

A citizen science website: the ideas of people with rheumatoid arthritis



Lieke Heesink
Universiteit Twente



Monique Tabak
Roessingh Research &
development en
Universiteit Twente



Christiane Grünloh
Roessingh Research &
Development



Ria Wolkorte
Universiteit Twente



Erik Koffijberg
Universiteit Twente



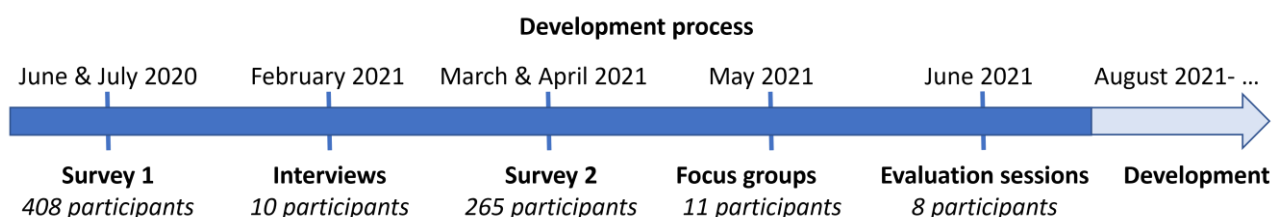
Michelle Kip
Universiteit Twente

Rheumatoid arthritis is a chronic condition. Although much research is being done on it, not everything is known and patients often have questions. For example, about what things contribute to the onset of rheumatoid arthritis, about the best treatment or management of certain symptoms, or about the use of medication.

Patients live with the condition on a daily basis. As a result, **they have gained considerable experience** about the impact on their daily lives, possible treatments, and strategies that can provide relief. This knowledge is a **valuable addition to the knowledge researchers have** about doing research and the knowledge they gain from the scientific literature. Therefore, as researchers in the Citizenlab, we would like to conduct research together with patients. This close collaboration in research is also called citizen science. In order to properly shape this collaboration, there is a need for a place where researchers and patients can have contact with each other and where the research can take place. A website for citizen science seems to be a possibility for this.

Development path

In [previous research](#), 265 people with rheumatoid arthritis indicated that they found such a website important and useful. They also gave their first ideas about what such a website could look like, what should be possible with it and what kind of research should be done there. We used this information as a starting point and then explored it further in group discussions. These group discussions took place in May 2021. Based on those group discussions, we built a sample website - a prototype - and then evaluated it. Those evaluation sessions took place in June 2021.



Group conversations and evaluation sessions

A total of 11 people with rheumatoid arthritis and 5 researchers participated in the **group conversations**. We held 4 group conversations, and each conversation involved 3-5 people with rheumatoid arthritis and 3-4 researchers. The conversations took place digitally via Zoom and lasted 2 hours per conversation. During the conversations, different themes were discussed.

After the group discussions, the researchers built a **prototype** for the website based on all the information. This was a very simple version of the website. This made it clear what a website could look like and what functions the website should have. This prototype was then discussed in the evaluation sessions, so that we got an even better idea of what the final website should look like.

The **evaluation sessions** were also digital via Zoom. An evaluation session was a conversation between one person with rheumatoid arthritis and two researchers. In total 8 people with arthritis and 4 researchers participated. During the evaluation session, we went through a prototype of the website, each time discussing certain parts of it.

The outcomes of the conversations and sessions are used to shape the final citizen science website, as well as to set up the first research on the website.

Outcomes

A lot of information was gathered during all the conversations. All of this will be taken into account when building the website and designing the first survey. Below we list the most important findings.

Privacy and consent

On the website, the intention is to collect data about rheumatoid arthritis. This means that personal and medical data will be collected on the website. In doing so, it is very important that security is ensured and that issues surrounding privacy and consent for the use of data are properly addressed. People with arthritis indicate that it is crucial that the data on the website is **well protected and secured**. Therefore, it is important that data is only shared after people have logged in and are on a secure page.

Furthermore, it became clear that people with arthritis find it important that **they themselves determine who can see their data**. In this respect they find sharing their data with trusted parties, such as researchers connected to the university, no problem. When commercial parties are involved, people with arthritis would like to receive more information to determine whether they want to share their data with them.



People with arthritis also believe that **only relevant data** should be requested and collected, i.e. that careful thought should be given to whether certain information is necessary for research.

People with arthritis indicated that **transparency** is an important condition for gaining people's trust. This can be achieved, for example, by being open about the goals that researchers have with the data collected, as well as about who has access to data. It also helps here if it is made clear which people are involved in the website, as administrators and/or as researchers. It also helps if people can contact the administrators and/or researchers easily.

In addition, people find it pleasant if the website offers the option of adjusting the permission, but also of receiving a **reminder** at regular intervals about the consent that has been given, with the question of whether they still agree to this.

Insights from the data

When people themselves provide a lot of data about their situation, this can be very useful for researchers. It can also provide knowledge to the person providing the data. That is why it is important that the data supplied by people can be viewed. If this is done in a **logical and orderly way**, for example in the form of a graph, it can help to **gain insight into certain aspects of arthritis**. However, to be able to learn something from the data, it is very important that the way of displaying it is easy to understand and that combinations of data are also possible. Therefore, we also paid attention to this.

People with rheumatoid arthritis liked to be able to **view data over time**. It would help here if multiple sources could be placed in one graph, for example, both fatigue and the amount of activity in a day.



Some people like to be able to **compare their own results with average values of other people with arthritis**. This gives them an idea of their own situation. At the same time, there are also people who do not like this at all; because each person is unique and one situation cannot be compared with another, they do not think they can get much added value from such a comparison. It would be nice if the website did offer the option to see average data from the group, but that this option could also be turned off.

Here it is important that the graphs are **easy to understand**. It is unpleasant when you first have to delve deeply into a graph before you understand it.

The website

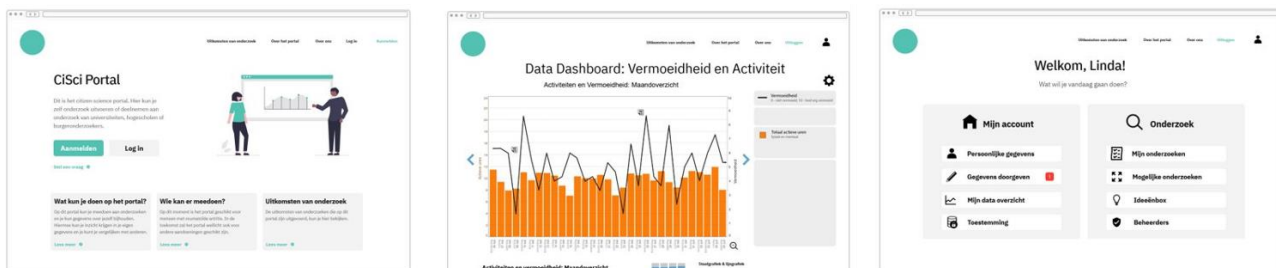
The purpose of the website is to collect data. This means that people should use it regularly to share data. It is therefore important that the website is **easy to use** and that reminders are sent about surveys on the website if necessary. But what makes this website convenient to use? What should it look like? How often and when should (can) reminders be sent?

The people with arthritis who participated in the interviews think it is important that the website is appealing; there should be a **recognizable logo**. Also, **the colors and the use of icons** should support the purpose of the page and be cheerful and appealing.

A very important point is that the website must be **user-friendly**; this means that the website uses **easy-to-understand language**, gives **clear explanations**, and is also **easily accessible** for people with arthritis. The latter means, for example, that account is taken of the fact that boxes to click on are not placed too close together and that there is not too much scrolling. It was also indicated that pages **should not contain too much information and text**.

The website should consist of a **generally accessible part**; this should contain information about the website, such as its purpose and working method. Preferably a combination of text and film is used. It must also be possible to read back the results of the studies. In addition to the generally accessible section, there should also be a **section that you can only access by logging in**. This is the part where data is collected and where it is securely stored and possibly shared with researchers.

Furthermore, it was indicated that researchers and/or administrators should be **easily contacted** in case of questions.



The first research - fatigue

Although it is intended that the future citizen science website will host a lot of research on a variety of topics, we have to start somewhere. From the questionnaires conducted earlier, it was clear that people with rheumatoid arthritis would like to see research on fatigue conducted on the website. **Fatigue due to arthritis is really different from the 'normal' fatigue** that people may experience after a busy period or too little sleep. In the interviews, it became clear that fatigue has a great impact on daily life for a large group of people with rheumatoid arthritis. The fatigue resulting from arthritis is noticeable both physically and mentally. It was further indicated that the threshold at which overload is reached is generally lower, that rest sometimes has a positive and sometimes a negative effect on the feeling of fatigue, and that pain symptoms often seem to exacerbate fatigue. It was also noted that fatigue amplified negative emotions and that it evoked stress. Participants indicated that they try to dose activities, by spreading them out over the day or week, for example. This has a direct effect on the people around them, because people with arthritis sometimes have to cancel activities.

Lack of understanding from those around them is a problem that many people with arthritis face; fatigue is not visible on the outside and because of its capriciousness, more is possible at one moment than at another. One of the biggest frustrations that people with rheumatoid arthritis have with fatigue is its **erratic nature**; it proves difficult to predict how tired someone will feel on any given day. As a result, plans often have to be changed or cancelled. People with arthritis would like to get a better grip on this; **what are factors that contribute to the feeling of fatigue and how can you better predict and/or prevent fatigue complaints in the future?** This is the focus of the first study.



During the interviews we also discussed **what such a study might look like**. People think it is important that **data is collected over a period of time**, because this gives you a better idea of fatigue and what it is related to. At the same time, passing on data is time-consuming and therefore it is **not feasible to keep this up for a very long time**. The right balance has to be found here. **The amount of data** to be collected at a time is also important. **The way in which data is provided** also makes a difference; do you have to keep a diary, assign a score of 1 to 10 each day, or share data by linking a smartwatch or pedometer to the website? People with rheumatoid arthritis indicated that data collection should be as simple as possible, but enough data should be collected to conduct research of high quality.

Conclusion and future

Sport Data Valley

All the information given during the meetings and evaluations helped us to create a list of requirements for the website. After the meetings, we started talking to Sport Data Valley. This is a reliable non-profit organization of several universities that is financially supported by the government. Sport Data Valley has a lot of experience in collecting and displaying people's health data. So far they focus mainly on sports, but we will now work together to make their website suitable for research on chronic conditions such as rheumatoid arthritis. Sport Data Valley already has an existing infrastructure for data collection, so we can be sure that there is a lot of focus on security. In addition, they have the same values and ideas about, for example, ownership of the data (which lies with the person providing the data). In the coming time, Sport Data Valley will build the citizen science website, taking into account the list of wishes that has been drawn up in recent months by people with arthritis and researchers. The plan is that the website will be completed by the end of 2021, so that we can start the first research in 2022.

Complementary research

Although people with arthritis and researchers together have already collected a lot of information, it appears that there are still some questions.

For example, there are questions surrounding the **sharing of data that has been used for research**. There is a growing movement within science to share this type of data - anonymously - publicly with anyone who is interested. Especially for citizen science, openness and transparency is an important issue. For example, others can view or reuse the same data. While this is not a problem for data about air quality, for example, it can raise additional questions for health research. In addition to openness and transparency, guaranteeing the privacy of participants is also very important. Since citizen science is relatively new, little is known about it. Therefore, in the coming period we would like to talk to people with arthritis to hear what they think about it.

We also now have a good idea of the **first study** on the citizen science website. This should be about the erratic nature of fatigue. But what data do we now need to collect to really be able to say something about this? And how are we going to collect that data? How long should people keep track of that data and share it with the platform? As researchers, we also want to answer these questions together with people with rheumatoid arthritis, so that the study produces relevant results, is of good quality, and is practical to carry out for people with rheumatoid arthritis.

For more information or participation in follow-up studies, please contact us via r.wolkorte@utwente.nl.