should be designed was a part. To continue this close cooperation with the target audience, members from this target audience were involved at multiple points in the design process, both for eliciting design requirements and evaluating the prototype.

Overview of the Thesis

This thesis describes how a PV tool was designed for the Citizen Science Portal. First, background research performed on Personal Visualization and insight will be discussed in Chapter 2.

Creative Technology Design Process

The PV tool was created following the Creative Technology Design Process, which is a design process that has been created for the bachelor study Creative Technology [6]. It covers four separate design phases: ideation, specification, realization, and evaluation.

Further details on this are described in Chapter 3. Each of these phases is described in detail in Chapters 4, 5, 6 and 7 respectively.

A reflection on the research and the design process is given in Chapter 8. Finally, the conclusion of the research and recommendations for future works are described in Chapter 9.

Chapter 2 – State of the Art

Introduction

To answer the question of how a PV tool should be designed within the Citizen Science Portal to support citizens gaining insight on their wellbeing, previous research on the topic of personal visualization must first be considered. Not only is this important to find a proper definition for insight, but also to establish what relevant context already exists for the research described in this document. Within this context, it needs to be ensured that this research is not repeating already performed work but is instead expanding the greater scientific knowledge on the topic of personal visualization. A literature review was performed to find a definition for insight and how it could be evaluated, and to explore related work. This related work was then used to find common factors that should support people without experience in data visualization in gaining insight.

The following sub research questions will be answered in this chapter through the literature review:

- How can insight gained from personal visualizations be defined?
- What factors support people without data visualization experience in gaining insight from personal visualizations?

Literature Review

Method

To find relevant literature for this thesis, the Web of Science literature database was used. This search started by using different search terms related to both personal visualization and data visualization in general. These search terms are stated in table 1. From the search results, possible relevant articles were selected based on the title and abstract and bookmarked. When a possible relevant article was found, the documents referenced in the article were also explored to find further related work. In total, 32 works were found that had the potential to be relevant to the research performed in this thesis. From these 32 works, non-peer reviewed works were removed. The remaining works were then skimmed through and were removed from the list if the research could not be used to answer either of the sub research questions. After this a smaller selection of relevant literature remained. This selection included 10 works, 4 of which were used to define insight and how it could be evaluated, and 7 of which were used to define factors that could support the gaining of insight from personal visualizations.

Topic	Search terms
Personal visualization	“Personal visualization”, “Quantified self”, “Self tracking visualization”
Data visualization	“Data visualization”, “Information visualization”, “Human-information interaction”, “visual analytics”
Visualization of health data	Search terms stated under data visualization “ + “health”, “healthcare”, “wellbeing”
Design patterns in data visualization	“Data visualization design pattern”, “Design guidelines visualization”
Insight	Search terms stated above + “insight”

Table 1: Search terms used for finding relevant literature to perform a literature review

To find these supporting factors, it was investigated what commonalities could be found in research on the interactions of people without data visualization experience with (personal) data visualizations. This was done by summarizing the results of each article discussing related research and identifying any theme that appeared more than once. These themes included both problems that were encountered by these people, which were named ‘areas of concern’ by the researcher of this thesis, as well as design solutions that supported them in gaining insight from (personal) data visualizations, named ‘encouraging factors’. In total, six themes were identified, three of which were areas of concern, and three of which were encouraging factors.

Defining Insight

Many experts claim that the ultimate purpose of visualization is insight, yet its definition has remained informal [7]. To define insight, different perspectives on what insight means need to be considered. Chang et al. elaborate on this, separating insight into two different concepts: spontaneous insight and knowledge-building insight [8]. Within cognitive science, insight is often defined as an event that can be experienced. An example of this would be, the sudden realization you have found the solution to a riddle. This is called spontaneous insight, referring to this moment in which insight is experienced. Visualization experts generally look upon insight differently. They define insight as a unit of knowledge that can be gained. An example of this would be, identifying a relationship between the growth of a plant and the sunlight it receives after studying data gathered on this process. Chang et al. refer to this as knowledge-building insight. These two concepts, although defined differently, go hand in hand. Experiencing spontaneous insight will over time lead to the gaining of knowledge-building insight, and vice versa. As the goal of the Citizen Science Portal is to enable citizens to learn new things about their condition, knowledge-building insight is the priority. For the current research, a definition adapted from North et al. will be used to

describe insight in the context of personal visualization: **an individual observation about personal data by a person gained through the studying of a data visualization** [7]**.**

To further elaborate on what the nature of such an individual observation can be, a strategy previously created for the purpose of communicating and evaluating insight will be discussed. This strategy was first presented by Chen et al. in the form of a fact taxonomy [9]. This fact taxonomy can be used to express knowledge discovered from data analysis. For the PV tool for the Citizen Science Portal, it is especially important to identify how insights are defined from the perspective of people who are analyzing their own personal data. Choe et al. build further on the fact taxonomy established by Chen et al., defining different categories of visualization insight as part of their research on how Quantified Selfers, people who enjoy collecting and analyzing their personal data through means of self-tracking, visualize their own personal data [10]. The types of visualization insight defined in this taxonomy are especially relevant when talking about knowledge-building insight, because they describe kinds of knowledge that can be gained. As knowledge-building insight is what the Citizen Science Portal wants to encourage first and foremost, the taxonomy defined by Choe et al. will be used to further define what an individual observation about personal data can be. The types of visualization insights described in this taxonomy can be found in table 2.

Areas of Concern

The three areas of concern that were identified in related work are understanding, context and relation. These were identified in the works of Amar et al [11], Choe et al [10], Huang et al [5], Grammel et al [12], and Rapp et al [13].

Understanding

The first area of concern is understanding. Understanding as an area of concern is defined as the amount of confidence a person can express about an insight about their personal data they have gained. This shows up in two different ways. The first way shows up in the research done by Amar et al. They describe gaps present between perceiving representations of data and being able to analyze this data [11]. One of these gaps is the Rationale Gap: “the gap between perceiving a relationship and actually being able to explain confidence in that relationship and the usefulness of that relationship”. The second way in which understanding is a concern, is when insights are not statistically significant. Choe et al. identify that non-experts presenting their insights about their own data did not seem to be

Type	Subtype	Description
Detail	Identify extreme	Explicitly state the identities of the data points possessing extreme values of the measure variable
	Identify value	Explicitly specify the measured value, its range for one or more clearly identified data points, or the difference between
	Identify reference	Explicitly state the values of categorical variables, labels from the axes, or legends
Self-reflection	External context	Uncaptured data provided by the presenter to understand and explain a phenomenon shown in the data
	Contradiction	Collected data contradicts existing knowledge
	Prediction	Predict the future based on the collected data
	Confirmation	Collected data confirms existing knowledge
Trend		Describe changes over time
Comparison	By factor	Compare measured values by a factor (other than time)
	By time segmentation	Compare measured values segmented by time
	Against external data	Bringing in external data for comparison
	Instances	Compare two specific instances
Correlation		Specify the direct relationship between two variables (but not as comparison)
Data summary		Summary of collected data (such as number of data points and duration of tracking)
Distribution	Variability	Explicitly state the variability of measured values
	By category	Explicitly describe the variation of measured values across all or most of the values of a categorical variable
Outlier		Explicitly point out outliers or state the effect of outliers.

Table 2: Types of visualization insights with their subtypes and definitions as defined by Choe et al [10].

aware of the statistical significance of their findings, sometimes pointing out facts they believed to be true without evidence [10]. This is a risk that should be addressed, because insight gained from personal visualizations can have an impact on how people live their lives. In both scenarios, the lack of knowledge about statistics is a barrier. Thus, addressing this knowledge gap could both help citizens gain more confidence in their discoveries, and reduce the risk of visualizations reinforcing bias.

Context

As a second area of concern, context is discussed. Context as an area of concern is defined as the lack of contextual information that is necessary for a person to properly gain insight from this data. Choe et al. found that meaningful insights were gained not just because the Quantified Self-ers that participated in their study were quantifying their behavior, but also through self-reflection [10]. Reflecting on additional personal context to their data allowed them to come up with possible explanations for why something interesting would happen in

their data. Huang et al. also identify this as a challenge in the field of personal visualization [5]. They state that necessary context for the interpretation of data cannot always be found in the form of easily accessible data. Addressing this area of concern means compensating for this lack of necessary contextual information.

Relation

The third area of concern that was identified is relation. Relation as an area of concern is defined as the difficulty experienced by a person when relating an abstracted visual representation of data back to the real-world realization of this data. In a study done by Grammel et al., problems occurred when the participants were asked to interpret visualizations [12]. The researchers refer to the gaps between representation and analysis described by Amar et al [11]. Emphasis is put on difficulty that is experienced when a visualization needs to be related back to concepts in the participants' mental model, which is their mental image of how something is represented in the real world. The worldview gap is highlighted here, which is described as “the gap between what is being shown and what actually needs to be shown to draw a straightforward, representational conclusion”. Addressing this concern means offering appropriate ways to display data as well as assisting citizens in finding relationships in this data. This can also be found in the case study on the design of a personal information system for non-expert users, where highlighting possible data correlations as a means of assisting citizens is defined as a user requirement [13].

Encouraging Factors

The three encouraging factors that were identified in related work are exploration, individuality, and variation. They were identified in the works of Wang et al [14], Huang et al [5], Rapp et al [13], and Choe et al [10].

Exploration

The first factor that was found to encourage insight is exploration. Exploration as an encouraging factor is defined as a person's ability to interact with a data visualization to discover additional information. In Wang et al's study on how the design of a visualization can affect someone’s reaction to data, it was found that more abstract visualizations, which encouraged the participants to explore their data more, lead them to gaining more insight on their data [14]. Exploration also plays into another important aspect of personal visualization. As stated by Huang et al, 'While someone using a PV tool might be focused on discovering complex insights, they might be equally likely to use it for purposes such as fun or awareness' [5]. Exploration makes the process of analyzing personal data more enjoyable, making it more likely that people will continue to do it.

Individuality

The second factor that was found to encourage insight is individuality. Individuality as an encouraging factor is defined as a person's ability to customize how their personal data gets visualized. Rapp et al. found that participants in their study expressed a desire to recognize themselves in their data [13]. Statistics and graphs were found to be impersonal. This idea is also found in Choe et al.'s work, where it was noted that some presenters made use of custom visual annotations to explain interpretations of their personal data [10]. Huang at al. describe the need for diversity in design perspectives as one of the challenges in the field of personal visualization [5]. Allowing people to customize a visualization to the point of feeling like they have designed it themselves could address a distance currently found between system designers and the people using their systems.

Variation

The third factor that was found to encourage insight is Variation. Variation as an encouraging factor is defined as a person's ability to view data in more than one distinct visualization. Rapp et al. note the importance of offering variation in how data is visualized. They found that displaying data in the same way continuously can lead to decreasing engagement over time [13]. Giving multiple options for how to visualize personal data can satisfy both the users who desire easy and accessible ‘traditional’ graphs, and users who want to explore their data on a deeper level.

Conclusion

Using the determined definition of insight, the literature research performed leads to six themes that can have an impact on how much insight people without data visualizations experience can gain from personal visualizations. First there are three areas of concern that should be addressed. These areas are understanding, context and relation. They are combined with three factors, exploration, individuality, and variation, that are shown to improve the experience of people analyzing their personal data. The impact of these six factors will be evaluated in this thesis using the taxonomy described in this chapter. It must be considered that these six factors are not isolated influences on how insight is gained, rather a part of a more complex process. They are based on a still limited investigation into previous work, and thus could be of a different significance than currently expected. They should be thoroughly evaluated and extended upon during the design of the PV tool.

Chapter 3 – Methods and Techniques

In this chapter, the Creative Technology Design Process (CTDP) and how it was used during this thesis is explained. An overview of which methods were used during this process is given, which are detailed further in later chapters of this thesis. Next to this, the ethical procedures followed for this research are described.

Creative Technology Design Process

The CTDP describes the development of a product based on an initial design question through four separate phases: ideation, specification, realization, and evaluation [6]. In figure 1, an illustration of these phases and what they entail is given. It is important to note that each of these phases exists of two parts; a divergent part, in which different options or solutions can be explored, and a convergent part, in which the number of different options or solutions are reduced.

Ideation

The ideation phase of this thesis entailed the development from the problem statement to the creation of a set of mock-up prototypes. The first part of this was the exploration of the problem statement, which happened through background research into previous work, and was described in Chapter 2. Based on the results from this background research, ideas for how to translate these results into an effective design were explored. Mock-up prototypes were created using a set of data concerning a pre-determined research topic, fatigue and its relation to activity. These prototypes were improved upon based on feedback from other Citizen Science Portal researchers, as well as a pilot test. The ideation phase concluded with a final set of mock-up prototypes, to be discussed with the target audience during the specification phase.

Specification

During the specification phase, the created mock-up prototypes were discussed with target audience members through an online group meeting. This group meeting was one of four so-called co-creation sessions organized by the Citizen Science Portal researchers. For this co-creation session a script was developed and improved upon after feedback gathered through a pilot test, as well as feedback from other Citizen Science Portal researchers. The conversations were analysed through a deductive analysis strategy. Based on the results design requirements for the PV tool were elicited. As part of this, the results from

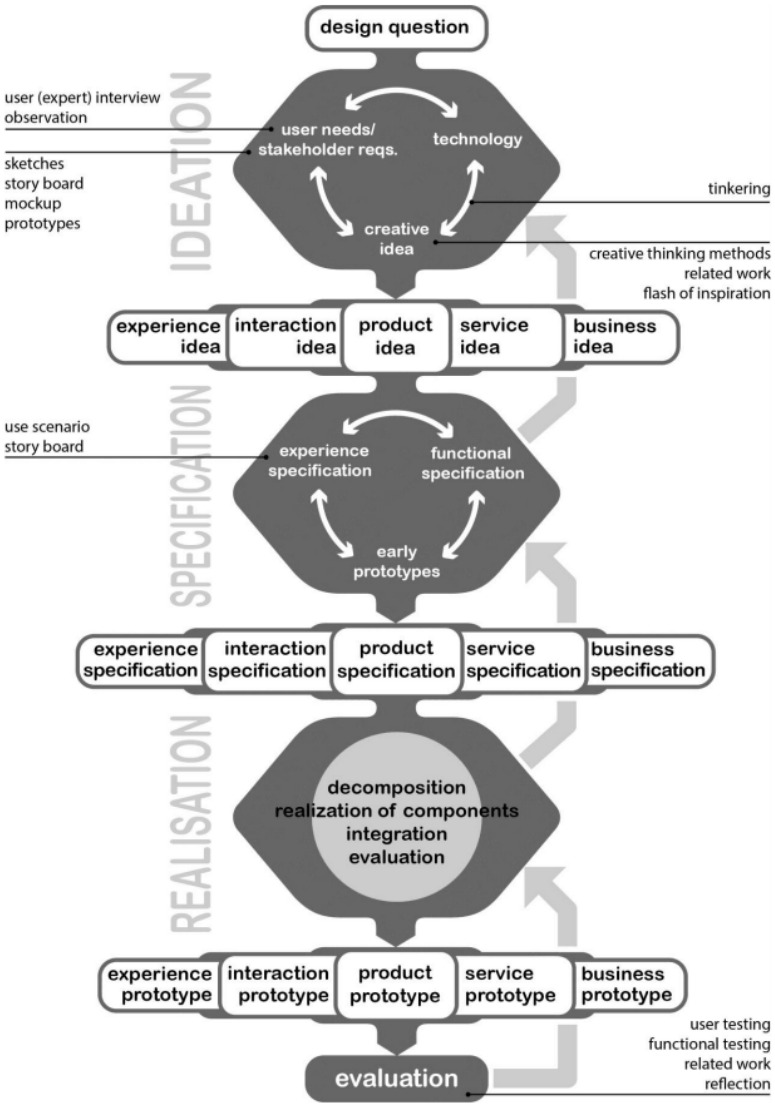

Figure 1: The Creative Technology Design Process

the background research were also reflected upon, and the ideas for the implementation of them were adjusted accordingly. For this, additional design requirements were added where necessary. The specification phase ended with the description of five system components that were further realized in the realization phase.

Realization

During the realization phase, a final prototype was developed based on the design requirements elicited in the specification phase. This started with a description of the overall system architecture, and an elaboration on possible use cases of the PV tool. The prototype was then developed as part of a prototype showing the entire Citizen Science Portal, which meant that close cooperation with other Citizen Science Portal researchers took place. Through this cooperation, feedback on the prototype was consistently gathered, and the

prototype was improved. After the prototype was finished, a reflection was done on how successful the design requirements were implemented in this prototype.

Evaluation

Finally, during the evaluation phase, the developed prototype was evaluated with the target audience. This evaluation of the prototype was part of a broader evaluation strategy, which was meant to evaluate the entire Citizen Science Portal prototype. Multiple online evaluation sessions were organized, in each of which one member of the target audience participated. A script was developed for this evaluation session to ensure consistency between sessions and improved upon after a pilot test. The results of the evaluation sessions were analysed to answer three sub research questions. The answers to these questions lead to the description of four design guidelines for the further development of the PV tool.

Ethical Procedures

To ensure that the co-creation session and evaluation sessions adhered to proper ethical guidelines, an ethics request containing a description of the research was send to the ethics committee of the faculty of Behavioral, Management and Social Sciences of the University of Twente and subsequently approved (req. nr. 210583). This request concerned all research that would be performed during the development of the Citizen Science Portal, including all relevant information about the co-creation session and evaluation sessions. Prior to participating in the co-creation session and/or an evaluation session, the participants received information about the research, which also included an informed consent for the participants to sign. This information and the informed consent can be found in Appendix I. At the start of each session, any present participant was asked verbally if they would consent to the session being digitally recorded in addition to this.

Chapter 4 – Ideation

In this chapter, the ideation phase of the design of the PV tool is described. Here it can be found what method was used to create the first mock-up prototypes for the visualizations in the PV tool, a description of these prototypes, and finally a conclusion with recommendations for the next phase, specification.

Mock-up Prototypes

For the ideation phase of the CTDP, possible design solutions for the PV tool had to be explored. First it was explored what visualization techniques could be used in the PV tool to visualize the personal data. This was done through the creation of several mock-up prototypes.

Methods

Before the final mock-up prototypes were created, different options for how these mock-ups could be created were explored. As the mock-up prototypes would be evaluated by members of the target audience of the PV tool, it was first considered whether to investigate how members of the target audience would visualize their own personal data through already existing online data visualization tools. This would mean that rather than the researcher creating mock-up prototypes themselves, the mock-up prototypes would be created by the target audience. However, this idea was not followed through on, for several reasons. First, this would not allow for the inclusion of the background theory in the mock-up prototypes. Secondly, it would not be feasible to execute this on a technical level, as the contact with the target audience would happen solely through online methods. Asking the participants to make use of specific digital tools would exclude possible participants from the research if they would not be able to use these tools on their personal devices. Lastly, this would limit the exploration of visualization methods to already existing methods used by online data visualization tools.

Because of this, the decision was made to create mock-up prototypes that could then be shown to the participants through online methods. With these mock-up prototypes, multiple visualization methods and options for content of the visualizations could be evaluated. To decide how these mock-up prototypes would be created, the researcher explored several different methods. To allow for more rapid prototyping, but still create mock-up prototypes of decent quality, the decision was made to primarily use an existing data visualization tool, and manually modify the visualizations this tool created using Adobe Photoshop [15] where desired. Multiple data visualization tools were considered, and the decision was made to use Tableau [16], an interactive data visualization program created by Tableau Software, to

create the base mock-up prototypes. This was because Tableau offered the most options for creating custom visualizations, which meant that the visualizations could already be largely created in Tableau and would need minimal manual modification, making the prototyping process quicker.

The mock-up prototypes were continuously improved through a cycle of feedback from other Citizen Science Portal researchers, as well as through a pilot test with volunteer participants outside of the target audience, before they were evaluated with members of the target audience. Details of this evaluation can be found in Chapter 5.

Dataset

Before making the mock-up prototypes, a set of data to visualize in the prototypes was created. It was pre-determined by Citizen Science Portal researchers in cooperation with people with Arthritis that the topics this data would have to cover were fatigue experienced by people with Arthritis and their activities, as the relation between these topics would be the first research that would be performed through the Citizen Science Portal. It was first explored if an existing set of data was available for this, but this was not the case. Instead, a set of example data was created. This example data included information on how much time a fictional person with Arthritis had spent on certain activities each day for a week, measured in minutes. These activities included: sports, gardening, travelling, work, busy work, outdoor activity, hobby, family, friends, television, resting moments and sleep. Each of these activities were part of a broader category: physical activity, mental activity, resting moments, or sleep. Further data was also available for this fictional person for an entire month. This included the number of minutes the person spent being active per day, which included both physical and mental activity, and for each day a number between 1 and 10 representing how fatigued this fictional person felt that day. Next to this, a second set of both of this data was created and manually adjusted to represent an average of a group of people.

Description of the mock-up prototypes

All axes and legends presented with the graphs were created in Dutch, as the target audience of the Citizen Science Portal was Dutch. A larger version of the figures in this sub chapter can be found in Appendix II.

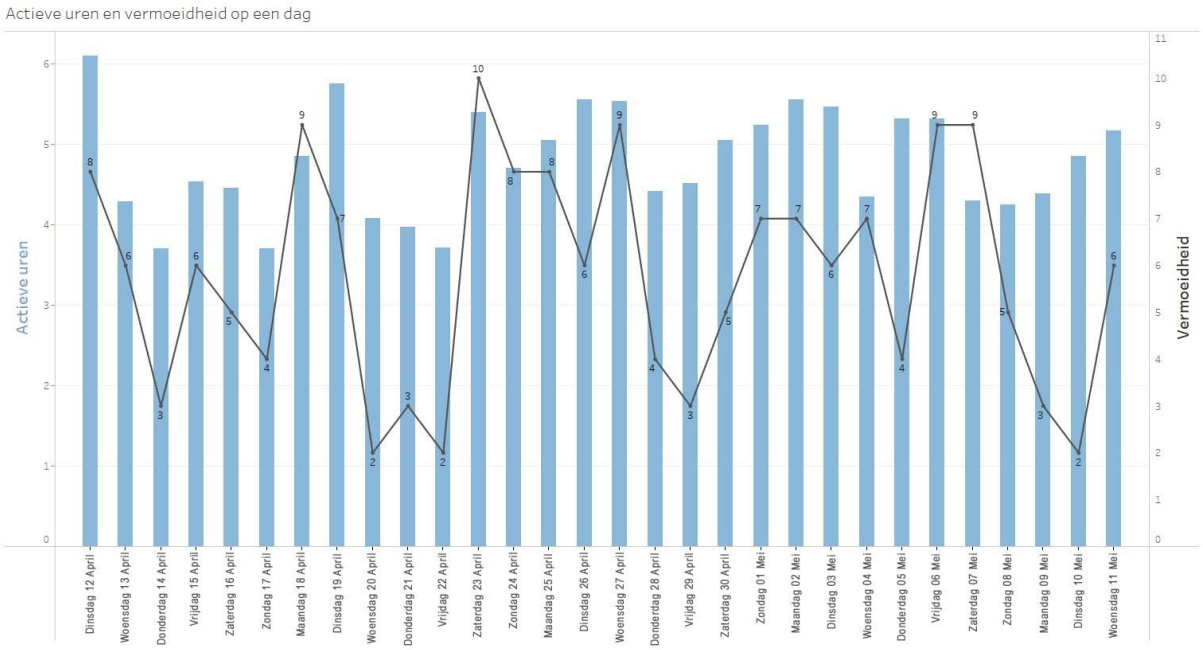

Figure 2: Mock-up prototype #1

Mock-up prototype #1

The first mock-up prototype, shown in figure 2, gives an overview of how much time a person spent being active per day for a month, as well as how fatigued they were during this time. Here, the minutes spent being active are visualized using a bar graph, and the fatigue is visualized using a line graph. This mock-up prototype was created using visualization techniques that may be familiar to the target audience, to give an idea for a base visualization that could be at the heart of the PV tool, before additional encouraging factors are introduced.

Mock-up prototype #2

Figure 3 shows the second mock-up prototype. This prototype shows the same information as is shown in the first mock-up prototype (figure 2) but uses a different visualization technique: a scatter plot. This visualization technique is often used to determine possible correlation between two measurements. It was included in the mock-up prototypes both to explore a different visualization method to see if one would be preferred by the target audience, as well as to incorporate variation as an encouraging factor. The target audience would get to see both visualization methods, and comment on if they would find benefit in having access to both visualization methods rather than just one.

Mock-up prototype #3

Figure 3 also shows the third mock-up prototype. This prototype visualizes how much time was spend by a person on specific activities during a week, using a bubble graph. The color of the bubbles was darker or lighter based on how fatigued this person felt on average during the days that included this activity. This prototype was included because it is more

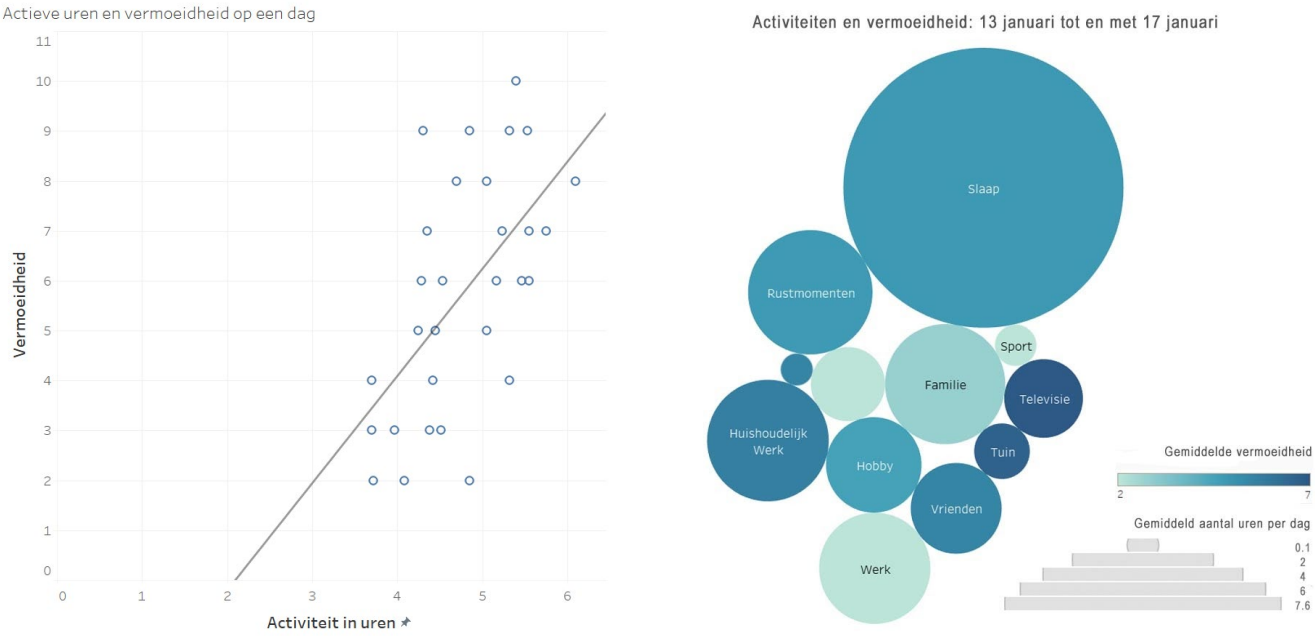

Figure 3: Mock-up prototype #2 (left) and #3 (right)

abstract, and according to the background theory detailed in Chapter 2, could thus introduce the encouraging factor of exploration. To address the area of concern of relation, legends were included with the visualization to assist any person viewing the visualization in relating the abstract visualization back to the real-life counterpart of this data.

Mock-up prototype #4 and #5

The fourth and fifth mock-up prototype can be found in figure 4. In these prototypes, the amount of time a person spend on certain activities during a day is visualized. Mock-up prototype four shows these activities in broader categories, while mock-up six shows these activities more specifically. These mock-up prototypes were made so it could be evaluated on what level of detail members of the target audience would prefer to see their activity visualized so that they could best use the visualizations to gain insight. It could also be explored if offering both options (variation) would be of interest.

Mock-up prototype #6 and #7

The sixth and seventh mock-up prototype are shown in figure 5. These visualizations show the same data as in mock-up prototype #4 and #5, but use a different visualization method: a pie chart. Additionally, the size of the pie chart represents how fatigued the person felt, where a bigger size indicated more fatigue. Similar as to why mock-up prototype #2 was shown, these prototypes were included both to see if there was a preference for one or the other visualization method, and to see if the target audience believed there to be merit in having both visualizations available. Next to this, new information was added to these mock-up prototypes, namely the average of time spent on an activity per week. This was done to

inquire with the target audience if they believed averages to be useful to them to gain insight on their wellbeing.

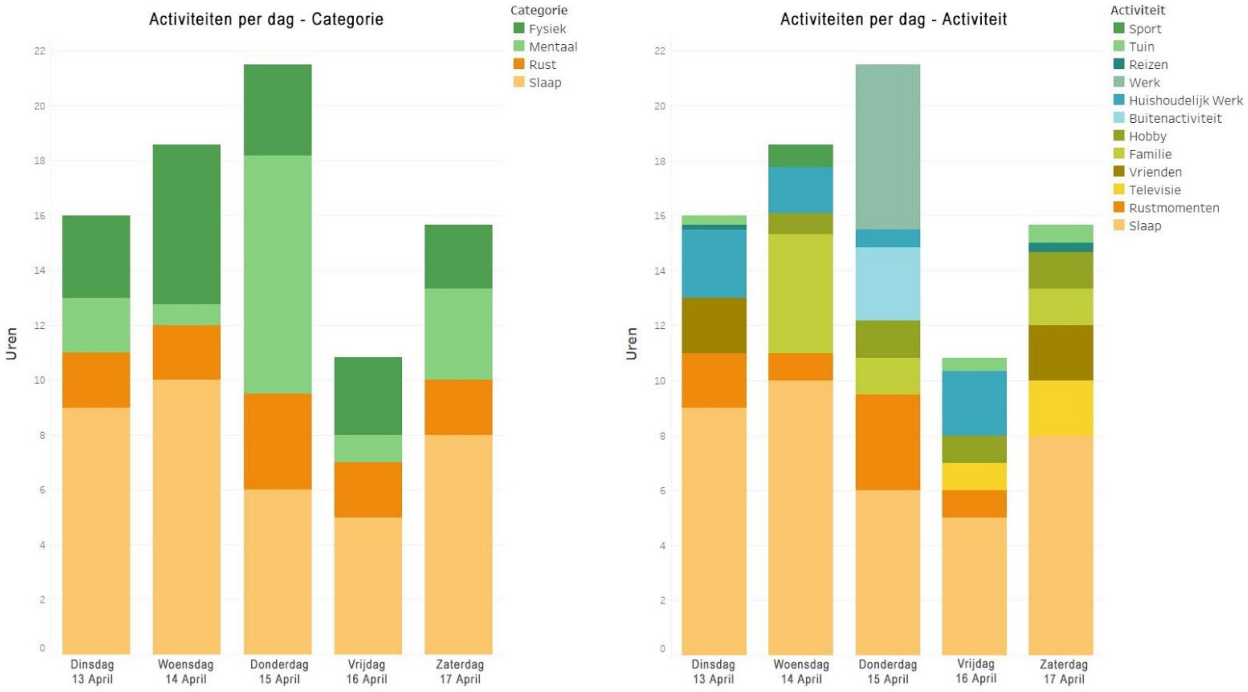

Figure 4: Mock-up prototype #4 (left) and #5 (right)

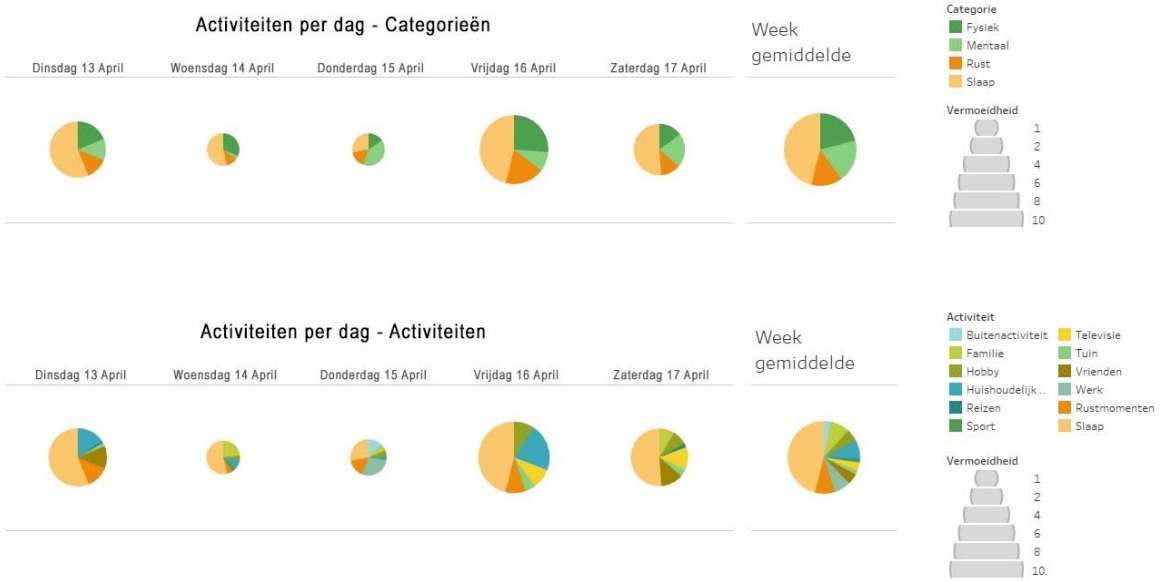

Figure 5: Mock-up prototype #6 (above) and #7 (below)

Mock-up prototype #8, #9 and #10

Mock-up prototype #8, #9 and #10, shown in figure 6, were created to incorporate comparisons with an average of participants in a research as a possible feature of the PV tool. The mock-up prototype each show a previously discussed mock-up prototype, but with the average of other people included with the original visualization as well. These mock-up prototypes would be used to ascertain if the target audience members would be interested in seeing these averages, and to identify if this may help them in gaining additional insight about their own wellbeing.

Figure 6: Mock-up prototype #8 (above left),), #9 (above right) and #10 (below)

Conclusion

In this chapter, mock-up prototypes for possible visualizations to be used in the PV tools are described. These prototypes were based both on the background research, as well as on additional questions that had to be answered before the development of further prototypes for the PV tool. It was not yet possible to address all areas of concern and include all encouraging factors in just the mock-ups for the visualizations, as some areas of concern, like understanding, rely on the addition of features outside of the visualizations themselves. How to address the areas of concern and incorporate the encouraging factors should thus be further investigated. It is recommended that during the specification phase, the developed mock-up prototypes are evaluated, as well as that further conversations are held with members of the target audience to discover how the background research can be further incorporated into the PV tool, as well as to discover any additional needs the target audience has.

Chapter 5 – Specification

This chapter describes the specification phase of the design process, during which design requirements for the PV tool were determined. Here is described how a co-creation session was organized to get informed on the wants and needs of the target audience, and how the theory of the six common themes was reconsidered to determine these design requirements. These design requirements led to the determination of several components of the PV tool that were necessary for the design requirements to be implemented into the final PV tool, which are described at the end of this chapter.

In this chapter, the following sub research question is discussed:

- What is important to people with Rheumatoid Arthritis when it comes to the design of a personal visualization tool?

Co-creation session

To identify the needs of the citizens for the Citizen Science Portal, multiple co-creation sessions were organized. One of these co-creation sessions was on the topic of data collection and visualization within the portal. Part of this session was designed to answer the question: *What is important to people with Rheumatoid Arthritis when it comes to the design of a personal visualization tool?* The session was also used to evaluate the mock-up prototypes described in Chapter 4.

Method

Design and Setting

The co-creation session consisted of two separate parts. In the first part, a conversation was held about data collection and visualization within the portal. In the second part, the mock-up prototypes were shown to the participants, so feedback could be given and further relevant information could be discovered. A pre-written script was used by the researchers to guide the conversation during the co-creation session, ensuring that important questions would be addressed. This script was improved upon through feedback from other Citizen Science Portal researchers, as well as through a pilot test. In this pilot test, the co-creation session was practiced with volunteer participants outside of the target audience, who were able to give feedback on the session afterwards. Processing this feedback ultimately led to the final script that was used for the co-creation session. This script can be found in Appendix III, and further elaboration on the procedure can be found under “Procedure” in this chapter.

During the co-creation session, three researchers were present. The researcher behind this thesis was responsible for guiding the first part of the session, while the other two researchers were responsible for giving a general introduction about the Citizen Science Portal, as well as offering technical assistance. During the second part of the session, where feedback was given on the mock-up prototypes, the participants were temporarily split up in two smaller groups. Each group had at least one researcher present responsible for guiding the session, and one group had a second researcher present offering technical assistance. In total, the session lasted for two hours, including a ten-minute break. The session took place in Dutch, the native language of the participants.

Participants

Four people with Rheumatoid Arthritis participated in the co-creation session. For one of the participants, it was their first time participating in a co-creation session organized for the development of the Citizen Science Portal. They had previously been introduced to the development of the portal through a survey sent out to Arthritis patients. On this survey, they indicated their interest in getting invited for further involvement of the design of the portal. After this, they were invited to join in one or more co-creation sessions, and indicated their interest in joining the co-creation session focused on data visualization. This was also how the other the three participants were recruited. They also joined a previous co-creation session, which took place a week earlier. All participants were further informed about the research before the co-creation session took place and gave their informed consent. The participants were all women, between the ages of 54 and 70. Each of them had been diagnosed with Rheumatoid Arthritis for at least 13 years. Each participant received a €15,- gift voucher as compensation for their participation.

Tools

The co-creation session took place through a video call on the video conference platform Zoom [17]. All participants could join this call on their personal devices and were given the opportunity to receive additional guidance in the use of Zoom before the session took place. They received an invitation link through which they could join the call a week prior to the co-creation session, and a reminder of the meeting a day before it took place. During the second part of the co-creation session, the mock-up prototypes were shown to the participants in two separate groups. To facilitate this, the group of participants was split up using Zoom's break out room feature, with which separate rooms could be created within the same video call. In each room, one researcher shared their screen which showed a power-point with the mock-up prototypes.

Procedure

As mentioned before, a script was pre-written describing the procedure that would be followed during the co-creation session. This script detailed what would happen during the session, how long should be spent on the different parts of it, and detailed which researcher was responsible for guiding it. First, a general introduction was given about the Citizen Science Portal by one of the researchers. After this introduction was given, each researcher and participant was given the chance to introduce themselves. At this point, a recording of the session was started with the informed consent of all participants. The researcher behind this thesis then introduced the topic of the co-creation session in more detail and explained what would happen in the first part of the session. The participants were able to ask any questions about this if they desired and were also informed that they could ask any questions through the Zoom chat if needed.

During the first part of the co-creation session, a semi-structured conversation took place between the participants and the researchers. This conversation was guided by the questions detailed in the script, as these questions would hopefully lead to answers that could give a clear idea of what the design of the PV tool would have to include. However, the conversation was allowed to deviate from these specific questions as well, as this could also lead to new information not yet considered by the researcher.

At the half-way point of the session, a ten-minute break took place. During this break, the researchers decided on how the participants of the session would be split up into two separate groups for the second part of the session. This was decided based on their previous experience with data visualization related to their condition, so that the participants that were more experienced would be paired together. After the break was over, the participants received an explanation about the second part of the session and were guided to two separate break-out rooms. In this break-out room, one researcher shared their screen showing a power-point with the mock-up prototypes for the visualizations. This power-point can be found in Appendix IV.

As limited time was available for this part of the session, two separate versions of this power-point were made. Each version would start off with a different slide, with the intention of making it such that each slide was shown to at least one group of participants. One of the groups was shown a power-point in the order given in Appendix IV. The second group was shown a power-point in the following order: slide 1, slides 6 – 8, slides 2 – 5, and finally slides 9 – 10. After having spent the allocated time discussing the mock-up prototypes, the

two groups joined together again and shared what had been discussed. Because one of the groups had not yet gotten to see the slides of the power-point showing a mock-up prototype where a comparison with other people was present in the visualizations in their separate room, this was discussed with the entire group as well.

The session ended with a short conclusion remarking on some key points that had been talked about during the co-creation, and a general goodbye statement that was given at all of the organized co-creation sessions for the Citizen Science Portal.

Analysis

After the end of the session, the recording that was made was transcribed. First, the session was automatically transcribed with the use of Amberscript [18]. This automatic transcription was subsequently edited manually, to accurately contain all that was said during the session. This transcription was analyzed making use of a deductive analysis strategy. To perform this analysis, ATLAS.ti was used [19]. In figure 7, the strategy used to analyze the co-creation session can be found.

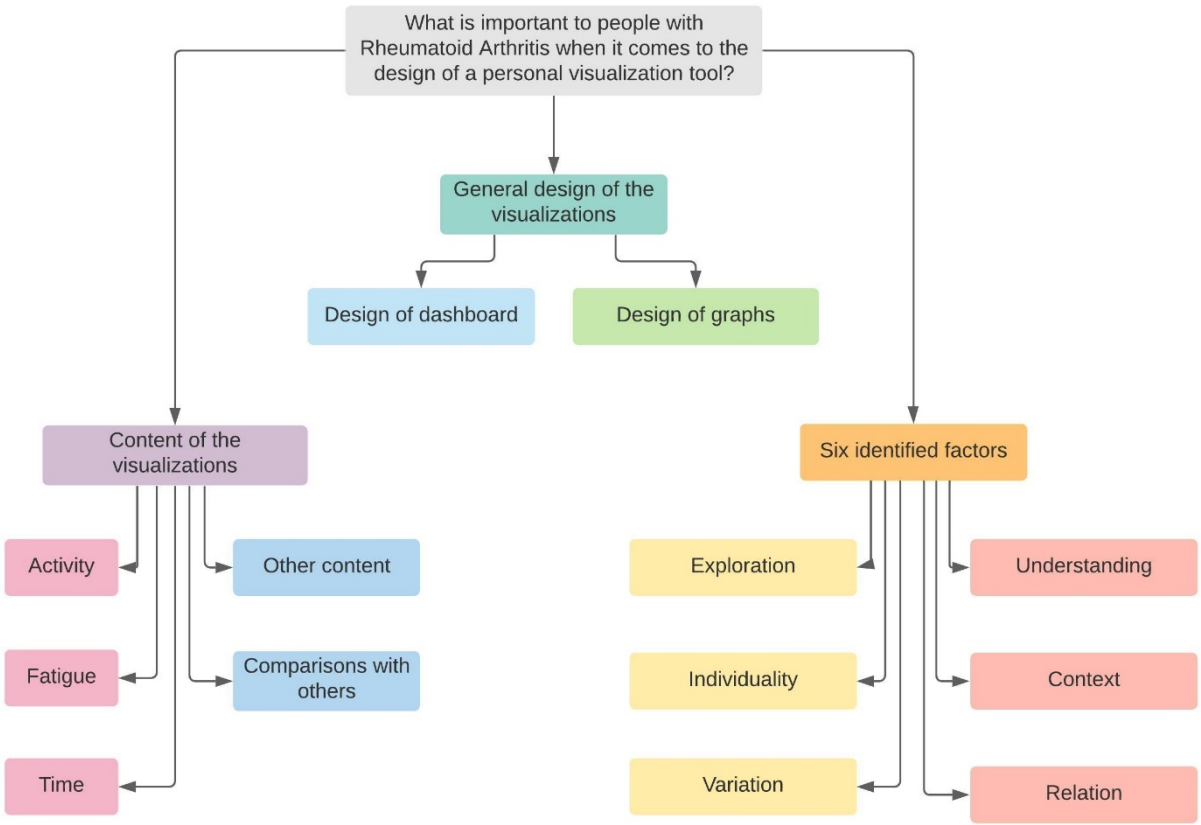

Figure 7: Analysis strategy used to analyze the co-creation session. Created using Lucidchart. [21]

This analysis strategy was pre-determined using the question: *What is important to people with Rheumatoid Arthritis when it comes to the design of a personal visualization tool?.* It was also determined with the idea that based on the analysis, design requirements had to be specified. Next to this, the six common themes that inspired the mock-up prototypes would also be reconsidered, and thus these were also included in the analysis strategy so that relevant information could be collected on them. The transcription of the co-creation was read through thoroughly, and whenever a remark was made related to one of the pre-determined topics in the analysis strategy, this remark was labelled with a corresponding code. To illustrate how this worked, table 3 shows when each of these labels was applied, with a corresponding example from the transcription.

After the transcription was analyzed in this way, a summary of all remarks was created for each code under the “General design of the visualizations” and “content of the visualization.”, which can be found in the results section. Based on the results, a list of design requirements was constructed.

Results

Content of the Visualisations

Activity

The opinion is divided on whether or not activity should be visualised in broader or more specific categories. One participant is very enthusiastic about being able to reflect on their activities at a detailed level, the reason for this being that they are really looking for this insight in regards to their condition. In line with this, one participant who currently is not looking for this insight anymore, does not want to reflect on their activities anymore in very specific categories. However, shortly after they had been diagnosed with Arthritis, this would have very useful to them. The other two participants prefer the less detailed categories. This is motivated by the fact that the visualisation itself gets too busy with too many activities being visualised. Upon further elaboration, the suggestion is made to split some of the broader categories into two categories (physical activity into outdoor activities and indoor activities as an example).

One participant mentions a possible feeling of guilt when a ‘fun’ activity seems to worsen symptoms. In this case, knowing what activities lead to which feelings does lead to insight, but it is not a positive insight. This is not wanted by the participant. Something similar is mentioned when a participant talks about how comparing their specific activities to those of

Code	Applied when…	Example
Activity	… a remark was made related to how they would prefer to see their activities integrated into the PV tool, either in content or in form.	*Participant: And if you know what kind of activity you did, you can see if you get extra fatigued from certain activities or the opposite.*
Fatigue	… a remark was made related to how they would prefer to see fatigue integrated into the PV tool, either in content or in form.	*Participant: Because I think it is very confusing sometimes… one time when scoring between zero and ten, ten Is very good … and sometimes you have to give that a zero, or a two.*
Time	… a remark was made related to how they would prefer to see time represented in the PV tool visualization, either in content or in form.	*Researcher: What time the activities take place on a day, is that something you find important as well then?* *Participant: Yes, then I could for myself maybe make out the fact that my fatigue may always be at a certain time of the day.*
Other content	… a remark was made about the inclusion of data not related to activity, fatigue or time.	*Participant: I think I would find it nice to indeed know kind of my pain score, how much symptoms I experience from my Arthritis.*
Comparisons with others	… a remark was made related to comparing personal data to the personal data of others.	*Participant: At the end of the day improving my own life is what it is about for me, and it is nice of course if others can do that to, but in principle you look, at least I look at myself in the first instance…*
Design of dashboard	… a remark was made about the participants' needs regarding the overall design and features of the PV tool.	*Participant: I think the graph offers a relatively good overview. I just think that on one page it is a lot of information.*
Design of graphs	… a remark was made about the participants' needs regarding the design of the personal visualizations, including visualization methods.	*Participant: Yes, this is what I meant with colors, I like that myself.*
Understanding	… a remark was made relating to the area of concern understanding, and any possible way to address it.	*Participant: You have to read what it is about of course, you have to have a little bit more of an explanation with it, what it means.*
Context	… a remark was made relating to the area of concern context, and any possible way to address it.	*Participant: … the first question that arises in me is sleep. Is that the time I am laying in bed? Or that I am asleep?*
Relation	… a remark was made relating to the area of concern relation, and any possible way to address it.	*Participant: Is the ten that you are super fatigued, or that you feel very well actually?*
Exploration	… a remark was made relating to the encouraging factor exploration, and any possible way to implement it.	*Participant: And that you then from one such cockpit, so said, can click through to more detailed information, if you wish to do so.*
Individuality	… a remark was made relating to the encouraging factor individuality, and any possible way to implement it.	*Researcher: But it is good to know that it should perhaps be possible to be able to do both options, either detailed, or really, ehm…* *Participant: Yes.*
Variation	… a remark was made relating to the encouraging factor variation, and any possible way to implement it.	*Participant: Yes, for me one way is , is actually enough, but I do not, not really mind to see it in two ways like this.*

Table 3: Explanation on the application of the analysis strategy codes for the co-creation session.

the day before can make them feel guilty about not doing enough. On the other hand, this also works as a motivation for them.

Fatigue

When it comes to fatigue caused by Rheumatoid Arthritis, the capriciousness of this fatigue is very real according to the participants. Because of this, there can be many different levels of fatigue throughout one day. The visualizations should be able to reflect this. To properly do this, only one measurement per day may not be enough. But, having to open the laptop to fill in a questionnaire multiple times a day is not desirable. At the very least, the time of day that a fatigue score is given is a very important bit of context to the participants. If only one score is given per day, it should be noted at what time this is.

Multiple participants indicated that it is difficult for them to reflect on when they are experiencing fatigue, and they will instead discover they are fatigued due to external factors. Scoring fatigue on a scale from one to ten is still possible for them, but they do not feel like they will be properly aware of the fatigue every day. It is also not easy to differentiate between physical fatigue and mental fatigue for all participants. The two are intertwined, and influence each other a lot. For other participants, this comes easier. However, it should not be expected that all users of the portal are able to properly differentiate between the different kinds of fatigue.

Some participants had trouble with immediately recognizing how a number represented an amount of fatigue. It was not clear whether a higher number represented more fatigue, or if it represented a day in which they felt better.

Time

All participants of the co-creation session indicate that it is important to them that they are able to compare their data across multiple days, and even between weeks or months. This is not only to be able to find out why there is a difference in fatigue between days even though the amount of activities performed is the same, but also because fatigue is impacted by activities happening on previous days. There is also interest in seeing an average over a period of time, such as a week or possibly even a month.

Other possible content

A few remarks are made about additional content for the PV tool related to activity and fatigue that was of interest to the participants. Throughout the co-creation session, it is

mentioned a few times that also being able to compare the activity and fatigue to other Arthritis symptoms, like pain, is of interest. For one participant that uses a Fitbit, the inclusion of data from an activity tracker is very interesting. It is also indicated that including lab results, such as blood tests, can give further context to fatigue as well. In current Arthritis treatment, these results often have an important impact on what medication and treatment a patient receives. This is not the case for one of the participants, but they still see the importance of the results being included.

Comparisons with other participants

Inquiries are made into whether the participants of the co-creation sessions are interested in comparing their own data to the average of other participants, and how this can be visualized. The opinion on whether or not the participants would like to see their own data compared to that of other participants is mixed, and some participants are unsure. The ability to compare the data is of interest to some participants, especially if it can be used in a way to improve their own wellbeing, but the downside of this is that comparing oneself to others could lead to feeling depressed about yourself if you are not doing well. The option of being able to turn this comparison on and off is preferred amongst the participants. In a comparison, offering the ability to compare to your own age group, or to people who have been diagnosed with Arthritis for a similar amount of time, is also of interest.

Design of the Visualizations

Design of the PV tool

When it comes to the general design of the PV tool, it becomes apparent that the most important value of the participants is that the PV tool should offer a good overview of their personal data and be uncluttered. All the data should be accessible on one page, where additional details can be hidden behind interactions. The specific term ‘usability’ is repeated often throughout the co-creation. One of the remarks made by the participants regarding usability, is that the PV tool should be immediately available after data for the relevant research has been filled out. The PV tool should, next to after filling in data, be easily accessible and easy to find.

The participants indicate that an overview of the personal data regarding activity and fatigue throughout a month is a useful and intuitive visualization, and it is preferred to the other shown visualizations (as seen in figure 2). They also indicate that it is intuitive for them to receive more information upon interacting with the visualization. The participants also do not

like it if there is too much information available on “one screen”, because this impacts the amount of overview they have about their data.

Remarks are also made about what should be available on the PV tool next to the visualizations itself. This includes additional information about both the data visualization method itself, and a proper explanation on what the measurements in the visualization mean. There are differences in how, for example, the participants interpret a difference in size when looking at the pie charts showing activity per day (figure 5).

Most participants correctly understand how the graph showing the month overview (figure 2) should be read. One participant remarks how the line representing the fatigue score going down in the graph is, in their mind, associated with their general wellbeing improving. When describing previous experiences with seeing visualizations related to their condition, the decreasing of a line also indicates a better wellbeing. However, it is not immediately clear for all participants that this line is supposed to indicate their fatigue score, until this is explicitly mentioned to them.

General Design

General feedback on the design of the visualizations is also given. Through this feedback, details are identified that were still lacking in the first ideations of the design. Some of the participants remark that the colors used in the visualizations are not appropriate. One participant remarks about their worry for possible colorblind users of the portal, as differentiating activities with colors does not seem to be suitable for this. Another participant has difficulty distinguishing some of the chosen colors from each other, noting that they are too similar. In contrast to these participants critiquing the use of color as a design element integral to being able to read data from the visualization, another participant remarks that color can be added to a visualization to emphasize when a fatigue score was ‘bad’ or ‘good’.

As for the general method of visualization, the participants greatly prefer visualization techniques that are already familiar to them. One participant specifies that if too much time is needed to understand a visualization, even with the needed explanation provided, there was a serious doubt about whether the PV tool will be used by the participant at all. At first glance, it should already be clear what is being represented, and how it can be read. This sentiment is, all be it not always with the same conviction, present in all the participants. The participants also unanimously prefer to see their data represented through bar graphs, as these are easier to read than the presented pie graphs.

Conclusion

In the co-creation session, it was investigated what is important to the target audience of the Citizen Science Portal when it comes to the design of a PV tool. Their preferences for what data should be available in the PV tool related to fatigue and activity and in what form was discussed, as well as their preferences for how this should be visualized. Next to this, information was also discovered about the usability needs of the target audience, which should be considered during the further development of the PV tool. Based on these results, design requirements for the PV tool can now be elicited.

Design Requirements

Based on the results of the co-creation session a list of design requirements for the PV tool was determined, which can be found in table 4. Below, explanations are given on how the requirements have been elicited from the results of the co-creation session. The format used to state the design requirements was inspired by the work of Van Velsen et al [20].

Content of the Visualisations

Activity

Because of the difference in preference between the participants, an idea that also relates back to individuality as an encouraging factor, it should be possible for the users of the Citizen Science Portal to customize at which level of detail they want to view their activity. This addresses not only the fact that the desired level of detail changes from person to person, but also that it can change depending on a person's current wellbeing. However, there should still be a standard base level of detail in the form of broad categories of activities, which can then be expanded upon by adding further detail or compacted into less detail. The broad categories given in the mock-up prototypes were generally approved, but based on the suggestion made by one of the participants, the "physical activity" category will instead be split up into two categories. It will also have to be made clear what these broader categories actually mean, as this was not yet clear in the shown mock-up prototypes. An example of this is, does the 'sleep' category mean, actively being asleep, or spending time in bed. This information should be accessible. Based on this, the requirements in table 5, 6 and 7 can be determined.

ID	Requirement definition	Type
#1	Activities visualized in the PV tool should all fall under one of five broader categories: outdoor activity, indoor activity, mental activity, rest, sleep.	Content
#2	For each of the five broader activity categories, an explanation must be present.	Usability & User experience
#3	It should be possible for a user to customize at which level of detail their activity is visualized regarding the nature of the activity.	Functional
#4	Activities in the PV tool are measured in amount of time spent on them in minutes, and visualized on a scale of hours.	Content
#5	The time of day for a fatigue measurement should be made apparent in the PV tool.	Content
#6	Fatigue measurements should be translated into quantitative data, and with this a proper legend to explain the translation has to be available.	Usability / User experience
#7	A user should be able to compare their data in detail across multiple days, as well as compare their average data across weeks, and months.	Content
#8	The option should be available for a user to see their data compared to the average of citizens using the Citizen Science Portal.	Content
#9	The average of other citizens using the Citizen Science Portal can be given for all citizens, citizens in their age group, or citizens with a similar Arthritis history	Content
#10	After filling in data for a research project, the user should be able to navigate to the PV tool in one click or less for immediate feedback.	Usability & User experience
#11	The PV tool should be easy to find, in two or less clicks from the home page	Usability & User experience
#12	Upon accessing the PV tool, the user should see their data over the timespan of a month.	Content
#13	Explanations about the PV tool, what data is being represented, and how to read the visualizations should be easily accessible to the user	Usability & User experience
#14	Proper legends should be available for all measurements in all visualizations	Usability & User experience
#15	The visualizations should be appropriate for color-blind users	Usability & User experience
#16	Activity should be visualized using bar graphs, and fatigue should be visualized using line graphs.	Functional
#17	The user should be able to add their own notes about additional context that is relevant to their understanding of their personal data to the visualizations	Functional
#18	The data visualization should offer more detailed information upon interaction with the visualization	Functional

Table 4: Design requirements for the Citizen Science Portal Personal Visualization tool

Requirement ID: #1	*Content requirement*
Description: Activities visualized in the PV tool should all fall under one of five broader categories: outdoor activity, indoor activity, mental activity, rest, sleep.	
Rationale: There should be broad categories of activities that can be visualized in the PV tool, to which further levels of detail can be added. These categories were suggested to the target audience and improved upon.	
Source: Co-creation session (evaluation of mock-ups)	

Table 5: Design requirement 1

Requirement ID: #2	*Usability & user experience requirement*
Description: For each of the five broader activity categories, an explanation must be present.	
Rationale: It should be clear what each of the broader activity categories means to the user, for this additional explanation is necessary.	
Source: Co-creation session (evaluation of mock-ups)	

Table 6: Design requirement #2

Requirement ID: #3	*Functional requirement*
Description: It should be possible for a user to customize at which level of detail their activity is visualized regarding the nature of the activity.	
Rationale: Target audience shows a difference in preference for the level of detail of activity both between individuals as well as between different states of wellbeing per person.	
Source: Co-creation session (evaluation of mock-ups)	

Table 7: Design requirement #3

Requirement ID: #4	*Content requirement*
Description Activities in the visualization are measured in amount of time spent on them in minutes and visualized on a scale of hours.	
Rationale: Measuring activity in time spent on an activity is an appropriate measuring method according to members of the target audience.	
Source: Co-creation session (evaluation of mock-ups).	

Table 8: Design Requirement #4

There were no complaints made about time spent on an activity being a good way to measure and visualize activity, this will be how activity will be visualized in the PV tool. Thus, the requirement in table 8 can be determined.

Fatigue

In the co-creation session, the participants expressed that to accurately represent fatigue during a day, more than one measurement would be necessary. A good option to facilitate

this without asking the users of the Citizen Science Portal to fill in a questionnaire multiple times a day, would be to allow for more than one score given a day, but make it possible to give these scores at the end of the day. However, how often a measurement will be given has yet to be determined by the Citizen Science Portal researchers, and since this will not happen prior to the development of the PV tool prototype, this will not be made into a design requirement. What can be translated into a design requirement, is that the time of day of a fatigue measurement is important and should be apparent in the PV tool. This requirement is given in table 9.

Requirement ID: #5	*Content requirement*
Description: The time of day for a fatigue measurement should be made apparent in the PV tool	
Rationale: To be able to use a fatigue measurement to properly reflect on their wellbeing, the target audience indicated knowing the time of day this measurement was taken to be essential.	
Source: Co-creation session results (discussion)	

Table 9: Design Requirement #5

Requirement ID: #6	*Usability & user experience requirement*
Description: Fatigue measurements should be translated into quantitative data, and with this a proper legend to explain the translation must be available.	
Rationale: Because it is not possible for all target members to indicate their fatigue in a quantitative manner, it is likely that it will be measured in a qualitative manner. To be able to visualize this data, it must be translated into quantitative data. This translation should be communicated to the user, so they can relate this back to the data they filled in.	
Source: Co-creation session results (discussion)	

Table 10: Design Requirement #6

To make the measuring of fatigue more accessible for the users of the portal, a possible solution is to let the participants measure their fatigue on a less abstract scale, making it easier for them to assess their level of fatigue in comparison to previous measurements. Rather than asking for a score from one to ten, using a Likert scale would be more appropriate. Once again, the exact method of data collection will not yet be determined before the prototype must be finished. However, as the qualitative nature of this measurement is possible, any data resulting from this measurement must be translated into quantitative data before it can be visualized. Next to this it was also not clear whether a higher number represented more fatigue, or if it represented a day in which they felt better. This is a manifestation of the relation area of concern, meaning that in the initial ideations, this problem was not yet properly addressed. These findings together, led to the requirement

in table 10.

Time

As the participants show interest in both seeing their data on a precise scale as well as a larger scale, this variation in how they view it should be available in the personalization tool. This relates back to the encouraging factor of variation, but by introducing a variation in content rather than a variation in the visualization method. Depending on the implementation of this variation, it can also add exploration to the visualization tool. If, for example, the user of the tool could find more detailed information by interacting with the graph, this could encourage them to interact with the graph more. Based on this, the requirement in table 11 is elicited.

Requirement ID: #7	*Content requirement*
Description: A user should be able to compare their data in detail across multiple days, as well as compare their average data across weeks, and months.	
Rationale: Target audience members indicate that they would like to see their data on a smaller time scale with more detail, as well as summarized over a larger timescale.	
Source: Co-creation session results (discussion and mock-up evaluation), literature (variation)	

Table 11: Design Requirement #7

Other possible content

During the co-creation session, multiple suggestions for additional content for the PV tool were made. These suggestions included information on other Rheumatoid Arthritis symptoms, the inclusion of activity tracker data, and lab results related to their condition. While these suggestions are valuable as ideas for future research, they will not yet be included in the first attempt at a design of the PV tool.

Comparisons with other users

The participants of the co-creation session showed mixed interest in being able to see the summarized data of other citizens using the Citizen Science Portal next to their personal data. However, if this was given as an option rather than an always present feature, it was of interest to most of them. Adding the ability to choose a more selective group to compare to increased this interest. Because of this, the requirements in table 12 and 13 have been determined.

Requirement ID: #8	*Content requirement*
Description: The option should be available for a user to see their data compared to the average of citizens using the Citizen Science Portal.	
Rationale: Target audience members were interested in being able to compare their data to other research participants, if they would have the ability to turn it on or off.	
Source: Co-creation session results (evaluation of mock-ups)	

Table 12: Design Requirement #8

Requirement ID: #9	*Content requirement*
Description: The average of other citizens using the Citizen Science Portal can be given for all citizens, citizens in their age group, or citizens with a similar Arthritis history	
Rationale: Target audience members showed additional interest in being able to compare their data to other research participants if offered more selective groups of research participants.	
Source: Co-creation session results (discussion)	

Table 13: Design requirement #9

Design of the Visualizations

Next to eliciting design requirements based on the participants' preferences related to the content of the visualization, the analysis also sought out remarks related to the visual design of the PV tool. This included both remarks about the placement of the tool in the larger context of the portal, as well as more specific design details. First, the design and placement of the PV tool will be discussed. Within the context of the PV tool, the more specific visualization methods will be discussed.

Design of the PV tool

The specific term 'usability' was repeated often throughout the co-creation session and should be a priority in the further design of the visualization. Based on the remarks made related to the position of the PV tool in relation to the rest of the Citizen Science Portal, the design requirements shown in table 14 and 15 have been determined.

Requirement ID: #10	*Usability & user experience requirement*
Description: After filling in data for a research project, the user should be able to navigate to the PV tool in one click or less for immediate feedback.	
Rationale: Target audience members mentioned the importance of having the PV tool be immediately available after filling in data for a research.	
Source: Co-creation session results (discussion)	

Table 14: Design Requirement #10

Requirement ID: #11	*Usability & user experience requirement*
Description: The PV tool should be easy to find, in two or less clicks from the home page.	
Rationale: Target audience members mentioned the importance of the PV tool being easy and quick to find.	
Source: Co-creation session results (discussion)	

Table 15: Design Requirement #11

In general, the participants believed a visualization showing their personal data for an entire month to be the most useful and intuitive. Because of this, the PV tool should, when accessed, first show an overview showing data across a month. This led to the design requirement in table 16.

Requirement ID: #12	*Content requirement*
Description: Upon accessing the PV tool, the user should see their data over the timespan of a month.	
Rationale: Target audience members indicated that out of all mock-ups shown to them, the visualization showing an overview of their activity and fatigue data throughout a month would be the most useful and intuitive to them.	
Source: Co-creation session results (evaluation of mock-ups)	

Table 16: Design Requirement #12

During the co-creation session, it became apparent that it should never be assumed that a visualization can intuitively be read and understood by all citizens, and thus clear explanations should be available for those who desire to read them. Because of this, the design requirements shown in table 17 and 18 were added.

Requirement ID: #13	*Usability & user experience requirement*
Description: Explanations about the PV tool, what data is being represented, and how to read the visualizations should be easily accessible to the user.	
Rationale: Target audience members indicated a desire to see additional information about the visualizations in the PV tool.	
Source: Co-creation session results (evaluation of mock-ups)	

Table 17: Design Requirement #13

Requirement ID: #14	*Usability & user experience requirement*
Description: Proper legends should be available for all measurements in all visualizations.	
Rationale: During the co-creation session, it was not always clear for the target audience members how the measurements in the visualizations should be read. To ensure this will be clear in the PV tool, legends should be available.	
Source: Co-creation session results (evaluation of mock-ups)	

Table 18: Design Requirement #14

General Design

The colors chosen for the mock-up prototypes were not appropriate, as they were at times too similar, and this method of differentiating values was also not appropriate for color-blind users. To avoid this, the design requirement described in table 19 was added.

Requirement ID: #15	*Usability & user experience requirement*
Description: The visualizations should be appropriate for color-blind users.	
Rationale: The PV tool should be accessible to target audience members who are color-blind. This will also ensure that any user of the PV tool will not have trouble understanding the data because of color similarities.	
Source: Co-creation session results (evaluation of mock-ups)	

Table 19: Design Requirement #15

The participants in the co-creation session preferred seeing their data visualized using techniques already familiar to them and showed a unanimous preference for the mock-up prototypes using bar graphs to represent amount of activity. Next to this, using a line graph to represent something related to their wellbeing, in this case fatigue, was intuitive to them because of prior experiences. This led to the design requirement described in table 20.

Requirement ID: #16	*Functional requirement*
Description: Activity should be visualized using bar graphs, and fatigue should be visualized using line graphs.	
Rationale: Target member audience showed a preference for the visualization methods that were familiar to them. The use of a bar graph for visualizing activity was the preferred option out of those shown to the target members, and the use of a line graph to visualize fatigue was intuitive to them.	
Source: Co-creation session (evaluation of mock-ups)	

Table 20: Design Requirement #16

Reconsideration of areas of concern and encouraging factors

Based on the analysis results of the co-creation session, the identified areas of concern and encouraging factors, and how these inspired the design of the first ideations for the visualization tool could be reconsidered. Based on these reconsiderations, additional design requirements were added where necessary.

Understanding

During the co-creation session, the participants did not indicate any problems related to the trust that they had in their observations about the data. Instead, whenever an observation was made about the data, this was stated as if the participants would assume their observation to be fact. This is comparable to observations made by Choe et al., [10] where participants in their research were not aware of the statistical significance of their findings. While this does indicate that indeed, understanding is a present area of concern in personal visualization, the first ideation of the visualization tool does not yet properly address this area of concern. The participants, not being made aware of this being a possible issue, did not themselves indicate a desire to gain more statistical knowledge. They did, however, indicate a need for clear explanations about the used visualization techniques. With this, it was remarked that these explanations themselves should be accessible, and short enough that it would still be of interest to read. This conflicts with the inclusion of further explanation about statistical methods. For the further development of the PV tool, rather than fully explaining statistical methods, it will be tested if an offered explanation about what is being represented in the graph already helps address this area of concern, or if even this explanation is deemed unnecessary. The inclusion of these explanations was already detailed in previously stated design requirements; thus, no new design requirement will be added for this.

Context

At multiple points during the co-creation session, it was indicated by the participants that the offered visualization still missed information they deemed important. When asked what other information should be included in the visualizations, participants were able to identify context that was still missing for them. This exact context, however, did differ between participants. Because of this, it should be possible for participants to determine themselves what context is important for them to understand their data. While future development of the Citizen Science Portal might allow for the inclusion of other data, this is not yet viable for the development of the PV tool discussed in this document. Rather than detailing specific context to be added, the design requirement stated in table 21 is detailed.

Requirement ID: #17	*Functional requirement*
Description: The user should be able to add their own notes about additional context that is relevant to their understanding of their personal data to the visualizations.	
Rationale: Literature suggests that it a lack of external context to the available data in a personal visualization should be addressed before insight can be gained from this visualization. Which external context is relevant differs per target audience member, and making manual notes makes it possible for each user to choose what context they add to the visualizations.	
Source: Literature (context), Co-creation session results (discussion)	

Table 21: Design Requirement #17

Relation

Attention was paid to how well the participants of the co-creation session were able to identify how the visualizations related back to their real-life counterparts. It was found that there was significant difficulty expressed by multiple participants in identifying what an abstract numerical representation of a qualitative experience meant, as this translation of qualitative data into quantitative data was not yet properly explained. Color was in general experienced as a good way to differentiate between different activities, and it was still possible for the participants to make comparisons between time spent on these activities both within a day, and over a longer time span. In a similar vein, the use of bar graphs seemed to be the visualization method that was easiest for the participants to relate back to their mental model. When more abstract visualizations were shown, like a bubble graph, the unfamiliarity of these visualizations made this more difficult. Thus, the further use of familiar visualization methods, paired with clear explanations, should properly address the relation area of concern. Previously detailed requirements already encompass these needs, and thus no new requirements will be added.

Exploration

A preference for the use of familiar visualization methods conflicts with the earlier established theory that offering more abstract visualization would encourage the user to explore their data more, which would in turn lead to the further gaining of insight. When faced with a more abstract visualization, the sentiment surfaced that if the participant had to put effort into understanding something, they would have to be sufficiently triggered to do so. This was not the case with the visualization they were seeing at that moment. Combining these sentiments, offering abstract visualizations does not seem to be a fruitful avenue to introduce exploration as an encouraging factor. What did become apparent, however, is that the exploration of a visualization through interaction was intuitive for the participants. By hiding further details about their personal data behind interactions the sense of exploration is

evoked. Next to this, it would make the base visualization less detailed, which would provide more overview according to the participants. Because of this, the design requirement stated in table 22 is added.

Requirement ID: #18	*Functional requirement*
Description: The PV tool should offer more detailed information upon interaction with the visualization.	
Rationale: Literature suggest that adding an element of exploration to a PV tool through offering more information upon interaction with a visualization will increase the amount of insight that is gained from this visualization. Hiding more detailed information behind interaction will also make the PV tool less detailed at first glance, which will offer a better overview of the users' personal data.	
Source: Literature (exploration), Co-creation session results (discussion and evaluation of mock-ups)	

Table 22: Design Requirement #18

Individuality

Individuality was the only encouraging factor that was not yet introduced through the mock-up prototypes, as it was not possible to let the participants customize the prototypes. Instead, inquiries were made into what the preferences of each individual participant would be at multiple points throughout the co-creation session, through which it was determined what the extent of the need for personalization of the visualizations in the PV tool would be. In multiple different aspects of the visualizations, personalization was preferable to the participants. Ensuring that an appropriate amount of personalization is available in the visualization tool, as has been previously detailed in design requirements, will introduce individuality as an encouraging factor.

Variation

Contrary to initial expectations, when shown different visualizations the participants had no desire to see the same data visualized using a different visualization method. Instead, the additional visualizations did more to confuse the participants, rather than enhancing their understanding of their personal data. However, this did not mean that the participants preferred seeing their personal data visualized in only one way. Instead, seeing their data in different levels of detail was appealing, including the introduction of summary data. Some of the participants were also interested in introducing comparisons between their personal data, and the average data of other participants. While the variation in visualization method did not have the expected result, the variation in visualization content still introduces a

dynamic experience of personal data, to be adapted to the wishes of the user. So, using the previously established design requirements related to this, variation is incorporated into the final design requirements.

PV tool Components

To incorporate the stated design requirements into the PV tool, the PV tool will consist of some different components. Most of the determined design requirements described what content should be found in the visualization part of the PV tool. This component, which will be referred to as the visualization field, will include all data visualizations present in the visualization tool. To make the PV tool uncluttered, only one visualization should be visible at a time. Because of this, the content of this visualization field had to be dynamic, as multiple requirements specified the need to see the personal data on different scales. To allow for this, a second component was added: the settings menu. Through the settings menu, the content of the visualization can be personalized.

Next to the visualization field and the settings menu, a legend component has to be included in the design of the PV tool. Through this legend component, the measurements present at any time in the visualization field can be explained, as the design requirements specified was needed. Next, an explanation component has to be added, in which explanations about the visualization method used in the visualization field, as well as additional information about the functioning of the PV tool can be included. Finally, a commenting tool has to be added, which will allow the user to note down any desired context to the visualization field.

Conclusion

In the ideation chapter it has been described how during the ideation phase a total of 18 design requirements (table 4) were elicited, based on a co-creation session and a reconsideration of the background research. To allow for the implementation of these design requirements, multiple necessary components of the PV tool have been determined: the visualization field, the settings menu, the legend component, the explanation component, and the commenting tool. In chapter 6 it will be described how these design requirements and PV tool components were implemented in a final prototype for the PV tool.

Chapter 6 – Realization

In this chapter, the realization phase of the design process is described. First, a description of the overall architecture of the PV tool and possible use cases of the PV tool are given. Then the further realization of the design requirements into a final prototype of the PV tool is given. The chapter ends with a reflection on the implementation of the design requirements is.

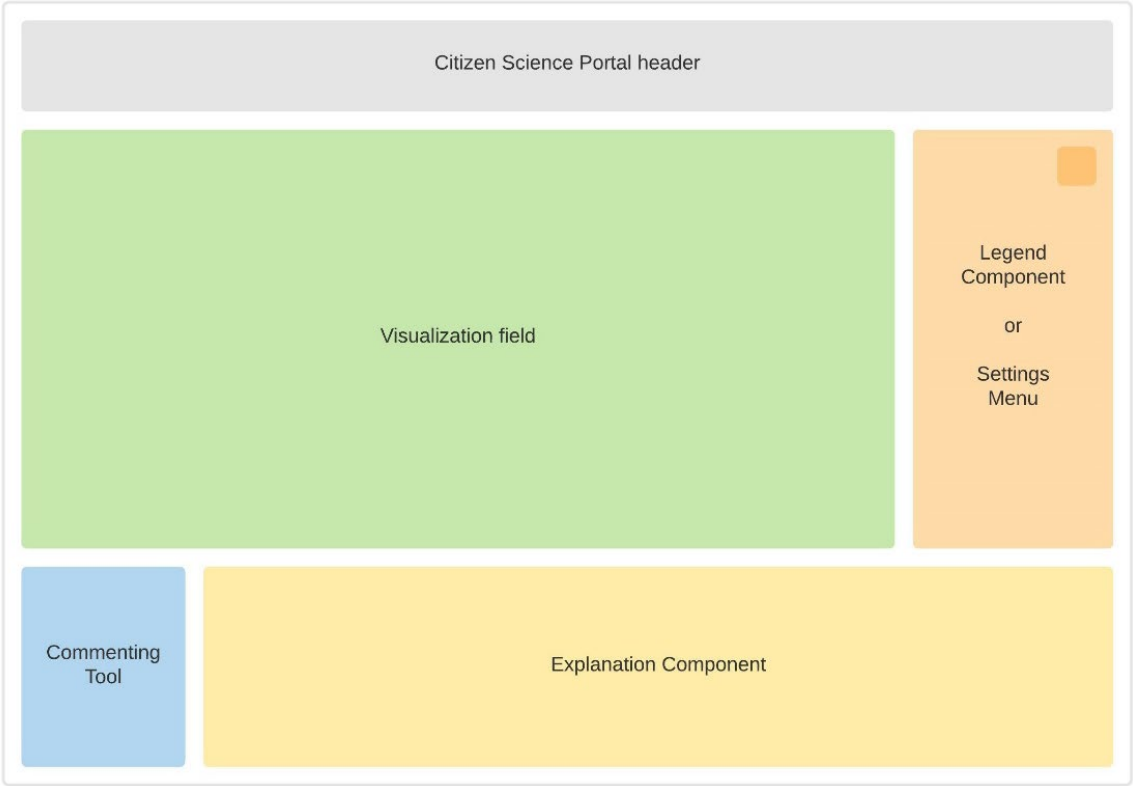

Figure 8: Mock-up for the layout of the PV tool. Created using Lucidchart [21]

System architecture and interactions

In chapter 5, different components of the PV tool are described: the visualization field, the explanation component, the legend component, the commenting tool, and the settings menu. It was important that all these components were easily accessible and easy to find for the user. To ensure this, the layout for the PV tool shown in figure 8 was determined. In this layout, both the visualization field and explanation about this visualization are immediately accessible at all times. To leave enough room for the visualization field, the legend and the settings menu are interchangeable, taking up the same space in the layout. The settings menu can be accessed through the use of a button.

The system architecture of the PV tool design discussed in this thesis consists of two parts: a citizen user and the PV tool, presented to them through a web page. Details about the back-end integration of this web page into a larger system architecture is outside the scope of this thesis. What can be detailed further are different use cases for the PV tool, which describe the possible interactions of the user with the PV tool. Below five different use cases are given, for each of which it is described how the PV tool components will adjust based on interactions from the user.

Use case #1: The user explores the visualization field

User	PV tool
Visits the PV tool through the Citizen Science Portal	Visualization field shows the user an overview of their data throughout one month
Interacts with the visualization to see their data from a longer time ago.	Visualization field adjusts the data being shown accordingly
Interacts with the visualization to see their data in more detail	Visualization field 'zooms in' on the data, showing the data in more detail per day.
	Explanation component and legend component adjust accordingly.
Interacts with the visualization to see their data summarized over time	Visualization field 'zooms out' on the data, showing the data summarized per week or per month.
	Explanation component and legend component adjust accordingly.

Table 23: Use case #1

Use case #2: The user changes the contents of the visualization.

User	PV tool
Visits the PV tool through the Citizen Science Portal	Visualization field shows the user an overview of their data with some of the available content.
Clicks the settings menu button to access the settings menu.	Legend component disappears and settings menu appears.
Interacts with the settings menu to change the current contents of the visualization.	Visualization field changes its contents depending on what the user chooses.
	Legend component adjusts accordingly.
Clicks the settings menu button to close the settings menu.	Settings menu disappears and legend component reappears.

Table 24: Use case #2

Use case #3: The user looks for what the measurements in the visualization mean.

User	PV tool
Visits the PV tool through the Citizen Science Portal	Visualization field shows the user an overview of their data with some of the available content.
Looks at the legend component to see what the measurements in the visualization mean.	Legend component shows what the measurements currently present in the visualization mean.

Table 25: Use case #3

Use case #4: The user looks for additional information on the PV tool.

User	PV tool
Visits the PV tool through the Citizen Science Portal	Visualization field shows the user an overview of their data.
(Scrolls down if necessary) Looks at the explanation component to see how the visualization method used should be read.	Explanation component shows how the visualization methods used in the overview currently being shown should be read.

Table 26: Use case #4

Use case #5: The user adds a custom note to the visualization field.

User	PV tool
Visits the PV tool through the Citizen Science Portal	Visualization field shows the user an overview of their data with some of the available content.
(Scrolls down if necessary) Clicks a button in the commenting tool to add a new note to the visualization field.	Shows a pop up where the user can fill in what they want the note to contain.
Fills in what the note should contain and clicks on the visualization field to add the note.	Closes the pop up and places an icon on the visualization field where the user indicated they wanted the note to be placed.
Hovers with their mouse over the new icon that has appeared on the visualization field.	Shows a popup containing the information the user put on the note.

Table 27: Use case #5

Final Prototype

The implementation of the PV tool design into a final prototype for the PV tool will now be discussed.

Methods

Through discussion with the Citizen Science Portal researchers, it was determined that the final prototypes for each part of the portal would be developed with the use of a prototyping tool, Proto.io [20]. The benefit of this would be that during the evaluation of the portal prototype, all components would be accessible through one prototype, creating a sense of unity rather than the evaluation itself being divided across multiple prototypes. Next to this, Proto.io lends itself well to rapid prototyping, which was of large benefit considering that the prototype would be built in a short time span, and feedback on the prototype from the Citizen Science Portal researchers would have to be incorporated quickly. This did mean, however, that the options for interaction with the prototype would be more limited than would have been ideal for incorporating all the design requirements properly. This meant that for some interactions, rather than being implemented into the prototype, an explanation of the function would have to be given during an evaluation of the prototype.

Dataset

Before the prototype could be created, data had to be generated that could be visualized as an example. Ideally, when evaluating the prototype, it would be possible to do this using actual personal data of the participants. However, the integration of this was not yet possible within the scope of this thesis. Instead, example data was created which would represent an example of what personal data on activity and fatigue could look like for a fictional Arthritis patient, taking into consideration the remarks about this made during the co-creation session. This was done using Microsoft Excel, in which four separate tables were created. One table contained a month of data, on which for each day the amount of time in minutes spent on an activity category by a fictional person was given. This data was created by randomly generating a number within a set interval for each of these categories, and then adjusting this slightly to fill close to a full 24 hours of time. The set intervals differed between weekdays and weekend days, where more time was spent on mental activity from Monday to Friday to simulate having work during the weekdays. This table also contained the average amount of time in minutes from other fictional people. A second table contained the same data, averaged per week. This table contained an additional two months of data, making for three months in total.

A third table contained fictional data about the fatigue experienced by a person during a month. For each day, three separate measurements were given, one for 9:00 am, one for 13:00 pm, and lastly for 22:30 pm. Each fatigue score was an integer between 1 and 10, 1 indicating a low level of fatigue, and 10 indicating a high level of fatigue. These scores were manually created, manipulating the data slightly to form some correlation between the number of active hours (including physical and mental activity) and the fatigue experienced by the fictional person. This was done so during the evaluation it was possible for the participants to find a correlation in the data. Finally, the fourth table contained this same data, yet again averaged per week. This also included two months of additional data.

Visualizations

The data visualizations present in the visualization field of the final PV tool prototype were created in two steps. First, the created dataset was imported into Tableau, an interactive data visualization program created by Tableau Software [17]. Using Tableau, several data visualizations were created using the developed data sets. These data visualizations were created to use as a base, as the automatic visualization functions of Tableau made for an easy way to accurately visualize the created data. In the second step of creating the data visualizations, the final visualizations were made using Adobe Illustrator [21]. Illustrator would allow for all separate elements of the data visualizations to be created on different layers and exported separately. This was necessary to implement the feature in which the content of the visualization field could be adapted using the settings component. Illustrator also allowed for a higher exporting resolution of the visualizations, as it could export most of these separate elements as vector images. Using these two programs, four different visualizations were created, each of which showed a different timescale and had separate content elements that could be interchanged.

Proto.io

After the different visualizations and their components had been created and exported, they were incorporated into an interactive prototype. Using Proto.io a webpage was designed showing the PV tool, which was part of a larger prototype showing the entire Citizen Science Portal. For this, the mock-up of the page layout was used. This way, each intended system component was sure to be incorporated. The prototype went through multiple feedback cycles, where the latest version of the prototype was shown to other Citizen Science Portal researchers, and subsequently any comments on the prototype would be adjusted or discussed further. Alongside this, the design of the evaluation of this prototype was improved, which is detailed in Chapter 7. The final prototype and its evaluation were tested with a volunteer participant outside of the target audience through a pilot test, in which the

researchers that would lead the final evaluation were given a chance to practice it's procedure as well receive feedback on the prototype from the participant. After receiving this feedback, the final adjustments to the prototype before evaluations were made.

Proto.io prototype

Location of the prototype

The PV tool prototype can be accessed from the homepage in the Citizen Science Portal prototype through three separate ways. The first of this, shown in figure 9a, is directly after a citizen user has handed in data for a research they are participating in. By clicking on the highlighted area, they will immediately get access to the PV tool to explore the personal data they have collected for this research. The second way is through a page showing each research a citizen user is participating in, which is shown in figure 9b. Here, the PV tool can be accessed through the highlighted button. Lastly, the PV tool can be accessed through the homepage directly. Here, by clicking on a button labelled "My data overview" (figure 9c), the user will be directed to a page showing them different topics they have collected personal data under (figure 9c). By selecting one of these topics, they will be directed to the PV tool as well. In further development of the portal, these three different ways may lead to a PV tool containing different data than was used in the PV prototype discussed in this thesis.

Layout

In figure 10, the final layout of the prototype is shown. It includes the visualization field (labeled VF), the legend component and the settings menu (labeled LC / SM), a component for explanation about the prototype (labeled EC), and a commenting tool (labeled CT). The prototype has a few different interactions possible; in the visualization field, any user can 'zoom in' on their data by clicking on one of the data points in the bar graph. This feature was not fully implemented yet when the prototype was evaluated, but at least one data point worked for each time scale. This will be further elaborated on in this chapter. By clicking on the gear symbol above the legend component, the settings menu can be opened and subsequently closed again. Through this settings menu, the content shown in the visualization field could be customized. This will be further elaborated on in this chapter. By using the provided button for adding comments, the user should be able to add new notes to the visualization graph, which will show up as note symbols on the visualization field after they have been added. Using the blue arrows next to the visualization field, the user will be able to move forward and backwards in time. This last feature was not functional when the prototype was evaluated with the target audience, but the intended functionality was explained and discussed.

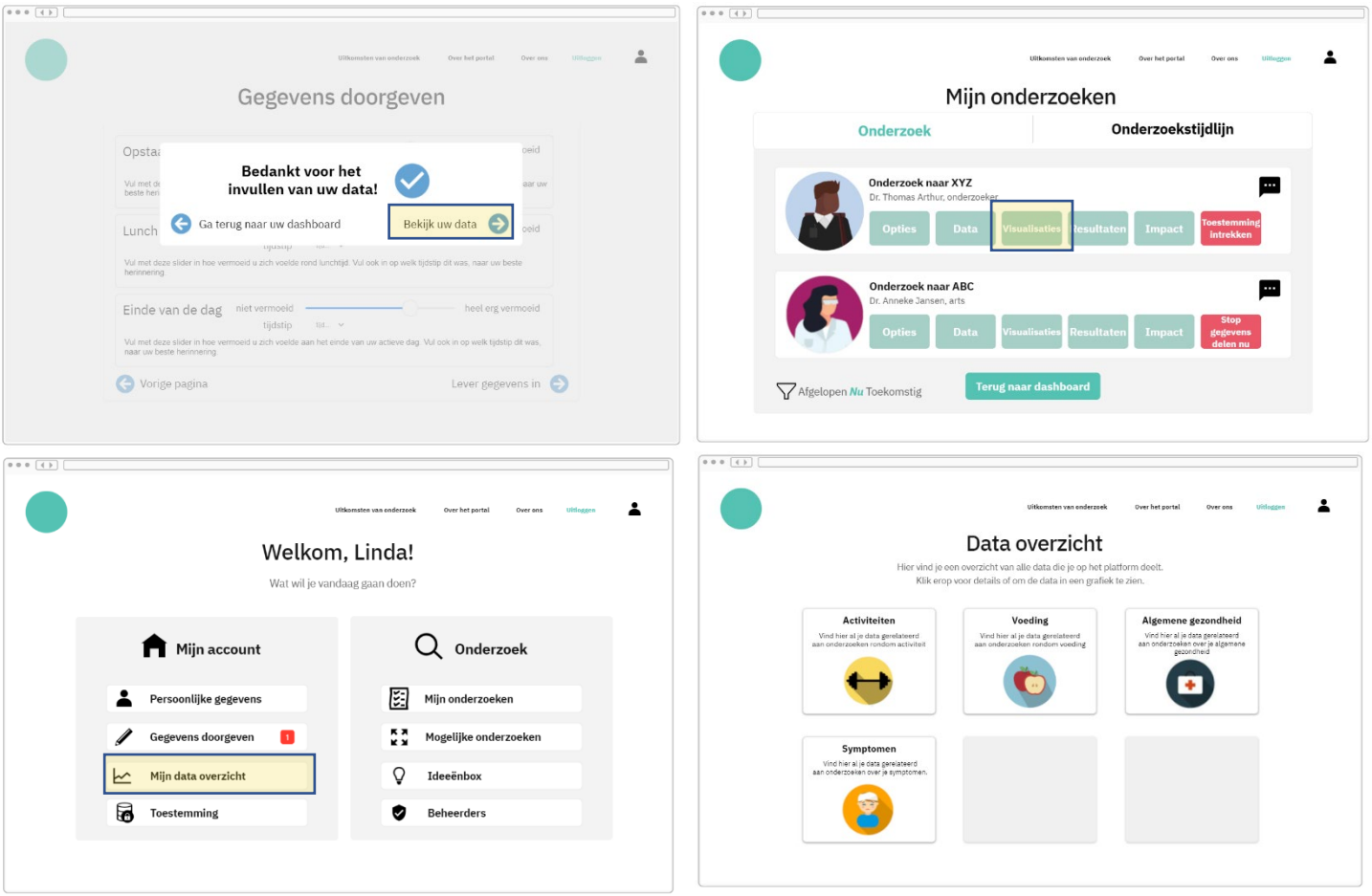

Figure 9a - 9d: Locations of the PV tool on the Citizen Science Portal. Upper left (a), upper right (b), lower left (c), lower right (d).

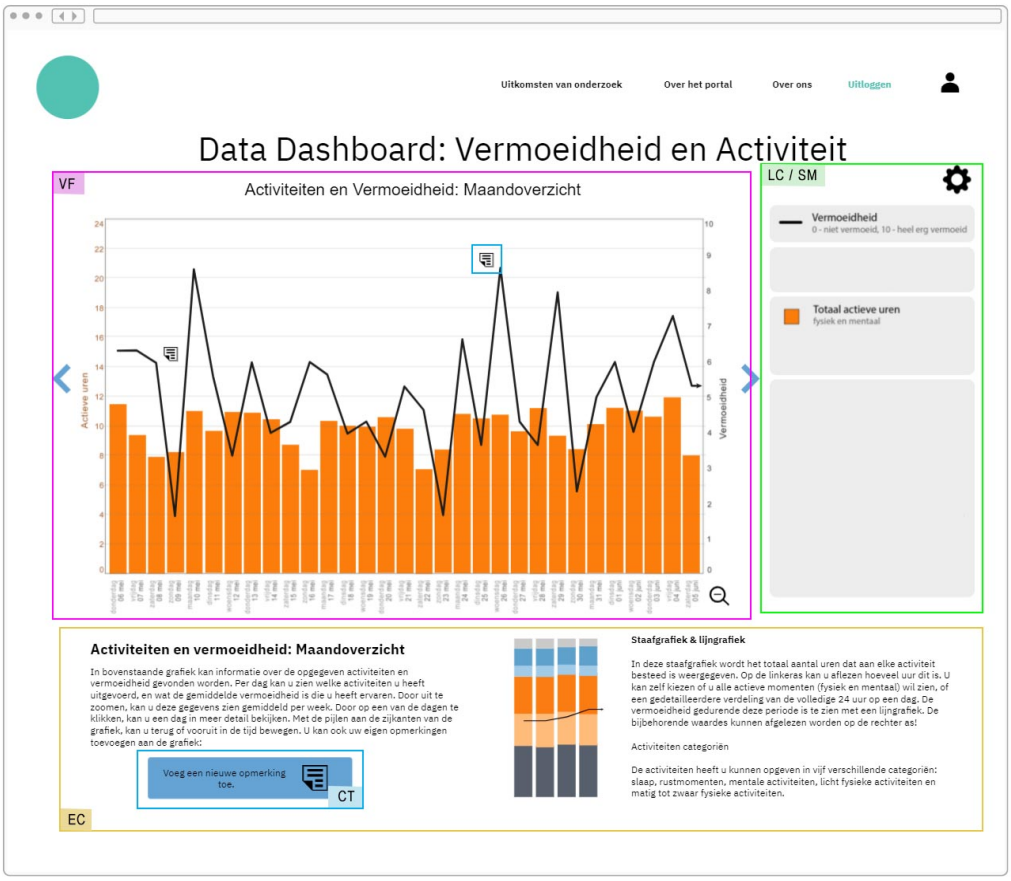

Figure 10: Layout of the PV tool in the Citizen Science Portal

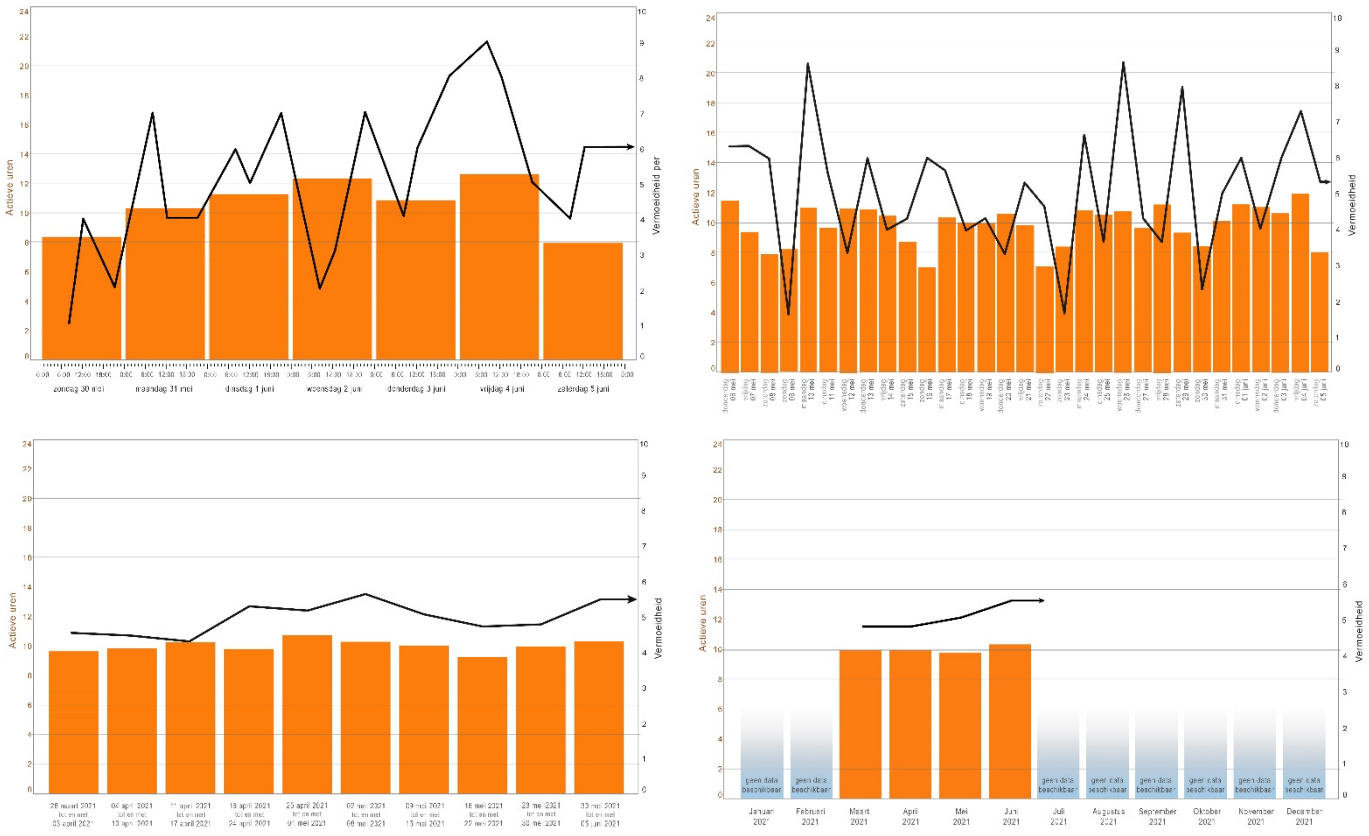

Figure 11a – 11d: Visualization field week overview (a, upper left), month overview (b, upper right), quarter overview (c, lower left), and year overview (d, lower right).

Visualization field: variation of Scale

Figure 11 shows what the four different time scales are that can be navigated to through interaction with the visualization field. Figure 11a shows the most detailed visualization, where the users data about activity and fatigue can be seen for one week. Per day, multiple measurements for fatigue are shown, of which the times correspond to when the fatigue measurements were made. Figure 11b shows the visualization that is first shown when navigating to the PV tool, offering the user an overview of their data over the last month, with one measurement for fatigue for each day. By 'zooming out' further, the user will be able to see the quarter overview shown in figure 11c. Here, the personal data has been summarized per week, giving the user the ability to see what their activities and fatigue experiences have been on average. By 'zooming out' one last time, the user will be able to see their own data across an entire year, summarized per month. The title above the graph also changes depending on what time scale the user is viewing.

Visualization field: personalization in Content

Next to viewing their personal data on different time scales, the user of the PV tool is be able to adapt what is shown in the visualization at the same time. There are six different

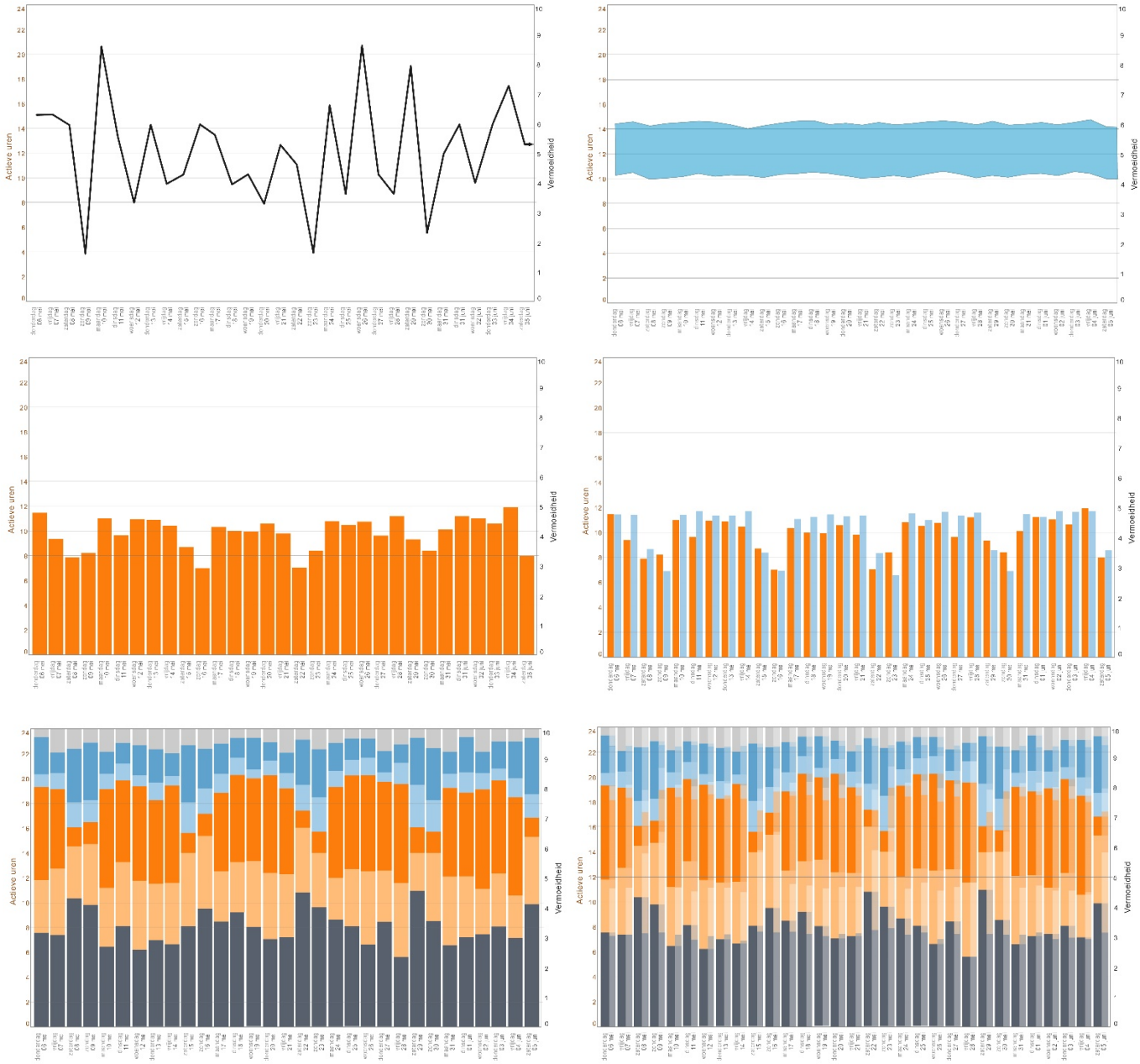

Figure 12a - f: Content available for the visualization field of the PV tool prototype. Fatigue (a, upper left), average fatigue (b, upper right), activity per day (c, middle left), average activity per day (d, middle right), detailed activities (e, lower left), and average detailed activities (f, lower right).

datasets available for them to view, which are detailed in figure 12a - f. By using the setting component (figure 13a), each of these six possible views can be seen interchangeably, in such a way that all six can be turned off as well as turned on independently. Figure 12a shows the visualization of fatigue measurements by means of a line graph. In figure 12b, an area graph shows information about the data of other participants in the example research. This area contains 50% of the fatigue measurements closest to the average out of all participants participating in the research. In figure 12c, the visualization of the amount of time a user spent being active on one day is shown. These active hours include any activity

that the user has entered on the website as being either mentally active, or physically active. This personal data can be compared to the average of all participants as well, as is shown in figure 12d. The users of the portal are also able to see their activities in more detail, as shown in figure 12e. Here, their activity is shown divided into five categories. These categories match with the categories that the users fill out their activity data as in the Citizen Science Portal prototype; sleep, resting time, mental activity, light physical activity, and intermediate to heavy physical activity. Finally, as shown in figure 12f, this data as well can be compared to the average data of other Citizen Science Portal users.

Legend component and settings menu

The setting component shown in figure 13a, which allows for control over what data was present at any time in the graph, can specifically be controlled per different available time scale. The PV tool prototype is not able to remember the previous state of the setting menu for each time scale between different moments viewing them. What is present, however, is that the contents of the legend component also adapt based on what is selected in the settings menu. The legend component, shown in figure 13b, also gives additional information about the measurements shown in the visualization field, for all the possible contents of this visualization field.

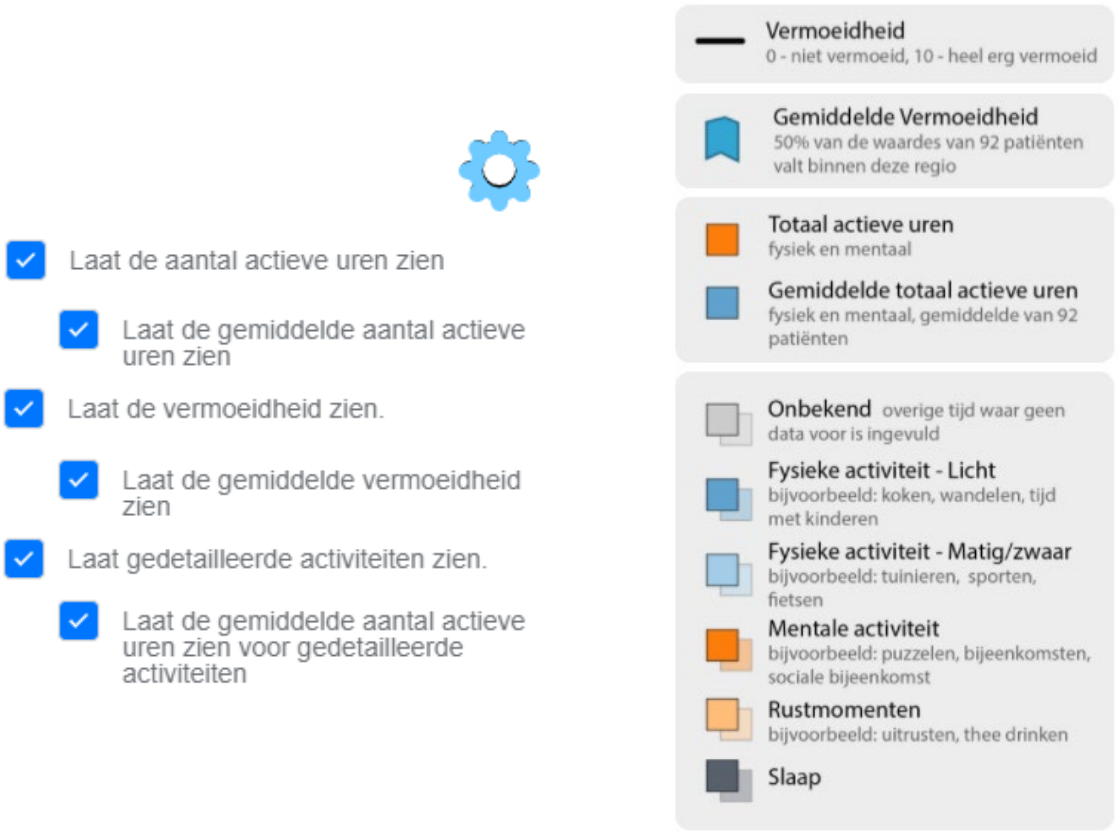

Figure 13a and b: The setting component (a, left) and legend component (b, right) of the PV tool prototype.

Explanation component and commenting tool

The implementation of the last two components are shown in figure 14. The first of these is the explanation component, which shows information about the visualization method and contents of the visualization field. Next to this, an overview of the different features available on the PV tool was present. The contents of this explanation component differ slightly between available time scales. Lastly, the commenting tool can also be found on top of the explanation component. This button to add comments was not functional in the prototype, as the time to implement this with Proto.io was not available. However, to demonstrate what it would be able to do, example notes were added in the month overview. When hovering over these notes, which were indicated on the visualization using a note icon, text would appear. One of these example notes said “Sam’s birthday”, and the other note said “Weekend in Scheveningen”.

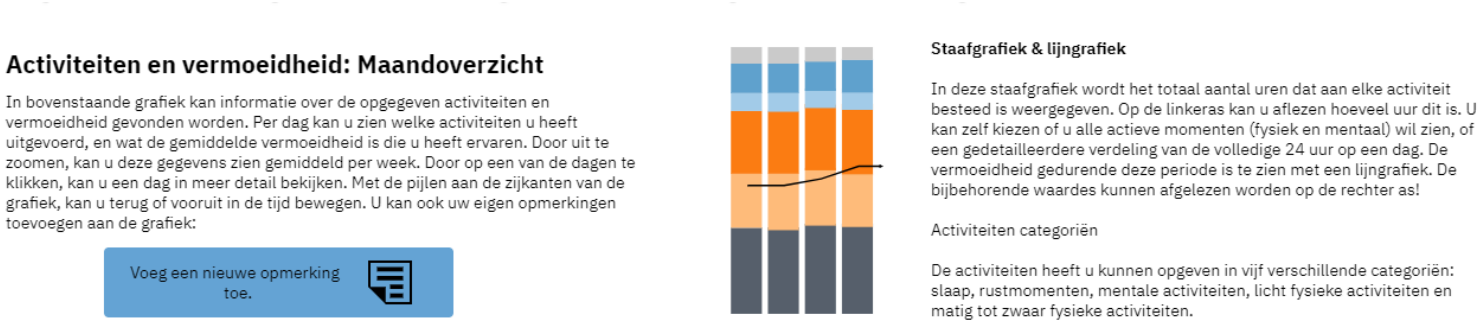

Figure 14: The explanation component and commenting tool in the PV tool prototype.

Conclusion

Most of the design requirements detailed in chapter 5 were implemented into the final prototype. In table 23, it is indicated which of the design requirements were implemented. Some of the design requirements were adjusted slightly based on feedback given on the prototype. Below, additional explanations are given on how the design requirements were or were not implemented where necessary.

#1 – Based on feedback from Citizen Science Portal researchers, the activity categories “indoor activity” and “outdoor activity” were replaced by “light activity” and “medium to heavy activity.” This was done because the initially suggested categories would not give as much valuable information to the user as the new proposed categories.

#3 – The PV tool prototype allows the user to view their activity data in two separate ways: either as the total of active hours, which includes three of the activity categories, or in the

five separate activity categories. If more time had been available, the prototype could have offered further customizability and allowed for further specification of activity within these categories as the user desired. However, this was not implemented for this prototype.

ID	Description	Completed?
#1	Activities visualized in the PV tool should all fall under one of five broader categories: ~~outdoor activity, indoor activity~~ light physical activity, medium to heavy physical activity, mental activity, rest, sleep.	
#2	For each of the five broader activity categories, an explanation must be present.	
#3	It should be possible for a user to customize at which level of detail their activity is visualized regarding the nature of the activity.	
#4	Activities in the PV tool are measured in amount of time spent on them in minutes, and visualized on a scale of hours.	
#5	The time of day for a fatigue measurement should be made apparent in the PV tool.	
#6	Fatigue measurements should be translated into quantitative data, and with this a proper legend to explain the translation has to be available.	
#7	A user should be able to compare their data in detail across multiple days, as well as compare their average data across weeks, and months.	
#8	The option should be available for a user to see their data compared to the average of citizens using the Citizen Science Portal.	
#9	The average of other citizens using the Citizen Science Portal can be given for all citizens, citizens in their age group, or citizens with a similar Arthritis history.	
#10	After filling in data for a research project, the user should be able to navigate to the PV tool in one click or less for immediate feedback.	
#11	The PV tool should be easy to find, in two or less clicks from the home page	
#12	Upon accessing the PV tool, the user should see their data over the timespan of a month.	
#13	Explanations about the PV tool, what data is being represented, and how to read the visualizations should be easily accessible to the user	
#14	Proper legends should be available for all measurements in all visualizations	
#15	The visualizations should be appropriate for color-blind users	
#16	Activity should be visualized using bar graphs, and fatigue should be visualized using line graphs.	
#17	The user should be able to add their own notes about additional context that is relevant to their understanding of their personal data to the visualizations	
#18	The data visualization should offer more detailed information upon interaction with the visualization	

Table 28: Design requirements for the Citizen Science Portal PV tool, with completion status.

#5 – The time of day for each fatigue measurement is only specified in the week overview, as only this overview allowed for this detailed information to be shown. For the other timescales, this data was averaged for either the entire day, a week, or a month.

#9 – Due to a lack of available time, this design requirement was not incorporated into the final prototype. Including this design requirement would have asked for another level of complexity to be added to the prototype on top of the customization already in place, which would have been difficult to achieve using proto.io. Because of this, the decision was made to not include this feature in the prototype.

#15 – To ensure appropriateness for color-blind people, a color scheme was chosen which is appropriate for color-blind people. It was inspired by the colorblindness friendly palette designed by Tableau [17].

#17 – The note adding feature was not yet fully implemented in the final prototype. However, indicators of this feature were added, and during testing of the prototype the presence of this feature could be explained further.

#18 – In the current prototype, the more detailed information that is available through the prototype is limited to the changing in time scales. While this does meet the set requirement, it would have been good to implement further interaction, such as labeling the data if hovering over a data point. This was not implemented due to time constraints.

Chapter 7 – Evaluation

This evaluation chapter focusses on how the prototype described in chapter 6, realization, was evaluated. Here is described what methods were used to evaluate the prototype, the results from this evaluation, and finally four design guidelines for the further design of the PV tool are discussed. During this, the following three sub research questions are discussed and answered:

- Does the designed personal visualization tool allow citizens to gain insight about their wellbeing?
- What impact does the addressing of the identified areas of concern and implementing the identified encouraging factors have on the ability of citizens to gain insight from personal visualizations?
- What other factors influencing the gaining of insight on wellbeing from a personal visualization are important to consider when designing a personal visualization tool for the Citizen Science Portal?

Evaluation Sessions

Similar to how the first ideations of the prototype were evaluated through direct conversation with the people who would be using the PV tool, the final prototype was evaluated through evaluation sessions. These evaluation sessions aimed to evaluate the entire Citizen Science Portal prototype. This meant that the PV tool was evaluated within the context of the Citizen Science Portal, rather than only on its own. However, this did mean that there were restrictions on what methods of evaluation could be used, as these methods had to be fit to evaluate the entire portal. In total, four evaluation sessions were performed, each with one participant representative of the target audience. During these sessions, qualitative testing of the prototype took place, with the goal of evaluating the design choices made during the realization phase.

Method

Design and Setting

Four Citizen Science Portal researchers were involved in the design and execution of the evaluation session. These researchers were all responsible for the development of a different part of the prototype, and thus a different part of the total evaluation. As to not overwhelm any participants, the decision was made to have at most two researchers present

for each evaluation session. To ensure that each evaluation session would be executed in the same way, and that each researcher would be able to evaluate the entire prototype as well as the part they developed themselves, a detailed script was written for the evaluation session. This script guaranteed consistency between each of the evaluation sessions, regardless of whom lead the evaluation. It can be found in Appendix V.

Before the evaluation sessions took place, a pilot test was run in which the evaluation procedure was practiced and subsequently improved upon. This pilot test happened in an informal environment, where a volunteer participant outside of the target audience who had experience with the Creative Technology Design Process, and the researchers were all present. The pilot followed the same method as described for the final evaluation session, and after its execution, some final changes were made to the evaluation script and prototype. These changes are incorporated in the description of the final prototype given in Chapter 6 and the script given in Appendix V.

The entire evaluation session took an hour and a half, of which about thirty minutes could be spent on evaluating the PV tool prototype. The session took place in Dutch, the native language of the participants in the evaluation. Because of this, the script was also written in Dutch.

Participants

Four people with Rheumatoid Arthritis participated in the evaluation sessions. All of the participants had previously joined one or more co-creation sessions organized for the Citizen Science Portal and were informed about the research in advance. The participants were between the ages of 47 and 69 and were diagnosed with Rheumatoid Arthritis between 8 and 21 years prior to the research. Three of these participants were women, and one was a man. Each participant received a €15,- VVV-bon as compensation for their participation.

Tools

The evaluation session took place through a video call on the video conference platform Zoom [17]. All the participants could join this call on their personal devices and received an invitation link a week prior to the evaluation session, as well as a reminder a day in advance. During this session, one of the researchers present shared their screen, which showed the developed prototype. It was also possible for this research to give control over this shared screen to the other researcher present, as well as the participant of the session.

Procedure

As mentioned previously, a script was designed describing the procedure that would be followed during each step of the evaluation session. Part of this procedure was focused on evaluating the PV tool, through allowing the participant to interact with the developed prototype and asking them open questions. The evaluation sessions were recorded with the informed consent of the participant.

Upon seeing the developed PV tool prototype for the first time, the participant in the evaluation session would get to control the shared screen, showing the prototype, themselves. For the entire duration of the evaluation of the PV tool, the participant would keep control over the prototype. If the user was not able to properly control the prototype, due to the device they joined the Zoom video conference on or any other technical reasons, the researcher asking them the evaluation questions would interact with the prototype on their command. The first question asked of the participant, was to identify which different functionalities of the PV tool they could find or would expect to find. This question was asked to evaluate if the design of the PV tool and the placement of the different components were intuitive and satisfied the participant's usability needs. After the participant would give their own answer, any missing components and interactions were explained to them, before further questions were asked.

After receiving these explanations, the participant was asked to imagine the data to be their own personal data, and to tell the researchers what information they could see in the data and any interesting things they noticed. This question was asked to determine if the personal visualization tool allowed the user to make insights about the data presented. By counting the individual observations made by the participants in the analysis of the evaluations, something could then be said about whether the tool succeeded at this. In this part of the evaluation session, a distinction was made between what insights were made without using the tool's ability to 'zoom in' on the available data, and with the use of this function.

Lastly, the participants were asked per component of the personal visualization tool how helpful they believed each component to be in the analyzing of the available data. As each different component was designed based on different identified areas of concern and encouraging factors, this would help with eliciting a judgement on the contributions of each of these factors to the participants' ability to gain insight.

Analysis

After the evaluation sessions had all taken place, the sessions were transcribed using Amberscript [18], as well as additional manual transcription. To then analyze these transcriptions, first a deductive analysis strategy was constructed that would allow for the answering of the first and second sub research questions:

1. Does the designed personal visualization tool allow citizens to gain insight about their wellbeing?
2. What impact does the addressing of the identified areas of concern and implementing the identified encouraging factors have on the ability of citizens to gain insight from personal visualizations?

This analysis strategy was then expanded upon using through inductive analysis, where the session transcriptions were read through a few times, so that some different topics that were not initially planned to have a discussion on, such as “motivation for use of the tool”, were made part of the overall analysis strategy. The results of would be used as a part of answering the final sub research question:

3. What other factors influencing the gaining of insight on wellbeing from a personal visualization are important to consider when designing a personal visualization tool for the Citizen Science Portal?

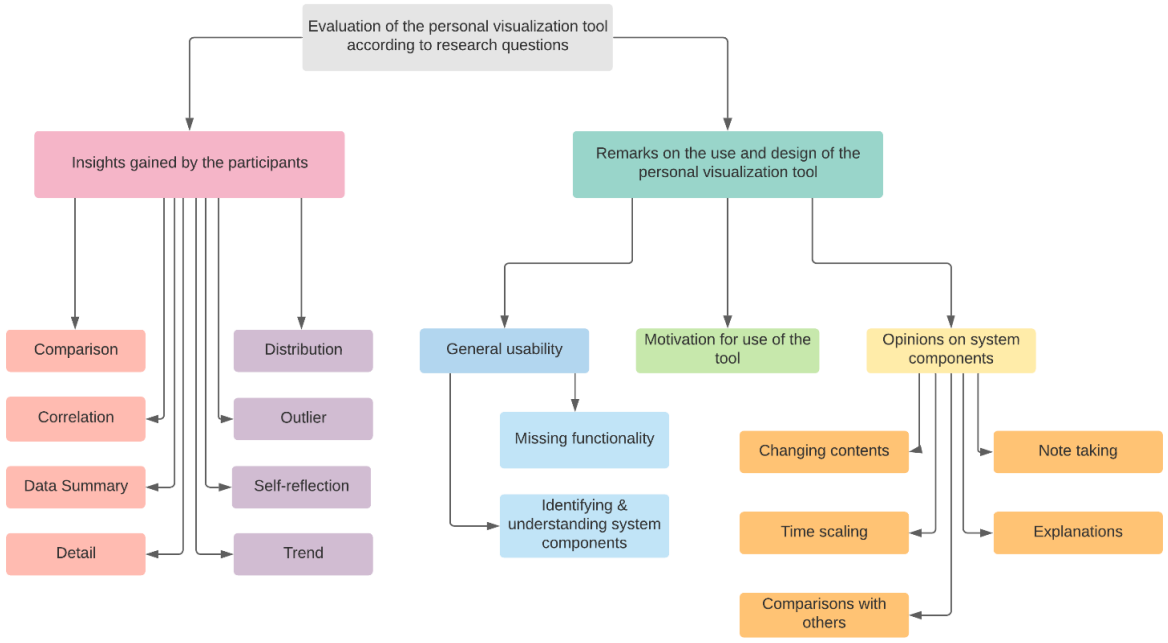

Figure 15: Analysis strategy used to analyze the evaluation session results. Created using Lucidchart. [21]

Code	Applied when…	Example
Identifying & understanding PV tool features	… a remark was made about the participants' ability to identify and understand the features available in the PV tool.	*Participant: … so I do get it, it is very informative or very supplementary, but when I see that page I do not immediately realize that and it is not immediately clear.*
Missing functionalities	… a remark was made by the participant about a feature they were missing in the PV tool.	*Participant: Imagine I click on that out of interest for a second, but it does not interest me any further, then I would find it useful if I could return to the starting state of this page.*
General Usability	… a remark was made about the usability of the PV tool to which no other labels applied.	*Participant: Yes… the word 'dashboard', that, ehm… in Jip and Janneke language, it does not exsist.*
Motivation for use of the tool	… a remark was made about the participants' motivation for the use of the PV tool.	*Participant: You know, I like to analyse, but I know … at some point you have had enough of it. … If you are an amateur and you are starting out, I think it is a lot, also a lot.*
Changing contents	… a remark was made about the PV tool feature allowing for the changing of the contents of the visualization field.	*Participant: Oh, cool. Yes, personally this makes me very happy.*
Comparisons with others	… a remark was made about the PV tool feature offering the possibility to see the data of others in the visualization field.	*Participant: Oh, it is the average of everyone, oh that was not clear to me.*
Time scaling	… a remark was made about the PV tool feature allowing for the changing of the time scale shown in the visualization field.	*Researcher: What do you think of that you can see it (your data) on different scales? Do you think it is helpful?* *Participant: Not for me, no.*
Note taking	… a remark was made about the PV tool feature where additional notes could be added to the visualization field.	*Participant: … that is pretty useful, I think, because then I can for, for myself also keep track of or indicate to myself that 'oh, at that time I was, I had a party' or something.*
Explanations	… a remark was made about the explanations offered in the PV tool about the data, visualization method or PV tool itself.	*Researcher: Is that legend then also clear and helpful?* *Participant: Yes, for sure, yes. I think a well for people who are actually not familiar with bar and line graphs that such a legend is very good.*

Table 29: Explanation on the application of the analysis strategy codes for the evaluation sessions.

This analysis strategy, shown in figure 15, was performed using ATLAS.ti [19] and was divided into two separate parts. The first of this was the identification of insights that the participants identified during the evaluation sessions, based on the definition of insight explained in Chapter 2. Here, eight types of visualization insight were specified, as defined by Choe et al [11]. Each of these visualization insight types got their own code in the analysis strategy. The transcriptions were read through thoroughly, and any time in the transcriptions a visualization insight was given by the participant, it was labelled with the corresponding code describing the type of insight. After all transcriptions were analyzed in this manner, the total amount of visualization insight under each category were counted per participant and noted down. Using this data, the first sub research question was answered.

The second part of the analysis focused on the opinions of the participants on the developed prototype. The transcriptions were once again read through thoroughly, and any remark made on one of the pre-determined topics in the analysis strategy was labelled with the according code. Table 24 shows when each of these labels was applied, with a corresponding example from the transcriptions. After the transcriptions were analyzed in this way, a summary of these remarks was created for each of the codes. These summaries were then discussed to answer the remaining two sub research questions.

Insight	P1	P2	P3	P4	Total Amount
Comparison	3	-	-	1	4
Correlation	-	-	-	-	0
Data Summary	1	-	-	-	1
Detail	2	2	1	-	5
Distribution	1	1	-	-	2
Outlier	2	-	-	-	2
Self-reflection	2	2	1	2	7
Trend	-	-	-	-	0
Total Insights	11	5	2	3	21

Table 30: Occurrences of insight during the evaluations of the PV tool by category.

Results

The following description of the results of the evaluation session will be a summary of the remarks made by the participants during the sessions, categorized following the deductive analysis strategy mentioned previously.

Insights gained by the participants

All four of the participants were able to articulate different insights they got from exploring the data with the data visualization tool. The amount of insights in total, which are shown in table 25, varied from participant to participant. The most commonly identified insight category was self-reflection category, followed by detail and comparison. No remarks about correlation or trends were made during the evaluations.

Motivation for use of the tool

Throughout the evaluation sessions, multiple participants remarked on their personal interest in the use of the presented PV tool, as well as potential motivations behind this. Two of the participants indicated that they saw the use of the PV tool as an assistant in communicating with healthcare professionals. One of these participants also indicated that they would be interested in making use of the PV tool to reflect on their own wellbeing, but this interest would only be peaked if they would experience problems related to their wellbeing. Related to this, another participant remarked that they were at a point in their experience with fatigue

related to Rheumatoid Arthritis where they had already found the answers to their questions, making the detailed analysis that this prototype for the PV tool offered not relevant anymore. The last participant explained having an interest in using a PV tool as a way to improve their life, but that the tool in its current form did not yet lend itself to this purpose, as it just displayed information rather than incentivize improvement.

General Usability

In general, the opinion on the design of the PV tool was divided. One of the participants was very positive about it throughout the entirety of the evaluation, the second and third participant were positive about the design overall, but had some individual remarks on the usability, and the fourth and final participant found themselves to be overwhelmed by it, as they indicated getting lost in the number of possibilities despite their usual interest in analyzing their own personal data. While the first participant believed the PV tool to offer a beautiful and clear overview of the personal data, the layout of the PV tool as well as the clarity of availability of some of the features left room for improvement according to the other participants. These were the more specific remarks made, in no specific order:

- The world “dashboard” was used twice in the prototype, which was confusing. In a similar fashion, the word “dashboard” was too abstract according to a second participant.
- The text on the x-axis was not big enough for one of the participants, after which they noted their confusion about the magnifying glass symbol being present next to this axis, as this did not enlarge the text in contrast to their expectations. Following up on this, using this magnifying glass icon to change the time scale did not make sense to them, and it would be preferable to use arrow symbols as to indicate the changing of state.
- The title above the graph indicating what overview was currently present in the graph went initially unnoticed by one of the participants. They instead remarked that they would prefer to see “changing text” below the graph, which also stated the title, to the right of the graph, underneath the legend.
- One of the participants would prefer to have all the different features to be available in one place rather than split up, as now was the case with having the button to add notes to the graph at the bottom of the page and not available through the settings, where the other interactions to change the contents were possible.
- None of the participants realized they were able to scroll down on the page until this was mentioned to them. Because of this, both the ability to add notes to the graph

was not immediately clear to the participants, as well as that additional information on the graph was available. After seeing the button for adding notes, three of the participants did grasp how they would be able to use this function, and the fourth participant realized this after reading the text above the button.

- One of the participants realized that they could interact with the gear symbol to open a settings menu by themselves, while the three other participants had to be directed towards it.
- None of the participants realized they could change the time scale at which they viewed the data, even though this was mentioned in the description below the graph. One of the participants did interact with the magnifying glass icon, but not for the reason of scaling the data.

A few remarks were made by different participants about functionalities they were still missing in the current prototype. This included a possibility to “reset” the PV tool back to its original state, showing the monthly overview graph with in it the total active hours per day and the fatigue score. Another participant noted their desire to receive more information when moving their cursor across the graph about what is being shown in the graph. Thirdly, one of the participants indicated that they did not feel stimulated enough by the PV tool to improve upon their behavior, missing an indication of whether their results were good or bad.

Opinions on the PV tool features

Changing the contents of the graph

Two of the four participants believed that the ability to change what the graph in the PV tool displays would be helpful to them in understanding their personal data. One of them reflected on the fact that a lot of information was available especially, which they enjoyed greatly. The other specified that they would start out looking at the graph showing only the active hours per day, as this gave them the clearest overview of the data, and then turn on the other views whenever they desired more information. The third participant believed they would rather decide on one of the available options and stick to this throughout their use of the PV tool, rather than varying the contents a lot. They did however appreciate that the choice of what is shown in the graph is given in the first place, as interest may vary from person to person. The last participant did not explicitly give their opinion on this component.

Comparison with other users

Two of the participants, when asked about the option to see the average data of different users in the portal displayed in the graph, showed some interest. This comparison could,

according to them, possibly help people develop stability or offer perspective on their wellbeing. An example that was given that it could be comforting to see that their own values do not actually deviate much from the average value, despite their own expectations. A third participant did not believe it to be useful to them in the given context, as they indicated that fatigue is very subjective, and an average would thus not show relevant information. The last participant did not explicitly give their opinion on this component.

Timescales

Out of the four participants, two participants indicated that they think their ability to change the time scale in the graph would help them in understanding their personal data. Both viewing the data at a more detailed level to explain certain phenomena in the data, as well as looking at a summarized version of the data were mentioned as being useful. The third participant was not personally interested in using this feature, finding all the information they wanted from the month overview, but believed that it could be very helpful for others. The last participant did not think viewing their data on different time scales would be useful for them and was not interested in this system component at all.

Adding notes

Three of the four participants reacted positively to the ability of adding custom notes to the graph. Two of them specified the usefulness of this feature to them as reminders before discussions with their doctors, one of them specifying this for remembering the context of their data, the other for writing down conclusions they derived from analyzing their personal data. The third participant believed this feature to be especially useful as a reminder of the context of data from a longer time ago. The last participant did not explicitly give their opinion on this component.

Explanations

Three out of four participants gave their opinion on the legend offered next to the graph in the PV tool, and indicated that it helped them in understanding either the graph or their personal data better. One of these participants preferred the idea of all of the legends being available at all times, rather than it changing based on what the graph showed. One of the participants did not give their opinion on the legends. As mentioned earlier, the other explanations offered beneath the graph were hard to find, and an opinion on these explanations was not given by two of the participants. One of the participants did not believe the additional information to be of use to them as the legends and axis of the graph gave them enough information already but indicated that it may be useful to other people. The last participant at first impression indicated it to be “a lot”, and showed a lack of interest in

reading the contents of the text itself. When later discussing the available features in the PV tool, they did refer back to this text as they realized a feature (adding notes) was explained in it, which they did not initially realize, as they did not feel incentivized to read it.

Conclusion

Having performed and analyzed the evaluation of the PV tool prototype, the sub research questions that should be answered through this evaluation can now be discussed.

Does the designed personal visualization tool allow citizens to gain insight about their wellbeing?

As seen in the presented results, the designed PV tool allows citizens to gain insight about their wellbeing in its current state. What must be noted is that the tool seems to lend itself particularly well to specific categories of insight, and other categories of insight were not identified at all, such as correlation and trend. A reason for this could be that the dataset used for the PV tool prototype did not contain any exaggerated correlations or trends, making it difficult to pick up on these specific insights in the limited amount of time the participants spend talking about the data shown. In contrast to this, the PV tool seemed to lend itself particularly well to self-reflection. As the purposes of the PV tool is to allow the users of the Citizen Science Portal to reflect on their own wellbeing, this is not surprising. The variation in amount of insight could be a result of both the differences in how the time was spent on allowing the participant to identify insights during the different evaluation sessions (sometimes extra input was asked, other times the conversation moved on), and by the variation in general understanding the participants had about how to use the data visualization tool, as well as their motivation behind their potential use of the tool.
Whether the designed PV tool allows citizens to gain insight better than another possible design solution, is not possible to determine through the used evaluation method, as all participants were experiencing the same design, and thus no comparison can be made.

What impact does the addressing of the identified areas of concern and implementing the identified encouraging factors have on the ability of citizens to gain insight from personal visualizations?

To determine the impact that the identified areas of concern and encouraging factors had on the ability of the participants of the evaluation session to gain insight from personal visualizations, the participants were asked to reflect on the different features present in the

prototype. As each of these features were created based on these areas and factors, it is now possible to reflect on the theory.

Understanding

Understanding as an area of concern was defined as the amount of confidence a person can express about an insight they have gained. After the co-creation session took place, it was determined how this area of concern would be addressed in the PV tool prototype. The impact of understanding, as addressed in this prototype, is limited. The prototype did not offer explanations on statistical methods to increase the confidence of its users, and instead tested if offering explanation about the visualization method and features would help the users of the PV tool in gaining insight.

The legends present in the PV tool offered an explanation about what was being shown in the graph, and this was appreciated by the participants, as it helped them in understanding what data they were viewing. Consequently, it helped them in gaining insight. In contrast, offering further explanation about the graph and method of visualization in text form was not effective, as the participants did not feel inclined to read it. A reason for this difference could be that that the information offered here was not as concise as in the legend, and that the participants did not feel like they needed the extra information.

In general, the participants did not experience any problems in understanding how to read the graph, what data it represented, and stated their observations about the data without indicating uncertainty. This does not yet mean that the current prototype sufficiently addresses understanding as defined and brings into question if this area of concern has a significant impact on the gaining of insight at all. This can be further investigated in future research. Improving the users' understanding of the graph in a literal sense, as being able to read it, did have a positive impact. This, however, is perhaps closer related to another of the defined areas of concern, relation.

Context

Context as an area of concern was defined as the lack of contextual information that is necessary for a person to properly gain insight from data. This was implemented in the prototype through giving the user the ability to add their own notes to the graph. All participants who gave an explicit opinion on this appreciated this. Discussing this also brought up how recalling context would not only make the PV tool useful to a user themselves, but also made it so it could serve as an assisting tool for conversations with healthcare professionals. The addition of example notes to the PV tool graph also helped

two of the participants make observations about the data, and thus gain insight. Because of this, it can be included allowing for any user of a PV tool to recall relevant contextual information improves not only their ability to gain insight, but also gives the user more reasons to use the PV tool.

Relation

Relation as an area of concern was defined as the difficulty experienced by a person when relating an abstracted visual representation of data back to the real-world realization of this data. To address this area of concern, the PV tool made use of visualization techniques likely familiar to the user of the tool, as well as providing a legend with the visualization. In the evaluation sessions, the participants showed no difficulty in connecting the visualization to what was being represented, and thus the implemented solution addressed this area of concern adequately. Addressing it made it so that the participants were able to use the graph to accurately interpret the given data, and gain insight.

Exploration

Exploration as an encouraging factor was defined as the ability to interact with a data visualization to discover additional information. This was implemented through the time scaling feature in the final prototype, where the participants could interact with the graph to change at what level of detail in time they could see the available data. The opinion on whether this implementation of exploration would someone gain more insight, was divided among participants.

While this encouraging factor was implemented into the prototype, the way in which this was done was not intuitive, as its presence had to both be pointed out and explained to the participants. Next to this, there could have been more exploration through interaction implemented, for example by offering additional details about the available data upon hovering over a data point in the graph. Similarly, the ability to move back and forth through time, which would have added more exploration, was not functional when the prototype was evaluated. It can thus be concluded that while allowing for exploration of data through the implemented interaction would help at least a part of the potential users in gaining insight, to what extent exploration in general can help has not yet been properly investigated.

Individuality

Individuality as an encouraging factor was defined as the ability to personalize how a person’s personal data gets visualized. This was implemented in the PV tool prototype through a general level of personalization possible, for example in choosing the contents of

the graph. It must be noted that this implementation only addresses individuality in the content of the visualizations, and not in the form of these visualizations. The customization of the form of the visualization was not implemented in the evaluated prototype, as this was not possible due to both time restraints and a limit in the technical capabilities of the prototyping method. Because of this, the impact of individuality as an encouraging factor cannot be determined with the results of the performed evaluation. What can be discussed, however, is the effect of personalization as a new, independent encouraging factor. This will be discussed later in this chapter.

Variation

Variation as an encouraging factor was initially defined as the ability to view the same data in more than one distinct visualization. However, during the co-creation session variation in the visualization method confused the participants, rather than increasing insight into the data. Because of this, variation was instead implemented as a variation in the level of detail available data would be shown at. Next to this, more variation was also introduced through the variation of content shown in the graph. Especially this second implementation of variation in content, however, can once again be better described as personalization.

The opinion on the ability to change of the content of the graph, which included both a variation in detail and the inclusion of different data, was generally positive. Two of the participants indicated that they believed the use of this feature throughout their use of the PV tool would help them gain more insight, while a third showed appreciation that they could choose what data they would like to see going forward. The first two participants here reflect more upon variation as an encouraging factor, indicating that this prototype's implementation of variation does have a positive impact on insight being gained. However, what the third participant appreciates relates closer to personalization.

What other factors influencing the gaining of insight on wellbeing from a personal visualization are important to consider when designing a personal visualization tool for the Citizen Science Portal?

In the analysis of the evaluation session, attention was paid to remarks the participants had about the PV tool that were not related to the pre-determined features of the prototype which reflected the background theory. Based on these remarks, as well as on the conclusion about the impact of the identified areas of concern and encouraging factors, other factors of importance could be identified. These other factors will now be discussed.

Personalization

At multiple points during the evaluation sessions, the participants remarked that while they themselves would likely not use a specific feature, they could see the use of such a feature for other participants. This, in combination with the varying opinions on the usefulness for the gaining of insight of the implemented features, shows that there can be a big difference in what the ideal PV tool would have to offer people to allow for the proper gaining of insight. While the background theory showed the importance of offering a user a complex PV tool with many features such as varying the visualization method and interaction with the visualization field, the discussions with the Rheumatoid Arthritis highlighted that this can certainly be interesting for a patient with many questions about their wellbeing, but it may deter other patients from using the PV tool at all, even if they are still interested in learning more about their wellbeing. Instead, their needs call for a simpler design, where they can find the information they desire without being distracted by ‘fancy’ features. This suggest that designing a PV tool with the goal to encourage the gaining of insight cannot lead to one static design, but instead should lead to a dynamic design that can account for these different needs.

Usability

Both during the co-creation session and the evaluation session, most of the feedback that was given on the prototypes was feedback related to usability. This varied from details such as the position of text and the use of certain symbols to larger issues, such as that it was not clear that certain features of the PV tool were present at all. These issues would occupy the participants and stop them from looking at the data itself. Usability is important for any design, and should be properly accommodated in any product, including the PV tool for the Citizen Science Lab. If not addressed properly, it will hinder the citizens in gaining insight on their wellbeing.

Design Guidelines

In this chapter, the three remaining sub research questions have been answered. Based on these answers, four guidelines can now be introduced for the for further design of the PV tool for the Citizen Science Portal.

No one visualization fits all

Through conversations with people who have Arthritis, it has become very clear that the questions that people have about their conditions differ not only from person to person, but also from time to time. Someone who has recently been diagnosed with Arthritis and is still

figuring out how to manage their symptoms, may find much greater use out of looking at their data more regularly, and in more detail. However, someone who currently has a good idea about how their condition affects them, may only be interested in seeing whether they are doing better this month than they were three months ago. A PV tool for the Citizen Science Portal should offer a dynamic design that can account for these different needs.

Offer support for remembering context

The evaluation of the PV tool prototype showed that according to people with Arthritis, having a feature that could support them in remembering external context to their personal data would be of use to them in more than one way, including the gaining of insight.

Show something the user is familiar with

Through the evaluation of the PV tool prototype, an appreciation was shown for the use of familiar visualization techniques. While in the background research the benefit of showing a visualization they may not be familiar with to encourage exploration was mentioned, in practise this did not come through. In the final prototype, a bar and line graph were used. In contrast to the more unfamiliar visualization techniques shown in the co-creation session, the participants did not have trouble reading the visualizations because they could not accurately translate the abstracted data back to the real-life counterpart of the data. Making use of these familiar visualization techniques in combination with the addition of clear legends addresses the relation area of concern identified in the background research.

Keep it as simple as possible

Usability of the PV tool has come into focus throughout the development of the PV tool, most prevalently in the desire of the target audience to have the tool offer an immediate clear overview of their data. Both the visualization methods themselves as well as the features present in the PV tool must be kept simple, as overcomplication of them led to a hindrance in using the PV tool effectively to gain insight. Multiple parts of the design of the PV tool are influenced by this desire for simplicity. This includes the layout of the page, which has to effectively communicate the available features without getting cluttered, as well as for where the PV tool can be found on the website. This desire for simplicity also extends to the offering explanations about the measurements in the legend, and explanations about the PV tool. This information was believed to be useful, but largely disregarded when it was not presented in a clear and precise way.

Chapter 8 – Discussion

In this chapter, the quality of the performed research is discussed. First, the results of the research and how they relate to the original background theory is discussed. After this, the used methods are reflected upon, and ways to improve them are described. Finally, limitations on the research caused by COVID-19 and the role of the research as part of a larger development project will be discussed as organizational limitations.

Discussion of the Research

At the end of chapter 7, four design guidelines for the further development of the PV tool for the Citizen Science Portal were given. This included ‘no one visualization fits all’, ‘offer support for remembering context’, ‘show something the user is familiar with’ and ‘keep it as simple as possible’. However, under no circumstances should these guidelines be taken as absolute truth. It is likely that other design guidelines of importance have been missed, or that the stated guidelines are based on the misinterpretation of qualitative data. While based on the results of research, there is a level of subjectivity of the researcher present when interpreting these results into actionable guidelines. It should neither be assumed that the four guidelines exist solely as isolated entities, but rather they should be assumed to be part of a more complex process. Using a familiar visualization technique could be considered as keeping things simple, as it removes complexity that an unfamiliar visualization could introduce. Allowing for the manual addition of external context inherently changes what data will be available in the visualization going further, having now customized it to fit more to the needs of the specific users.

The most notable difference between the conclusion of this research and the performed background research can be found in the third suggested guideline, ‘show something the user is familiar with’. It contradicts what Wang et al. found in their research, in which they explored the reaction of their participants to three distinct personal visualization designs [14]. They conclude that a more abstract visualization design encourages exploration more successfully, and through this the gaining of insight. A reason for this difference could be that the participants of both studies were of different age groups. Another possible explanation for this difference can be found when taking the possibility of limited health literacy into account. This was not considered during the evaluation of the PV tool discussed in this thesis. It was considered when Stonbraker et al. investigated the data visualization method preferences of chronic-disease patients for reports on their symptoms [22], which also concluded that a bar graph visualization was the method preferred by the largest

number of participants, especially when incorporating emojis as an additional visual cue. This correlated with this being the easiest format for the participants to interpret. Their participant group included a large majority of people with limited health literacy. Whether the demographics of the participants in this research influenced whether a more familiar visualization or a more abstract visualization would lead to more insight cannot be determined through the performed research, but further investigation could bring light to this.

Stonbraker et al. also comment that in their research, it also became apparent that there is no ‘one size fits all’ visualization method [22]. This is in line with the first guideline proposed in this research, ‘no one visualization fits all’. This sentiment is also shared by Rapp et al., who recommend offering a variety of data views in a PV tool if this tool is to be attractive to a larger audience, as this audience will have many different exploration styles [13]. However, in our research it was found that the participants valued maintaining a clear overview of all their data over the inclusion of multiple visualization method. This suggest that increasing the amount of available data views is not the appropriate method of introducing personalization in the PV tool for the Citizen Science Portal. This difference could be explained by the difference in format between the PV tool in the Citizen Science Portal, which is already part of a larger encompassing website, and the PV tool developed by Rapp et al., which stands on its own.

In the proposed design guidelines, the suggestion to keep the PV tool as simple as possible stemmed from the participants indicating this is what would increase the usability of the PV tool for them. That complexity of visualizations can pose a problem can also be found in Grammel et al’s research into how data visualization novices construct visualizations, where they also investigated what problems occurred when these novices were asked to interpret the visualizations [12]. Two of the common interpretation problems they encountered were ‘high visual complexity’ and ‘difficulties understanding semantics of measurements’, both of which can be addressed by keeping things simple. The second problem stated here is primarily addressed through additional information offered in the designed PV tool as textual information present in the legends. Previous studies using eye tracking methods found that people viewing data visualizations devote a large amount of viewing time to text-based regions of these visualizations, especially on the title, data labels and axes, as well as legends [23]. This could explain why the addition of legends that were generally found to be concise and informative about the data helped the participants in understanding the visualizations better.

Keeping the PV tool as simple as possible could lead to conflicts with addressing that no one visualization fits all, as one guideline recommends losing complexity where possible, yet the other guideline calls for many different options for personalization to be available in the PV tool. Here, the guideline of keeping things simple can be applied to the component of the PV tool where these personalization options are offered. Simplicity is not just applied by removing unnecessary complexity, but especially in communicating about what complexity is necessary in clear and concise ways. One example of this is that rather than placing personalization settings in multiple locations on the PV tool, they can instead be placed together. This way, a user does not have to look for additional interactions, as they can all be found in one standard location.

The design guideline stating that support should be offered for remembering context to the personal data being shown in the PV tool is in accordance with the previous research discussed in Chapter 2. As proposed by Huang et al., allow for the recollection of relevant context to personal data is one of the challenges in the design of a personal visualization tool [5]. In the PV tool discussed in this thesis, this challenge is addressed by asking for the manual input from it is users. Whether this is the appropriate way of addressing this challenge is not yet determined in this research.

The research presented in this thesis aimed to evaluate the common themes in existing design guidelines for achieving the gaining of insight through PV presented in previous work, and suggest new guidelines based on this. Not all the implementations of the defined six common themes had the expected impact on the gaining of insight, and there are multiple reasons for why this could be the case. First, it must be considered that the originally defined areas of concern and encouraging factor were, while based on previous research, partially defined through intuition as well. Another researcher investigating the same literature and following the same methods, could have come to a different conclusion on the common themes, as well as on whether a common theme would be an area of concern or an encouraging factor. Next to this, the definitions offered for each theme were still open for interpretation. Because of this, the final prototype included features that were based on addressing and implementing these definitions, but in hindsight did not accurately address the problems as initially stated. This was the case for both exploration and understanding. Further research will be necessary to properly determine their influence.

Discussion of Methods

State of the Art

In the state-of-the-art phase of this thesis, research was done into previous work on the topic of personal visualization, based on which six common themes were identified. This made for a good background to base the first mock-up prototypes on during the ideation phase, as well as a clear theoretical base to reflect upon in different phases of the design process. However, there are limitations to the performed background research. The first thing to note is that while this previous work included research done on other projects like the design project described in this thesis, no further research was done on other similar projects. Because of this, insights on appropriate design choices could have been missed. It would have been useful to investigate other online platforms that offer the user the ability to collect data, and see this data visualized. For example, multiple websites exist for the Quantified Self-movement, on which PV tools are used. Because this related work was not properly considered due to a lack of proper investigation, the chance exists that the design solutions described in this thesis have already been implemented and tested elsewhere.

Another subject that could have been researched, as it would have provided valuable information, is investigating how the design of personal visualizations could be made more accessible. This would have been valuable information to know before developing the prototype, as remarks about accessibility (for colorblind people, as an example) were made later in the design process. Next to this, the Citizen Science Portal is being developed for users with health issues, who may have accessibility needs that should be addressed.

Ideation

During the ideation phase, the first ideas for the PV tool based on the background research were developed. In hindsight, it would have been beneficial to spend more time on exploring different options both for visualization methods, as well as for how the background theory could be translated into design components for a prototype. While only later in the design process, during the realization phase, a final decision on the prototyping medium could be made, there was room for exploration of possibilities through methods such as sketching and storyboarding. Spending more time on this during the ideation phase, could have made for a stronger design in the final prototype, which did a better job at implementing the background theory.

Specification

During the specification phase, the wants and needs of the target audience were identified through a co-creation session, which was an online video call with a focus group. A lot of information about what the target audience wanted out of the PV tool was explored through this, and conflicts with the literature were already uncovered. Having direct contact with the target audience in a group context rather than individually brought with it the benefit that the participants could elaborate on each other's remarks and offer different views on the topics being discussed. This was not only useful for information that could be gathered, but it was also enjoyable for the participants.

While the participants in this co-creation session were representative of the target audience, this being people with Rheumatoid Arthritis, there is a potential for bias, as the group were invited after indicating their interest in the development of the Citizen Science Portal as well as the topic discussed during the co-creation session. This meant that each of them was already either somewhat experienced with personal visualization, data visualization related to their condition, or interested in data tracking. Organizing the same co-creation session with participants unaware of the topic beforehand may have very different results. The design requirements that were elicited based on the co-creation session were not given a level of priority. If they had been given a level of priority, for example using a MoSCoW analysis, this could have made it easier to ensure a good implementation of the most essential design requirements if prioritization became necessary due to time constraints or other limitations.

Realization

During the realization phase, the final prototype for the PV tool was developed. To do this, a rapid prototyping application, Proto.io [22] was used. Because of this, any feedback given on the PV tool prototype could be incorporated quickly, and a prototype implementing most of the design requirements could be evaluated within the time scope of this research. However, if a different prototype medium had been used for this prototype, some of the intended system components could have been implemented more effectively, as interactions that required a higher technical complexity, like the commenting tool, would have been possible. Using a different prototyping medium, such as coding a custom webpage rather than using proto.io, could also have automated the visualization of the numerical data, which was done manually for this prototype. If the visualizations did not have to be created manually, it would have been possible to implement features that relied on the generation of many different images within the available time.

Evaluation

During the evaluation phase, semi-structured conversations happened with members of the target audience about the developed PV tool. This evaluation method did not only give the target audience the opportunity to give elaborate feedback on the developed prototype, but it also brought to light additional points of interest like the motivation of the participants to use the PV tool that may not have become apparent if the evaluation would have happened through a fully structured questionnaire, or by observation only. Additionally, this allowed researchers to ask follow-up questions where necessary. It was also a good decision that evaluation session was practiced beforehand through a pilot test with a volunteer participant outside of the target audience, both because this participant was able to give constructive criticism on how to improve the evaluation session, as well as that it allowed the individual researchers to get better acquainted with the parts of the Citizen Science Portal they did not develop themselves, but that were part of the evaluation sessions they had to execute.

However, there are several aspects of the performed evaluation that could have been done differently, or that can be improved upon in further research. First and foremost, it has to be considered that the evaluations that took place used example data, and not the participants actual personal data. While this was not possible in the scope of this project, to accurately evaluate the effectiveness of a personal visualization tool, personal data should be used. With the use of example data, a good estimate can be made of how well a design works, but it does not accurately represent the real world application of the design in which a user would try to gain insight on their own personal data.

Next to this, the design of the prototype was evaluated with four participants. While this did give a lot of information, the four participants alone do not yet fully represent the entire possible user base for the portal. A similar point of contention as posed for the co-creation session is also applicable for the evaluation sessions, as the participants were already familiar with the Citizen Science Portal before the evaluation session took place, as all of them had participated in one or more co-creation sessions. Out of the four participants, two participants had participated in the co-creation session on the topic of data visualization described in this research. So, once again, it must be considered that the opinions of the participants may have been biased towards the PV tool, as it was not their first time interacting with it.

Lastly, the appropriateness of the evaluation method used also must be considered. The impact of the implication of an area of concern or encouraging factor was measured based

on the verbal opinion of the participants, after limited interactions with the PV tool prototype, as sharing the prototype through a video conferencing call caused the occasional technical difficulties. This made it difficult to precisely determine the impact, especially because there was no point of comparison where the prototype was shown to a member of the target audience without these implementations.

Organizational limitations

As with any research, the research discussed in this thesis faced several limitations during its execution. The first of these limitations was the effects of the COVID-19 pandemic. Because of the presence of COVID-19, people were strongly recommended to stay home, meaning that both any meeting between Citizen Science Portal researchers as well as any contact with people with Rheumatoid Arthritis had to happen through online video calls. The co-creation session and evaluation session were impacted by this. First, as the participants were recruited through a digital survey as well as that the sessions took place digitally through video conferencing, this could have excluded possible target audience members with limited digital literacy. However, it did allow for the inclusion of target audience members that would not have been able to join a physical focus group meeting, as it would have been too far of a distance to travel. Secondly, the options for developing a prototype were also limited, as it had to be evaluated through screen sharing.

Secondly, there was a limited amount of time available to perform the research. Next to this, the research discussed in this thesis was part of the larger development process of the Citizen Science Portal, meaning that there was a general planning this research was dependent on, and vice versa. Because of this, the co-creation session with the target audience, analyzing this session, as well as the development and evaluation of the prototype all had to happen in the span of a few weeks. With more time available, the prototype could have been expanded on, and more evaluation sessions could have been held and analyzed for this thesis.

Chapter 9 – Conclusion and Recommendations

This thesis described the design of a PV tool for the Citizen Science Portal being developed by the TOPFIT Citizenlab and research into insight gained from personal visualization alongside this. The main research question of this thesis can now be answered.

How can a personal visualization tool be designed for the Citizen Science Portal that supports citizens gaining insight on their wellbeing?

Through research into previous work in personal visualization, six common themes in the form of three areas of concern (understanding, context, and relations) and three encouraging factors (exploration, individuality, and variation) were discovered that influenced the gaining of insight from personal visualizations. Based on this previous work insight was defined as well, as an individual observation about personal data by a person gained through the studying of a data visualization**.** The areas of concern and encouraging factors inspired the design of mock-up prototypes, which were evaluated in a co-creation session with multiple members of the target audience. Through this co-creation session it was determined what was important to the target audience when it came to the design of the PV tool, and the design requirements shown in table 4 were determined. A prototype of the PV tool was created and evaluated with the target audience, and it was determined that this prototype would allow the participants of the evaluation to gain insight on their wellbeing. The impact of the implementation the six common themes on the gaining of insight was discussed as well, and it was concluded that context, relation, and variation were both sufficiently addressed in the prototype, as well as that they would positively impact the gaining of insight according to the participants. Understanding and individuality were found to not yet be sufficiently addressed in the prototype. Finally, the implementation exploration was concluded to be of help to some, but not all of the participants. Next to this, the evaluation led to the identification of two additional factors of influence on the gaining of insight: personalization and usability. Based on these conclusions, four guidelines were determined that should inspire the further design of the PV tool for the Citizen Science Portal: no one visualization fits all, offer support for remembering context, show something the user is familiar with, and keep it as simple as possible.

Recommendations

With the completion of the research discussed in this thesis, much information has now been discovered about how a personal visualization tool can be designed for the Citizen Science

Portal. The developed prototype already shows much promise, yet it will have to be improved upon further based on the suggested design guidelines, and subsequently evaluated upon further with the target audience. First, according to the first design guideline, the dynamic design of the PV tool should be further improved upon by increasing its usability as well as expanding on the options for personalization already present in the PV tool prototype. It is also recommended that the commenting tool present in the PV tool is further improved, and that its availability as a feature is made more explicit. It should also be further investigated how the PV tool can be made more accessible to people with limited health or digital literacy, as well as how the usability in general can be increased. Attention should be paid to keeping the PV tool's interface simple, and to use visualization techniques that are more likely to be familiar to the target audience.

Next to further development of prototype for the personal visualization tool, it is also recommended to critically examine if what have been determined to be important design guidelines for designing the PV tool for the Citizen Science Portal are indeed of importance. For further evaluations, it is recommended to use the personal data of the participants as only this will allow for testing the real-world application of the PV tool. These evaluations should also include a larger group of participants, including people with Arthritis who have not yet been involved with the development of the Citizen Science Portal and people who have been diagnosed with Arthritis more recently. Further investigating the influence of the demographics of users on the appropriateness of the suggested design guidelines is also necessary. Personal Visualization is still a relatively new field of research, and there is still much room to look for and evaluate such design guidelines. With the research presented in this thesis, a meaningful contribution to this process has been made.

The future of the Citizen Science Portal, and the developed PV tool, will not be limited to people with Rheumatoid Arthritis as a target audience. On the horizon lies the inclusion of people living with other conditions, and with this the collection of many kinds of personal data. With the growth of the Citizen Science Portal, the personal visualization tool will also have to grow, and new challenges like the management of a larger variety of data within the PV tool, the technical integration of data from wearable devices, or the development of a mobile application will have to be overcome. With these new challenges, new opportunities for further research and development in personal visualization will surface as well.

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Appendix I - Ethical approval documents

Vormgeven van een Citizen Science Portal website

Wie zijn wij?

Wij zijn het TOPFIT Citizenlab. Binnen het TOPFIT Citizenlab werken verschillende organisaties zoals de Universiteit Twente, Roessingh Research and Development, bedrijven en burgers of patiënten samen aan onderzoek. Deze samenwerking wordt ook wel citizen science genoemd. Het doel is om nieuwe kennis op te doen over gezondheid en technologie. Op dit moment kijken we hoe we aan de slag kunnen met citizen science op het gebied van reuma.

Wat hebben we al gedaan?

Wij hebben eerst gesprekken gehouden met 10 mensen met reumatoïde artritis. Daarin hebben wij besproken of zij samen met onderzoekers willen werken aan onderzoek, op welke manier en op welke onderwerpen. Vervolgens hebben wij diezelfde vragen, met alle kennis uit de interviews, nog eens aan een grote groep mensen met reumatoïde artritis voorgelegd. Dit hebben we gedaan door een digitale vragenlijst, waar 265 mensen aan hebben deelgenomen, waaronder uzelf.

Uit deze vragenlijst kwamen enkele interessante uitkomsten. Zo vonden 233 van de 265 mensen het idee van een website waar patiënten en onderzoekers samen kunnen werken – een citizen science portal – nuttig. Daarom hebben wij nu besloten om zo'n website te gaan maken. Hierbij gaven patiënten aan dat het belangrijk is dat zij ook hierbij betrokken zijn.

Vermoeidheid kwam naar voren als het onderwerp waar de meeste mensen onderzoek naar zouden willen doen. Daarom zal het eerste onderzoek op de website zich richten op vermoeidheid, maar wij hopen in de toekomst vele andere onderwerpen te kunnen onderzoeken.

Voor verdere resultaten, zie de website www.topfitcitizenlab.nl/reuma.

Wat willen we nu gaan doen?

We willen nu aan de slag om als onderzoekers samen met patiënten met reuma de website vorm te geven. Dit willen we doen door in gesprek te gaan met elkaar. We willen 5 bijeenkomsten organiseren. Elke keer zal een ander deel van de website besproken worden. Dit zijn:

- **Onderzoeksonderwerp**: welke vraag rondom vermoeidheid willen we graag beantwoorden en welke gegevens hebben we daarvoor nodig?
- **Informed consent en privacy**: hoe moeten we op de website toestemming vragen voor deelname en welke gegevens willen mensen wel of niet delen op zo'n website?
- **Functionaliteiten**: Wat moet je allemaal kunnen op de website? Welke functies moet de website hebben en wat moet je als gebruiker ermee kunnen?
- **Data visualisatie**: hoe moeten gegevens op de website te zien zijn (bijvoorbeeld in grafieken, of als tekst)? Hoe zorg je dat iedereen begrijpt wat de gegevens betekenen?
- **User interface**: hoe moet de website eruit zien? Welke pagina's moeten erin zitten en hoe moet je binnen de website kunnen navigeren?

U heeft geen specifieke kennis nodig hebt om hierin mee te denken. Het gaat er vooral om dat u uw eigen mening wil geven zodat we een website kunnen maken die voor zoveel mensen nuttig, interessant en makkelijk in gebruik is.

Met alle informatie die we tijdens de bijeenkomsten krijgen, zullen we een simpele versie van de website maken of het idee wat verder uitwerken. Dit willen we vervolgens met enkele mensen bespreken; als u de website kunt zien, kan het zomaar zijn dat er nog nieuwe ideeën komen over hoe iets zou moeten werken of eruit zou moeten zien. Dit doen we in aparte bijeenkomsten.

Daarna zullen wij aan de slag gaan om de website echt te gaan maken.

Wilt u samen met ons hiermee aan de slag gaan?

Wanneer u met ons aan de slag wilt, kunt u aansluiten bij één of meerdere bijeenkomsten. De bijeenkomsten duren 2 uur per keer en zullen plaatsvinden in de maanden mei en juni. Waarschijnlijk zal dit digitaal gebeuren, via beeldbellen (bijvoorbeeld via Zoom of MS Teams)*. Via dit formulier [link] kunt u aangeven welke bijeenkomst(en) u bij zou willen wonen. Wij zullen vervolgens contact met u opnemen om verdere afspraken te maken.

Deelname aan dit onderzoek is geheel vrijwillig. U kunt op elk moment stoppen zonder opgaaf van reden. Alle deelnemers ontvangen een VVV cadeaukaart van 20 euro.

Privacybescherming en verwerking van uw gegevens

De bijeenkomsten zijn vertrouwelijk. Uw antwoorden worden vertrouwelijk behandeld. Dit betekent dat persoonsgegevens zoals uw naam, adres en geboortedatum nooit worden gebruikt voor de analyses, ook niet door de onderzoekers. Daarnaast worden overige gegevens die naar u zou kunnen leiden uit de resultaten gefilterd. De verwerking van de gegevens gebeurt volgens de wetgeving over de verwerking van persoonsgegevens (AVG). De gegevens kunnen gebruikt worden voor (wetenschappelijke) publicaties. Dat betekent onder andere dat onderzoekers er een artikel over schrijven en dat dit in een tijdschrift komt te staan. Meer informatie over de privacy van uw gegevens kunt u vinden op: www.utwente.nl/nl/cyber-safety/privacy. Deze studie is goedgekeurd door de Ethische Toetsingscommissie van de faculteit Behavioural, Management and Social sciences (BMS) van de Universiteit Twente. Dat betekent dat er is onderzocht of dit onderzoek vooral wetenschappelijk zorgvuldig en volgens uw rechten als deelnemer wordt uitgevoerd.

Contact en meer informatie

Voor verdere vragen of opmerkingen over deze vragenlijst kunt u contact opnemen met dr. Ria Wolkorte, onderzoeker bij het TOPFIT Citizenlab, via r.wolkorte@utwente.nl of 053-4893292. Ook vindt u informatie op www.topfitcitizenlab.nl/reuma.

* Als u hier geen ervaring mee heeft, kunnen wij u voor de sessie bellen om dit eens te proberen en om te begrijpen hoe dit werkt.

Informed consent [geplaatst op het formulier waar men ook aangeeft aan welke workshops men deel wil nemen]:

O Ja, ik ga akkoord met deelname aan dit onderzoek. Ik verklaar hiermee dat ik de informatie over het onderzoek hebt gelezen. Ik begrijp dat mijn gegevens niet meer naar mij herleidbaar zijn en gebruikt kunnen worden voor wetenschappelijke publicaties. Ik doe vrijwillig mee aan dit onderzoek en weet dat ik op elk moment kan stoppen met mijn deelname.

Appendix II – Mock-up prototypes

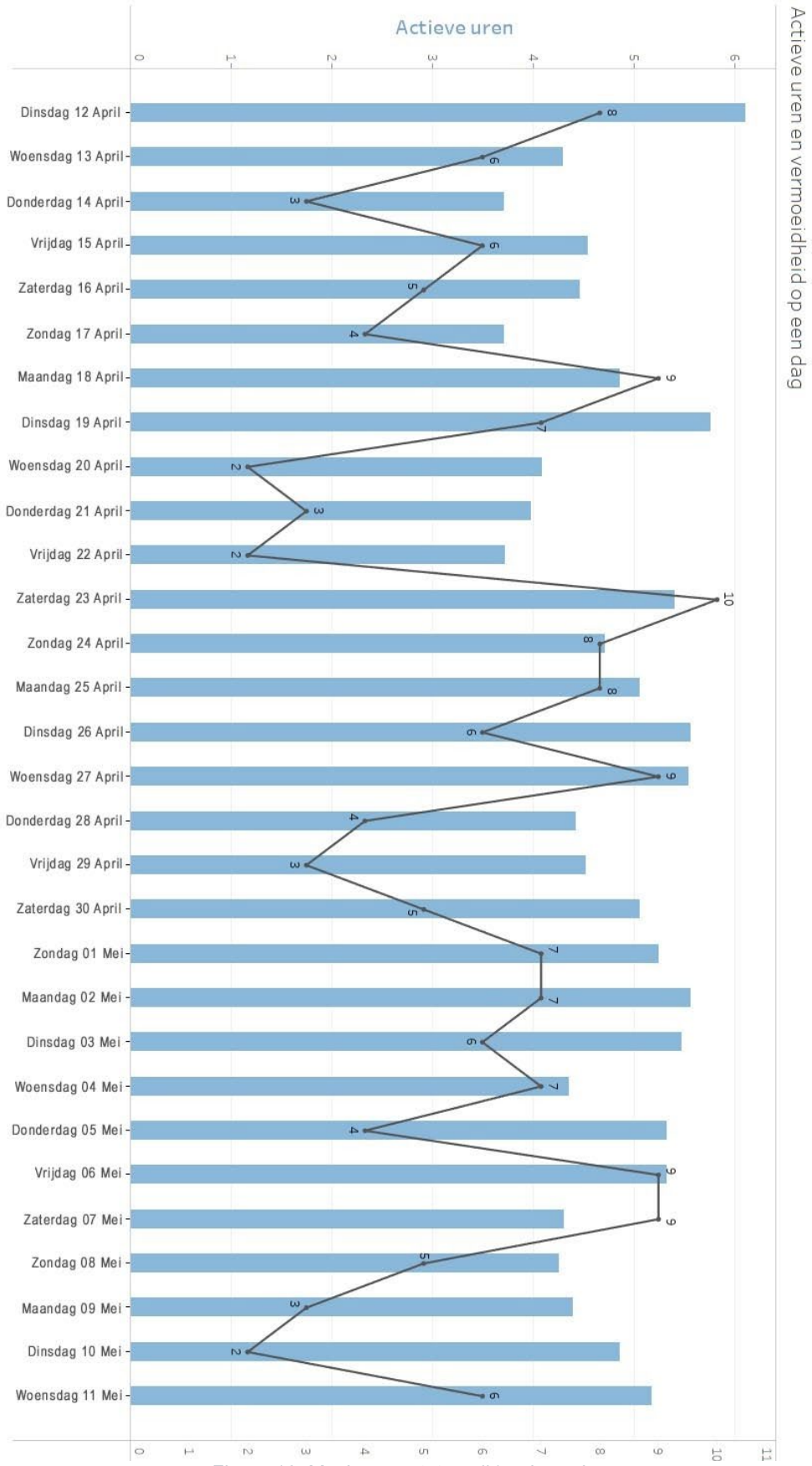

Figure 16: Mock-up prototype #1 enlarged

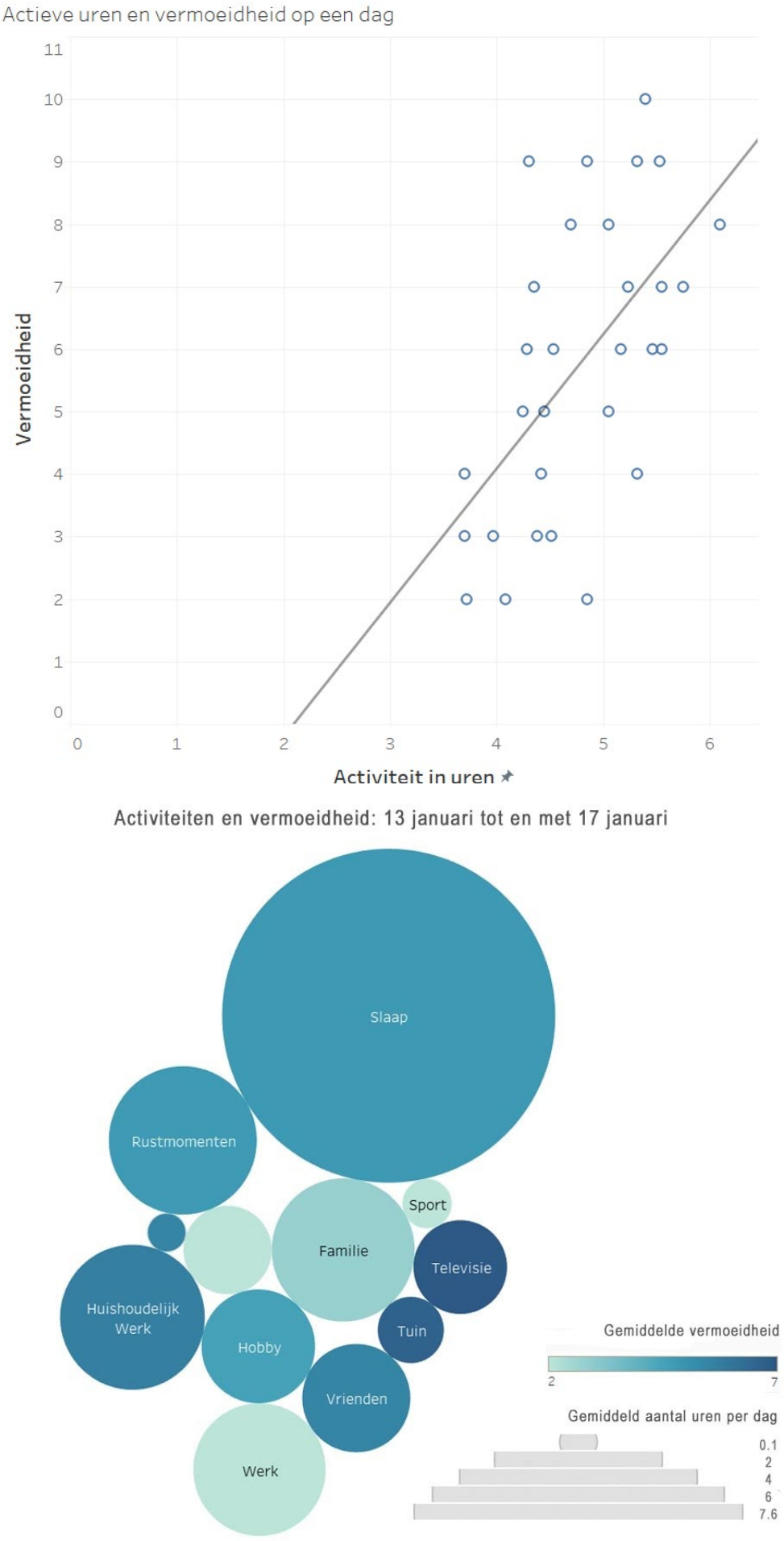

Figure 17: Mock-up prototype #2 and #3 enlarged

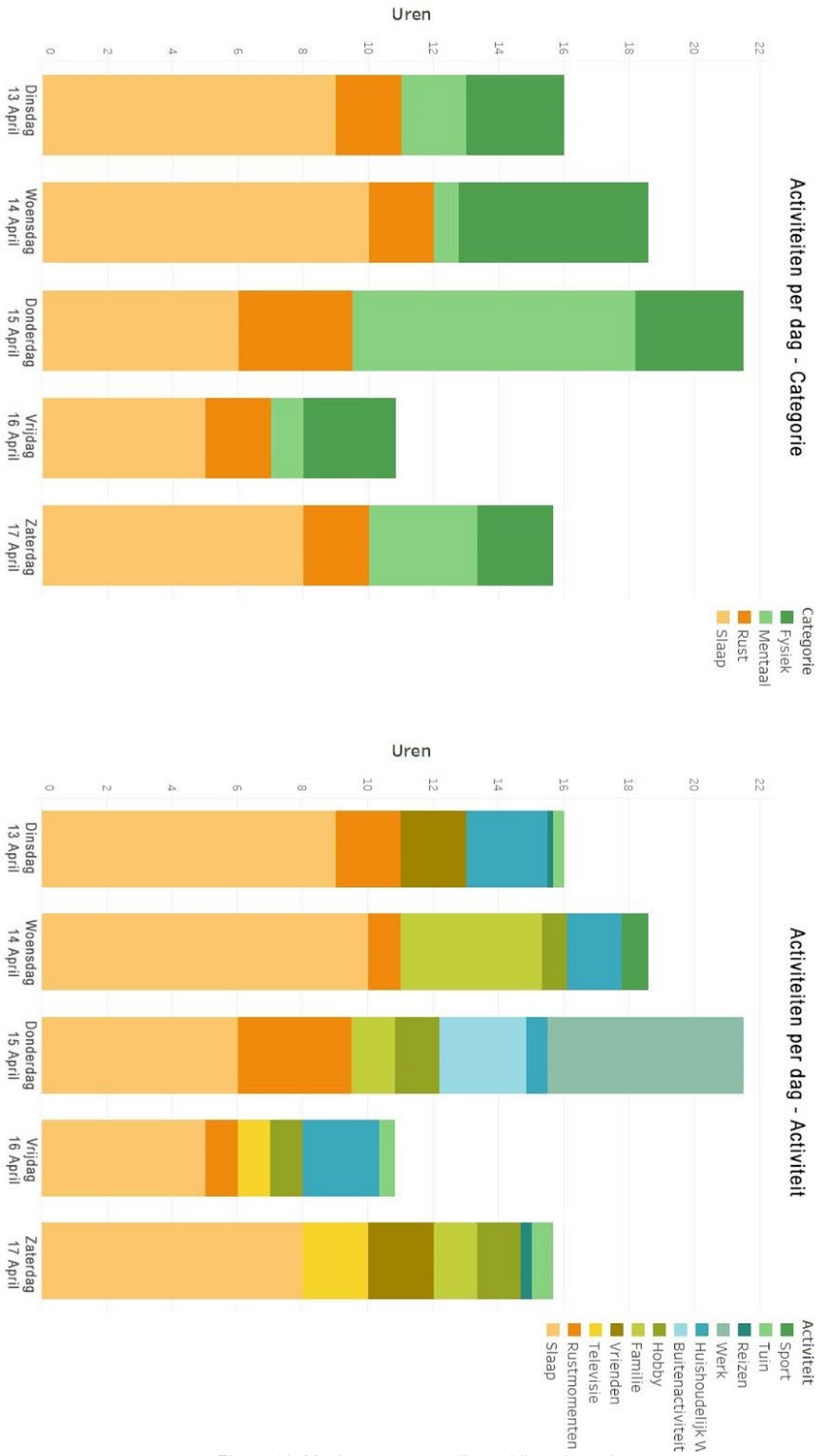

Figure 18: Mock-up prototype #4 and #5 enlarged

Figure 19: Mock-up prototype #6 and #7 enlarged

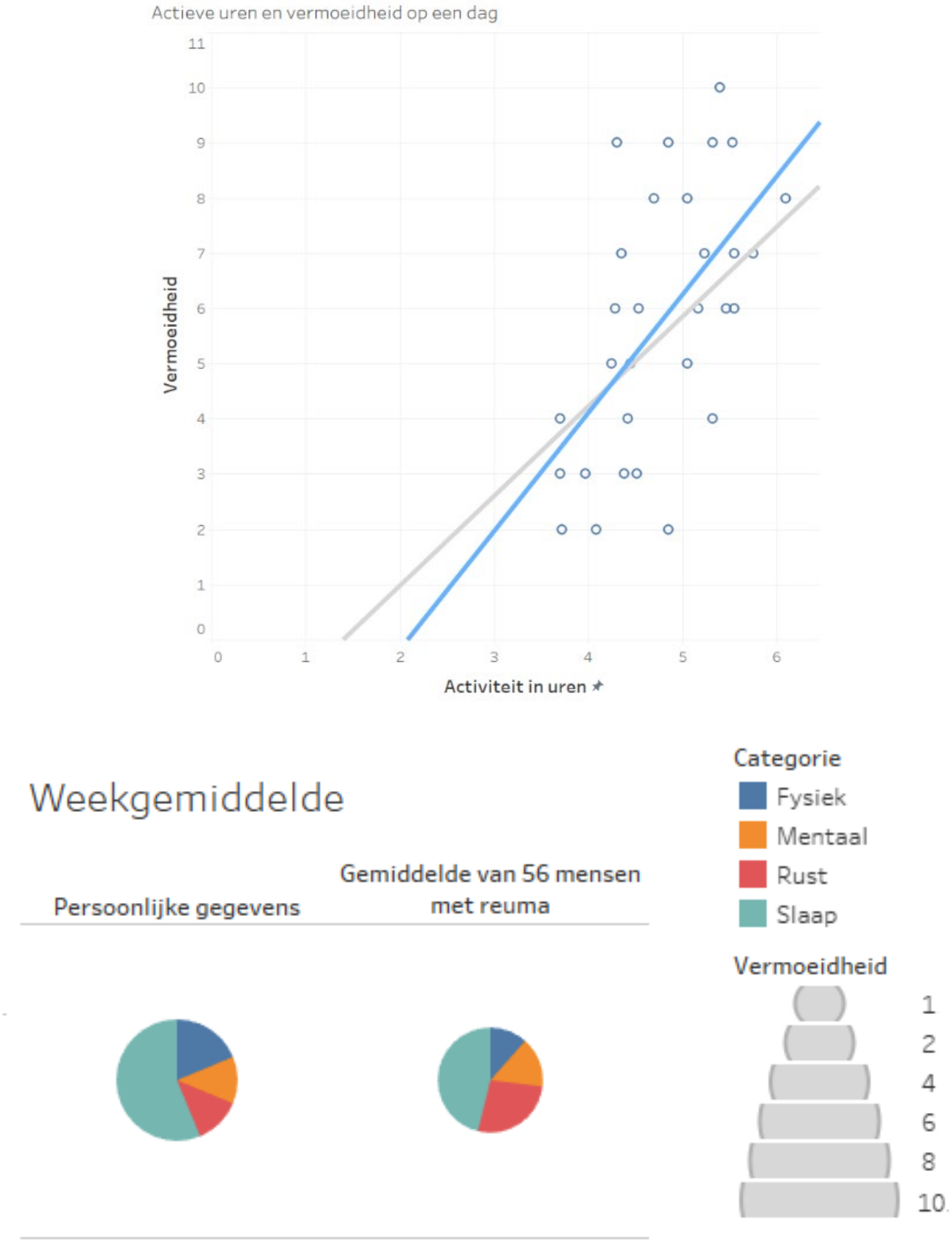

Figure 20: Mock-up prototype #8 and #9 enlarged

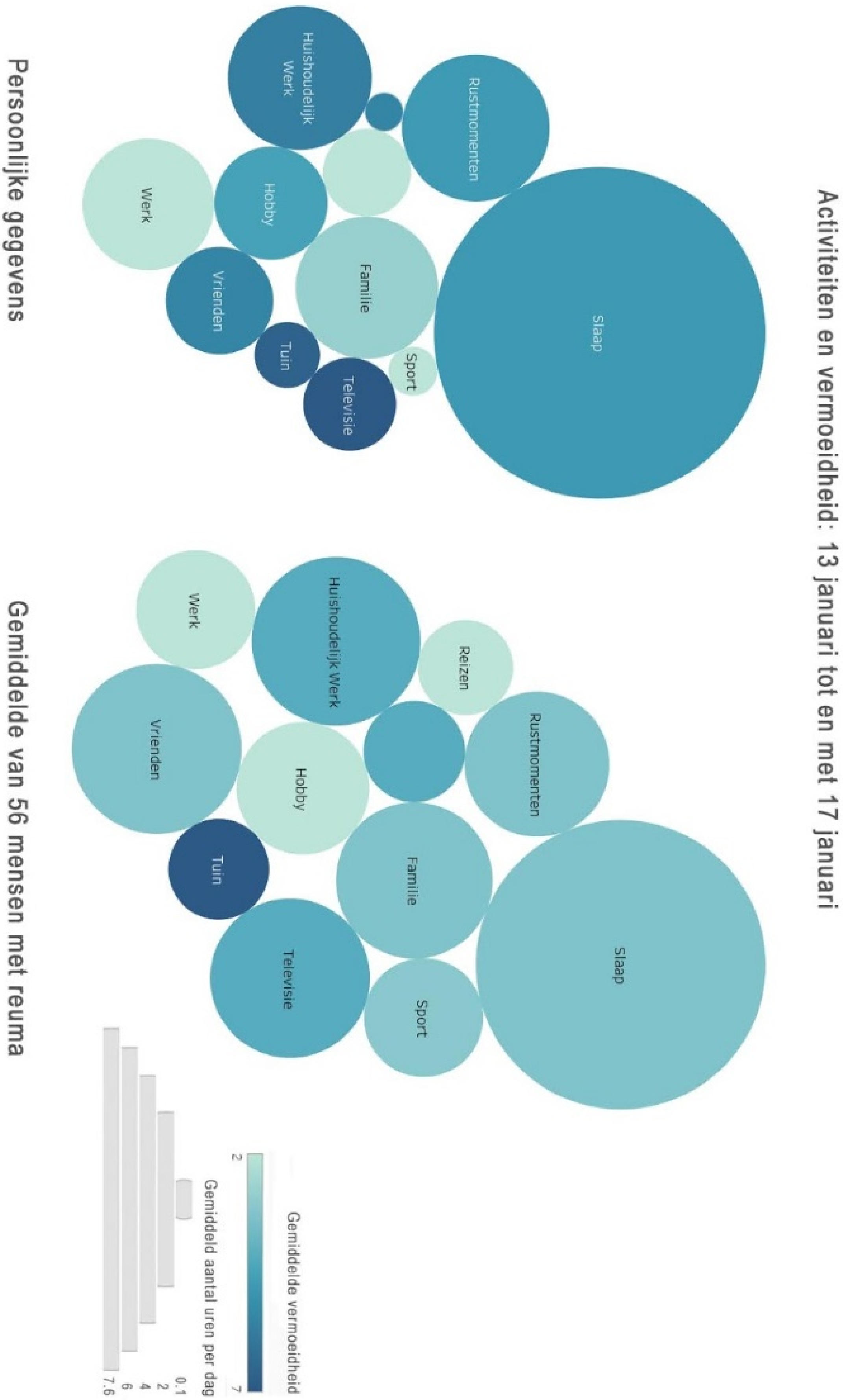

Figure 21: Mock-up prototype #10 enlarged

Appendix III - Co-creation session script

Start	End	Wat?	Details
-20:00	-15:00	Voorbereiding	Onderzoeker 1 & 3 host maken van de meeting
-15:00	0:00	Drop in	Gasten komen aan, welkom heten!
0:00	0:15	General introduction + say hello	Uitleg over wat er gaat gebeuren tijdens de co-creatiesessie, wat er verwacht wordt van de deelnemers. (Onderzoeker 2) Voorstelrondje! + **opname aan**
0:15	0:20	Data visualisation explanation	Uitleg over wat data visualisatie is en hoe het belangerijk is voor het citizenlab project; introductie tot het onderwerp. (Onderzoeker 1)
0:20	1:00	Questions / Open conversation	**0:20 - 0:35** - Wat voor data zou je willen aanleveren? In welke vorm? **0:35 - 0:45** - Is visualisatie van deze data interessant voor jullie? Waar zou jij ze voor gebruiken? **0:45 - 0:55** - Wat voor visualisaties kom je tegen in het dagelijkse leven, en wat vind je ervan? Wat is goed / slecht? **0:55 - 1:00** - Overige vragen als die opkomen. (Onderzoeker 1)
1:00	1:10	Break	Koffiepauze!
1:10	1:50	Visualisation slideshow	**1:10 - 1:15** – Instructie & opsplitsen naar breakout rooms (Onderzoeker 1) **1:15 - 1:40** – Slideshow visualisatie. **Aanzetten van opname in breakout rooms** **1:40 - 1:50** – Groep weer samen. **Uitzetten van opname onderzoeker 3.** Bespreken van ervaringen ermee. Vragen: • Wat waren problemen waar men tegenaan liep? • Wat waren dingen die juist wel duidelijk waren? • Wat zijn de meningen over de meer “onbekende” visualisaties In tweetallen/drietal met begeleiding van een van ons
1:50	2:00	Conclusions + goodbye	Wat hebben we vandaag gesproken, en wat heb ik van de deelnemers geleerd; informatie over wat er nu verder gedaan gaat worden met deze informatie.
2:00	??	Drop out + questions	Iedereen kan weg gaan, of nog iets langer blijven hangen als ze nog vragen hebben, of meer te zeggen!

General Introduction

Onderzoeker 2:

Data Visualisation Explanation

Onderzoeker 1:
Voordat we verder gaan wil ik jullie laten weten dat als je op enig punt vragen of opmerkingen hebt, je deze altijd kan stellen. Mocht het zo zijn dat je het gesprek niet wil onderbreken, kan je deze vragen ook in de chat zetten, zodat ze zo snel mogelijk beantwoord kunnen worden.

Zoals Lieke al eerder al vertelde, op deze website zul je mee kunnen doen aan onderzoeken. Als een van de eerste onderzoeken op deze website, zal er worden gekeken naar hoe beweging in het dagelijkse leven een effect kan hebben op de vermoeidheid die komt kijken bij Reuma. Hiervoor zullen gebruikers van de website zelf data kunnen verzamelen. Vervolgens zal deze data bekeken kunnen worden door de gebruikers zelf. Hiervoor zullen we de data op een visueel weergeven; dit noemen we datavisualisatie. Dit kan op heel veel verschillende manieren worden gedaan; hetgeen waar jullie zelf waarschijnlijk het meest bekend mee zullen zijn, is grafieken. Zo wordt er bijvoorbeeld, als er gepraat wordt over de laatste corona cijfers, vaak een grafiek gebruikt waarin je over tijd het aantal besmettingen per week kan zien groeien. Als onderzoeker bij het Citizenlab is het mijn taak om uit te vogelen hoe deze data visualisatie het beste gedaan kan worden op de website!

Om te beginnen wil ik in het eerste deel van deze sessie graag in gesprek gaan over de dataverzameling en visualisatie op de Citizenlab website. Hierbij zijn voor mij alle meningen belangrijk, zowel van degene onder jullie die meer ervaring hiermee hebben, als degene onder jullie die hier weinig of misschien wel geen ervaring mee hebben.

Zijn er nog vragen?

Visualization Slideshow

Slide 1: Uitleg vermoeidheid en activiteit.

we gaan ons nu richten op datavisualisatie voor de vraag hoe vermoeidheid en activiteiten samenhangen. Later hopen we veel meer onderzoek te kunnen starten, maar dit zal het eerste startpunt zijn. De volgende grafieken gaan allemaal over dit onderwerp. We horen graag van jullie op welke manier informatie het meest duidelijk en informatief wordt weergegeven. Denk hierbij ook aan de hoeveelheid informatie die je aan moet leveren en het inzicht dat dat oplevert.

De grafieken zijn in elkaar gezet met voorbeelddata - dit is dus nog geen echte data opgemeten door reumapatiënten.

Slide 2: Vermoeidheid en Activiteit op een dag

In deze grafiek wordt er voor een volledige maand weergeven hoeveel minuten aan activiteit een reumapatiënt heeft besteed op een dag, en hoe vermoeid ze zich voelde aan het einde van de dag (op een schaal van 1 tot 10). Hierbij is alles wat deze patiënt beschouwde als een ‘activiteit’

- Zijn er dingen die je opvallen in deze grafiek? Is de grafiek voor jullie te begrijpen?

- Zou je de ‘activiteit’ op willen splitsen? Of verschillende activiteiten in beeld kunnen laten verschijnen? Zou je andere extra informatie willen krijgen? Hoe zou je deze informatie dan willen krijgen?
- Activiteiten in het algemeen kun je makkelijk aanleveren door de smartwatch te koppelen, dus met weinig tijdsinvestering. Details zullen misschien handmatig aangeleverd moeten worden. Dit kost meer tijd. Is dat het waard volgens jullie?

Slide 3: Vermoeidheid en Activiteit - Extra grafiek 1

Deze grafieken worden vaak gebruikt om een mogelijke relatie te vinden tussen twee dingen; de relatie die hier dus weergegeven wordt, is tussen de hoeveelheid aangegeven actieve minuten en de vermoeidheid op een dag. Dit is dezelfde informatie als in de vorige grafiek, maar dan anders weergegeven.

- Zijn er dingen die je opvallen in deze grafiek? Is de grafiek voor jullie te begrijpen?

Slide 4: Vermoeidheid en Activiteit - Extra grafiek 2

Deze grafiek is abstracter en mogelijk onbekend voor de deelnemers. Hier wordt de grootte van de cirkels en de kleur van de cirkels gebruikt om twee verschillende waardes aan te geven op een schaal. De grootte geeft de hoeveelheid tijd er aan de activiteit is besteed in de aangegeven tijdsperiode (13 - 17 januari). De kleur is het gemiddelde van de vermoeidheid op een schaal van 1-10 op dagen dat de activiteit plaatsvond. Een legenda voor grootte van cirkels niet beschikbaar voor deze visualisatie in het programma.

- Heb je ooit een grafiek als dit gezien?
- Zou je tijd willen besteden aan leren hoe deze grafiek, of andere onbekende grafieken in elkaar zitten?

Slide 5: Vermoeidheid en Activiteit - Vergelijking extra grafieken

Hier worden beide ‘extra’ grafieken uit de vorige grafieken naast elkaar gezet.

- Zouden deze grafieken een mooie aanvulling kunnen zijn op figuur 1, of vinden jullie het niet veel toevoegen?
- Welke van de grafieken geeft dan een prettiger overzicht van figuur 1?
- Zou er voor jou waarde te vinden zijn in deze grafieken allebei te zien?

Slide 6: Figuur - Activiteit per dag, staafgrafiek

In deze grafiek wordt weergegeven hoe actief een reumapatiënt is geweest op een dag, gemeet in minuten. Deze informatie is gemeten in verschillende categorieën. In de linkse grafiek is dit in vier meer abstracte/bredere categorieën; in de rechtse grafiek is dit in meerdere kleinere categorieën.

- Zie je liever de activiteiten op een dag opgesplitst in kleinere, meer specifieke categorieën, of in bredere categorieën? (Hoeveel wil je bijhouden voor hoeveel inzicht?)
- Nu wordt hier een activiteit of categorie aangegeven met een kleurverschil; is het voor jullie goed te doen om te vergelijken in deze grafieken welke dag bijvoorbeeld het meeste fysieke activiteiten bevatte? Soortgelijke vergelijkingen?

Slide 7: Figuur - Activiteit per dag, taartgrafiek

Hier wordt de informatie over welke activiteiten plaatsgevonden hebben op een dag op een andere manier weergegeven.

- Is de mening over voorkeur voor bredere categorieën of specifieke categorieën anders voor deze grafieken?
- Zou je een overzicht als dit ook willen zien als weekoverzicht / maandoverzicht?

Slide 8: Staafgrafiek vs. taartgrafiek

- Als je zou moeten kiezen, welke van deze grafieken zou je liever hebben om je data te bekijken? Waarom?
- Zou er voor jou waarde te vinden zijn in deze grafieken allebei te zien? Waarom?
    - Zo ja, hoe zou je ze dan naast elkaar willen zien? (Direct naast elkaar, of op een losse pagina, bijvoorbeeld)

Slide 9: Vergelijking eigen data met andere deelnemers (5 en 4)

Op deze slide zie je twee voorbeelden waarin je eigen data vergeleken wordt met de data van andere deelnemers in een onderzoek. In de linkse grafiek kan je naast elkaar je eigen gegevens vergelijken met het gemiddelde van alle deelnemers. In de rechtse grafiek kan je je eigen gegevens vergelijken met het gemiddelde van alle deelnemers in dezelfde grafiek.

- Is deze vergelijking iets waar je in geïnteresseerd bent?
- Zie je deze vergelijking graag in dezelfde grafiek (zoals in voorbeeld 1), of in een losse grafiek (zoals in voorbeeld 2)

Conclusions & Goodbye

Onderzoeker 1:
Ik denk dat we hiermee wel tegen het einde van dit gesprek zijn, helaas. Ik wil jullie heel erg bedanken voor jullie deelname! Wat ik op dit moment hier vooral uit heb gehaald is dat ….. [voorlopige conclusies van tijdens de sessie].

Onderzoeker 2:
Volgende week zal er nog een laatste sessie plaatsvinden, waar sommige van jullie ook nog deel zullen nemen. Nadat deze laatste sessie heeft plaatsgevonden, willen wij aan de slag om een eerste versie van de website te maken. Deze willen wij dan graag aan een aantal mensen voorleggen om te testen en om te horen wat er wel of niet goed aan is. Dit is belangrijk voor de ontwikkelaars die vervolgens de website daadwerkelijk gaan maken. De meeste van jullie hebben zich daarvoor ook aangemeld. Zouden
jullie het fijn vinden om dat weer in een groep te doen, of liever apart? Tot slot: wij willen jullie allemaal hartelijk danken voor jullie deelname, onder andere door een VVV-bon aan te bieden. Wij zullen jullie na deze bijeenkomst allemaal een mail sturen om u te vragen naar het postadres waar we deze heen kunnen sturen.

Appendix IV – Co-creation session power-point

Figure 22: Power-point used in co-creatin session

Appendix V - Evaluation session script

Tiid in minutes	What	Comments	Extra questions
-0.05-00.00	Digitale binnenkomst		
00.00-00.10	Introductie	-Welkom (Lieke/Ria)	Goedemiddag, welkom. Fijn dat je weer wilde deelnemen. aanwezig kunt zijn. [Voor als de deelnemer nog **niet** alle onderzoekers kent: voorstelrondje] [Voor mensen die **niet** hebben deelgenomen aan een van de cocreatiesessies: *Het TOPFIT Citizenlab is een samenwerking van de Universiteit, Saxion Hogeschool, ROC van Twente, Roessingh Research en Development, verschillende bedrijven en organisaties. Het doel is om mensen langer en gezonder te laten leven.* *Om goed samen te kunnen werken denken wij dat het belangrijk is om een website te maken waar we als patiënten en onderzoekers contact kunnen hebben en waar het onderzoek kan worden uitgevoerd. Op de website kun je gegevens delen met bijvoorbeeld onderzoekers of andere deelnemers aan dat onderzoek. Ook kunnen mensen aangeven welk onderzoek ze graag willen starten. Het zal zo echt een samenwerking zijn. Zo'n samenwerking tussen patiënten en onderzoekers in onderzoek wordt ook wel citizen science of burgerwetenschap genoemd.* *Deze website bestaat nog niet, maar die willen wij graag gaan ontwikkelen. Dit willen we liefst samen met u doen en daarom zijn we hier.]* Er zijn vier bijeenkomsten geweest, en aan de hand daarvan hebben we een beeld gekregen van wat voor soort onderzoek er op de website gedaan kan worden, welk onderwerp belangrijk is, functies die de website moet hebben en hoe de website eruit moet zien. We hebben al deze ideeën geprobeerd te verwerken in een prototype, om deze samen met jou te bekijken en te praten over wat je hier van vindt. Het gaat hierbij nog niet zo zeer over het design, dus alle kleurtjes en details, maar meer over: zou je hier alles weten te vinden? Zitten alle functies die je graag zou willen zien er bij? Wij zouden graag de bijeenkomst van vandaag opnemen, zodat we deze later nog eens terug kunnen kijken. Die opname is echt alleen bedoeld door gebruik van onszelf, wij zullen deze niet delen met anderen of op internet plaatsen. Vind je dat goed? Dan zetten we nu de opname aan.
00.10-00.15	Uitleg website	*Wat willen mensen kunnen op de website?* (Lieke/Ria)	De website zal een plek worden waar onderzoek wordt gedaan. Voor dit onderzoek werken mensen met reuma en onderzoekers samen. Wij hebben door alle informatie uit de vragenlijsten en de eerste 3 bijeenkomsten al een goed beeld van wat er mogelijk zou moeten zijn op de website. Uit de eerste bijeenkomst weten we dat het eerste onderzoek dat we gaan starten op de website over vermoeidheid en activiteiten gaat, maar later ook andere onderwerpen. Vandaag willen we bespreken hoe het er uit moet komen te zien, en wat je er allemaal moet kunnen doen, dus welke functies. Het lijkt ons dat dit gesprek makkelijker gaat als we een voorbeeld hebben. Dit voorbeeld is een eerste idee van wat de website zal worden. We zullen tijdens het doorlopen van dit voorbeeld, ook een aantal vragen aan jullie stellen. Deze vragen zijn bedoeld om erachter te komen wat er werkt aan ons voorbeeld, en wat niet. Als je dus niet een antwoord weet om te geven,

			of iets niet duidelijk is, dan is dit helemaal oké, en laat dat dan ook vooral horen! We zijn hier niet om jullie kennis of begrip te testen, maar om te testen of wij in de goede richting zitten. Geef dus vooral je eerlijke mening en wees niet bang om kritisch te zijn, dat vinden wij alleen maar prettig.
00.15-00.20	Onboarding	Pagina voor de inlog; wat gebeurt er als je je aanmeldt; informed consent procedure (Lieke/Ria) Scherm delen: Sanne/Ummu	5 min: Een deel van de website zal algemeen toegankelijk zijn. Vragen: • wat vinden jullie ervan dat een deel zonder inlog beschikbaar is? • Moet het login stuk een prominente plek innemen? • Moet de uitleg over het portal direct zichtbaar zijn of doorklikbaar zijn? • Zou de uitleg hier alleen in tekst moeten staan, of ook bv als filmpje of als infographic? • Welke informatie missen jullie nog?
00.20 - 00.30	Informed Consent	Sanne/Ummu neemt het gesprek over over	Nadat je bent aangemeld, krijg je een deel met vragen. Ik zou graag willen dat je die stappen neemt, en ons terwijl je dat doet, vertelt wat je vindt. Zo kunnen we je reactie zien op specifieke delen. We zullen je ook vragen stellen als we graag iets specifieks willen weten. Als ze het zelf niet opnoemen: Eerste pagina over persoonsgegevens: (controle en begrip) • Vind je het fijn om te kunnen zien waar de gegevens precies voor worden gebruikt? • Helpen de plaatjes het sneller te begrijpen/er sneller doorheen te komen? Tweede pagina en derde met personalisatie vragen: (autonomie, controle, personalisatie, begrip) • Is de toevoeging van dit soort keuzes belangrijk, waarom? (keuze op een schaal van 1-10) • Laat het je voelen alsof je in controle bent? (controle keuze op een schaal van 1-10) • Hoe voel je je over de herinner mij aan mijn keuze knop? • Wat vond je van de pop-ups (wanneer je herinner mij uitzet, dus op de knop klinkt en ook wanneer je op nee klikt) • Vind je het fijn dat het stap voor stap is, met minder tekst? Quiz: (communicatie, begrip) • Houd de quiz je attent? • Helpt dit soort communicatie met je begrip? • Vind je het fijn het uit te kunnen zetten?
00.30-00.35	Dashboard (Sanne/Ummu)	Algemeen	Als je eenmaal bent ingelogd, kom je bij je Dashboard. Er is een verdeling gemaakt tussen Mijn account en Onderzoek, wat vind je van deze verdeling?
		Accountgegevens	Op deze pagina kan je alle accountgegevens en standaard persoonlijke gegevens die we bewaren vinden en wijzigen. Wat vind je hier van?
00.35 - 1.00		Gegevens doorgeven	Op deze pagina kun je gegevens doorgeven aan de onderzoeken waar je aan mee doet. Wat vind je van dit overzicht? Per onderzoek, kan je gegevens invullen. Hier hebben we een voorbeeld van hoe dit gedaan zou kunnen worden voor ons onderzoek over vermoeidheid en activiteit. • Wat vind je hiervan?

			• Is er genoeg duidelijkheid over hoe deze vragenlijst ingevuld moet worden? Nadat je deze gegevens ingevuld hebt, kan je meteen doorklikken naar een data dashboard, waar je de gegevens, samen met eerdere gegevens, terug kan vinden in een data visualisatie...
		Mijn data overzicht; Deelnemer (waar mogelijk) neemt controle over het prototype.	...vragen data visualisatie: 1. Op eerste zicht van dit data dashboard; wat zie je hier? Welke tools denk je te kunnen gebruiken? 2. Stel je nu voor dat deze data informatie is over jou in de afgelopen periode. Kan je ons vertellen wat je hier ziet, en dingen die je eventueel opvallen aan de data? (zonder in te zoomen / uit te zoomen). 3. Maak nu gebruiken van de 'zoomfunctie'. Welke extra dingen kan je nu zien, en/of vallen je op aan de data? 4. Op een schaal van één tot tien, hoe behulpzaam zijn de volgende functies bij het begrijpen en analyseren van je data? a. Zien van je data op verschillende schalen (Variation, Exploration) a. Hierbij ook: het visueel aangeven van welke data je zojuist op hebt geklikt b. Het kunnen aanpassen van wat er te zien is in de grafiek (Variation, individuality) c. Het toevoegingen van opmerkingen over je data (Context) d. De toelichting over de grafieken (Understanding, relation) 5. Wat mis je nog?
01.00-01.20		Toestemming	Toestemming Algemene toestemming: (autonomie, communicatie, controle) • Op het eerste gezicht, wat vind je van zo'n overzicht? • Waarvoor zou je verder een keus voor willen hebben/ vind je de keuzes goede toevoegingen? Instellingen per onderzoek: (controle, communicatie) • Wat vind je van de instellingen per onderzoek? • Vind je het fijn zo veel keuze te hebben in dingen? Is het te veel? Voel je je in controle?
		Mijn onderzoeken	Bij mijn onderzoeken vind je 2 kopjes: (trust, communication, understanding, altruism) • Wat vind je van de inhoud? Is het belangrijk om deze info te weten? Mist er iets? • Vind je het fijn vragen te kunnen stellen over het onderzoek? • Creeert het vertrouwen? (1-10 vertrouwen) • Geeft de impact page je het gevoel dat je aan onderzoek hebt meegedaan die echt waarde heeft voor mensen? vind je dat belangrijk? • Wat vind je van de onderzoekstijdlijn?
		Mogelijke onderzoeken	Bij mogelijk onderzoek vind je onderzoeken waar je aan mee kan doen. Als je op de eerste klikt, word je doorgestuurd naar Jeroen's verzoek. Dit soort verzoeken zul je ook vaker krijgen wanneer je bijvoorbeeld net bent ingelogd en een nieuw persoon je een verzoek heeft gestuurd, om je up to date te houden. (privacy, trust, communication, choice, further personalisation, understanding) • Wat vind je daarvan? • Vind je het fijn dat je jeroen vragen kan stellen als je dat nodig hebt? • Is het fijn dat dit met een alias/gebruikersnaam kan? • Wat vind je van de inhoud van meer informatie?

			• Geeft het rapporteren knopje je het gevoel dat je in controle bent? • Zijn alle antwoorden duidelijk te begrijpen ook?
		Ideeënbox	Op deze pagina kan je ideeën doorgeven aan het Citizenlab. Dit kan je zowel anoniem doen, als met je eigen naam. Wat vind je hier van?
		Beheerders (en algemene vragen over consent)	Beheerder pagina: (trust through association, privacy) • Wat vind je ervan dat er beheerders zijn? Stelt dit je gerust? • Welke dingen op deze pagina creëren vertrouwen, als ze dat doen? • Als je door alles bent geweest, heb je het gevoel dat er goed met je data om wordt gegaan? • Voel je je in controle over je datagebruik? • (Vind je het fijn om al die keuzes zelf te kunnen maken, dat het in jouw handen is?) • Stellen alle updates en reminders en vragen je gerust? • Van een reuma patients invalshoek, wat vinden jullie dat er nog mist?
01.20-01.25	Vragenrondje	Lieke/Ria neemt het gesprek opnieuw over.	Wat zou je graag op de website terugzien dat nu nog niet langs is gekomen? Wat zou je absoluut niet op de website willen (wat we nu hebben laten zien of iets wat we niet hebben laten zien maar wat je graag wil benadrukken?) Zijn de locaties van alle functies logisch? Zou je iets aanpassen en/of toevoegen hieraan? Wat voor kleur zou je voorkeur hebben? Heb je nog vragen? Wil je nog iets opmerken? Hoe vond je deze bijeenkomst?
01.25-01.30	Afsluiting	-VVV-bon -evt verdere betrokkenheid bij portal (Lieke/Ria)	Heel erg bedankt voor je deelname! Wij gaan nu in gesprek met de ontwikkelaars om alle ideeën hopelijk concreet te kunnen maken. Om je te bedanken voor je deelname, willen we graag (weer) een VVV-bon aanbieden. We hebben het adres nog in ons bestand dus deze zullen we binnenkort opsturen/ik stuur straks een mail om je te vragen naar je adres. Het kan zijn dat wij in de komende maanden nog wat aanvullende vragen hebben. Zouden wij je mogen benaderen met een specifieke (waarschijnlijk relatief kleine) vraag? En mocht je vaker met ons samen willen werken over de website, laat het ons weten! Fijne dag!