Towards value sensitive dynamic e-consent in eHealth solutions

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Abstract

Current traditional informed e-consent is seen as a one time agreement for participating in a research project over a limited period of time. Within the context of Citizen Science, research is done in a significantly different way, with a lot more variables in play, such as data usage over long periods of time, multiple parties accessing and using data at different points in time and others. This makes consent within Citizen Science more complex, thus, traditional informed e-consent is not a good approach for it. A new solution is necessary that is more dynamic and allows for more personalisation as to fit all the data usage contexts of Citizen Science.

The proposed solution is to implement dynamic e-consent, while focusing on user values, needs and expectations. The first goal is for the foundations of dynamic consent, taken from literature, to be put into practice and evaluated with a user group in order to gauge the reception of dynamic consent in an applied context. The second goal of the research is to see if the user values, needs and expectations derived from previous research match what actual users think. Finally and most importantly, the aim is to evaluate if combining these values, needs and expectations with the concepts of dynamic consent would yield a good solution for consent in Citizen Science.

The way the goals of the research were achieved is by developing two prototypes. First, an initial prototype of the proposed solution was developed and evaluated with the user group in the form of a focus group, later analysed using Thematic analysis. The results showed a very positive reception of implementing dynamic consent and a good indication that combining it with a user-centred focus is beneficial. Based on the feedback from the initial evaluation, a iterated prototype was developed and evaluated with users, in the form of an interview. The reception was again positive, with only minor points for improvement.

The research done shows that a dynamic e-consent solution can work and a good design for it would most likely implement a focus on user values, needs and expectations, as they make the overall user experience better and mostly align with the already established foundations of dynamic consent. There is still room for improvement, so such systems should be explored more in research perhaps with a particular focus on personification. Regardless, this thesis provides a good first step in the relative infancy of such systems.

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Chapter 1 - Introduction

Consent is a concept that has changed and developed over time. In its most basic form, it means that one person gives permission for something or agrees to something [1]. This concept is important in research, but that has not always been the case. For example, in ancient Greece, freeborn men were only granted consent by freeborn doctors and slaves did not even get the option to consent from their slave doctors [2]. The consent from that time was simple, as it did not have specific criteria and was close to the meaning's most basic form. The free men got the option to give permission to something or agree to something with the limited information and understanding they had. The difference in knowledge and understanding between the free men and doctors was too large for the former to make a truly active choice. Instead, this consent was more akin to passive agreement and acceptance. Nowadays, consent looks very different, as it has evolved to become informed consent, changing it from a passive agreement to an informed choice to actively provide consent to participate in a specific research [3]. This active consent is an ethical and legal requirement for research involving human participants, with several criteria to ensure this. Informed consent went through numerous stages to get where it is right now, but its importance was highlighted after the Nuremberg trials, leading to the Nuremberg Code, which focuses on voluntariness in consent [2]. The concept of informed consent became more refined in the 1970s and 1980s as there was a growing interest in it, raised by various social movements [4]. Informed consent in its current form highlights that its purpose is not to protect from risk, but to protect autonomy and personal dignity [4].

Besides giving informed consent to research, today people also consent to having their data collected and shared. This can be done on websites and applications, either by first-parties or third-parties. First-parties use it to personalize the content so the users stays engaged, while third parties use the data for advertising and competitive research purposes [5]. This is often done using cookies, which have to be consented to beforehand, as dictated by the GDRP [5]. Additionally, user data can be used for research purposes, as gathering and measuring data is done to conduct high quality research [6]. This is also based on electronic data, as it has a larger sample size and more reliable data than in-person data [7]. Moreover, it costs less and it can be collected and used faster [7]. Additionally, it has become much easier for people to take part in research through electronic means, due to various tools. For example, Apple's Research Kit [8].

As the digital tools made it easier to collect and share data, being actively involved in scientific research has become more accessible, as can be seen in the growing number of citizen science projects. Citizen Science is a space in which collective learning and scientific research about various topics are focal points [9]. In Citizen Science, the public shares data that they have collected themselves, but also works with data to create their own insights, which is how they contribute to an increase in scientific knowledge [9]. Citizen Science is often in collaboration with professional scientists also doing research [9]. Furthermore, Citizen Science initiatives can relate to different topics, one being health. When the topic is health, any data related to the mental or physical health of the user is considered health data [10]. This data is useful because it can help with understanding and managing the health of people.

Furthermore, different types of harm can still be done if the problems related to informed consent in Citizen Science regarding health data are not tackled. Citizen Science is a space in which many people potentially share a lot of their personal data, depending on the research. Many types of different data are collected and shared with potentially multiple researchers. This sharing is also not always for just a limited amount of time or with only one research purpose. Therefore, due to the many variables in place, more traditional e-consent cannot be applied to the context of Citizen Science. This is because the data sharing possibilities are not dynamic and not personalized to fit every context. This makes traditional e-consent not a good fit for Citizen Science. Furthermore, giving consent or even informed consent does not necessarily mean that people comprehend what they are consenting to. Companies seem to adhere predominantly to the legal requirements of collecting consent (e.g., users agree to the terms of service and hereby give consent) and depending on their business model, companies can benefit a lot when users share their data. This is reflected in their way of asking for consent, as it is often difficult to understand and focuses on making users click on the agree button, instead of enabling them to understand what the data is used for and thereby making an informed choice with space for nuanced options. The data collected and shared is also potentially sensitive, so it should be handled carefully. With all these issues in mind, a more dynamic and personalized way of obtaining consent that focuses on proper treatment of users and their data is necessary for conducting research in the Citizen Science context.

Project Context

TOPFIT Citizenlab is a collaboration of knowledge institutes with the aim to establish Citizen Science for Health in the Netherlands. This program encourages companies, professionals and citizens to work together on health research and health technology development by applying a citizen science approach, that is, to enable active collaboration between citizens and researchers throughout the research process.

Roessingh Research and Development (RRD) is a scientific research centre focussed on e-health and rehabilitation technology. RRD is leading one of the pilots in TOPFIT Citizenlab, which focuses on “Citizens and New Technology”. Part of this pilot is to investigate how a Citizen Science Portal would look like, that enables citizen to initiate and carry out their own research projects related to their health. To answer research questions related to one’s health, the collection of health data is essential. The portal supports citizens to collect, store, and process data. This data will potentially be shared with various researchers that can be individuals or part of a research team (e.g., researchers or other citizens). Naturally, users have to give permission for this. Usually, giving consent for data usage in research is quite specific and limited to a certain research project. This might change in the context of Citizen Science and health data, as there is much to learn. Also - as COVID-19 showed – there might be a more urgent need to understand health data for public reasons. Sometimes this data will need to be examined long term, such as the side effects of vaccinations. This makes consent much more complex. Asking for consent once for all sorts of purposes to cover those eventualities leaves out too much information for people to make an informed decision, like the specific researchers that are going to use the information and when and what they are exactly going to use it for. Furthermore, giving broad consent also makes the user more vulnerable to losing their autonomy and to being passive. Therefore, a more dynamic solution is sought for. Additionally, Citizen Science requires a lot of data over a long period of time, which means that more dynamic aspects like being able to change one's mind and being asked for consent periodically are necessary. These dynamic features cannot be implemented easily in a non-digital manner. Moreover, consenting digitally saves costs on paper and makes people more actively involved in the projects because they get the opportunity to revisit what they consented to and possibly change their mind. With the need for dynamic elements and the benefits of e-Consent in mind, dynamic e-Consent may be a good way to address the issues of traditional consent in the context of Citizen Science.

Value-sensitive design can be used to approach these problems. In this context, it means that human values, needs and expectations are the basis for design choices, as these give a good insight into what users want and which issues they would like to see being tackled. A solution can be found like this by thinking about the impact a system has on users and how to improve it.

For this user-centred approach, theory about dynamic consent and user values, needs and expectations should be combined, to see if these concepts are compatible and how they could work together in practice. This specific combination of topics is not sufficiently present in research either, so this thesis adds value to the exploration of this approach.

This thesis will focus on combining user values, needs and expectations with dynamic e-consent concepts to make a consent solution for the context of Citizen Science. The question that is central to this thesis is therefore ”*What is a good design for dynamic e-consent that addresses the user values, needs and expectations?*” This contributes to the research related to informed dynamic e-consent, as dynamic consent is a fairly new concept in which the possibilities for designs have not been explored sufficiently. Furthermore, this particular combination of user-centred design and dynamic consent is also not sufficiently present in research currently.

To answer the research question, background research has been conducted to collect and analyse information regarding the topic. This research can be seen in Chapter 2. Afterwards, a prototype of dynamic e-consent was created based on this, which was then evaluated with participants who are potential future users of the application. Both can be found in Chapter 3. Following this, the design was iterated, then evaluated again as per Chapter 4. While going through these steps, some sub-questions were answered to lead to an answer to the main research question. The sub-questions are categorized the following way:

Background research (Chapter 2)

- Based on literature, how can informed consent be improved in a digital environment that is related to healthcare, in comparison to how it is currently?
- Based on the state of the art, what is the gap between informed consent in current applications and “truly” informed consent?
- Which values, needs and expectations are already known from literature when it comes to data sharing?
- Are the values, needs and expectations in alignment with the improvements for informed consent?
- Based on literature, how is dynamic consent conceptualized?
- How does dynamic consent affect the values, needs and expectations of data sharers?

Initial design (Chapter 3)

- How can e-consent be made dynamic and user-centered?
- How can dynamic consent and values, needs and expectations be combined in a system design?

Evaluation initial design (Chapter 3)

- Which values do users consider when using the parts of the Citizen Science Portal relating to consent?
- Does dynamic consent work?
- To what extend does the prototype of dynamic consent satisfy the user’s values, needs and expectations?

Evaluation iterated design (Chapter 4)

- Answer research question: ”*What is a good design for dynamic e-consent that addresses the user-values?*”

Chapter 2 - Background Research

This chapter outlines the background research conducted to answer the specific questions about what is already known from the literature with regard to informed consent, the state of the art, implications for design, user-centred informed consent, dynamic consent and user-centred dynamic consent.

In particular, section 2.1 answers the question: *Based on literature, how can informed consent be improved in a digital environment that is related to healthcare, in comparison to how it is currently?* Section 2.2. outlines the state of the art and answers the question: *Based on the state of the art, what is the gap between informed consent in current applications and "truly" informed consent?* Section 2.3 describes the user values, needs and expectations and what they imply for the design. It does so by answering the question: *Which values, needs and expectations are already known from literature when it comes to data sharing?* Section 2.4 outlines user-centred informed consent by comparing the user values, needs and expectations with the foundations of informed consent. This is done by answering the question: *Are the values, needs and expectations in alignment with the improvements for informed consent?* Section 2.5 describes dynamic consent by answering the question: *Based on literature, how is dynamic consent conceptualized?* Section 2.6 outlines user-centred dynamic consent, by describing the relationship between dynamic consent and user-centred design. This is done by answering the question: *How does dynamic consent affect the values, needs and expectations of data sharers?*

2.1 Informed consent

Due to the digitalization of many services, a lot of things are moving to an online environment. In this environment, where data is collected, stored and shared with partners on many digital platforms, the right to privacy has become of significant importance. Yet, the effectiveness of digital consent as it is currently is questionable, due to different factors. One such factor is the just-tick-agree phenomenon [11]. This is a phenomenon in which people do not read the text they are consenting to and just tick the agree box, which makes the choice to consent an uniformed one [11]. This is especially troublesome for the data collection and sharing in the health domain, as these users share more sensitive information and a breach of their data can have large consequences depending on the data. Informed e-consent in its current state is flawed. The consent forms may be called "informed" officially, but what constitutes informed consent should be questioned. To make the e-consent truly informed, changes are needed. Therefore the question" *How can informed consent be improved in a digital environment that is related to healthcare, in comparison to how it is currently?*" will be answered.

To answer this question, several topics have been investigated. First, informed consent is explained and discussed. Then, the focus is on understanding and what that means, as there are many factors that should be accounted for. Finally, different design choices are discussed that may be effective for informed e-consent.

What does informed consent entail?

Informed consent means actively giving the user an autonomous choice and making sure that they are giving a genuine form of consent. This entails information disclosure, competence, comprehension, voluntariness and agreement [12][13]. Firstly, *information disclosure* means that the users should get all relevant information accurately, which could be about procedures, tests, equipment used, storing information etc [12]. Moreover, risks and benefits should be mentioned too, including how likely they are to occur. The values and interests of the participant should be taken into consideration here, as well. For example, jargon should not be used, because not everyone understands that. Secondly, *competence* is about the mental, emotional and physical ability of the user to make an informed decision [12]. They should be able to understand relevant information, explain it, make a decision and be able to explain why they made the decision. Thirdly, *comprehension* is about whether the user understands all the information that is being presented [12]. If they can apply the information or explain it in other words, it is a good indication that they understand it [13]. Fourthly, voluntariness is related to consenting with no pressure or coercion used against the user. [14] *Voluntariness* can also be affected by the design of an interface, the manipulation of information or psychological manipulation. Finally, *agreement* refers to the ability to accept or decline when making a decision, so in this case when consenting [13]. This means that it should be easy and simple to accept, decline and opt out of something [13].

The context of understanding

To make consent "truly" informed, informing consent-givers must be emphasized. However, just giving information is not sufficient to make informed consent what it is. Rather, users need to also understand this information. Understanding is made up of two of the criteria of informed consent, namely *comprehension* and *competence*. In a study by Pilter et al, participants got to choose between different designs of an interface. In the results, the participants mentioned that they chose their design based on understandability [15], indicating that this matters for the participants.

Furthermore, another positive effect related to understanding is that feedback has a positive impact on its users. Behavioural psychology research strongly suggests that empowering research participants results in greater participation [16]. This means that feedback, like a quiz, will not only challenge the users but also make them feel empowered [16]. Additionally, if a user is goal oriented, feedback will enhance their experience [17]. This may mean that users feel empowered by their understanding of what they are consenting to, as that is what the results of feedback are based on.

Yet, in the digital environment, understanding is underdeveloped. The just-click-agree phenomenon is one that has been observed in studies, as one study found that 74% of web users do not read privacy policies [15]. The participants that did read the privacy policies in this study spent 5 or less minutes on it, while it should have taken 15 - 17 minutes to read it [15]. This may have to do with the texts not being short, simple or understandable enough [15]. This suggests that the time participants spend on reading, may be related to the understanding of the design [18][15]. This understanding is also interrelated with information disclosure, since sufficient, clear information is necessary for better understanding.

Additionally, to improve understanding, a few adjustments can already make a big difference. As humans tend to absorb limited information at any one time [16], e-consent should be in simple language and presented in small parts to be understandable. Moreover, a variety of languages would make it easier to understand for users of different nationalities [17]. Furthermore, introducing something more interactive like a quiz may challenge the users to identify what they do and do not understand from what they have and have not read [19][17].

Design improvements based on literature

All of these informed consent criteria need to become part of a design for informed consent. From what has been gathered, the texts should be readable, simple and short. This could mean that sometimes, when contents are very long, only the relevant parts can be extracted from consent forms resulting in a shorter and more readable version [15].

Moreover, in a study related to extensions to privacy policies, the researchers had different types of extensions available. Extensions are online tools that shorten and simplify privacy policies with the goal to raise awareness [15]. When there were setup videos, tutorials or a website available in extensions, participants felt more trust [15][19]. Additionally, it was pointed out that ‘user control and freedom’, ‘flexibility and efficiency of use’, and ‘aesthetic and minimalist design’ principles were important to make participants more aware of their privacy needs [15]. This is because they make the design more effective, efficient and satisfactory [15]. Besides shortening the texts, adding visuals also make the texts easier to read [20][21][19][15]. An example of this are graphical representations. The information can become more accessible for everyone by adding both visuals [20][21][19][15], texts [15] and audios [21][19][20]. Colour schemes can also help as they affect individuals emotionally [15], and they could also affect the readability for the colour blind [15].

In summary, informed consent is a complex concept to make a reality, especially in a digital environment. To achieve informed consent, the five criteria information disclosure, competence, comprehension, voluntariness and agreement have to be considered and implemented [22]. Through creating a better design that is aimed at fulfilling these criteria and adding value to users, it is possible to achieve informed consent in a digital environment, which would protect the users in this domain. This can be done by making the content shorter, simpler and easier to read. Additionally, visuals, voice-overs and thinking about which colours to use in design will make it more accessible, readable and understandable for users. These qualities are all important, because they lead to better informed consent.

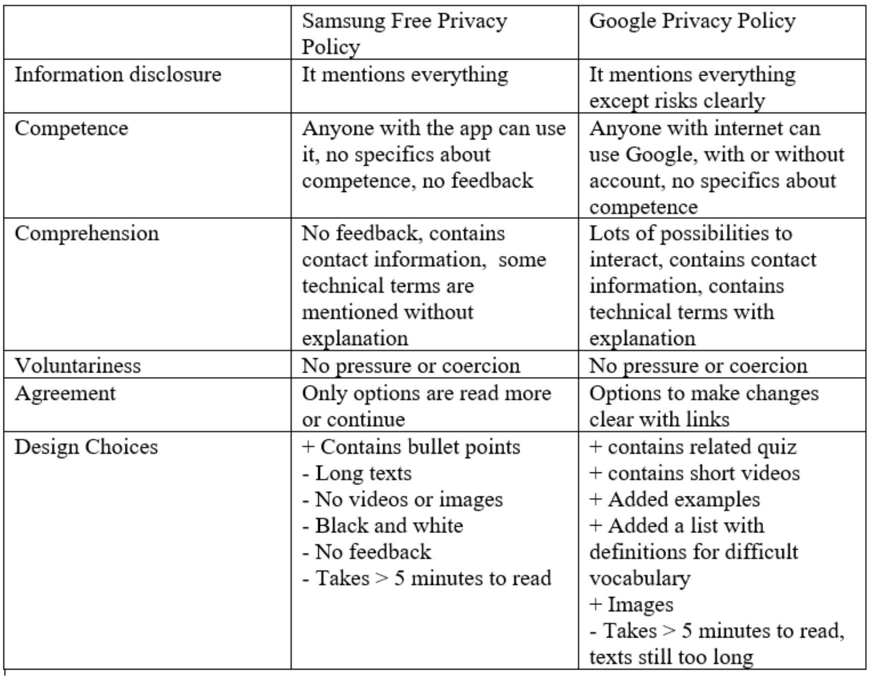
2.2 The state of the art

State of the art: informed consent

To get a better understanding of what consent is like currently and what could be improved about it, two examples of online consent on popular platforms were examined, as they are most likely to have the budget to afford to make changes in how they obtain consent. This means that they also are most likely to have a lot of money to invest into research about consent. Therefore, by analysing their privacy policies, a fairly accurate estimation can be made of how the consent process looks at its best currently. The first privacy policy is the one of Samsung Free and the second one is the privacy policy of Google.

Both were compared based on whether they satisfy the criteria from the literature that have been gathered, as described in section 2.1, and whether they incorporate any of the design choices mentioned in the same section. This comparison can be seen in table 1.

Table 1: Comparison of Samsung Free Privacy Policy and Google Privacy Policy



	Samsung Free Privacy Policy	Google Privacy Policy
Information disclosure	It mentions everything	It mentions everything except risks clearly
Competence	Anyone with the app can use it, no specifics about competence, no feedback	Anyone with internet can use Google, with or without account, no specifics about competence
Comprehension	No feedback, contains contact information, some technical terms are mentioned without explanation	Lots of possibilities to interact, contains contact information, contains technical terms with explanation
Voluntariness	No pressure or coercion	No pressure or coercion
Agreement	Only options are read more or continue	Options to make changes clear with links
Design Choices	+ Contains bullet points - Long texts - No videos or images - Black and white - No feedback - Takes > 5 minutes to read	+ contains related quiz + contains short videos + Added examples + Added a list with definitions for difficult vocabulary + Images - Takes > 5 minutes to read, texts still too long

As can be seen by the comparison, when it comes to information disclosure, both policies do a sufficient job, however, Google's neglects to mention risks clearly. Competence is addressed relatively well with little barrier for entry, but also with little done by both companies to actually ensure the competence of users. When it comes to comprehension, Google does a better job, as it presents a much more interactive and involved privacy policy. This makes the consent process much more engaging in and of itself and can be seen reflected in the various design choices used, such as the quiz, short videos, images and examples that all make information displayed more clear and engaging. This type of approach could be useful for the dynamic e-consent solution of this thesis as well. Consent there could also be made more engaging and visual as to ensure better understanding. However, the shortcomings of the solutions should also be kept in mind so they can be avoided. Primarily, the contents should be significantly shorter, while also being fully extensive.

2.3 Implications for design

As can be seen, the criteria for informed consent are strongly related to the users. Moreover, to improve informed consent and dynamic consent, it is beneficial to know the user values, needs and expectations in the context of consent and how they can be implicated in the design process [23].

First of all, basic ethical principles of research ethics imply that the purpose of consent is not to protect from risk, but to protect autonomy and personal dignity [4]. Autonomy refers to people's ability to decide, plan, and act in ways that they believe will help them to achieve their goals [4]. The value autonomy is of importance to incorporate into the design of consent. This is also how patients using e-health products feel. They want to play a bigger role in their health and want to feel empowered, as they want to make their own decisions [24]. This also relates to the value control. Additionally, privacy, security, and justice [25] are all ethical principles that are important to users. Yet, many of these values can clash if not implemented properly, causing value tensions. The concepts and their connection to good design for dynamic consent should be tested to find out whether it is feasible to implement all of them and to what extent. Additionally, the overlap between user opinions should be compared to find out which values are overall the most important.

Another value of users is trust. Trust involves being vulnerable towards others and willingly taking the risk of placing oneself in someone else's hands [26]. Oftentimes, consent relies on trust in the institution instead of completely understanding the particular project the individual is participating in [27].

Other than these values, patients in a digital environment care about their rights, freedoms and their safety [27] [28]. Furthermore, they often believe that altruistic benefits are worth the potential risks [13]. Therefore, it can be said that another value they hold is altruism.

Moreover, other than their values, users have specific needs and expectations which could result in issues with the system if they are not met. For example, an expectation that users of applications have is that the user experience is good. User Experience refers to the feeling users experience when using a product, application, system, or service. There are many aspects that are of significance to the user experience when consenting in an application.

Many users do not have any privacy expectations [15]. Data privacy means responsibly handling data about people, in line with the expectations of those people, regulations and laws [29]. Some users do not think about their privacy until they are actually reminded of it, as was shown in the study done in [15]. However, when they are reminded of it many of them trust the application they are using more [15]. Yet, these reminders do not actually mean anything, as 74% of consumers accept privacy policies without reading them anyway [15]. However, when the user becomes more aware of what is in these privacy policies, they are actually less willing to share information [15]. Therefore, privacy may be a user need. It is also demonstrated by the aspects users think are valuable, like demographics and data security [15]. In addition, it shows that the user changes their behaviour based on their knowledge, pointing at possible issues in competence and comprehension currently in place.

Another issue that needs to be explored is why people do not read privacy policies. This may be because of the fact that users are not using the application to consent to things, but to achieve their goals using the app. They desire to get to that goal as quickly as possible, looking for instant gratification instead of having to go through several steps to get to what they want. This is supported by the fact that individuals have an increased likelihood to focus on the immediate benefits from the disclosure of personal information [15]. This could explain why even when individuals read the privacy policies, they spend very little time on it, with 86% of study participants taking less than a minute to read the privacy policies [15]. They do not spend enough time to actually understand and digest what they read.

2.4 User-centred informed consent

The criteria information disclosure, competence, comprehension, voluntariness and agreement (from 2.1.1) should be met currently, but it is limited. Depending on the source, a good user-experience may be implemented. Other than these things, informed consent in its current state does not meet the values, needs and expectations.

However, there are many values, needs and expectations (from 2.3) that align with the improvements of informed consent (mentioned in 2.1.3). Users will know their rights, because of the criteria information disclosure that ensures this. Additionally, the value autonomy will improve together with the informed consent, as feeling empowerment from feedback helps with autonomy. Furthermore, colour schemes may help too, when colours are used that are not misleading. Users will also be more aware of security, because they have a better understanding of the data that is shared and collected. Also, users who want instant gratification will be satisfied more, as obtaining consent will take shorter and reading it will be simpler.

Another need that also aligns with the improvements is privacy, as users become more aware of what they can expect, because they have a better understanding of the content. This may lead to a decrease in willingness to share from the user's side because they are more aware of information related to the data sharing.

Moreover, the need for a good user experience will be satisfied, as the informed consent procedure would be more accessible, inclusive and comprehensible, due to the change in language, and the use of visuals and audio.

A design improvement that is mentioned is making use of the flexibility and efficiency of use principle [15]. The flexibility could lead to more choices for the user, which will make them feel more in control.

Other than these values, needs and expectations, there is no way yet to know how and if they align with the improvements of informed consent, as it cannot be found in the literature. This exploration can continue with empirical research.

2.5 Dynamic consent

According to Budin-Ljøsne et al, dynamic consent describes platforms that facilitate two objectives, namely facilitating the consent process and facilitating continuous communication between researchers and research participants in which both sides are active [30]. The researcher can communicate with the participant by, for example, giving regular updates about the progress of the research, which can help improve awareness of the subject. Other types of feedback may be used too, to aid the participants in understanding the research. This could be in the form of a quiz or some interactive questions. The communication helps the participants stay motivated and continue with the research [30].

Moreover, dynamic consent is flexible and can look like different types of consent depending on the research participant and the research. The consent forms can be tailored, as all participants want different things. At the same time, they are annoyed by different things to differing degrees too, because of various causes. The participants get a choice in how they handle this, making it more tolerable. A participant can, for example, choose aspects of the research they want to consent to and choose which third parties they share their data with. They can not only make choices about what they consent to, but also how the consent works, like how, when and by what means the participant is reminded of their choices [30]. These choices can be updated at any point. Through this, dynamic consent aims to make the participant active instead of passive [30].

2.6 User-centred dynamic consent

Dynamic consent has a significant effect on the values, needs and expectations of data sharers. Because dynamic consent can facilitate communication between the researcher and the participant, the user improves their awareness. On top of that, they can get feedback, which improves understanding. This is in line with values like altruism, security and trust, while also improving the user experience and the need for privacy. Moreover, because this type of consent can be tailored, users get a choice.

This turns them into active participants. These factors are in line with values like autonomy, justice, rights and instant gratification. The latter is because the user can change how much choice they want, leading to a simpler experience that takes shorter, if that is what they want. Therefore, dynamic consent may be an effective way to improve the design of how consent is in its current state by supporting human values.

Chapter 3 – Initial design

As the Creative Technology Design Process [35] is used as the basis for designing and developing the system, the steps that are taken to make the initial design are *ideation*, *specification*, *realisation* and *evaluation* (in that order) [35].

The first step of the Creative Technology Design Process is *ideation* [35]. Here, ideas for a dynamic e-consent solution that supports user values have been generated through brainstorming. The main goals are to implement dynamic consent concepts as derived from literature and to address potential user values, needs and expectations, also derived from literature. Looking through a lens that focuses on combining user-centred design and dynamic consent, it is important to see where they overlap and how they could be combined and implemented in a well-received manner.

3.1 Ideation

The goal of this ideation process is to investigate ways to create a prototype of dynamic e-consent that supports human values. This prototype is part of a website related to Citizen Science. The values, needs and expectations of possible users have to be taken into consideration when thinking of an idea. Moreover, the foundations of dynamic consent should be part of the design.

Based on Chapter 2, the identified possible values of potential users are trust, control, freedom, autonomy, safety, security, justice, altruism and instant gratification. Their needs and expectations include the user experience, understanding, privacy, inclusiveness and accessibility.

The elements that make up the foundation of dynamic consent are personalisation and communication. For the user values, needs and expectations, the relation to these foundational elements should be identified. Then, ways to combine both into a prototype should be ideated. Ways to implement the foundation of dynamic consent and the values, needs and expectations of users have been mentioned in chapter 2 and will be taken as inspiration for this chapter.

The relations between dynamic consent and user values, needs and expectations

The foundational elements of dynamic consent are communication and personalisation [31]. In this section, the possible relations between these elements and the user values, needs and expectations are explored. This is done as to come up with ideas for possible design elements that can address both of these at the same time.

A value users hold is trust. This relates to communication, as communication is the basis of trust and is necessary to build and maintain trust [32]. Furthermore, communication can make the system more personal, creating a bond that is stronger than simply a system and a user. This may boost trust too.

Another value held by users is that of control. For this, a clear relation can be made to both communication and personalisation. Communicating what is being done with user data at any given point in time can make the users feel like they have more control over the whole data sharing process, because it makes them more actively included in it. Moreover, personalisation gives users a lot more options in regards to how their data is handled, which quite literally gives them more control over it.

Freedom is another user value that relates to the foundations of dynamic consent. It is addressed by personalisation, as having more choice means that there is also more freedom in how users interact with the system.

Users also value autonomy. This relates to both communication and personalisation. Firstly, for a choice to be autonomous, all information should be given to a user to make said choice autonomously. This is done through good communication. Secondly, personalisation allows users to tailor their interactions with the system and how their data is shared and used, which makes them more autonomous in the research process done on the website.

The values of safety and security should be present in a system generally and are mostly the responsibility of the system designers and maintainers. However, communication can still be used to address them. This could be done to create awareness about them in users.

Altruism is similar, as it does not have a direct relation to either of the two foundational elements, but can be expressed through communication. Users could see the positive impact their actions have on others and this would appeal to their sense of altruism.

Aside from values, the users also have needs and expectations that require addressing. User experience is one of them. Here, both communication and personalisation can be effective for creating a good user experience. This is because they make a system more functional, engaging and tailored to what a user would like, need or want from their experience with a system.

Understanding is another need users have. This relates strongly to communication, as information needs to be communicated well in order to be understood.

Another need is privacy, which relates to personalisation. Different users have different desires for their privacy when using a system or sharing data on it. Therefore, giving them more options means that every user can decide for themselves how they want to address privacy within the website.

Every user should also be able to use the website and feel included in it. This relates to another two needs and expectations: inclusiveness and accessibility. They relate to personalisation, as it allows for each individual user to tailor the website to their liking, so that it is accessible to them and they are included.

Ultimately, almost all the user values, needs and expectations relate in some way to the foundational elements of dynamic consent. This means that a design that implements both could be very well-received by users. Such a proposed design is described in the next section.

The design

The consent on the website will have different phases. Initially, after a user makes an account, they will consent to the terms of service of the website. Moreover, questions related to personalisation will be asked here, so that the choices can ensure the tailoring of the website's content. This personalisation is a feature of dynamic consent but will also make the user feel in control and like they have the freedom to choose what they want. Furthermore, it will make the person feel like their choice is beneficial to them and appeal to autonomy. Going through this process will take no longer than a minute and be written in short, simple language, accompanied by visuals, to make the contents more understandable.

In this initial consent process, users will get to choose whether they want to be reminded of their choice and how often. This personalisation element will ensure understanding throughout time and appeal to safety, while also adding an extra layer of autonomy. The sketches of the initial consent process can be found in figure 1.

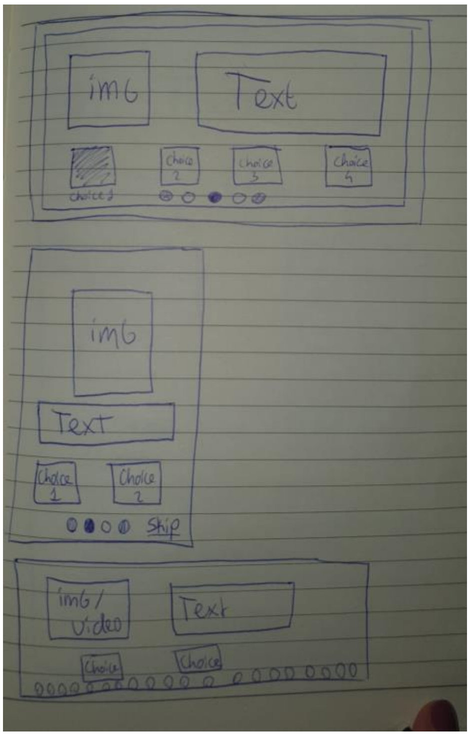


Figure 1: Sketches of initial consent process

To ensure the understanding of the user and create trust, a quiz will be part of the initial consent process. The sketches for the quiz can be found in figure 2. When the answer is right, it will turn green as visual feedback. When the user clicks on the wrong answer, they will get an explanation why it is wrong. This communication is to ensure that the user knows what they understood wrongly and what they have just consented to. Moreover, the box containing the explanation will turn red as visual feedback. The visual feedback could also not take colour blindness into account in the initial version, because there is also text that accompanies the wrong answer. This means that it is safe to assume colour blind users will still understand that they picked the wrong answer even without the colour ques. When someone picks the right answer, there is no feedback in text-format. Because this prototype is quite low fidelity and does not have any animations, colour-blindness was not taken into consideration for the right answer. However, the quiz is still accessible to colour blind users, because even though they cannot see the visual feedback, they know they have answered correctly, because when a user gets the answer right, the next page will be shown.

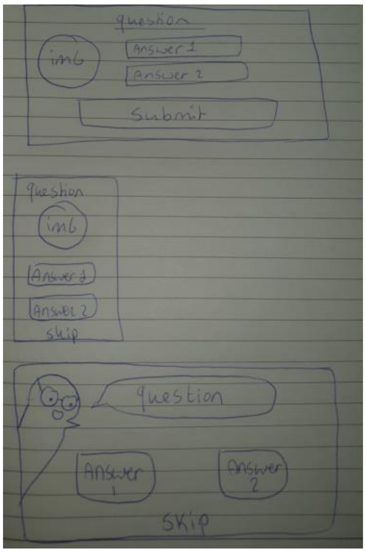


Figure 2: Sketches of quiz in the initial consent process

The next part of the design is one in which a researcher can reach out to a user and ask them to share their data with the researcher. This part will show one research request at a time, as to not overwhelm the user with information. The text will be short and simple with additional visuals, in order to be more understandable. Here, the user will be able to decide whether they want to join a research project. In figure 3, some sketches to visualise this idea can be found.

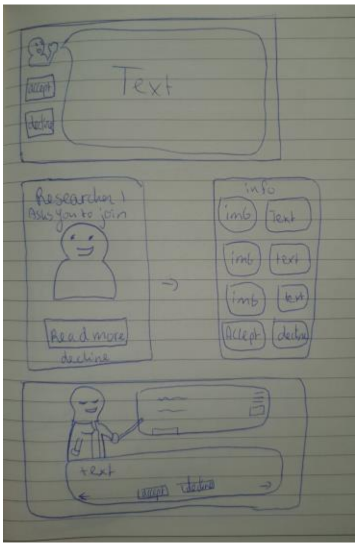


Figure 3: Sketches of the research request process

The final part of the design is one which is not mandatory for a user to interact with. The user can choose to look at it to find more information about the research projects they are participating in. This communication makes the system more transparent, which could give the users more information about the usage of their data. This information, in turn could lead to a greater awareness of their privacy and how their choices about it have been put into practice in research projects. Users can then reflect on these choices and tailor their privacy settings to better match how they would like their data to be used. Moreover, this part of the design will also explain why users joining each research project was useful to others, as to appeal to their altruism. Finally, it will show a user's data usage in a structured manner, for example in a graph. This is to clearly communicate this information to them in a visual form, ensuring they understand it. Figure 4 shows how this page with different tabs could look.

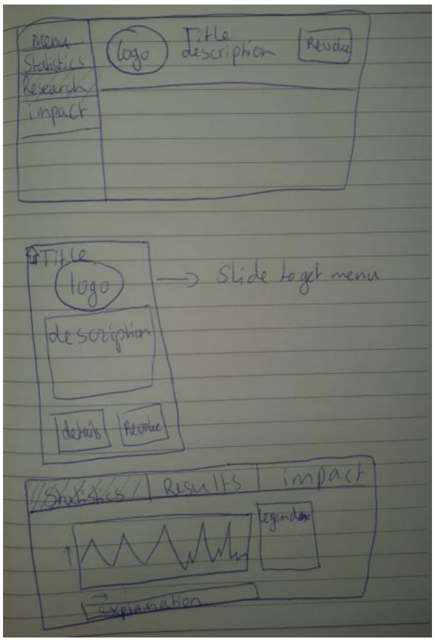


Figure 4: Sketches of the page with information and voluntary choices

3.2 Specification

Based on the ideation, a design specification must be given. In the specification phase, what the system should be is specified. This is in the form of various requirements, namely user requirements, practical requirements and system requirements in this case. These requirements are elicited based on the proposed design idea and various use case scenarios. The scenarios illustrate how a user is intended to interact with a system and what the system is expected to do in different situations. This chapter begins by outlining some use case scenarios and then listing the requirements based on them and the work done in the ideation phase.

3.2.1 Use cases

Three use cases are presented in this section based on the different phases of interaction mentioned in the design from the ideation phase. This is done in order to cover all the possible interactions of the system at this point. The use cases are presented in a sequential order.

Use case 1: Interaction with the initial consent process

Actor: George, who is 81 years old, wants to contribute to science through using this website and just started signing up for it.

1. George fills in his information on the sign up page and clicks on the button to get to the next step.
2. He sees a page with the terms of service, each having a descriptive visual next to it. On the other side of the terms he can see question mark icons.
3. He reads the terms of service, looks over the pictures and hovers over the question marks to find out more information about each individual term.
4. Once he understands all terms of service, he accepts them.
5. On the next page he sees the question “Who would you like to be able to ask you to join research?”. Under it, he sees a few grey boxes with answers like “citizens” and “researchers”. Accompanied with it, there are visuals with a dotted line connecting the boxes to them.
6. This step makes him a bit confused, but after rereading the question he starts thinking more consciously about his preferences in research.
7. Once he makes a choice, he sees a form of feedback, as the box and visualisation accompanying it become colourful and the dotted line becomes solid.
8. He notices that the user experience is quite enjoyable.
9. Then he notices a text on the bottom asking whether he wants to be reminded of his choice with a checkmark button right next to it.
10. He clicks on the button next to this text without hesitation, he feels heard.
11. In the next step he sees a new page that is titled quiz, with a question and two choices for answers. The question asks him what he just did.
12. The answers look similar to him and at first he does not notice the difference.
13. He clicks on the second choice.
14. The box turns red and a text is revealed, explaining why the answer he just picked was wrong.
15. He now understands what the right answer is and feels a little surprised for getting it wrong.
16. He thinks about his previous choices one more time and whether he still agrees to them and then decides to move on, feeling aware and comfortable.

Use case 2: Accepting a research request

Actor: Lea, who is 44 years old, wants to start sharing data and is going through her research requests.

1. Lea logs in to the website today, determined to start contributing to research.
2. Once she has logged in, a page appears that looks like a business card but with more details.
3. She sees a picture of a young man, his name, his occupation, a name of the research he is working on and a description. The young man is asking her to participate in his research.
4. She notices a button that says more information.
5. As the research has caught her interest, she decides to take a look into it.
6. Once she has finished reading about more information related to the research, she returns to the invitation.
7. At the bottom she can see the choices she can make: to accept, to reject, to always accept and to always reject.
8. At first she just wants to accept the invitation because it looks interesting to her and she wants to find out more about the topic herself.
9. However, she then notices that the picture resembles the best friend of her son – wait, it is her son's best friend!
10. She decides to always accept, as she wants to support this boy's career.

Use case 3: Finding out information about researches

Actor: Javier, who is 52 years old, wants to find out more about the research he joined a few months ago.

1. A few months ago, Javier joined a research about sport and food consumption.
2. He decides to check up on the progress of the research.
3. He clicks on a tab called "Research" and sees a page with all the research he is participating in currently. All research panels contain a title, researcher and picture, together with three buttons.
4. One of the buttons he noticed immediately, as the colour is different from the rest of the page, it is a subtle type of red. The button says "Stop gegevens delen nu".
5. He realises that if he does not want to participate anymore, he can click on this button, but he is not here for that reason today.
6. The other two buttons mention options and results.
7. He scrolls through the researches and stops when he notices the one he is looking for.
8. He clicks on the results button and sees that there are already some findings.
9. Excitedly, he goes back to the previous tab.
10. From there, he clicks on another tab called impact.

11. When this page opens he quickly scrolls to the research he is looking into right now.
12. There he sees a text message from the researcher, explaining to him how he contributed to the research and what this meant. He is happy to find out his contribution meant something and lead to a positive change.
13. Finally, he goes to the tab statistics from here, as he is curious how much of his data needed to be used for this result to be achieved.
14. On the statistics tab, he sees a graph displaying how much data he shared with every research he is participating in over a period of time.
15. He now feels fully up to date with the research.

3.2.2 Requirements

The requirements elicited are grouped into three different sections. Firstly, user requirements are mentioned, which in this case mean requirements users would have for the system. Secondly, practical requirements are listed, which in this case are requirements that need to be met in order to test the prototype. Thirdly, system requirements are mentioned, which in this case mean requirements about how the system should behave.

User requirements

Based on the use cases, these user requirements were identified:

- The user should be able to tailor their choices about research
- The user should be able to learn from the system, if the user does not understand something
- The user should be able to look into the research they are participating in
- The user should be able to change their mind about a choice and also change it in the system

Practical requirements

Because the prototype needs to be tested, some practical requirements are set in place to allow that:

- The prototype should be possible to be tested remotely through Zoom.
- The prototype should be interactive to the extent that one can go through it by clicking around.
- The prototype should be on a program that is available to the whole team that works on the Citizen Science Portal.

System requirements

Based on the use cases and proposed design in the ideation, these system requirements were elicited:

- The system should let the user accept or reject the terms of service.
- The system should let the user be able to select several choices in the personalisation section of the initial consent phase.
- The system should allow the user to control how often they are reminded of their consent.

- The system should accept answers to the quiz from the users and respond appropriately to them.
- The system should let the user choose whose research they want to participate in.
- The system should be able to display all researches someone is part of.
- The system should allow navigation between the “research”, “impact” and “statistics” pages.

3.3 Realisation

In the realisation, the developed prototype is outlined. The goal of the realisation is to provide a prototype to be used in empirical research. This usage is to illustrate specific concepts rather than provide fleshed out functionality. Therefore, the focus of the realisation is more on interface than architecture and usability.

Each page of the prototype is essentially a mock-up image created using GIMP. To interact with the images made in GIMP, PowerPoint was used. All images were added to PowerPoint. Then, invisible squares were placed on to top of UI elements in order to simulate their interactivity. The implemented interactions are all of the same type, as they all simply lead to an appropriate pre-chosen slide. This simulates navigation.

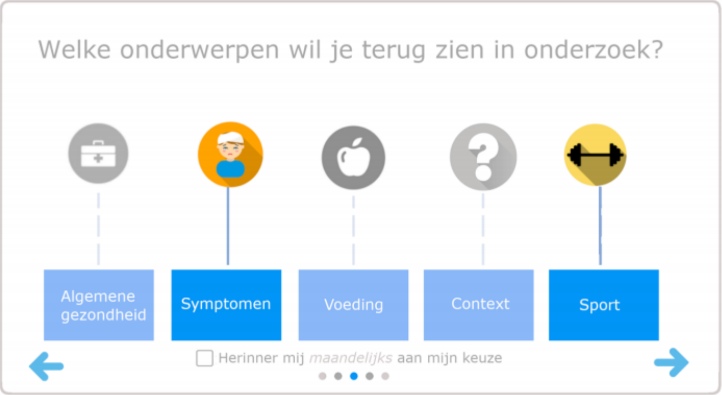
Interface

The sketches in the ideation phase were translated into polished user interface designs in GIMP. To get there, several steps needed to be taken. First, the sketches needed to be polished up into the final sketches. Then all the elements in the sketches had to be decomposed and understood individually. After identifying them they could be drawn layer by layer. A main colour was picked inspired by other popular media websites. Then, fitting secondary colours were found that fit the main colour well. For some of the pages, minimalistic art was made to create icons. At the end, all elements were put together to illustrate how the pages look with everything in them. Furthermore, because all elements were drawn on different layers, their properties like colour could be changed easily, to act as visual feedback for interactions.

Functionality

Because the prototype was used to illustrate a proof of concept instead of used as an end product, it did not need to have every requirement implemented.

In figure 5, it can be seen that the user can tailor their choices in the personalisation pages, which fulfils that user requirement. Additionally, the user can learn from the system, as making a mistake in the quiz does not punish the user but rather communicates why the option is wrong, teaching the user something valuable about the use of personalisation. This can be seen in Appendix 1, alongside the entire initial prototype of the concept.



Welke onderwerpen wil je terug zien in onderzoek?

☐ Herinner mij *maandelijks* aan mijn keuze

Figure 5: Choices in the personalisation page

Despite fulfilling some user requirements, the prototype does not fulfil all of them. For example, the user interface includes an indication of being able to look into research and being able to make choices about it and change said choices. However, this is not actually complete as learning about what participants thought of the idea of being able to do such things was more important than having a fully functioning prototype, that would not be fully used during testing anyway.

The practical requirements were all met and some of the system requirements were also met. The system is able to let the users accept or reject terms of service and select choices for personalisation. The system also accepts answers to the quiz from the users and responds appropriately to them. It also allows navigation between the "research", "impact" and "statistics" pages. However, some elements and features from the system requirements were not implemented in the system, for reasons similar to the examples from the previous paragraph. Users will not get reminders about their consent after clicking that they want to be reminded. They can also not scroll on the "research" page through all the research they are participating in. Only two examples of research are shown.

3.4 Evaluation

The goal of this evaluation is to find out which values, needs and expectations users have. Additionally, another goal is to find out what participants think of dynamic consent, by talking about it and by presenting them with a practical implementation of it in the form of the initial prototype.

The way these goals are achieved are by answering the following questions:

1. Which values do users consider when consenting (to the usage of the Citizen Science Portal)?
2. Does dynamic consent work?

3. Does the prototype of dynamic consent satisfy the user's values, needs and expectations?

This information will help to find out whether the literature examined in the background research is in line with how potential future users of the Citizen Science Portal think. Additionally, what is found in the evaluation can be used as the base for making an iterated version of the prototype. Finally, this information can help getting closer to answering the research question of this thesis, because more will be known about what the user values, needs and expectations are, how well received the implementation of dynamic consent is, and what participants like or would rather want to see.

3.4.1 Method of the focus group

For the evaluation of the literature and the prototype, a focus group method was used. This evaluation was conducted in several sessions, with each session being divided into three parts. The first part's goal was to identify user values, needs and expectations. The second part was to learn about the opinions of users on dynamic consent. The final part was to find out what the users thought of the prototype and whether that added anything to the conversations about the first two topics. The focus group guide of this session can be found in Appendix 2 together with the questions that were asked.

3.4.2 Method of the analysis

The method of analysis that was used is called reflexive thematic analysis [33], which is a method to analyse qualitative data through six phases. The six phases used and how they went for this analysis will be described individually.

Phase 1: Familiarizing yourself with data

This first step started with transcribing the focus group sessions. Then, some time was spent on getting familiar with the data and highlighting seemingly important points while reading through the transcriptions.

Phase 2: Generating initial codes

After Phase 1, initial ideas and thoughts were generated that seemed interesting. Taking a semantic approach, codes were identified that defined the meaning of different parts of the data. Coding was done of the entire data set on atlas.ti

Phase 3: Searching for themes

The codes were sorted into potential themes (see Appendix 3).

Phase 4: Reviewing themes

Some pieces of data could be taken out of a theme, as it did not particularly fit into it. Some themes had to be reworked, some themes had to be merged and some themes were not necessarily themes in and of themselves, so they had to be dealt with appropriately.

Phase 5: Defining and naming themes

Rereading the data is necessary in phase 5 to see if the themes actually fit with the data. Any additional data that could be coded or could be changed was handled appropriately. The themes now fit together and can tell a story.

Phase 6: Producing the report

The results of this phase is what can be found in 3.4.3.

3.4.3 Reflexive Thematic Analysis

Using the reflexive thematic analysis the following themes were developed (a thematic map of them can be seen in figure 6):

The meaning of patient input

Every participant has a desire to share their input and perspective, while also wanting to see and encourage other patient's inputs. This is because patient input contributes to improving the collective well-being of patients.

Privacy is multifaceted

Integrity, confidentiality and availability make up security. Depending on the context, participants may value some of them more than the others. Regardless, there are shortcomings in current systems relating to all three of these topics.

Personified trust

Personification creates trust and lessens distrust. This can be done by giving a system human attributes and behaviours.

Good communication leads to good understanding

Information disclosure is at the core of good understanding. Information disclosure is communicating information to a user, so when information disclosure is good, communication is good. Therefore, good communication can lead to good understanding.

Dynamic choice leads to control

When choices are made more dynamic, the user is given more options about what and how their data is being used, leading to them having more control over that.

The meaning of communication

Participants have a general need for communication/feedback. This communication/feedback needs to be consistent. This is especially important in communication between authorities and patients.

The good, the bad, and the missing of the initial prototype

The core design of dynamic consent is well-received. However, the prototype still has a few shortcomings. Recommendations have been made for the next iteration.

Figure 6: Thematic analysis map

These themes come back when answering the questions for this evaluation. The questions are:

1. Which values do users consider when consenting (to the usage of the Citizen Science Portal)?
2. Does dynamic consent work?
3. Does the prototype of dynamic consent satisfy the user's values, needs and expectations?

The first question is answered using the content of the themes *the meaning of patient input, privacy is multifaceted, personified trust* and *good communication leads to good understanding*. The second question is answered using the content of the themes *dynamic choice leads to control* and *the meaning* *of communication.* The last question is answered using the content of the theme *positives and negatives of the lo-fi prototype.*

1. Which values do users consider when consenting (to the usage of the Citizen Science Portal)?

The meaning of patient input

Participants have a desire to be an active participant in health-related research. A vast majority of them had reasons for joining this focus group that were altruistic in nature. For example, a participant pointed out this reason for joining the research: *"Ik vind het ook gewoon nodig om research te doen naar de contacten tussen wetenschappers en patiënten en dan ook patiënten met verschillende achtergronden zodat je daar ook een website aan kunt aanpassen omdat de een het heel anders zal benaderen en een heel andere betekenis aan een zin zal geven dan een ander dat doet" (Translation: I also just believe it is necessary to do research about the contact between researchers and patients and then patients from different backgrounds so that you can adapt a website based on that too because you can approach it differently and give a different meaning to a sentence than someone else does).* The participant mentions specifically that it is important to have peope with different backgrounds participate so a website can be made based on all the different views. This shows a form of altruism as the participant wants to ensure everyone has a positive experience using the website. This altruism stems from a general care for all patients and their input. The participants care about this input a lot, but also for patients generally, which is shown through their repeated mentioning of wanting inclusivity for everyone. One of the participants is also a member of a patient activist group.

Furthermore, the participants do not only think that patient input is valuable in research, but they also use this input to shape their own views. This can be seen from how the participants interact with each other, as they all listened intently to each other's experiences and opinions and changed their views based on this.

Moreover, patient input can make the participants feel supported while dealing with their condition. They want to give this to others too: *"Ik zou wel iets over bijvoorbeeld een interessant onderwerp over reuma delen. Dat deel ik wel, daar heb ik ook heel veel aan gehad van anderen" (Translation: I would share something about for example an interesting topic about rheumatism. I do share that, others sharing that has been very useful to me too.)*

Privacy is multifaceted

Privacy is a value that participants consider to be important. It has many different sides to it that could be explored.

Looking at the experiences of the participants, there is no standard of quality across healthcare systems, so the systems are prone to exploitation. This leads people to feel like their safety is threatened and that there is no way around that as there is no foolproof way to share data. Despite this, they still take part in these systems because they see it as a necessary evil. For example, one participant mentioned that they have decided to allow their health data to be shared with other hospitals in the country, because this person thinks that when any health-related emergency happens to them, they should be able to get treated and whichever hospital they go to should have enough information about them to help them in a bad situation.

There may not be a foolproof way to share data, but using the CIA-triad, methods to share data could be improved. Generally, the concept of security in a digital environment is based on this triad, which is made up of 3 elements: Confidentiality, integrity, and availability [34]. Confidentiality means that only authorized parties can access secure information. Integrity put in simple words means that only authorized parties can change secure information. Availability means that authorized parties can access the secure information they are authorized to access [34].

Participants believe data confidentiality is important. One of them even mentioned it to be the most important thing related to consent: *"Het belangrijkste is dat de gegevens die je opslaat, dat die niet ergens anders naartoe kunnen, dus dat die ook veilig opgeborgen blijven en de gegevens die je niet meer nodig hebt, dat die ook verwijdert worden." (Translation: The most important thing is that the data you store cannot go anywhere else, so that it is also stored safely and the data that you no longer need, that it is also deleted.)* Others described several experiences of theirs which show that they do believe confidentiality is important and it has also been mentioned that logins and passwords should be considered on the website, for both researchers and patients. This shows that confidentiality is certainly important to keep in mind when designing the website. Unfortunately, many users have seen or experienced cases in which this was not done. Sometimes this lack is because of negligence, not malice.

Moreover, integrity is so important to one of the participants that they decided to manage their own health data independently to ensure that they are the only one authorized to make changes to it. This made them feel like their way of sharing data is more secure. "*Maar ik dacht van ik houd het in eigen beheer en dan weet ik wat er mee gebeurd en hoe veilig het is." (Translation: But I thought I'll keep it under my own management and then I'll know what happens to it and how safe it is.)*

Availability is important because it can lead to better health, because physicians who need health information to treat patients should be able to have that information when needed.

For the participants, some aspects were more important than others. This was all up to their own experiences and interpretations. Furthermore, while most of the healthcare systems include all three of the elements, the problem lies in the fact that not all "authorized" parties should be authorized. This is because the authorization process is not strict or thorough enough. The participants point out different ways to make the authorization process better. For example, they suggest having an *"inlogcode"*

(Translation: Log-in code), that not everyone can have, as it should first be authorized by the people behind the website.

Not only should there be authorization, participants would also like to share their data anonymously as much as possible, because they feel most comfortable this way. This means that they want their data to be nontraceable, not unique to them and part of a bigger set of data. They are even more comfortable with it if they are sharing general data. Additionally, participants want to share their data when it has a meaningful purpose such as scientific research. In this, they only want to share the data that is necessary for the purpose.

Another aspect participants believe is important is that data is handled properly. This means ensuring that it is actually kept anonymous. It also means not exploiting the data by sharing or selling it, but also deleting data at an appropriate time and keeping the person who shared their information up to date about this. Then, only the data that is legally required to be stored is stored.

Ultimately, when privacy is not ensured, it sometimes has impactful consequences. For example, participants may not feel comfortable anymore with being truthful, so they might start lying about their data. They may also avoid any type of event where a data breach has happened or anything that makes it seem like privacy was not ensured. They could even become very passive participants in research. On the other hand, they could respond in a more active manner, such as one participant who took matters into their own hands and worked through the problems themselves.

Personified trust

The reason there is so much concern about privacy is because it is left in the hands of a system. Systems are not humanlike, so they lack the context that makes someone trust a person. This is also why companies tend to be trusted less by participants. For example, the larger the company is, the less it is trusted: *"Ik vind wel dat de grootte van een organisatie ook over het algemeen van belang is want ikzelf vertrouw Facebook niet." (Translation: I do think that the size of an organization is also important in general because I don't trust Facebook myself.)* This may be because larger companies are more dehumanized. Moreover, when the participants think more about companies doing research in the prototype, they start with a unified concept of a malicious company to a group of individuals, who then, according to the participants, "are not all malicious" or "bad". So they start with negative connotations and biases related to companies, but once they personify the company, they start trusting it more. Here is an example of someone mentioning this personification: *"Er staat bedrijven, maar als ik dat lees ben ik gelijk op mijn hoede want dan denk ik bij bedrijven weer daar werken ook artsen en burgers en onderzoekers en studenten." (Translation: It says companies, but when I read that I am immediately on my guard because then I think with companies again doctors and citizens and researchers and students also work there.)* This personification happens through getting more context.

Yet, it is very important for the participants to trust the system, because they value this a lot. Moreover, in all situations, some level of trust is necessary. This is because no one can have full awareness of everything. But if there are people who are dedicated to ensuring a system is trustworthy, this might make people feel like their situation is taken seriously. Therefore, it is likely that moderators are useful for this.

When the participants lack trust or start distrusting the system, the consequences can vary from becoming a passive participant to refusing to share certain information at all, due to high levels of distrust. These consequences happen because the participants believe good people are at risk, so they are trying to protect themselves from that.

Sometimes distrust is due to a practical reason like not being able to ensure that people online are always the same people in real life. This could lead to users trusting a researcher, but someone else getting access to their data. This type of issue is not necessarily avoidable via system design. In some cases, users have to put their distrust aside for the sake of their health.

In order to build trust, transparency, openness, and clarity need to be present. These can be built via several means. Majority of these means are related to giving more human attributes to a system.

Good communication leads to good understanding

Understanding is a need that users have. They often mention this as something that is lacking. When understanding is not present, this is due to a lack of awareness or lack of information disclosure. The latter can sometimes be caused by system unintuitiveness. Another cause could be because a system is not designed with understanding in mind, such as in traditional consent situations like agreeing to a website’s terms of service. These are often too long, like the one of Google. A user had tried reading this but mentioned that they stopped soon as there was way too much text and it would take too long. Other participants mention they would never read this in the first place.

By contrast, the consent in the prototype was designed with understanding in mind. This meant balancing texts and visuals. It meant having reminders and it meant having a good interface. As a result, the participants thought it was very clear and understandable for everyone. Other ways, according to the participants, to improve understanding and information disclosure, were by explaining what happens with the information a person shares and explaining the goal of what the researcher is doing and who they are.

In general, this and other good information disclosure results in understanding, which is made up of competence and comprehension, based on the literature review. To have good information disclosure, good communication about what is going to happen at any point is needed, the information should be shared in a transparent manner, not withholding anything and the information should always be up to date.

Another way to boost understanding is by making the system more engaging. This leads to participants being more attentive and curious. These things result in participants paying more attention and wanting to find out more about the things they are consenting to in this case. Ways to make things more engaging is by making a good first impression, using statistics and using quizzes. If someone is not engaged in the process they seek convenience, which could result in data risks because they become more careless and do not read the texts attentively anymore, leading to a lack of understanding and information disclosure.

2. Does dynamic consent work?

Dynamic choice leads to control

The dynamic nature of the choices makes participants less afraid to make the wrong choice, as it is not detrimental. To alleviate this fear, choices need to be withdrawable, flexible, reversable and something a participant is reminded of occasionally. These types of dynamic options also make participants feel more in control over their own data. This control is important because it creates trust in the system. When there is no feeling of control, participants indicated they are less willing to share data. This is detrimental, as the website's core goal is for users to feel safe in sharing data and collaborating in research. Moreover, when there is a lack of control participants seek it even more. Despite all this, sometimes participants are willing to compromise their control for the sake of their safety.

The meaning of communication

Being reminded of one's choices is an important factor to feel in control. However, it is not the only type of communication that is important. Participants have a general need for communication/feedback. This needs to be consistent and done in a simple and short manner. In this case, consistent can mean two things and both are crucial for good communication. One of the meanings of consistent is receiving communication/feedback at a set interval, while the other meaning of consistent is that all types of communication align and do not contradict each other. If the latter is not the case, a mismatch in words and actions or misleading explanations could occur. Here, it would be the case because the written communication does not align with what is being communicated through actions, or the written communication does not align with other written communication. This could lead to participants feeling like they cannot trust the system, because there are too many contradictions, which may lead to them no longer participating or protecting themselves through not being truthful.

Moreover, it is particularly important to have good authority-patient communication. Participants have mentioned repeatedly that they would like to share their opinions more often with researchers and physicians, because they believe they have something valuable to add. An example of this is that a participant said: *"Ik blijf het enorm belangrijk vinden om als patiënt je steentje bij te dragen want ik* *denk dat goede research niet zonder patiënten kan." (Translation: I continue to find it extremely important to contribute as a patient because I think good research cannot be done without patients.)* They also believe that the research that is done is to improve the patients' lives, so it makes sense to consider how the patients think research could be improved: "*Ik vind het ook belangrijk dat patiënten daarbij ideeën in kunnen hebben en meningen in kunnen hebben, want uiteindelijk zijn de patiënten ook afhankelijk van wetenschappelijk onderzoek om nieuwe behandelingen te kunnen krijgen, om een betere manier van leven te kunnen krijgen en dat soort zaken." (Translation: I also think it's important that patients can have ideas and opinions on that, because ultimately patients also depend on scientific research to get new treatments, to have a better way of life and things like that.)*

They would like to be able to play a bigger role in their health and this is a great way for them to do that. Additionally, users do not feel okay with not knowing what is written or said about them. They would like to be part of the discussion and no longer just listen, but participate.

3. Does the prototype of dynamic consent satisfy the user's values, needs and expectations?

The good, the bad, and the missing of the initial prototype

The prototype was made based on dynamic consent and the values, needs and expectations mentioned in the background research. These were expected to be the values, needs and expectations the participants share. As the prototype was well-received by the participants, it is a safe assumption that the values, needs and expectations listed in literature match those of the participants. However, it was found out that the participants do have specific values, needs and expectations they care about the most. These are altruism, privacy, trust, control and understanding. The participants have mentioned some of these values while talking about the prototype and have not mentioned others.

For example, the impact page was supposed to appeal to altruism by making the user know what the impact of them partaking in research is. This page would show insights which will be useful to patients and would have meaning to people other than themselves. However, this page did not have the intended effect, presumably because the example texts were not very good. The participants mistook it for short conclusions or summaries. This still had some positive responses related to inclusiveness like: *"Heel veel mensen zullen een wetenschappelijk onderzoek niet begrijpen en al helemaal niet in het Engels dus ik vind het heel belangrijk dat het zoals nu is toegankelijk is voor iedereen en ook voor iedereen te begrijpen is" (Translation: A lot of people will not understand a scientific research, especially not in English, so I think it is very important that it is as it is now, accessible to everyone and it can also be understood by everyone).* In the iterated prototype, it may be useful to make the altruism more explicit.

Furthermore, participants liked the remind me button at the personalisation pages, as those gave them a feeling of safety and security. A participant even mentioned they would always leave it turned on.

"Ik zou hem altijd aan hebben laten." (Translation: I would always have left it on.) Still, some things related to privacy could be added or improved. A participant mentioned: *"Dus aan de ene kant zorgen dat die inlog goed geregeld is, aan de andere kant duidelijk aangeven wat we doen en wie wat toegang toe heeft." (Translation: So on the one hand, make sure that the login is properly arranged, on the other hand, clearly indicate what we do and who has access to what.)* The participant here is referring to having a login procedure where the users and researchers have to be approved before they can use the website, as this ensures privacy and would keep the users out of harms way. Additionally, they mention that it should be stated clearly who gets access to what and who does what. This also appeals to the value of privacy, as it makes the users of the website more aware of who can see and do what, meaning they can choose what they want to do with their data. While there may not be enough features appealing to privacy in the initial prototype, great suggestions have been made which could be implemented into the iterated prototype.

The value trust is not mentioned when talking about specific features, which would make one think that it may not have been implemented sufficiently, but the participants have clearly stated that this prototype does create trust. Additionally, this trust is not created by just a few specific features, but rather the prototype as a whole. However, a participant mentioned a feature that may still be nice to add, as it has, in their experience, often improved trust: *"Wat veel vertrouwen geeft in mijn ervaring is dat als een student of een maakt niet uit wie, een arts in opleiding, met een onderzoeksvoorstel komt, medewerking vraagt, dat je een korte introductie krijgt". (Translation: What gives a lot of trust in my experience is that if a student or a, no matter who, a doctor in training, comes up with a research proposal, asks for your cooperation, that you get a short introduction.)* This suggestion is meant for the research request page. The participant believes that more trust will be created if a researcher introduces themselves and their research. This feature is a feasible option to add and should be considered for the iterated prototype, especially since it contributes to better information disclosure as well.

Control is another one of the values that has been addressed very succesfully in the initial prototype. Participants like that they get choices to personalise the website. They like the active participation that takes place on these pages, therefore, they do not mind spending more time on them. They are also willing to spend more time on it because the reminders help them to have more control. When asked about whether the participants would be willing to answer more questions to personalise their experience on the website, a participant said yes and added to that: *"Bovendien word je er nogmaals aan herinnert dat je dat allemaal zelf in de hand hebt." (Translation: In addition, you are reminded again that it is all in your own hands.)* This shows that the user feels in control because of the reminders as well. One thing that would add control with the remind me button on the personalisation page is adding a pop-up for when the participant turns off the button. The participants think this is important because they do not want to accidentally turn the button off: *"Stel dat ik hem nu uit zou* *zetten omdat iedereen dat nu wel mag weten dat je wel nog een melding geeft van herinner mijn keuze uitgevinkt wil hebben. Dat zou ik wel heel prettig vinden, want je kunt ook per ongeluk een keer klikken en dat ie uit is. " (Translation: Suppose I would turn it off because everyone can now know, that you still give a message of remember my choice, you want to have it unchecked. I would really like that, because you can also accidentally click and then it's off.)* They want to do everything intentionally, which shows that they do value control.

Finally, understanding has been addressed very well too, satisfying the participants need for it. One way understanding was addressed was by ensuring that the texts in the prototype are short and simple. In addition, visual elements were also added to stimulate understanding. The result of this shows through the participants' responses, as the first things they mentioned about these pages were: *"Ja het ziet er goed uit wat mij betreft" (Translation: Yes it looks good if you ask me), "En duidelijk"(Translation: and clear), "Ja heel duidelijk, ik denk heel begrijpbaar"(Translation: Yes very clear, I think very understandable)* and *"Begrijpbaar voor iedereen en duidelijk. Je hoeft er niet over na te denken van wat bedoelen ze nou eigenlijk."(Translation: Understandable for everyone and clear. You do not have to think about what they actually mean.)* Working in this way seems to be very succesful for this dynamic design and this short, simple and visual communication will be implemented in the next iteration as well . Furthermore, the quiz was also received very positively, as it kept users attentive and involved: "*Ik vind het heel goed, heel goed. Ik vind het echt een vernieuwende, voor mij een nog onbekende manier om mensen attent te houden betrokken te houden, ja compliment voor dit ja." (Translation: I think it's very good, very good. I think it's a really innovative, for me an unknown way to keep people attentive and involved, yes compliment for this yes.)* This quiz helps with understanding as well.

Conclusion

Based on this thematic analysis on the focus group's evaluation, altruism, privacy, trust, control and understanding have been found to be needs, values and expectations. Dynamic consent has been received positively and favourably compared to more traditional consent. The combination of dynamic consent and user values, needs and expectations was well-received. Moreover, the prototype mostly aligned with the participant's values, needs and expectations. However, there is room for improvement for the next iteration.

Chapter 4 – Iterated design

As the Creative Technology Design Process [35] is used as the basis for designing and developing the system, there is a lot of repetition in the steps that are taken. This is because the process is circular, meaning that iteration takes place [35]. Therefore, the steps that were taken to make the initial design, are also taken for the iterated design. These steps are *ideation*, *specification*, *realisation* and *evaluation* (in that order) [35].

The first step of the Creative Technology Design Process is *ideation* [35]. Here, problems and advice related to the initial prototype are addressed by brainstorming about possible solutions. Additionally, new ideas are generated to make the iterated prototype appeal to user values, needs and expectations more.

4.1 Ideation

The results of the evaluation of the initial design were used as the basis of the changes in the next iteration of the design. Because the initial prototype was generally very liked, there were not many points of critique to use as a basis to improve the prototype. Therefore, instead, a more useful focus seemed to be one on making the prototype even better. The user values, needs and expectations and what type of experiences the participants had before have been analysed and are useful for this approach. The amplification of these values, needs and expectations and some other changes were the main goal when making the iterated prototype. The user values, needs and expectations that are considered in the ideation, based on the results of the previous evaluation, are altruism, privacy, trust, control and understanding.

Privacy

One of the values the participants believe is important is privacy. It is of significance when sharing data on the website, but also in relation to consent. Many participants have mentioned that they would like to remain anonymous when possible. This could be implemented in parts where communication occurs between researchers and (potential) research participants.

Moreover, the participants mentioned that they would feel more secure in the privacy of their data if they are reminded more of its usage in research. They believe it is in their best interest if the system makes them more inclined to be reminded. This could be implemented in the pages related to personalisation.

Control

Participants mention that being in control when using the website is important. This could be implemented via different means. One of the ways to do this is by ensuring that the actions users take are intentional. This could be done using pop-ups in different parts of the website, which reaffirm a user's choice, giving some additional information. This is especially crucial to implement at places where important choices are made, like the personalisation page, the research page and when responding to research requests.

Additionally, ensuring that users can make decisions at a later point in time makes these choices less urgent, taking pressure off users. This could make the users feel more in control, as they can take their time to make a choice. This could be done by allowing users to postpone responding to research requests. Moreover, reversibility of choices could lead to users feeling more in control of the usage of their data. This could be implemented in the pages related to personalisation.

Furthermore, users may feel more in control if they can oppose inappropriate behaviour themselves. This should be possible before joining a research, by being able to notify authority figures on the website about inappropriate behaviour. This way users can take matters into their own hands and feel more in control.

Understanding

Another value users hold is understanding. By improving information disclosure, comprehension and competence this value can be satisfied better. This could be done by improving communication, by using clear, simple language and layouts and by sharing more information. A very simple and direct way of communicating is through direct messages, which may be beneficial to implement. Furthermore, researchers that want users to join their research should share more information about it and themselves. Additional information should also be present at places where biases or misunderstandings could occur. Small changes may also be necessary to be able to understand things quickly, as users prefer short, simple language. Finally, to improve understanding and be more transparent, an overview of all pages related to specific researches could be created.

Trust

Trust is often created through association and authority. The source of this type of trust often comes from moderators. Therefore, moderators could be added to the website. To create a better connection and more trust between moderators and users, the moderators could be introduced and messaged.

Altruism

Altruism is not a main focus of any of the changes that were ideated. However, it is still related to some changes. For example, being able to report inappropriate behaviour is not only important to individuals because if they know a research request is inappropriate they can decline to join it. However, when they actively choose to report a request, it shows their willingness to help the community and ensure everyone's safety. Such a feature would therefore appeal to their altruism.

4.2 Specification

Based on the evaluation and the ideation, the requirements needed to be updated. For the user requirements, it was mostly to match the user values, needs and expectations better. For the practical requirements, the focus was more to suit the empirical research that would follow. The system requirements changed mainly based on the features mentioned in the ideation.

User requirements

In addition to the previous requirements, these have been added based on what were found to be the most important values.

- The user should be able to communicate with the researchers and moderators directly
- The user should feel in control of the usage of their data
- The user should understand what is happening in the system at any time
- The user should understand the information that is shared with them
- The user should be able to trust the system
- The user should be able to contribute positively to other people's lives through the system

Practical requirements

For the practical requirements, some have been taken out, some have been changed and some have been added. Below is the final list.

- The prototype should be possible to be tested remotely through Zoom.
- The prototype should be possible to use by the participants.
- The prototype should be interactive to the extent that one can go through it by clicking around.
- The prototype should be created on proto.io
- The prototype should be integrated into the overall prototype of the Citizen Science Portal

System requirements

The system requirements have been expanded to reflect the changes in system behaviour necessary to improve the iterated prototype:

- The system should let the user accept or reject the terms of service.
    - If the user rejects the terms of service, a pop-up should be displayed with another explanation of what the page's purpose is.
    - The user should be able to respond that they understand it or that they do not understand it.
- The system should let the user be able to select several choices in the personalisation section of the initial consent phase.

- The system should allow the user to control how often they are reminded of their consent.
  - The system's default should be that the reminders are turned on.
  - If the users choose to not be reminded, there should be a pop-up that asks them whether they are sure.
  - If the users mention that they are sure, another pop-up should show up which explains how the user can turn the reminders back on, in case they change their mind at any point.
- The system should let the user choose whose research they want to participate in.
- The system should let the user choose which research topics they are interested in.
- The system should accept answers to the quiz from the users and respond appropriately to them.
  - The user should be able to decide that they do not want any more quizzes once they have finished the first quiz.
- The system should allow the user to make changes to the choices that they made in the personalisation related pages
  - This should be possible generally, for all research.
  - It should also be possible to make changes related to a specific research.
- The system should be able to display all researches someone is part of.
  - Per research, the system should show an overview and allow navigation of the topics related to it, namely options, data, visualisations, results and impact.
  - The system should allow the users the ability to revoke consent.
    - When a user clicks chooses to revoke their consent, a pop-up should be shown that asks for reaffirmation.
  - The system should allow an opportunity to directly message the researchers users are collaborating with.
- The system should show a timeline of which researches users have participated in and how much of their data has been used/collected for them.
- The system should display research requests to participants
  - Users should be able to decline, accept, always decline or always accept the researcher's requests. They should also get a choice to be able to postpone their choice if they prefer that.
    - If a user decides to always accept researches from a specific researcher, they should get a choice to participate in researches the researcher worked on in collaboration with others or only their individual researches.
  - Users should have an opportunity to ask questions directly to the researchers about their request and their research before deciding to participate.

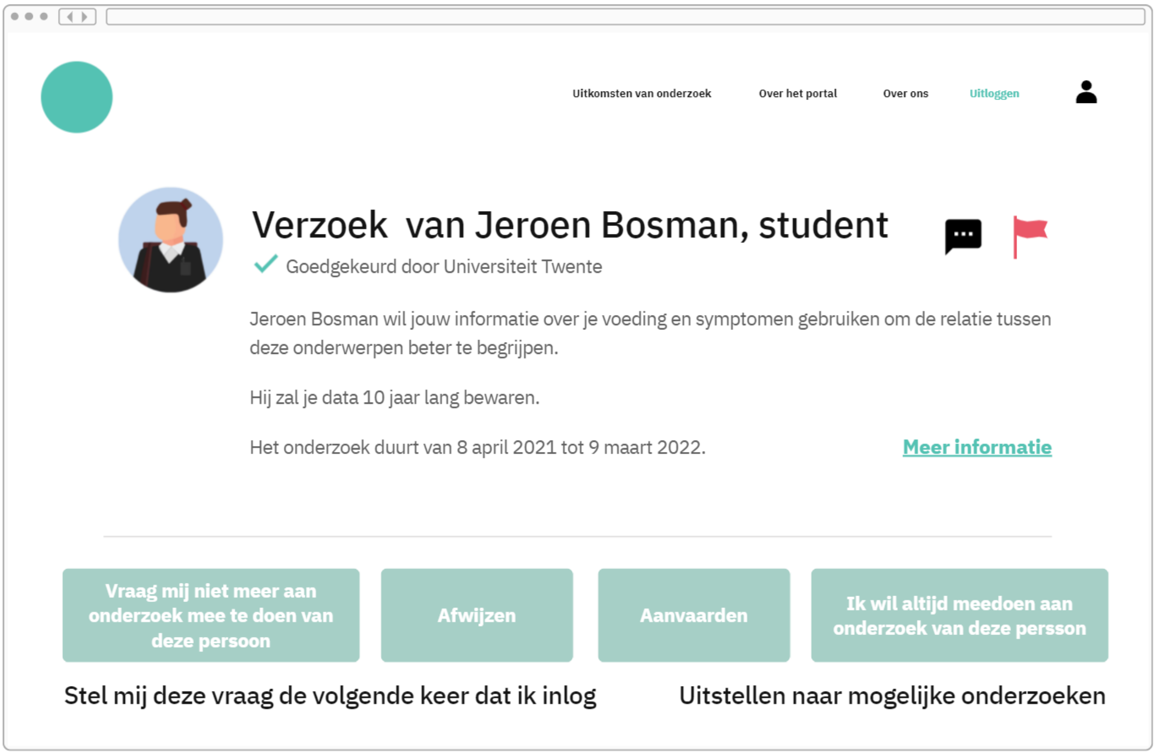
- The users should be able to learn more about the researchers, the goal of their current research and what type of research they have done before.
- There should be a report button for users to report research requests that are inappropriate.

4.3 Realisation

Based on the new requirements listed in the *specification* for the iterated prototype, a new realisation is necessary. This realisation differs from the initial realisation in several ways.

The first change to the iterated prototype is that it was developed with another system, namely proto.io. The main reason for this was because the prototype was going to be integrated into the general prototype of the Citizen Science Portal, which was a collaboration of several researchers. This collaboration and opportunity to work at the same time on the same project would not have been possible if the system that was used was still PowerPoint. Moreover, proto.io allows for simple and quick setup of user interactions and interface, as the program has a drag and drop type of visual programming. These user interactions are not only quicker to setup, but also far more advanced than what could be seen in the initial prototype.

The interface of the prototype visually matches the work that was already done on other parts of the overall Citizen Science Portal prototype. This means the colours, shapes and placements of elements are all based on what was already there. An example that can be seen of how the interface of the iterated prototype looks is figure 7.



Verzoek van Jeroen Bosman, student

✓ Goedgekeurd door Universiteit Twente

Jeroen Bosman wil jouw informatie over je voeding en symptomen gebruiken om de relatie tussen deze onderwerpen beter te begrijpen.

Hij zal je data 10 jaar lang bewaren.

Het onderzoek duurt van 8 april 2021 tot 9 maart 2022.

Figure 7: The Research request page

For the sake of simplicity, the features of this prototype will be examined in a structural manner. This means that the pages will be looked at together with their elements in a sequential order as the user would experience them when working with the system (with only the pages relating to dynamic consent being discussed).

First of all, once the user has made an account, they go through a page (terms of service), which asks them whether they are okay with the potential of their personal information being shared. The information that might be shared is also specified, including for what. There are visuals to support this information. With a quick look, a user should be able to get through it without any difficulties, as the focus here was on keeping communication short, simple and understandable.

The next two pages are related to personalisation and only show up once after the user makes an account. On these personalisation pages, a user can make choices to specify which topics they are interested in and what type of researchers they would allow to approach them. Having just the word "Companies" as a choice for researchers often created a negative bias for users. Therefore, additional information was added about such companies, so that their reason for doing research is clear. Moreover, users can also choose to be reminded of the choices they made about their personalisation of the website at a later point in time. The default for these reminders is that they are turned on, but they can be turned off. If they are turned off, a pop-up is displayed asking whether the user really does not want to be reminded. If the user confirms they do not want it, another pop-up is displayed which contains information about how to turn the reminders back on, in case the user changes their mind.

When the personalisation questions have been asked, the user gets to the dashboard of the website. Here, the user can find several topics related to consent, namely "Toestemming" (Consent), "Mijn onderzoeken" (My researches), "Mogelijke onderzoeken" (Possible researches) and "Beheerders" (Moderators). They will be examined in this order.

"Toestemming" means *consent* in English. Here, the user can find a general consent page and a page that leads to consent per research. The general one mentions questions specifically asked on the personalisation pages, as those are not permanent and can still be changed. It does this in a short way, again using visuals and having a possibility to see more questions and answers. This is all done to not overwhelm users and have a quick and short overview. Furthermore, the consent per research page is about similar topics and has a similar interface, but the changes made on it only affect the research that the user wants to make changes about.

The next page that is going to be discussed is called "Mijn onderzoeken", which means *my researches* in English. This is a modified version of the research, impact and statistics pages, with impact being added to research to make the page more like an overview (figure 8). This is because such an overview could improve the understanding of a user and look less cluttered, as everything can be found clearly in one place. What's more, on this page some other topics can be found, specific to each research.

These are mainly options, data, visualisations and results. On top of that, there is the possibility to revoke consent on a research by research basis via the use of a button. When the user chooses to do this, a pop-up shows up to reaffirm their choice, in case it happened accidentally or the user changes their mind at the last moment. Additionally, this page features a way for users to message the researchers directly, in case there are questions. Finally, the statistics page can still be found here as well, but it has been renamed to be called "onderzoekstijdlijn" (Research timeline), in order to be more understandable.

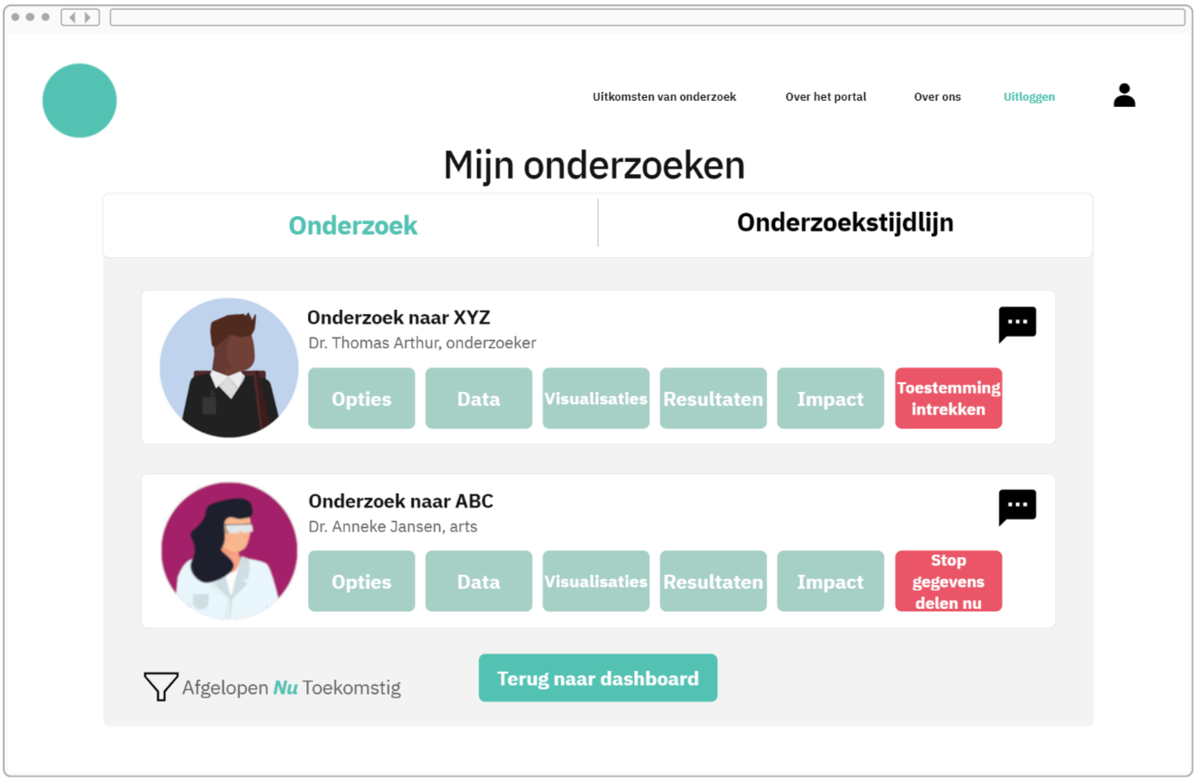
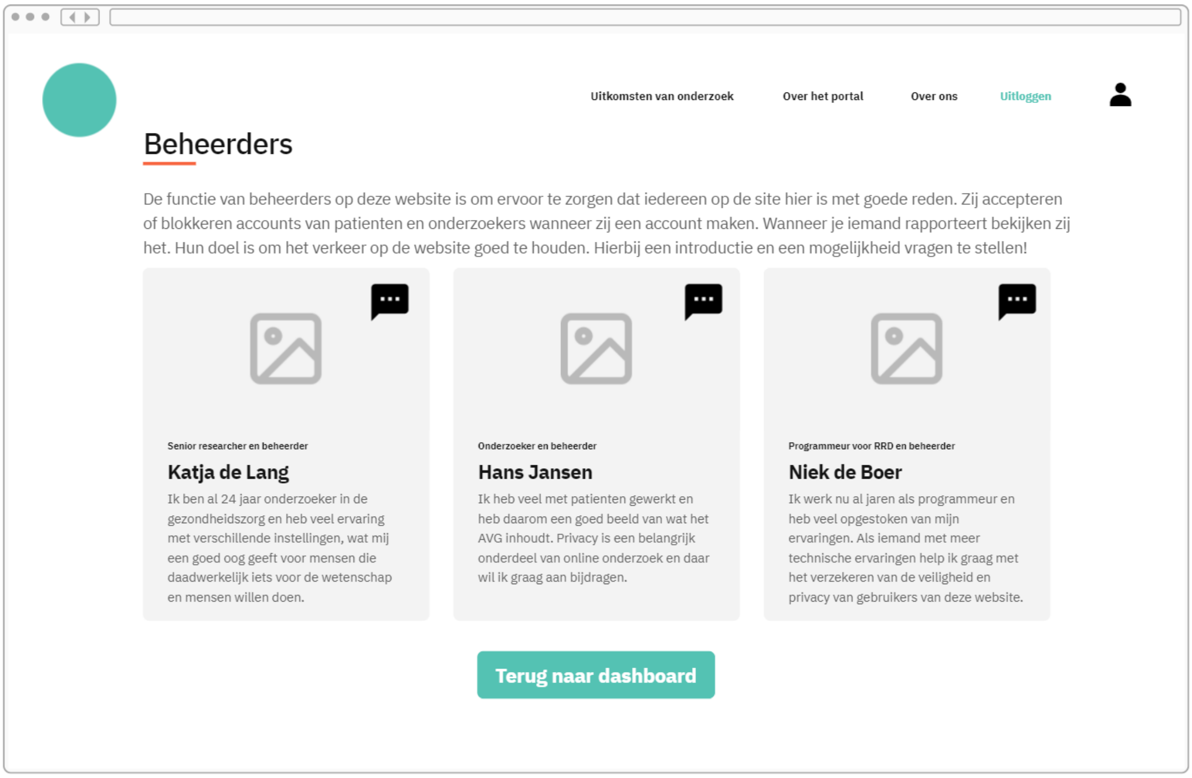


Figure 8: My researches page

Next, a page called "Mogelijke onderzoeken" has been added, which means *possible researches* in English. Here, the research requests that have not yet been responded to can be found. When a user clicks on one of the requests on this page, they are directed to a research request. Here, some new features have been added. The researcher can be directly messaged anonymously, in order to get answers to questions or more information, in case the user feels they are missing a piece of information needed to be able to make a choice. Moreover, there is a possibility to learn more without asking questions. This can be done by clicking on the more information button. This section now contains an introduction to the researcher, their goal with this research, a link to an information paper and a link to look at previous works. Furthermore, there is a report button that can be clicked on when users feel like something is inappropriate about a request. Usually, the research requests will be shown when a user logs in to their account, to keep the user up-to-date. However, if a user does not want to decide at this point, they should not have to. Therefore, two options have been added for when a user thinks they cannot decide yet. They are able to postpone it to the next time they log in or send it to their "Mogelijke onderzoeken" (Possible researches) page. If a user has made up their mind, however, they can also accept or decline the research. What's more, they can even choose to always accept research by this researcher or always decline it. When the user picks the former, they will see another pop-up to ask them whether they want to join both individual research and collaborations involving this researcher or only the researcher's individual research.

Finally, it seemed like a good addition to have moderators for the system as to make it more trustworthy and safe. Therefore, a moderator page has been added to create a more friendly and familiar environment for the users of the website. On this page, the users can read about what moderators do and what their goals are. They can also read specifically about the moderators personally, as they introduce themselves. There is also an opportunity to message the moderators directly, when the users have questions or comments they deem relevant or important for moderators. How the moderator page looks can be seen in figure 9.



Beheerders

De functie van beheerders op deze website is om ervoor te zorgen dat iedereen op de site hier is met goede reden. Zij accepteren of blokkeren accounts van patienten en onderzoekers wanneer zij een account maken. Wanneer je iemand rapporteert bekijken zij het. Hun doel is om het verkeer op de website goed te houden. Hierbij een introductie en een mogelijkheid vragen te stellen!

Senior researcher en beheerder

Katja de Lang

Ik ben al 24 jaar onderzoeker in de gezondheidszorg en heb veel ervaring met verschillende instellingen, wat mij een goed oog geeft voor mensen die daadwerkelijk iets voor de wetenschap en mensen willen doen.

Onderzoeker en beheerder

Hans Jansen

Ik heb veel met patienten gewerkt en heb daarom een goed beeld van wat het AVG inhoudt. Privacy is een belangrijk onderdeel van online onderzoek en daar wil ik graag aan bijdragen.

Programmeur voor RRD en beheerder

Niek de Boer

Ik werk nu al jaren als programmeur en heb veel opgestoken van mijn ervaringen. Als iemand met meer technische ervaringen help ik graag met het verzekeren van de veiligheid en privacy van gebruikers van deze website.

Figure 9: The moderator page

The complete iterated prototype can be found in appendix 4.

4.4 Evaluation

For the evaluation of the iterated prototype, 4 individuals with rheumatoid arthritis were interviewed over Zoom. These people were chosen because they are potential future users of the application and they formed the target group of the prototype of the Citizen Science Portal. Each session took one and a half hour and focussed on all parts of the prototype of the Citizen Science Portal. About half an hour of each of these sessions was focussed on the dynamic consent solution.

In this half an hour, the user could navigate through some of the parts themselves, while others were shown to them. The goal was to find out about what the opinions were of the users on the prototype, in order to ultimately get closer to answering the research question of this paper. This goal was achieved by asking questions about each part to get a better idea of what the users thought and felt. This resulted in learning about their opinions and why they have these opinions, what they think is positive, what they think is negative and what their advice is for future versions. The interview guide for these sessions can be found in appendix 5.

Coding

The coding was done in Atlas.ti in a deductive manner [36]. For this, the research question of this thesis was used as inspiration for the initial codebook. This codebook is based on a hierarchy that seemed like a good way to find out more about the topic. It starts with the two main features of dynamic consent, namely communication and personalisation. The codes then outline design choices in the prototype that fit these foundational elements. This can be done, because all features of the prototype primarily focus on one or the other. After this, the opinions of participants and the reasons for their opinions were coded, but these were not in the initial codebook, as it would be impossible to predict user opinions before examining the data. Ultimately, the code hierarchy looks like figure 10.

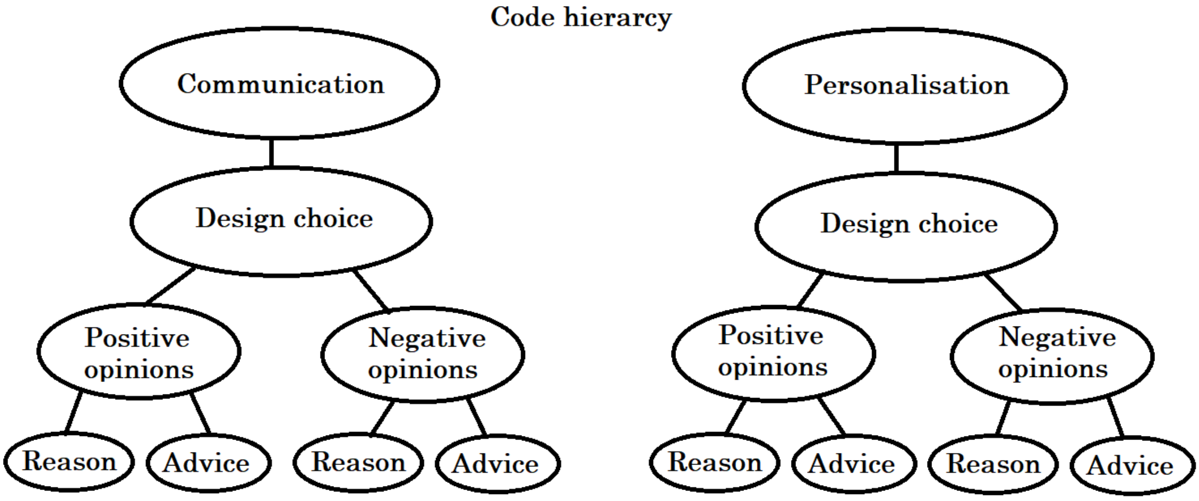


Figure 10: The code hierarchy

When the coding was finished, a content analysis was conducted, meaning that the content was read, put into different categories, summarised and analysed [37].

Analysis

The first step that was taken was coding which features were related to communication and which features were related to personalisation. After doing this, it could be seen that there are more features related to communication than to personalisation. The reason personalisation has fewer features is because the threshold for too much communication is way higher than that for too much personalisation. This is because personalisation often goes hand in hand with making choices, while communication does not. Too many choices can be just as demotivating as too few ones and balancing this is hard in personalisation, while communication does not have requirements to balance anything, as all communication is motivational. Therefore, having lots of communication features and a smaller amount of personalisation features seems like a generally good design choice and something to be expected in the prototype.

From here on out, the analysis will be done by discussing comments on a page by page basis, in order to make this process a more organized one.

Firs of all, the information on the terms of service page has a primary goal of being easy and quick to read and understand. However, half of the participants actually thought that the wording in the text could be more clear, while one participant thought some information was still missing (primarily like who the information asked of users is going to be shared with). However, participants did think that the page is generally very important to include because it has a strong relation with privacy. Therefore, they want to understand the text very well and most of them mentioned it is nice that they can see it all in one place at one time. This shows that there is a need for understanding and information disclosure in such systems. Furthermore, having a quick way to see the text is good but it should be understandable as well for effective communication disclosure. Another thing that was mentioned by many participants is that they expect to fill in their personal information here, as the page also gives the explanation of how it is going to be used. This would also allow participants to choose which data to fill in immediately. There was not much said about the pop-up on this page, except that it was clear.

The next pages that were discussed were the pages related to personalisation. Here, the choices are deemed as something important, as everyone has different interests, values and reasons for using the website. Regardless, all participants feel in control of their data usage because of these choices and being able to choose brings some participants ease, as well. This is the main takeaway.

These pages also have the possibility to get reminders for what a user is consenting to, which participants were generally positive about. This is because the reminders can lead to an informed choice for some (to change their mind about participating), be an extra form of confirmation and make users feel more involved. However, one user did mention that they would like to be “pushed” more to choose to be reminded every so often. Some users mentioned that the text should also be formulated a bit more clearly and be less generally. This is in line with the discoveries that were made, but not something that was considered for this specific part during the design process.

The quizzes were generally liked because they help with understanding, are a form of confirmation, facilitate an active form of communication and they are fun. However, users also mentioned that such quizzes should be used only once or occasionally. Even though some users said it made them more aware of what they were doing, others mentioned it did not help at all. They still had some positive things to say about the quiz, but it did not help them specifically. This may be why the ability not to have quizzes again was liked so much as well. Participants said it made this page feel more inclusive and it ensured that there is more choice for users, which could be useful for the ones who may think quizzes take too long or are annoying.

The "Toestemming" (consent) pages were generally liked a lot. The obvious reason for this would be because users can change their choices here, which helps with personalisation. This definitely was a factor for liking the page, as 3 out of 4 participants mentioned it. What was also really well-received is how accessible and comprehensive these pages are. Participants liked the visuals and thought they helped them focus again on which choices they had made. They thought the pages are very balanced and inclusive. This really helps with the users feeling in control of their data and it also creates trust in the system. However, participants also expressed one negative opinion, which was that there is too much choice. They suggest to take out the *consent per research page*, so that all researches get the same treatment, creating unity and simplicity while also taking less time overall.

In "Mijn onderzoeken", there is a heading called *impact*. This page appeals to altruism by mentioning the impact the research has on the world and other people. A lot of participants mentioned its importance, so it definitely is valued to a greater extent than first imagined. The only thing that should change on this page, as suggested by one participant, is that the links to each finished research should not be present here, but under the heading *results*, as that makes more sense to them.

What's more, the ability to send direct messages on the *"Mijn onderzoeken" (Translation: My researches)* page was viewed as something really positive, as it was described as *"fantastisch" (Translation: fantastic)* , *"super" (Translation: super)* and *"geweldig" (Translation: amazing)*. Participants mentioned the importance of direct contact, which, according to one participant, is lacking in the Netherlands. This direct contact is motivating to the patients and also makes them trust the website and a piece of research more. However, one participant also mentioned that it could have the opposite effect if a researcher responds very slowly, because it may make researchers seem arrogant and demotivate patients from communicating and participating in research. Therefore, the researchers should not be flooded with questions and should only asked ones when it is necessary and cannot be answered in any other way. In this way the researchers should be able to communicate back properly and in a timely manner, avoiding issues such as the aforementioned.

Additionally, participants could revoke their consent on this page. How to do this is clear and being able to do this is positively received, but the users thought that consistency in text was missing because not all sentences to revoke consent were worded in the same way. Moreover, they would like to be able to mention why they decided to stop sharing their data and participating in research. The ability for this type communication is missing for them.

The participants thought that overall, the *"Mijn onderzoeken" (Translation: My researches)* page is good. It creates trust and shows a complete picture of each piece of research. It motivates users and makes them feel more involved. However, half of the users mentioned that they do not view the *onderzoekstijdlijn (Translation: research timeline)* as useful or important, while the other half did not even mention it at all. Therefore, it may be better to leave it out in next iterations.

The request page has several features that have been discussed by the participants. First of all, they have mentioned more than once that some wordings are not very inclusive and should be made easier to understand or formulated better. They believe short sentences are good in particular. Additionally, participants think that the information shared with and about the research request makes it feel more personal, which in turn makes them more motivated to participate.

What's more, some users think that there are too many choices. They believe that the two choices "Always participate in research from this person" and "Never participate in research from this person" are not relevant and could be taken out. One participant also mentioned that they did not think the possibility to report was useful, as they would rather send a direct message to someone, because it is more personal.

Ultimately, the fact that the requests are also shown when logging in was liked by all. However, some users would prefer a notification, displaying an icon that signifies that there is an unanswered request. Adding to this, one user mentioned that they would also like to get pop-ups on their phone, as this would remind them of it.

Next, the moderators page will be discussed. This page was liked overall. It creates trust and shows the website being open and honest. This is clearly appreciated by the participants. Furthermore, the information that is shared about the moderators makes all participants trust them, possibly because of personification, as participants mentioned that they feel like there is actually a person on the other side, moderating the website. In particular, some of the participants mentioned that this makes them feel like the website is taken seriously, which makes them feel safe.

Some participants had a few additional remarks. They mentioned that this prototype makes them feel safe, at ease and like they have control. They believe their data is being treated properly. They also point out how understandable and discrete the website is. However, they would like some texts to still be a bit shorter and more explicit. One participant also mentioned that consent should get slightly less focus, as it does not feel completely balanced on the website currently.

Finally, the opinions of the participants give a lot of information, but what is also intriguing to examine is what they mentioned most often across and within pages, as how they perceive things may say something about their own values and interests. Some values, needs and expectations that were mentioned a lot were control, trust and understanding. Understanding could be improved by using more short texts and having a more clear overview. Additionally, although altruism was not mentioned explicitly, participants did talk about making the website more inclusive and accessible many times. Therefore, it may be better to think of ways to implement altruism directly, because it is very clear that the participants cared about other potential users of the application. Another aspect to focus on in future iterations, based on what the participants have discussed, is personification, which could be implemented more into the system, as it seems to create trust very well. Finally, involvement helps a lot with motivation, so ways to involve users and make them active should be considered.

Chapter 5 – Conclusion

The context of this thesis is based around Citizen Science related to health. In Citizen Science, health data is collected, stored and possibly shared with others. Since this is done with sensitive health data, it should be kept secure and protected. Because of the nature of this data, it is also crucial that the consent is “truly” informed.

Moreover, traditional consent in its current state is not dynamic enough to cover all variables that are present in the research done in Citizen Science. Traditionally, consent is obtained once, at the beginning of participation in a research, but in this context that is not sufficient. A more dynamic and flexible solution is necessary. Dynamic consent was considered as such a solution in this thesis, as its main goals are delivering a personalized form of consent and facilitating communication.

Yet, dynamic consent is a fairly new concept, which is why there are not many examples of it in practice. One of the goals of this thesis was to put these new, mainly theoretical concepts of dynamic consent into something tangible and see if this theory works in practice. Another goal was to address user values in the dynamic consent design that was developed. This was to be able to develop a well-received system that features dynamic consent. Therefore, theory about dynamic consent and user values, needs and expectations had to be combined, to see if these concepts are compatible and how they could work together in practice. This specific combination of topics has not been sufficiently researched before either, so this thesis adds value to the exploration of this approach.

The research question that is answered in this thesis is ”*What is a good design for dynamic e-consent that addresses the user values, needs and expectations?*”

To answer this question, first, background research was done, then based on this a potential design for dynamic e-consent was created that addresses the possible user values, needs and expectations. This design was then evaluated to see if what the literature implies is true in practice. Then this initial design and the results of its evaluation became the basis of creating the iterated design. The iterated design was then evaluated to answer the research question of this thesis.

The foundations of a good design for dynamic e-consent can be found in the design described in this thesis. This can be seen from the results of the evaluation, which were mostly positive. Some findings were that both communication and personalisation, which are the foundations of dynamic consent, are useful to implement into a design. However, while forms of communication can be added abundantly without becoming an issue, not as many personalisation elements can be added, because they would start having a negative effect quicker. Moreover, it was found that combining these foundations of dynamic consent with user values, needs and expectations works very well. When it comes to specific design elements, direct communication was particularly well received, because it personifies the system by allowing users to talk to other people directly. Other forms of personification had this effect too, as it made the website feel more personal and inclusive. Furthermore, involvement helps a lot with motivation, so ways to involve users and make them active should be considered. Moreover, all participants felt in control over their data due to the choices they could make and how those choices could be made. Control was one of the values that was mentioned often. Other values and needs that were mentioned repeatedly were trust and understanding. Therefore, a good design for e-consent should incorporate these and the other aforementioned user values, needs and expectations.

Despite the overall positive reception of the design, many steps are still left to fully answer this research question and arrive at a truly “good” design for dynamic e-consent focused on user values, needs and expectations. For example, the need for understanding was not completely fulfilled and can be made better by making communication short and simple. This simplicity should extend to interfaces as well. Otherwise, they can become overwhelming. Moreover, altruism should still be addressed in a more explicit manner than it was in this thesis’ solution. This is because users care a lot about other potential users of the application, therefore, there should be opportunities to express and act upon this in a good design for dynamic e-consent that focuses on user values, needs and expectations.

Chapter 6 – Discussion

It was suspected that dynamic consent could be a solution for consent in complex situations, which was confirmed by the evaluations that were done. Furthermore a certain list of user values, needs and expectations were suggested by literature. This list was mostly confirmed by the evaluation as well. A combination of dynamic consent and a focus on user values, needs and expectations was found to be an even better solution, which means this is a good way to approach consent in complex situations.

Some limitations of this research were that the sample size of the evaluations were rather small, which means that the results may not be very statistically significant. Moreover, since the research that was conducted was qualitative, there was bias, as the results were interpreted by a single researcher. This means that the results may not always represent participants' opinions.

Regardless of the limitations, this thesis presents a good first step towards the development of such systems. However, currently they are not sufficiently present in research and even less so in practice. Therefore, more research should be done about how to implement such systems. Aside from improving the shortcomings found in the evaluation of the iterated prototype, a possible avenue for this research would be to see how focusing on system personification explicitly could improve a solution such as the one in this thesis. This would be because personification creates a lot of trust and makes people feel more included in a community, which makes participants feel more motivated to do research. Personification also fits into dynamic consent because it is a form of communication and communication is a foundation of dynamic consent. All of the aforementioned makes this a good avenue for future research.

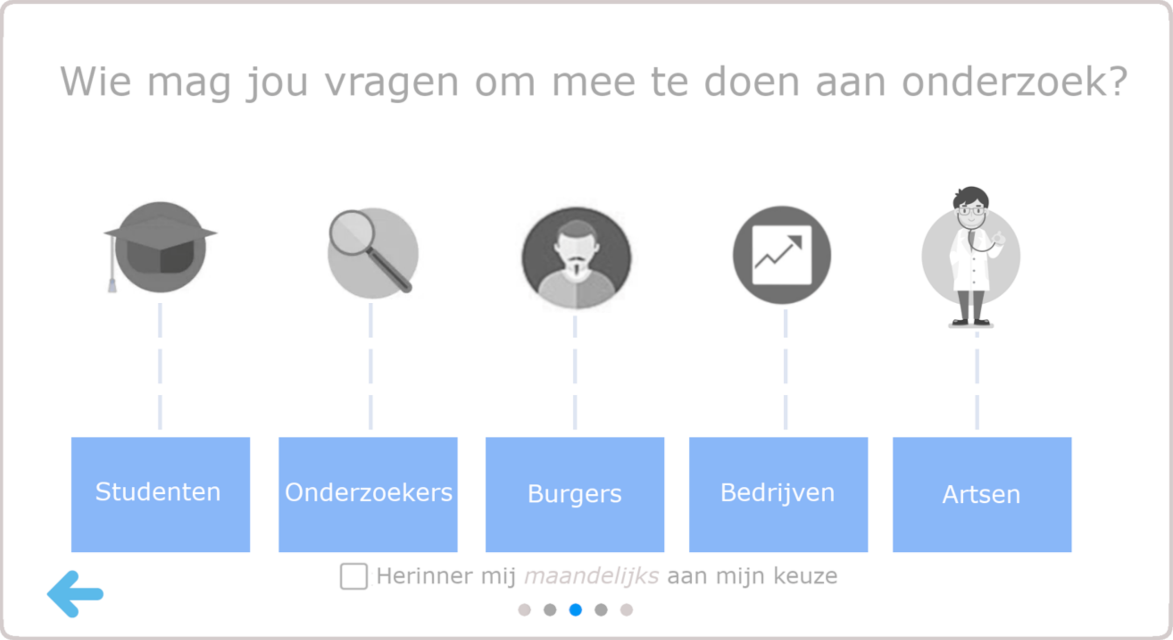
Overall, the research for this thesis went smoothly, however, it could have been planned out a bit more properly based on topics, to make it more balanced. Too much focus was put into implementing improvements when making the iterated design, without thinking about how they impact the core of the system. For example, the need of understanding was compromised when implementing several features to *"Mijn onderzoeken" (Translation: My researches).* It is recommended to think about this balance of improvements and core values if continuing to work on this or other similar systems in the future.

Appendices

Appendix 1: Initial prototype

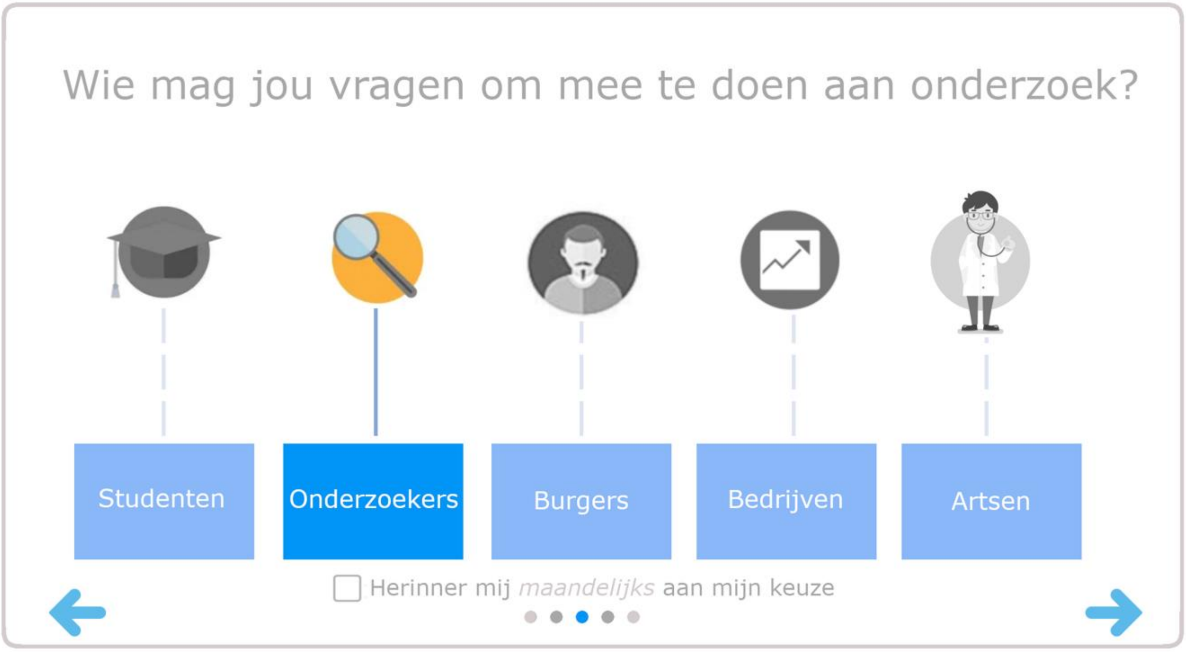
Wij bewaren uw persoonlijke gegevens zoals

Uw naam ?
Uw email adres ?
Uw adres ?
Uw geslacht ?
Uw telefoon nummer ?
Uw geboortedatum ?



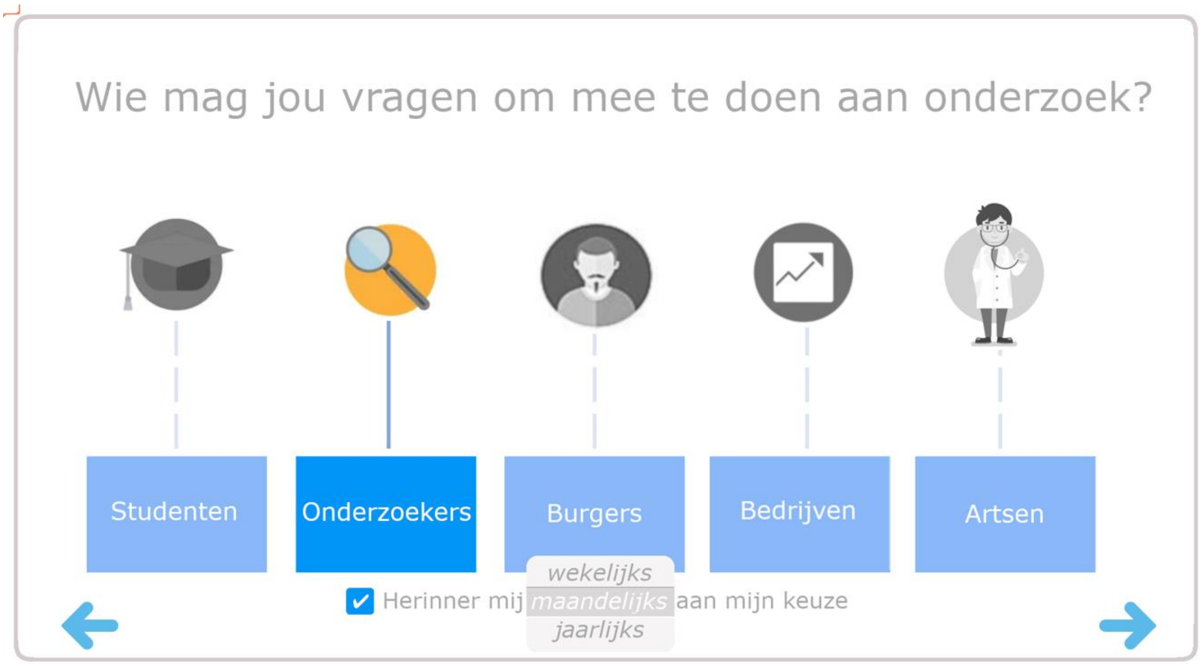
Wie mag jou vragen om mee te doen aan onderzoek?

☐ Herinner mij *maandelijks* aan mijn keuze



Wie mag jou vragen om mee te doen aan onderzoek?

☐ Herinner mij *maandelijks* aan mijn keuze



Wie mag jou vragen om mee te doen aan onderzoek?

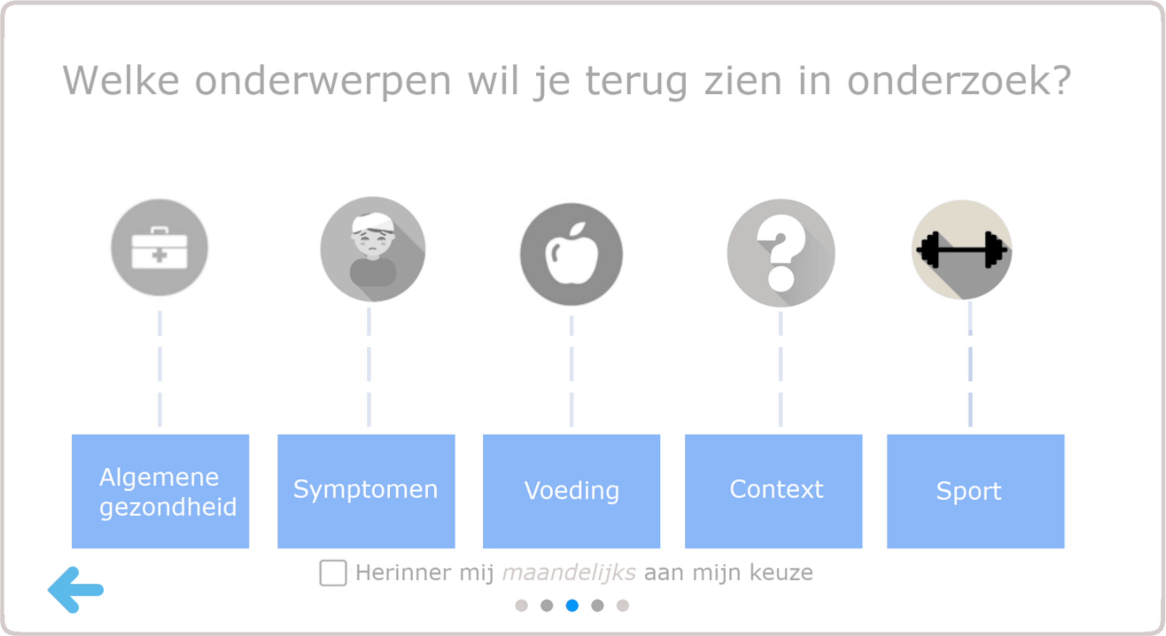
☑ Herinner mij *maandelijks* aan mijn keuze

Wie mag jou vragen om mee te doen aan onderzoek?

☑ Herinner mij *maandelijks* aan mijn keuze

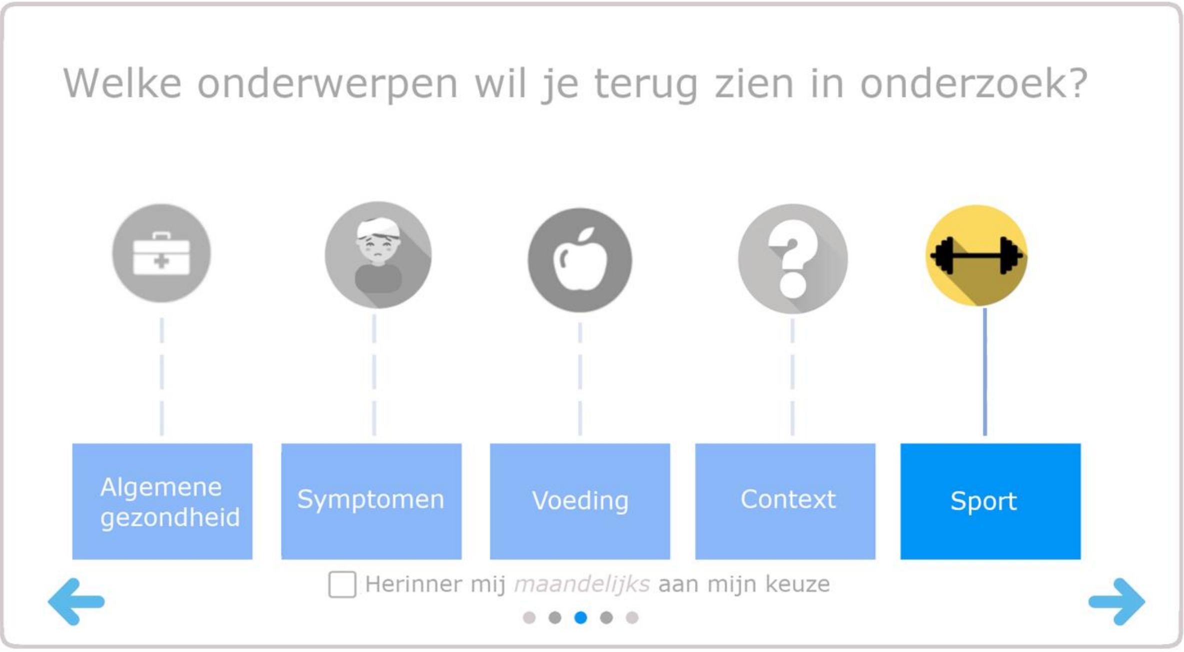
Wie mag jou vragen om mee te doen aan onderzoek?

☑ Herinner mij *maandelijks* aan mijn keuze



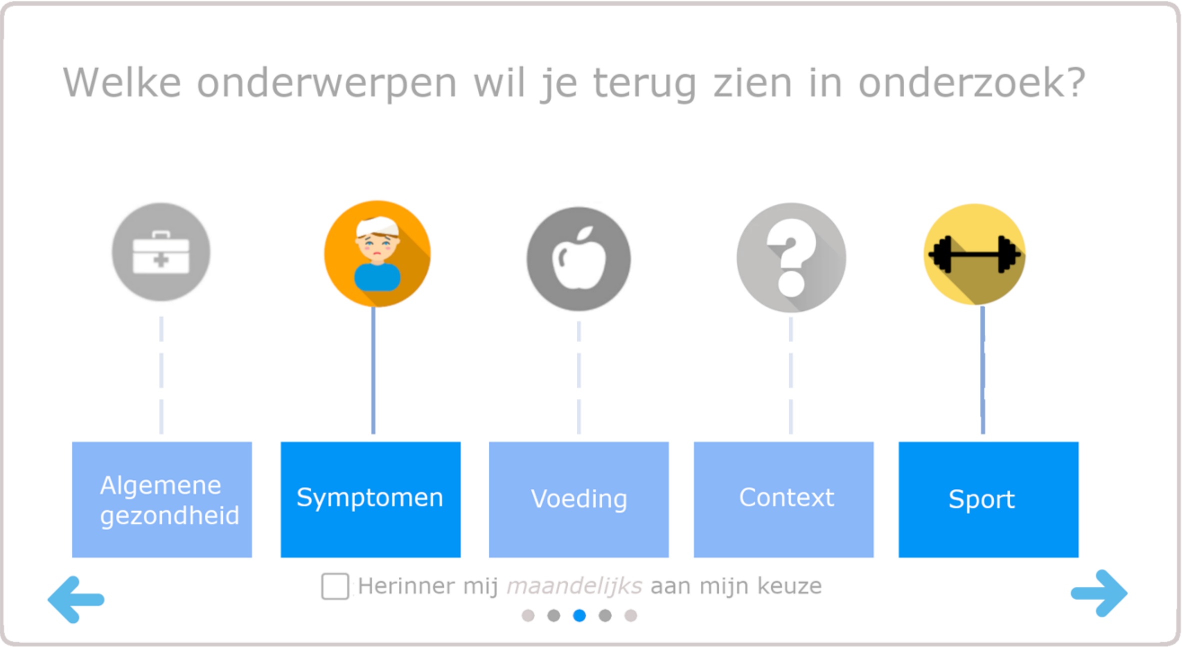
Welke onderwerpen wil je terug zien in onderzoek?

☐ Herinner mij *maandelijks* aan mijn keuze



Welke onderwerpen wil je terug zien in onderzoek?

☐ Herinner mij *maandelijks* aan mijn keuze


Welke onderwerpen wil je terug zien in onderzoek?

☐ Herinner mij *maandelijks* aan mijn keuze


Quiz

Wat gebeurt er met de keuzes die jij net hebt gemaakt?

Mijn keuzes zorgen ervoor dat ik alleen onderzoek aangeboden krijg waar ik modelijk aan mee wil doen

Mijn keuzes zorgen ervoor dat ik toestemming geef om mee te doen aan onderzoek waar ik interesse in heb

Quiz

Wat gebeurt er met de keuzes die jij net hebt gemaakt?

Mijn keuzes zorgen ervoor dat ik alleen onderzoek aangeboden krijg waar ik modelijk aan mee wil doen

Mijn keuzes zorgen ervoor dat ik toestemming geef om mee te doen aan onderzoek waar ik interesse in heb

☐ Stel mij geen quizvragen meer

Quiz

Wat gebeurt er met de keuzes die jij net hebt gemaakt?

Mijn keuzes zorgen ervoor dat ik alleen onderzoek aangeboden krijg waar ik modelijk aan mee wil doen

Mijn keuzes zorgen ervoor dat ik toestemming geef om mee te doen aan onderzoek waar ik interesse in heb

Quiz

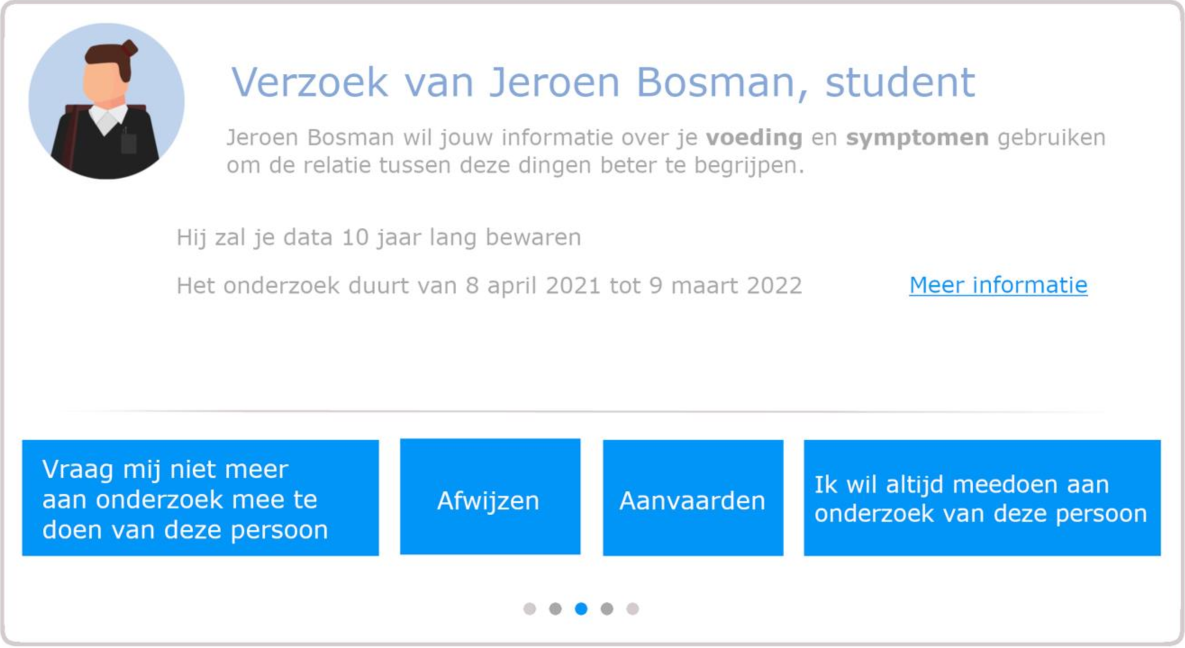
Wat gebeurt er met de keuzes die jij net hebt gemaakt?

Mijn keuzes zorgen ervoor dat ik toestemming geef om mee te doen aan onderzoek waar ik interesse in heb

Je hebt nog geen toestemming gegeven op het meedoen aan onderzoek.

Je keuzes zorgen er alleen voor dat wij je aanbieden waar je geïnteresseerd in bent. De keuze of je mee wil doen met specifiek onderzoek moet je dus nog maken.

☐ Stel mij geen quizvragen meer



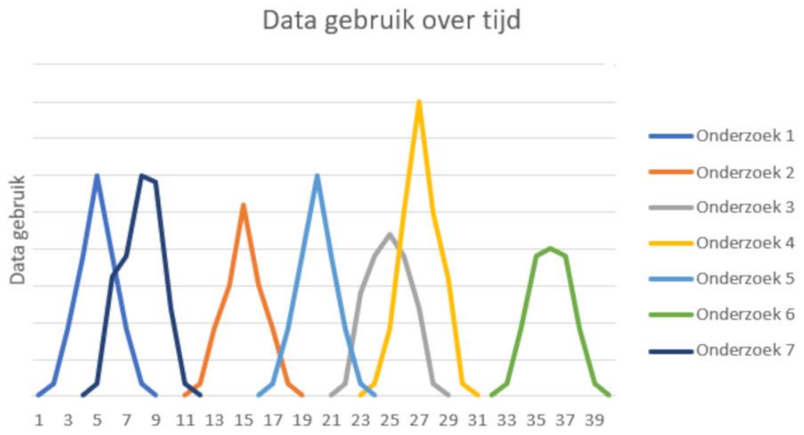
Verzoek van Jeroen Bosman, student

Jeroen Bosman wil jouw informatie over je **voeding** en **symptomen** gebruiken om de relatie tussen deze dingen beter te begrijpen.

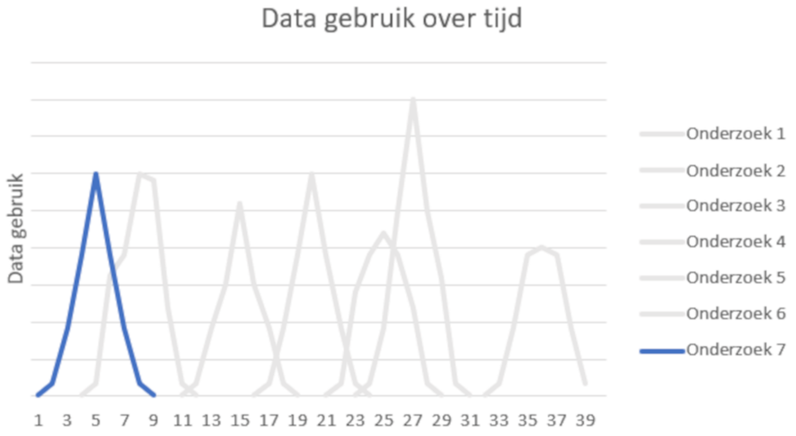
Hij zal je data 10 jaar lang bewaren

Het onderzoek duurt van 8 april 2021 tot 9 maart 2022

Statistics	Research	Impact



Statistics	Research	Impact



Research 2

Dr. Thomas Arthur, onderzoeker

Research 1

Dr. Anneke Jansen, arts

Onderzoek 2

Jouw hulp heeft ervoor gezorgd dat personen met reuma zich minder vermoeidkunnen voelen

Onderzoek 1

Door jou begrijpen we beter waarom personen met reuma zich vermoeid voelen

Appendix 2: Focus group guide

This guide contains a table and a list of questions. The table contains information about which topics were discussed, when they were discussed and what would be discussed. The list of questions are based on the topics discussed in the focus group and were used as an aid to remember the structure and discussion topics. Most of the questions that are mentioned were discussed in the session.

Time	**Point on agenda**	**Description**
	Participants arrive	Beforehand: Check whether technology works as I think it does
10 min	Welcome	explains the background for the event, purpose of the day, the program, what will happen with the results and how to stay involved (the first session I will tell them about the evaluation session, which also explains how their input will be incorporated) Any practical questions left?
5 min	Introductions	Everyone gets to introduce themselves and why they are here shortly
25 minutes	Identifying values, needs and expectations	What are values needs and expectations users have, based on their previous experiences with consent and based on their previous experiences sharing health data? Wat zijn jullie ervaringen met het delen van data(gerelateerd aan je gezondheid)? Hoe privé wil je dat mensen met je data gerelateerd aan je gezondheid omgaan?

		Wat is er belangrijk voor jou in je beslissing om je data te delen?
20 minutes	User opinions on dynamic consent: does it work?	5 minutes- Explain dynamic consent 15 minutes: How do participants feel about different aspects of dynamic consent? Wil jij de keuze zelf kunnen maken van wat er gedeeld wordt? Zo ja, hoe wil je dat hiermee om wordt gegaan? Wat vind je van meerdere malen toestemming geven? Wat vind je van feedback?
10 minutes	Break	
35 minutes	Prototypes	10-15 min: Introduce prototypes and show off the functionality 30-35 min: Ask questions from the section “prototypes” Taking the prototype as an example of what dynamic consent may look like, how do the participants feel about the concept? Kijk naar verschillende aspecten Wat vind je fijn/zou je veranderen?

		Do the participants think their values needs and expectations are reflected in this prototype? Why? Reflecteer op values Wat zou je veranderen?
15 minutes	End session	Thank everyone for their participation, mention the next session and that I hope to see them again with an improved prototype. Did you like how it was organized? Any final questions? Evaluation in group or individually?

Questions

Kunt u zich voorstellen en misschien meteen kort aangeven waarom u er vandaag bij bent?

Het onderwerp van "toestemming" klinkt jullie misschien niet bekend in de oren, maar jullie hebben er allemaal wel eens mee te maken gehad. Denk bijvoorbeeld aan wanneer je aan dit onderzoek mee wilde doen. Je kreeg hiervoor eerst een blad met informatie en een blad waarop je toestemming gaf mee te doen aan dit onderzoek. Ook kun je het bijv. terug zien wanneer je een website bezoekt, vaak wordt er gevraagd of je cookies accepteert. Kunnen jullie andere momenten bedenken waarin je toestemming moest geven voor iets? Waar denk je aan?

Identifying values, needs and expectations

Als we even terug gaan naar de cookies, we hebben er allemaal mee te maken gehad, maar weet je ook echt wat het is? Lees je de inhoud van zoiets? Waarom?
Als het op een aantrekkelijkere manier wordt weergeven, zou je er meer geïnteresseerd in zijn?

In dit onderzoek zullen we het voornamelijk hebben over hoe je toestemming kan geven op het delen van je data/informatie. Wat zijn jullie ervaringen hiermee? Wat vond je hierin belangrijk? Heb je verwachtingen wanneer het gaat om het delen van informatie? Waarom? Denk je dat dit anders zou

moeten? Hoe? Waarom? Wat is er belangrijk voor je wanneer je de keuze maakt je data te delen?
Heb je ook wel eens je data gerelateerd aan je gezondheid gedeeld? Hoe was deze ervaring? Hoe gaf je toestemming? Hoe kwam je op je besluit? Waarom koos je hiervoor? Wat vond je hierin belangrijk?
Met wie zou je dit delen? Onder welke voorwaarden, als je deze hebt?
Met wie zou jij je data gerelateerd aan je gezondheid delen? Waarom? Zou je mening hierin veranderen als je data anoniem gedeeld werd? Zo ja, hoe anoniem zou je dit willen?
Wanneer je hoort van ons project, wat zijn je eerste gedachtes wanneer je denkt aan je privacy? Zou je je comfortabel voelen met het delen van je data op website? Met wie? Wanneer zou iemand toestemming kunnen krijgen om dit van jou te bekijken? Bv Alleen in officiele onderzoeken of ook als iemand bv zijn eigen statistieken wil vergelijken met anderen?
Hoe vindt je het bijvoorbeeld op deze manieren?

Heb je ooit eerder meegedaan aan onderzoeken?
Was dit online of offline?
Voordat je aan onderzoek mee kan doen, moet je vaak toestemming geven dat je mee wil doen.
Herinneren jullie hoe dat ging?
Wat vonden jullie hiervan?
Waarom?
Heb je ooit toestemming gegeven om mee te doen, maar je besloot toch dat je niet wilde mee doen?
Hoe ging dit? Kon je makkelijk stoppen? Wat vond je hiervan? Waarom?

Wanneer je een privacy verklaring accepteert, waar kijk je naar in je beslissing? Als het online is, vind je het belangrijk dat dat de website er betrouwbaar uitziet?
Hoe belangrijk is het voor je dat je weet wat er gedaan wordt met je data? Zou je dit gedetailleerd willen kunnen zien?
Vind je het fijn als je zelf kan kiezen met wie je je data deelt?

Vraag over mensen willen helpen/een groter doel
Privacy
Geef je om een keus hebben in wat je doet-zou je dat meer terug willen zien?

User opinions on dynamic consent: does it work?

Keuzes zelf kunnen maken kan er verschillend uitzien. Stel je voor dat je wanneer je toestemming geeft op het delen van je data, dit gepersonaliseerd is. Wat zou je ervan vinden als jij kon kiezen met wie je je data deelt? Wanneer je je data deelt? Hoe je je data deelt?

Wat zou je ervan vinden als je toestemming zou kunnen geven op iets in delen? Bijvoorbeeld stap voor stap? Wat zou je ervan vinden als je niet al deze delen hoeft te accepteren, dus de keuze is aan jou wat je wel en niet accepteert? Als je iets niet accepteert, hoe zou je willen dat het systeem ermee om zou gaan? Zou je willen dat je alsnog anoniem gebruik kan maken van waar je mee bezig bent, of wil je het helemaal niet meer gebruiken, of alleen de delen waarop je wel toestemming hebt gegeven?
Wat zou je ervan vinden als je je toestemming terug in kan trekken wanneer je wil en verbreden wanneer je wil?
Wat zou je ervan vinden als je meerdere malen over tijd op iets toestemming zou moeten geven? Wat zou je ervan vinden als je dit als "herinnering" kreeg, om te kijken of je het er nog steeds mee eens bent?
Zou je het fijn vinden als er gecheckt werd of je de implicaties van toestemming geven op het delen van je data begrijpt?
In onderzoek, wat vind je ervan als je over tijd op de hoogte wordt gehouden met hoe het onderzoek gaat?
Vind je communicatie tussen jezelf en een onderzoeker belangrijk in onderzoek? Waarom? Hoe zou je dit terug willen zien in een applicatie/op een website?

Prototypes

Ik heb een voorbeeld gemaakt van hoe het toestemming geven dynamischer zou kunnen zijn in de website die we maken. Dit is een concept om te zien wat jullie ervan vinden. We kunnen er even samen doorheen gaan, zodat je het idee begrijpt. Als je vragen hebt terwijl ik het voorbeeld demonstreer, dan mag je dat natuurlijk delen.

Nu hebben jullie dit voorbeeld gezien en vraag ik me af, wanneer je het ziet, krijg je het gevoel dat het betrouwbaar is? Waarom/waarom niet? Hoe interpreteer je het?
Begrijp je wat er gebeurd? Kan je het volgen? Hoe maakt dit je voelen?
Als je dit vergelijkt met je eerdere ervaringen in het delen van je data, hoe bevalt dit?
Hoe voel je je over de keuzes die je kan maken? Waarom? Hoe zou je het liever/anders willen zien?
Voel je je alsof jij de touwtjes in handen hebt over je data, wanneer je al deze keuzes kan maken?
Zijn dit de type keuzes die je wil maken of wil je ze anders? Heb je andere dingen waarin je wil kunnen kiezen die je belangrijker vindt?
Wat vind je van de quiz delen? Hoezo? Is het leerzaam?
Mist er iets in dit voorbeeld, dat je graag had willen zien? Waarom?
Voel je je alsof je echt een keus hebt in of je je data wil delen of niet?
Heb je het gevoel alsof er communicatie is tussen jou en de onderzoekers? Waarom wel of niet? Wat vind je hiervan? Hoezo?

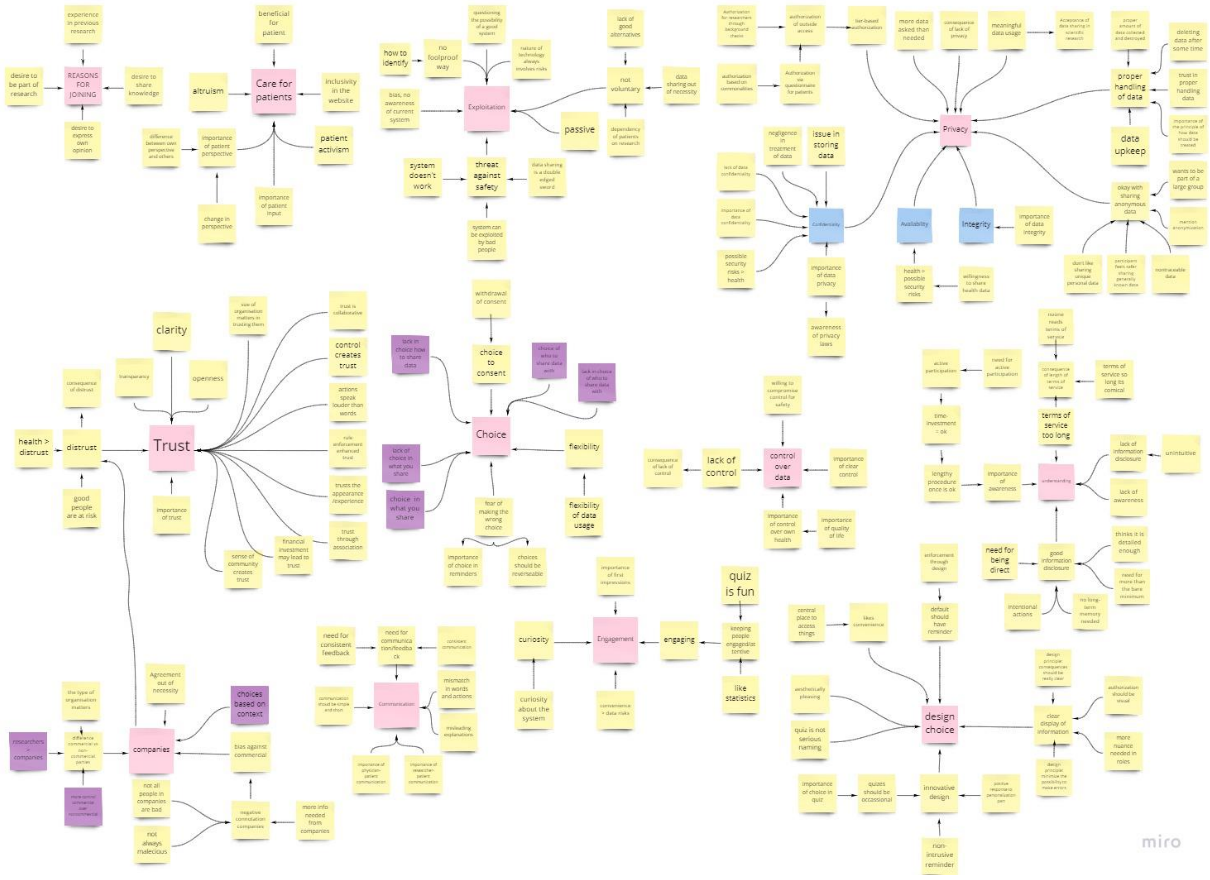
Wat vind je van de persoonlijke pagina? Waarom? Geeft het structuur? Zijn dingen waar je denkt dat ze zouden moeten zijn?

Wat zou je veranderen aan dit voorbeeld? Hoe? Waarom?
Verder nog gedachtes…?

Andere vragen:
Je hebt eerder gezegd dat je [waarde] belangrijk vindt, kan je dit terug vinden in deze prototype

Appendix 3: Initial thematic Map

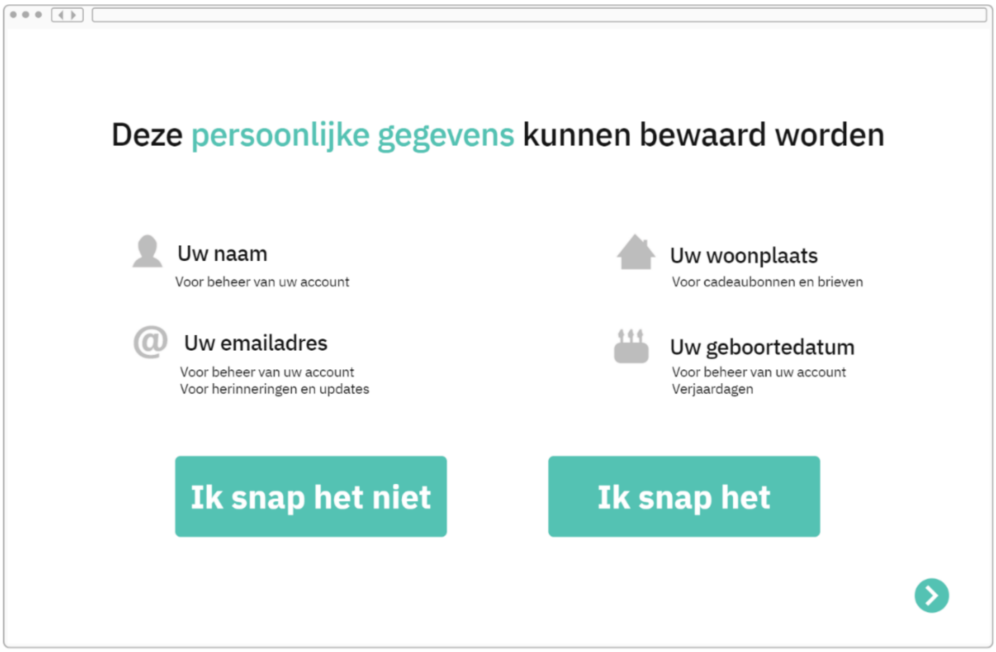
In this image, an initial map with codes can be seen. These codes were mapped based on how the topics related to each other. The final thematic map can be found in the Evaluation of the iterated prototype.



Appendix 4: Iterated prototype

The iterated prototype is integrated into the prototype of the website of the Citizen Science Portal. In this appendix are all parts related to this thesis. To get a better idea of where all these pages can be found, they will be gone through in a sequential order.

First of all, after making an account, a question about personal data will be asked.



Deze persoonlijke gegevens kunnen bewaard worden

Uw naam
Voor beheer van uw account

Uw woonplaats
Voor cadeaubonnen en brieven

Uw emailadres
Voor beheer van uw account
Voor herinneringen en updates

Uw geboortedatum
Voor beheer van uw account
Verjaardagen

When the participant clicks on "Ik snap het niet" (Translation: I don't understand), a pop-up shows up that explains what I happening in other words. If the participant still does not understand, they cannot participate. If they do, they go to the next page.

Deze persoonlijke gegevens kunnen bewaard worden

Het is niet verplicht al deze gegevens te delen. Je kunt later altijd bij je accountgegevens aanpassen wat je wil delen.

On the next two pages, personalisation related questions are asked.

Wie mag jou vragen mee te doen aan onderzoek?

*Alle onderzoeken en de organisatoren zijn goedgekeurd door de beheerders van het Portal

✓ Herinner mij *maandelijks* aan mijn keuze

When the participant hovers over the question mark, they get to see an example of what type of research companies participate in.

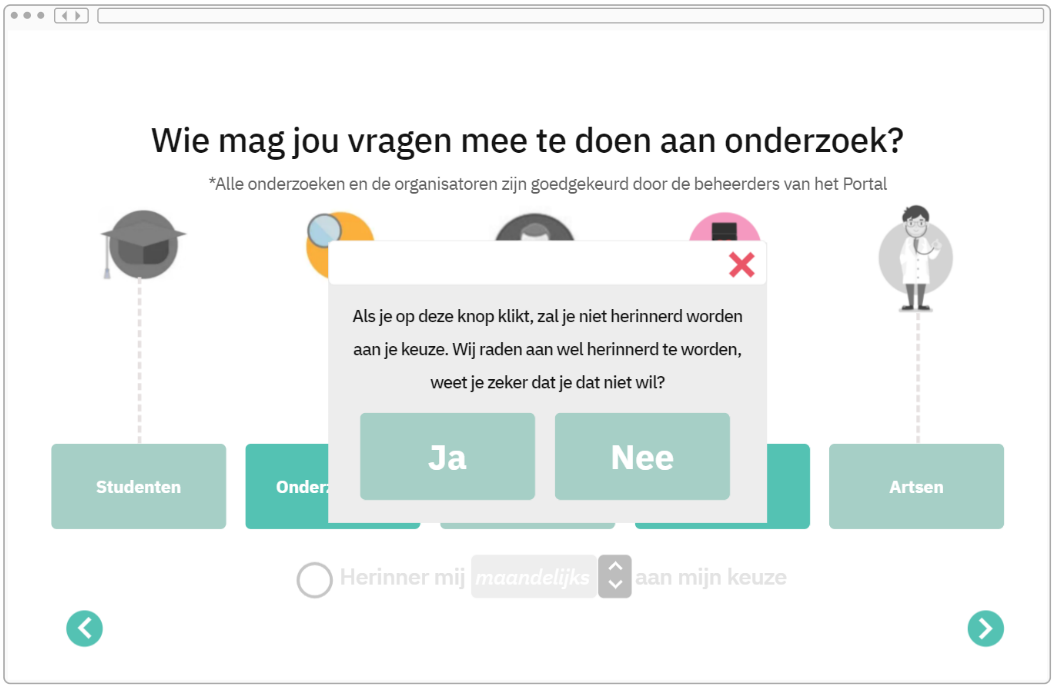
Wie mag jou vragen mee te doen aan onderzoek?

*Alle onderzoeken en de organisatoren zijn goedgekeurd door de beheerders van het Portal

Denk aan bedrijven die medische producten ontwikkelen

✓ Herinner mij *maandelijks* aan mijn keuze

If the user does not want to be reminded of their choice, they can choose to turn it off. When they do, the following pop-up will show up.

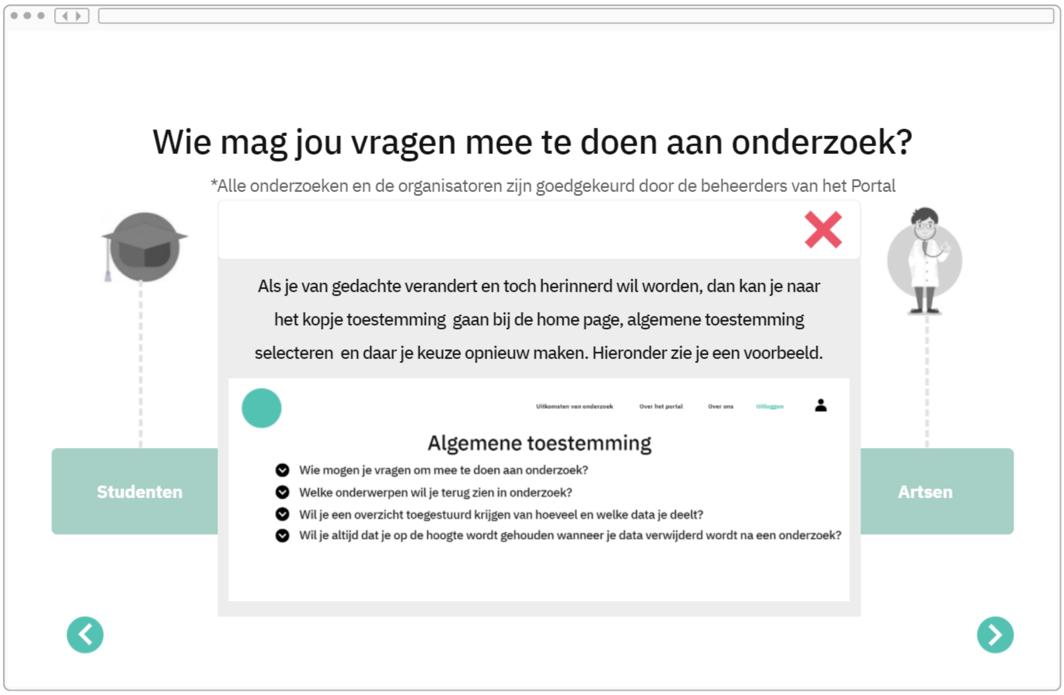


Wie mag jou vragen mee te doen aan onderzoek?

*Alle onderzoeken en de organisatoren zijn goedgekeurd door de beheerders van het Portal

Als je op deze knop klikt, zal je niet herinnerd worden aan je keuze. Wij raden aan wel herinnerd te worden, weet je zeker dat je dat niet wil?

If the participant clicked on “Ja” (Translation: Yes) on the previous page, they get to see the following pop-up, which explains where users can change back their choice to not be reminded.



Wie mag jou vragen mee te doen aan onderzoek?

*Alle onderzoeken en de organisatoren zijn goedgekeurd door de beheerders van het Portal

Als je van gedachte verandert en toch herinnerd wil worden, dan kan je naar het kopje toestemming gaan bij de home page, algemene toestemming selecteren en daar je keuze opnieuw maken. Hieronder zie je een voorbeeld.

Algemene toestemming

- Wie mogen je vragen om mee te doen aan onderzoek?
- Welke onderwerpen wil je terug zien in onderzoek?
- Wil je een overzicht toegestuurd krijgen van hoeveel en welke data je deelt?
- Wil je altijd dat je op de hoogte wordt gehouden wanneer je data verwijderd wordt na een onderzoek?

Welke onderwerpen wil je terug zien in onderzoek?

✓ Herinner mij maandelijks aan mijn keuze

After the personalisation pages, a quiz question is asked to see if the participants understand what they did earlier.

☆ Quiz ☆

Wat gebeurt er met de keuzes die jij net hebt gemaakt?

○ Stel mij geen quizvragen meer

This is what it looks like when they pick the wrong answer:

☆ Quiz ☆

Wat gebeurt er met de keuzes die jij net hebt gemaakt?

Mijn keuzes zorgen ervoor dat ik toestemming geef om mee te doen aan onderzoek waar ik interesse in heb

Je hebt nog geen toestemming gegeven op het meedoen aan onderzoek.

Je keuzes zorgen er alleen voor dat wij je aanbieden waar je geïnteresseerd in bent. De keuze of je mee wil doen met specifiek onderzoek moet je dus nog maken.

✓ Stel mij geen quizvragen meer

This is what it looks like when they pick the correct answer:

☆ Quiz ☆

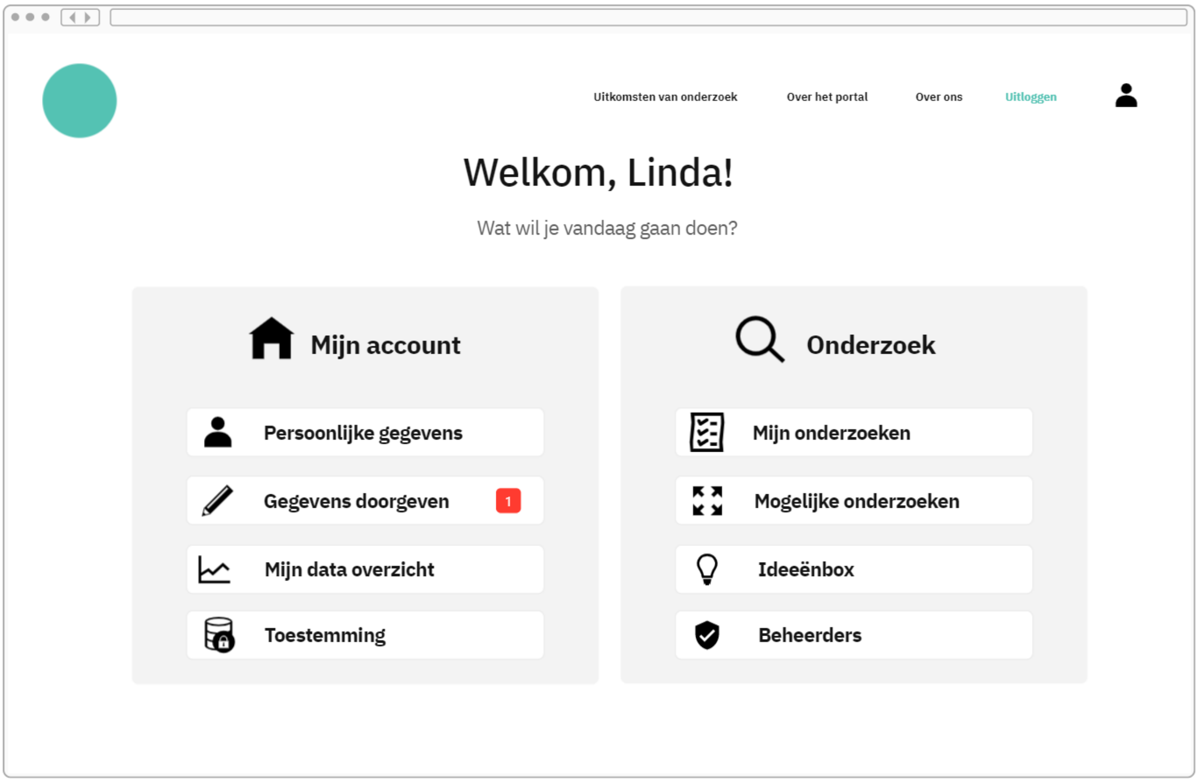
Wat gebeurt er met de keuzes die jij net hebt gemaakt?

Mijn keuzes zorgen ervoor dat ik alleen onderzoek aangeboden krijg waar ik mogelijk aan mee wil doen

Mijn keuzes zorgen ervoor dat ik toestemming geef om mee te doen aan onderzoek waar ik interesse in heb

✓ Stel mij geen quizvragen meer

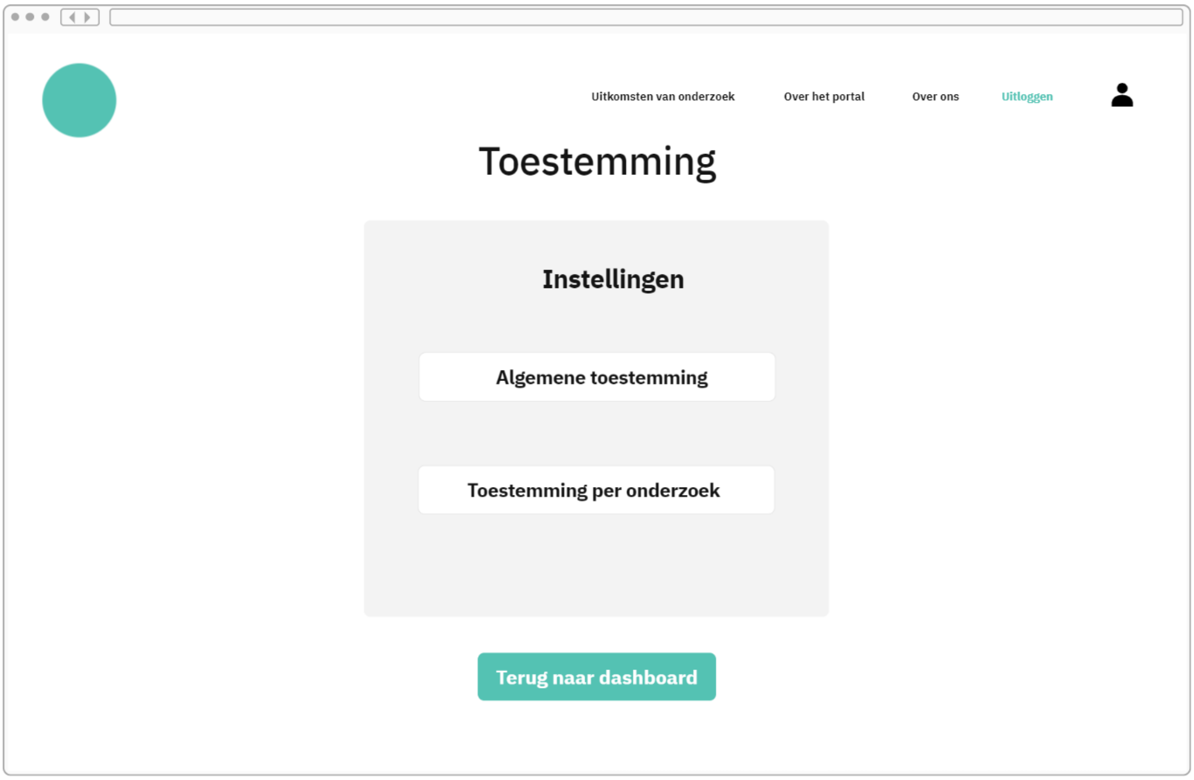
After this, the procedure of making an account is done. For the sake of following the structure of the website better, the dashboard will be the next image shown. This was not specifically created for this thesis, but was part of the general design of the website. The headings *“Toestemming” (Translation: Consent)*, *“Mijn onderzoeken” (Translation: My researches)*, *“Mogelijke onderzoeken” (Translation: Possible researches)* and *“Beheerders” (Translation: Moderators)* do lead to pages created for the sake of this thesis. They will be discussed from here onwards.



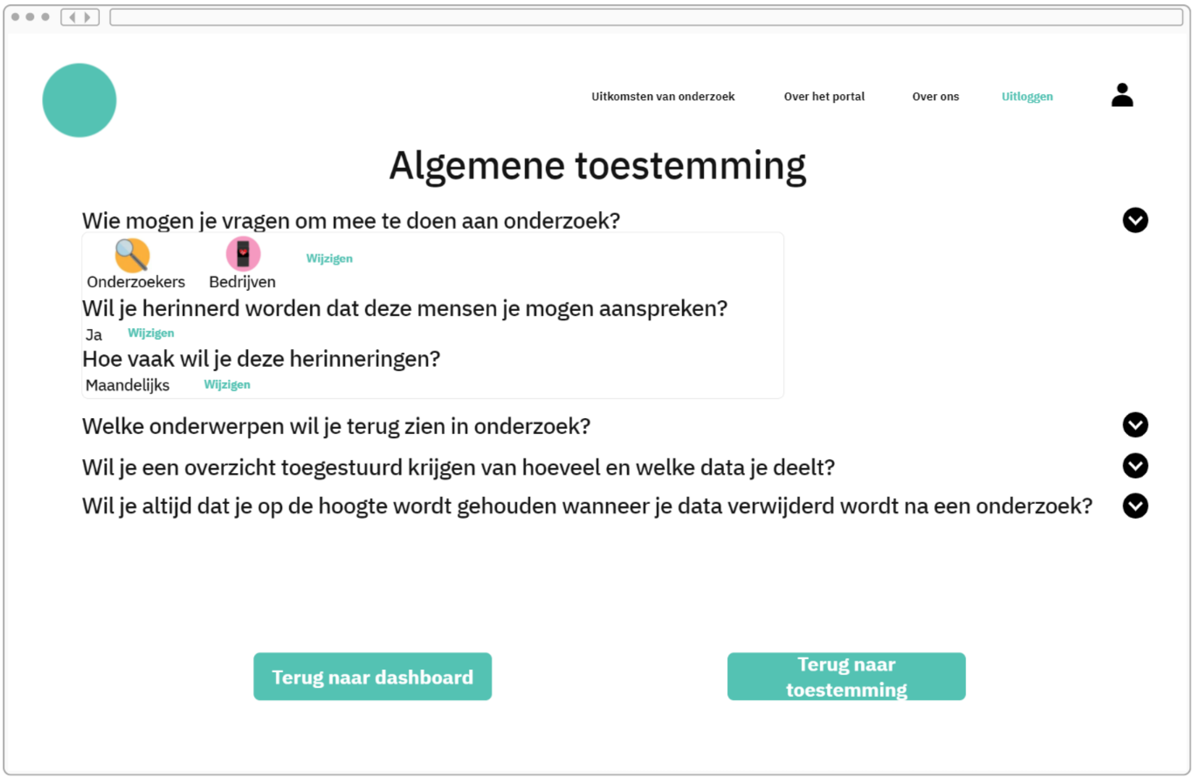
Welkom, Linda!

Wat wil je vandaag gaan doen?

The heading *“Toestemming” (Translation: Consent)*, leads to the following page. From here, the participant can navigate to *“Algemene toestemming” (Translation: General consent)* or *“Toestemming per onderzoek” (Translation: Consent per research).*



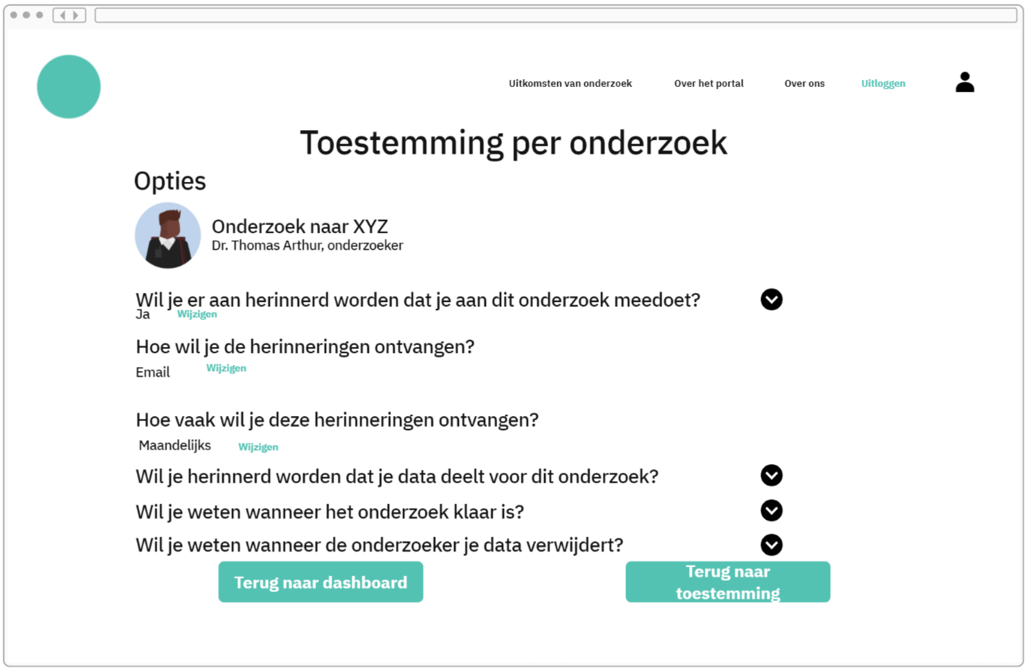
The page that displays general consent contains the personalisation questions mentioned when making an account. This is the page where these choices can be changed.



Algemene toestemming

Wie mogen je vragen om mee te doen aan onderzoek?
Onderzoekers Bedrijven
Wil je herinnerd worden dat deze mensen je mogen aanspreken?
Ja
Hoe vaak wil je deze herinneringen?
Maandelijks
Welke onderwerpen wil je terug zien in onderzoek?
Wil je een overzicht toegestuurd krijgen van hoeveel en welke data je deelt?
Wil je altijd dat je op de hoogte wordt gehouden wanneer je data verwijderd wordt na een onderzoek?

On the page with consent per research, similar options are shown but they can be changed per research.



Toestemming per onderzoek

Opties

Onderzoek naar XYZ
Dr. Thomas Arthur, onderzoeker

Wil je er aan herinnerd worden dat je aan dit onderzoek meedoet?
Ja Wijzigen

Hoe wil je de herinneringen ontvangen?
Email Wijzigen

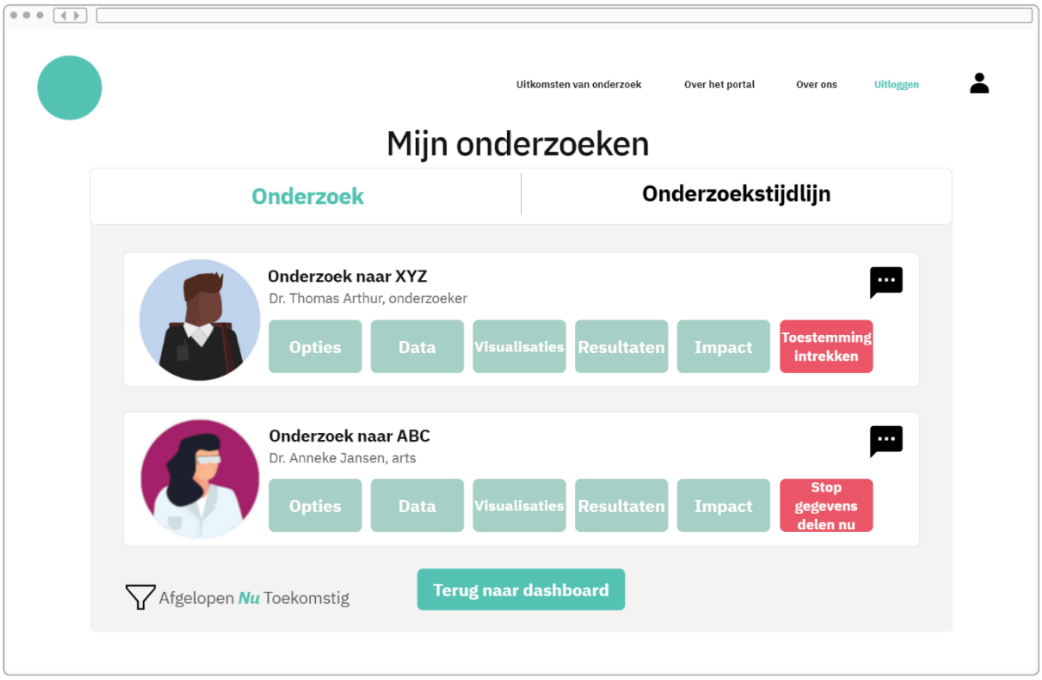
Hoe vaak wil je deze herinneringen ontvangen?
Maandelijks Wijzigen

Wil je herinnerd worden dat je data deelt voor dit onderzoek?

Wil je weten wanneer het onderzoek klaar is?

Wil je weten wanneer de onderzoeker je data verwijdert?

After navigating back to the dashboard, the next heading related to the topic is *“Mijn onderzoeken” (Translation: My researches)*. Here, an overview of the researches the participant is participating in are shown. The *“Opties” (Translation: Options)* button leads to the page with consent per research. The button called *“Visualisaties” (Translation: Visualisations) leads* to data visualisations based on the users data, which is not relevant for this thesis, but is relevant as a feature to make this overview as transparent as possible. The button *“Resultaten” (Translation: Results)* lead to a page that contain the results of the research.

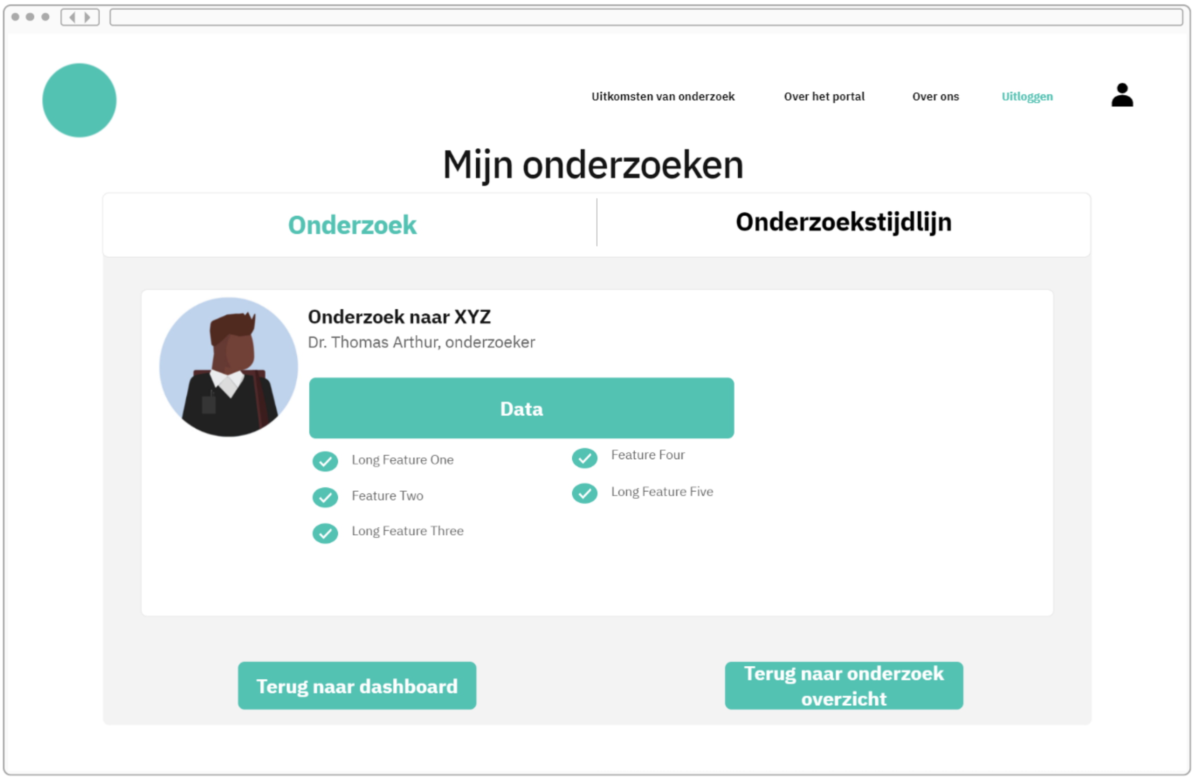


Mijn onderzoeken

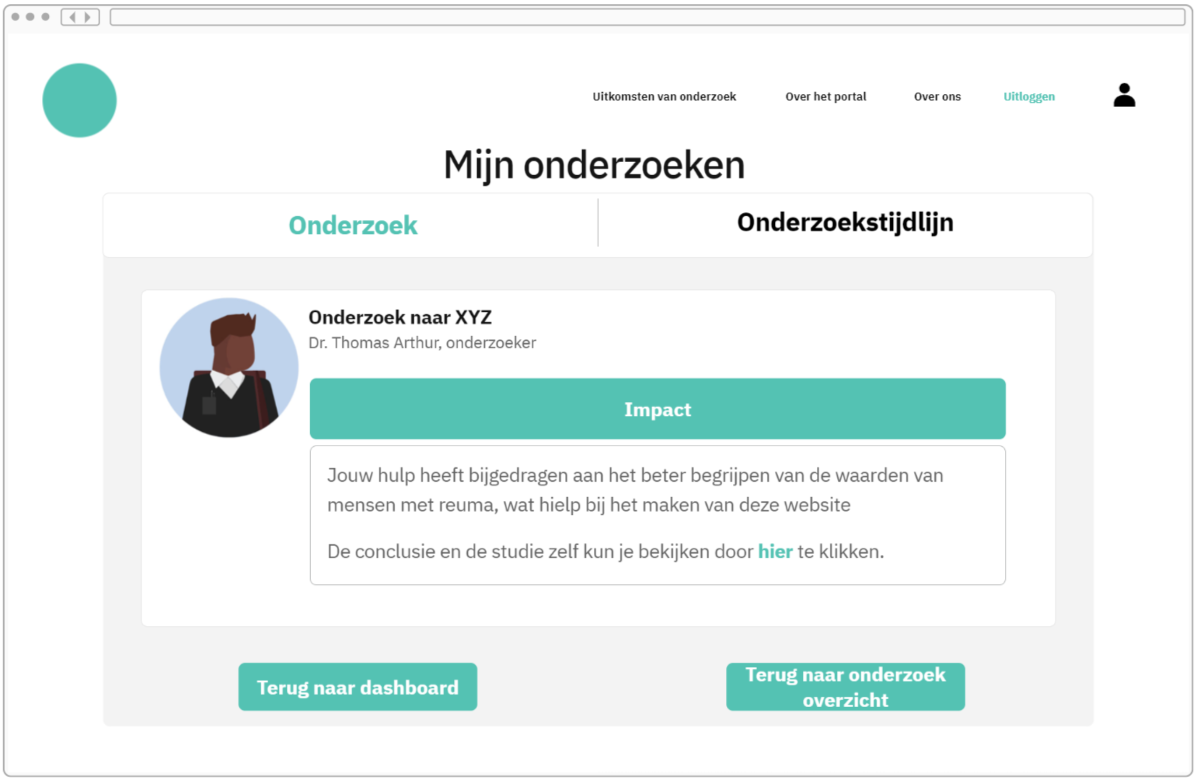
Onderzoek naar XYZ
Dr. Thomas Arthur, onderzoeker

Onderzoek naar ABC
Dr. Anneke Jansen, arts

The button “Data” leads to the following page, which displays which data the user is sharing for this specific research:



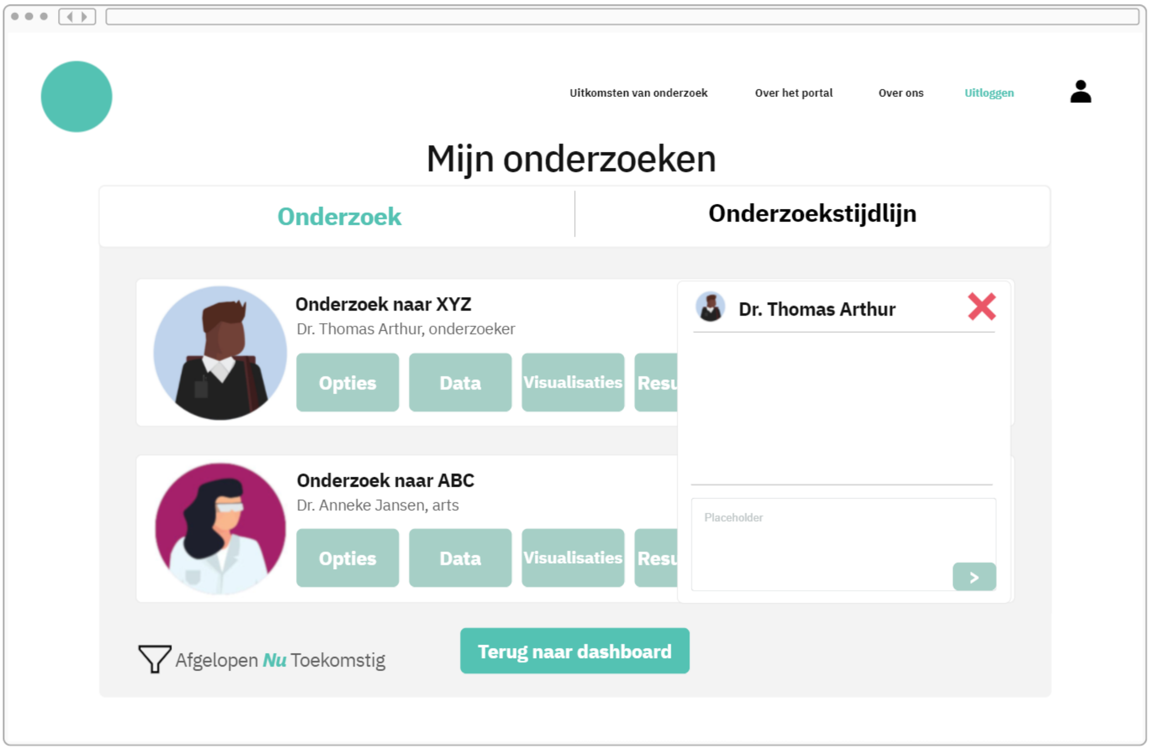
The button impact leads to this page, which shows how the participant’s participation has meaning an what that is.



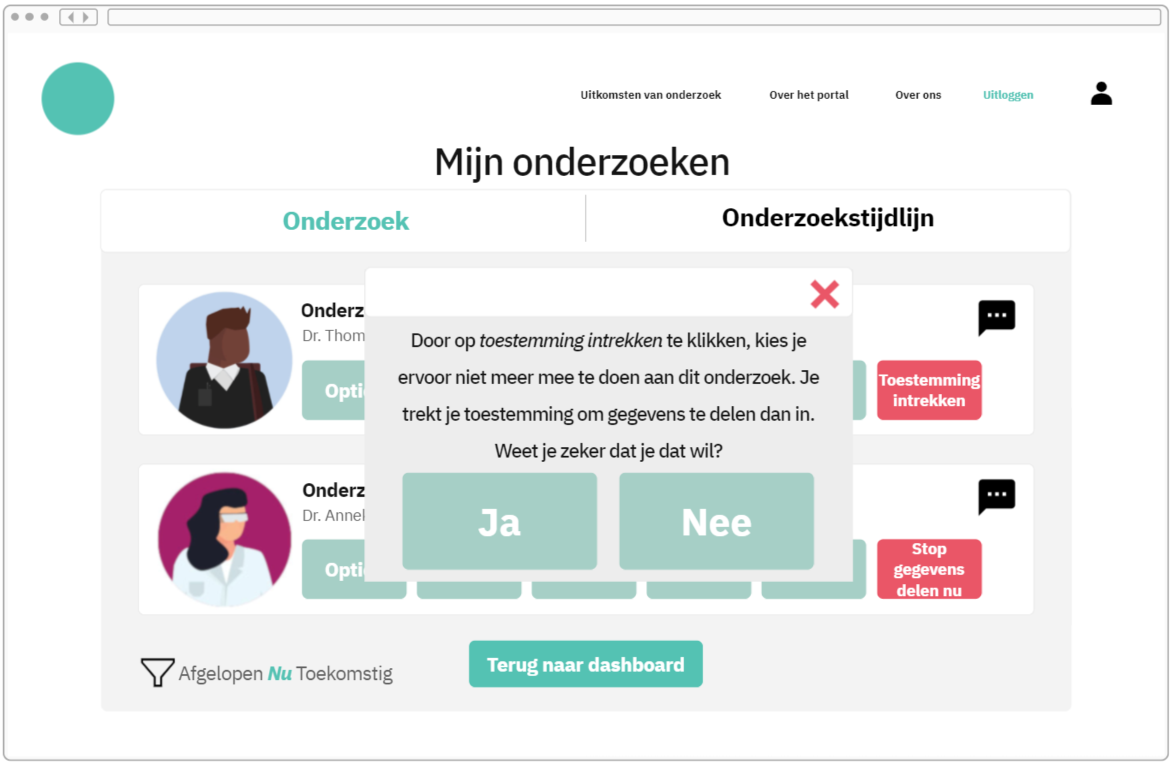
Jouw hulp heeft bijgedragen aan het beter begrijpen van de waarden van mensen met reuma, wat hielp bij het maken van deze website

De conclusie en de studie zelf kun je bekijken door hier te klikken.

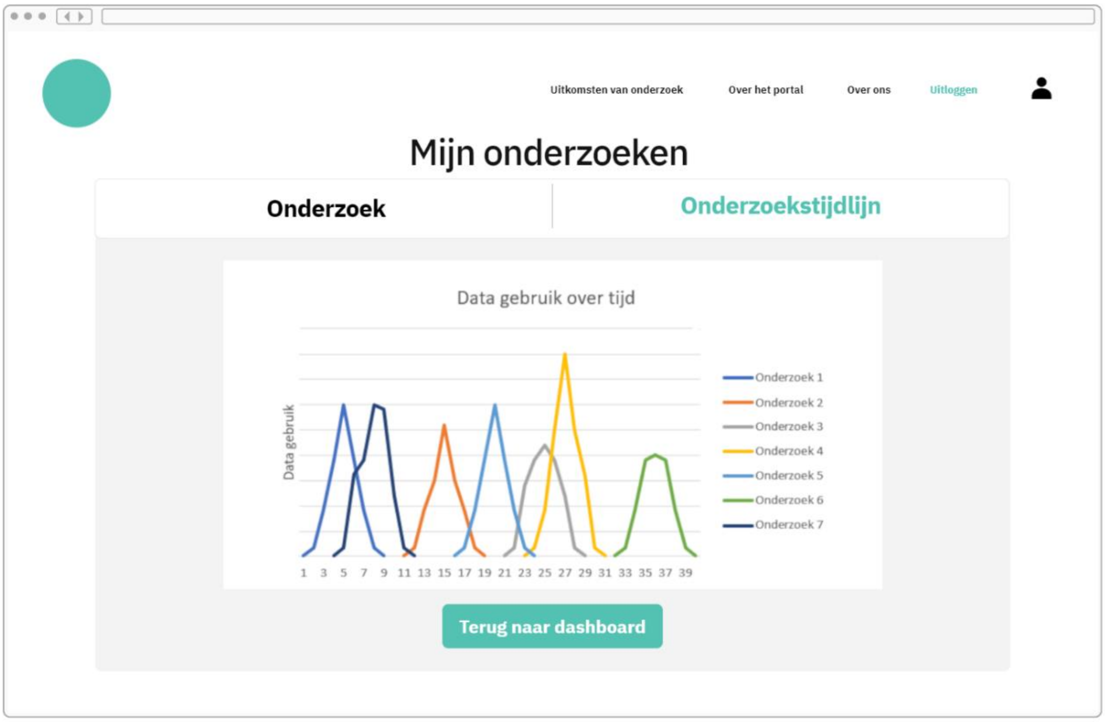
When clicking on 💬 participants can send messages directly to the researchers to ask questions.



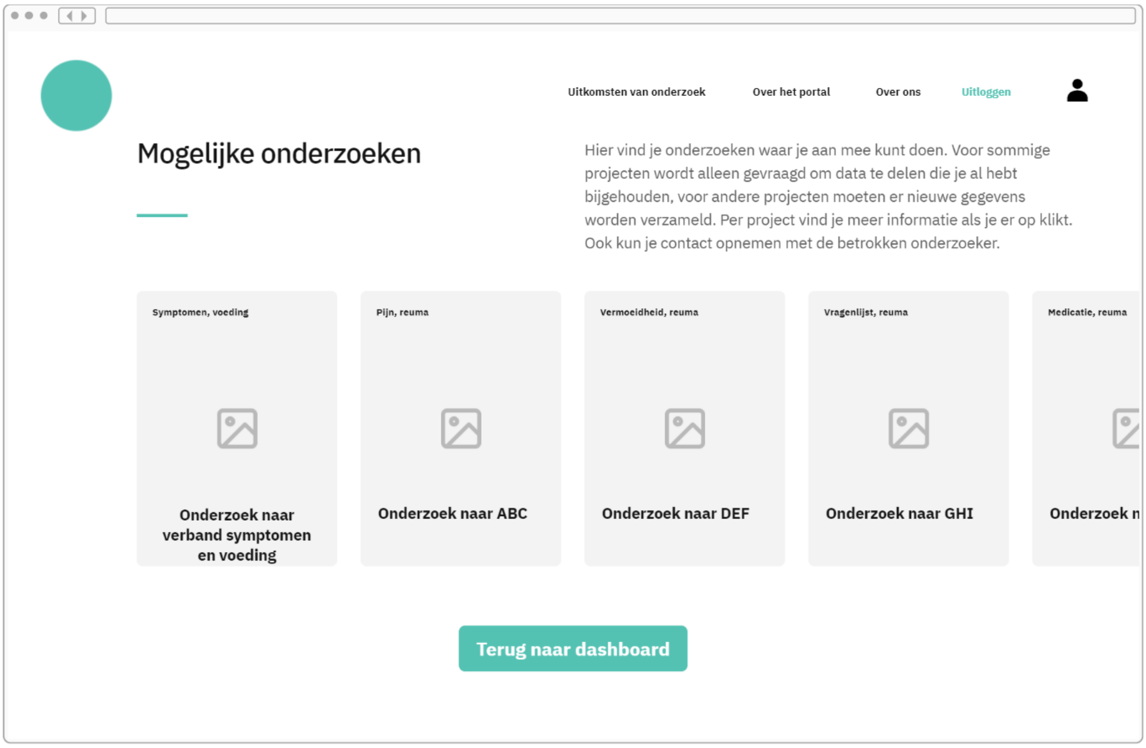
A participant can also withdraw consent by clicking on the red button, which then shows this pop-up to confirm if the participant really wants to stop.


Door op *toestemming intrekken* te klikken, kies je ervoor niet meer mee te doen aan dit onderzoek. Je trekt je toestemming om gegevens te delen dan in. Weet je zeker dat je dat wil?

When going to the *"Onderzoekstijdlijn" (Translation: Research timeline)*, the following page is shown:

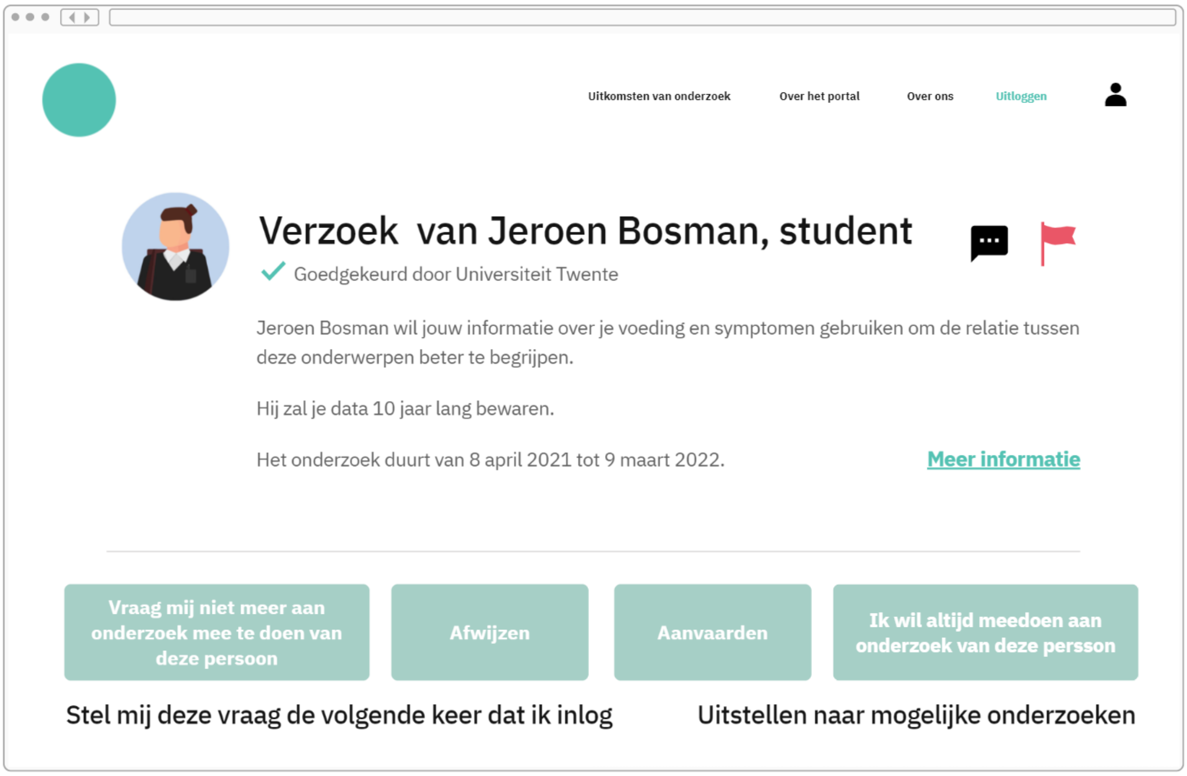


That was the last part of *"Mijn onderzoeken" (Translation: My researches)*. When going back to the dashboard, the next heading mentioned in relation to the thesis is "Mogelijke onderzoeken" (Possible Researches). From here, a user can click on a research request.



Hier vind je onderzoeken waar je aan mee kunt doen. Voor sommige projecten wordt alleen gevraagd om data te delen die je al hebt bijgehouden, voor andere projecten moeten er nieuwe gegevens worden verzameld. Per project vind je meer informatie als je er op klikt. Ook kun je contact opnemen met de betrokken onderzoeker.

Such a research request looks like this. The participant can report such a request to the moderators by clicking on the red flag.



Verzoek van Jeroen Bosman, student

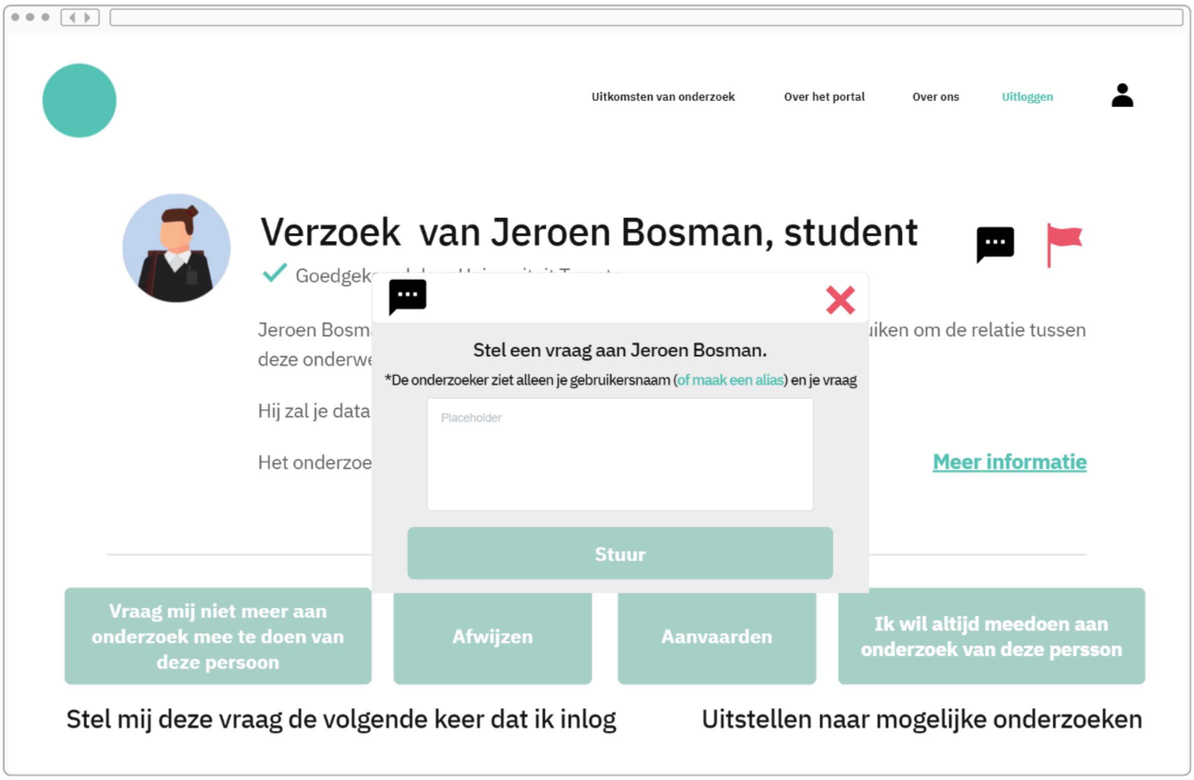
✓ Goedgekeurd door Universiteit Twente

Jeroen Bosman wil jouw informatie over je voeding en symptomen gebruiken om de relatie tussen deze onderwerpen beter te begrijpen.

Hij zal je data 10 jaar lang bewaren.

Het onderzoek duurt van 8 april 2021 tot 9 maart 2022.

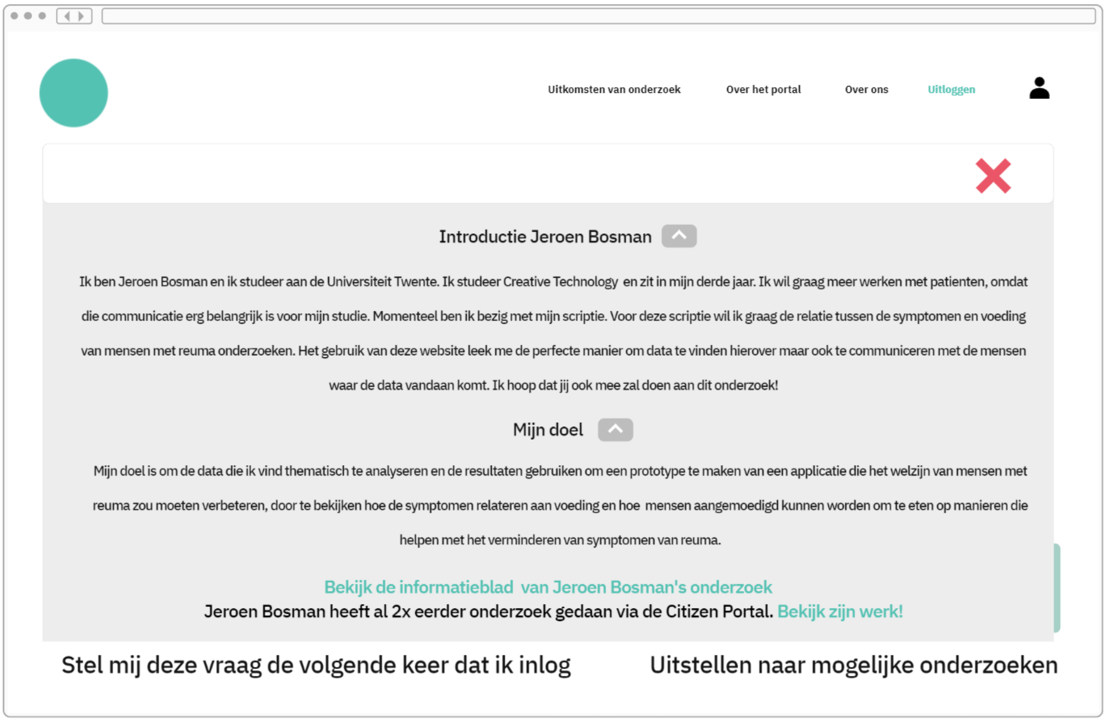
The participant can also send a message to the researcher anonymously to ask questions about the research request.



Stel een vraag aan Jeroen Bosman.

*De onderzoeker ziet alleen je gebruikersnaam (of maak een alias) en je vraag

When clicking on *“Meer informatie” (Translation: More information)*, information is displayed that introduces the researcher, their research and the goal of the research. It can also contain other information.



Introductie Jeroen Bosman

Ik ben Jeroen Bosman en ik studeer aan de Universiteit Twente. Ik studeer Creative Technology en zit in mijn derde jaar. Ik wil graag meer werken met patienten, omdat die communicatie erg belangrijk is voor mijn studie. Momenteel ben ik bezig met mijn scriptie. Voor deze scriptie wil ik graag de relatie tussen de symptomen en voeding van mensen met reuma onderzoeken. Het gebruik van deze website leek me de perfecte manier om data te vinden hierover maar ook te communiceren met de mensen waar de data vandaan komt. Ik hoop dat jij ook mee zal doen aan dit onderzoek!

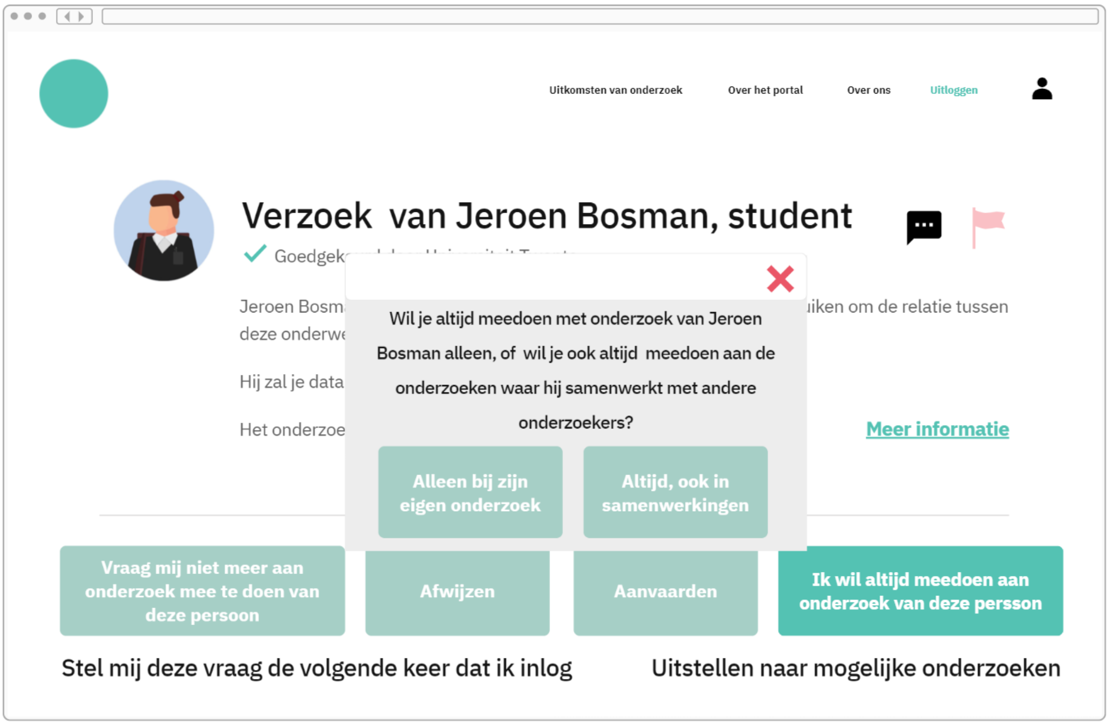
Mijn doel

Mijn doel is om de data die ik vind thematisch te analyseren en de resultaten gebruiken om een prototype te maken van een applicatie die het welzijn van mensen met reuma zou moeten verbeteren, door te bekijken hoe de symptomen relateren aan voeding en hoe mensen aangemoedigd kunnen worden om te eten op manieren die helpen met het verminderen van symptomen van reuma.

Bekijk de informatieblad van Jeroen Bosman's onderzoek

Jeroen Bosman heeft al 2x eerder onderzoek gedaan via de Citizen Portal. Bekijk zijn werk!

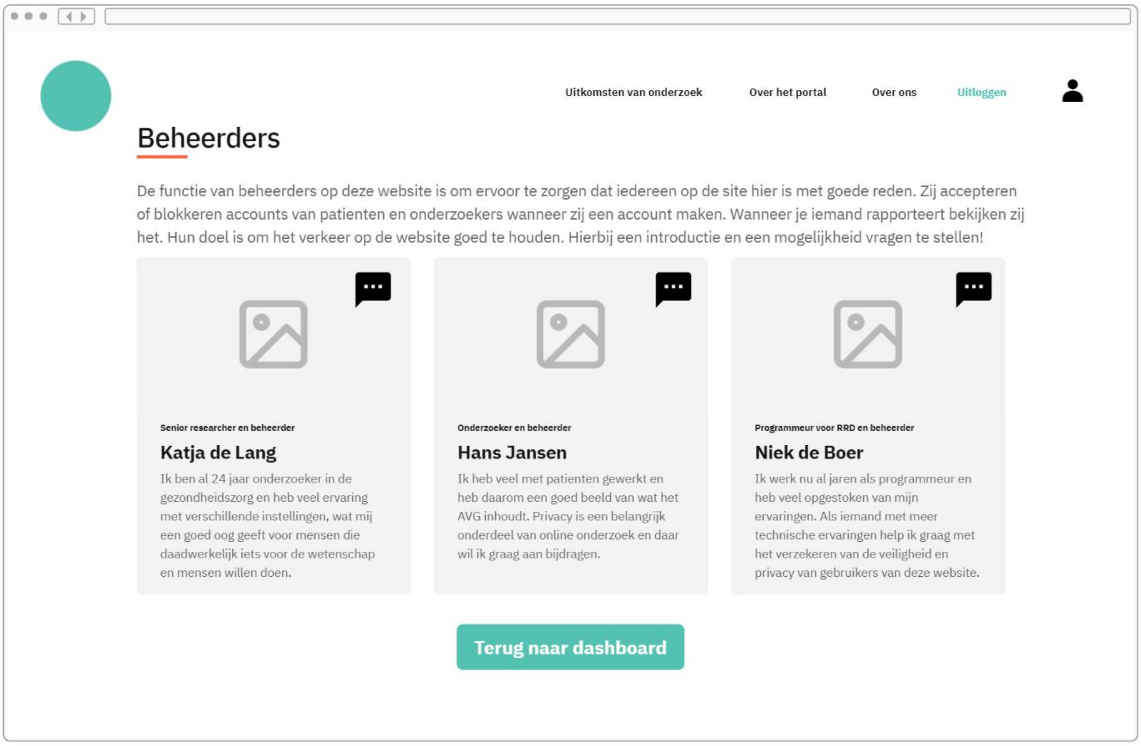
There are four choices to pick as an answer to the request. Most of them are very easy to understand, but the last one is quite broad. Therefore, a pop-up is shown when the participant clicks on that answer, to still make it a bit more specific.



Verzoek van Jeroen Bosman, student

Wil je altijd meedoen met onderzoek van Jeroen Bosman alleen, of wil je ook altijd meedoen aan de onderzoeken waar hij samenwerkt met andere onderzoekers?

That is all that can be done on the research request page. The final heading of significance is the heading *“Beheerders” (Translation: Moderators)*. An introduction to the moderators can be found on this page.



Beheerders

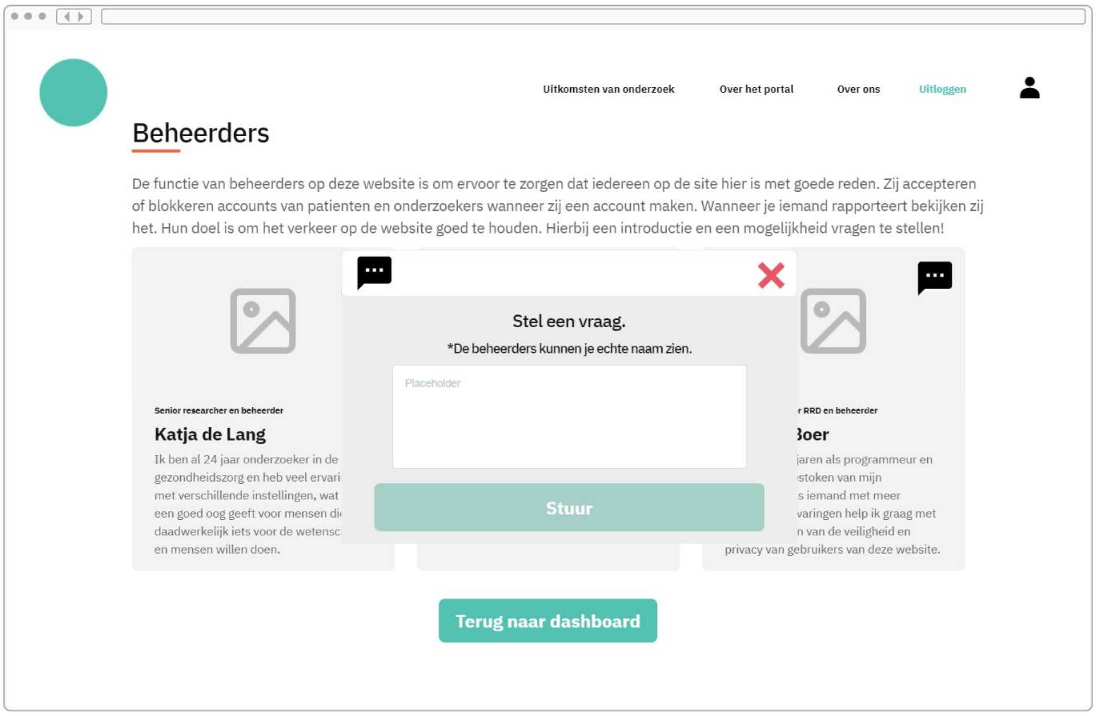
De functie van beheerders op deze website is om ervoor te zorgen dat iedereen op de site hier is met goede reden. Zij accepteren of blokkeren accounts van patienten en onderzoekers wanneer zij een account maken. Wanneer je iemand rapporteert bekijken zij het. Hun doel is om het verkeer op de website goed te houden. Hierbij een introductie en een mogelijkheid vragen te stellen!

Senior researcher en beheerder
Katja de Lang
Ik ben al 24 jaar onderzoeker in de gezondheidszorg en heb veel ervaring met verschillende instellingen, wat mij een goed oog geeft voor mensen die daadwerkelijk iets voor de wetenschap en mensen willen doen.

Onderzoeker en beheerder
Hans Jansen
Ik heb veel met patienten gewerkt en heb daarom een goed beeld van wat het AVG inhoudt. Privacy is een belangrijk onderdeel van online onderzoek en daar wil ik graag aan bijdragen.

Programmeur voor RRD en beheerder
Niek de Boer
Ik werk nu al jaren als programmeur en heb veel opgestoken van mijn ervaringen. Als iemand met meer technische ervaringen help ik graag met het verzekeren van de veiligheid en privacy van gebruikers van deze website.

Moreover, the participants can ask the moderators questions as well by clicking on the 💬 button. This is what that looks like:



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Stel een vraag.
*De beheerders kunnen je echte naam zien.

r RRD en beheerder
Boer
jaren als programmeur en stoken van mijn s iemand met meer varingen help ik graag met n van de veiligheid en privacy van gebruikers van deze website.

Appendix 5: Interview Guide

This guide was written by several researchers working on the Citizen Science Portal, as the interviews for the iterated prototype were done in collaboration.

Evaluatiebijeenkomst draaiboek

Doel bijeenkomst

Evaluatie van het prototype ontwikkeld aan de hand van de cocreatiesessies.

Schema

Tiid in minutes	What	Comments	Extra questions
-0.05-00.00	Digitale binnenkomst		
00.00-00.10	Introductie	-Welkom	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?*	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 Scherm delen: -	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		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	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		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	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!

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