

## Evaluation of Share Data Valley; a website for citizen science



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At the Citizenlab, we want to do research in which researchers and citizens work together, and in which everyone can contribute their own expertise. This is also called citizen science.

Bringing together the knowledge and expertise of people with arthritis and researchers can be done on a website, such as **Share Data Valley**. Here, people with arthritis can supply data about their condition. This way, they can hopefully gain more insight into their condition themselves. In addition, they can share their data with researchers for scientific research.

### Development process

In a [previous survey](#), 265 people with arthritis indicated that they find such a website important and useful. They also gave their first ideas about what such a website could look like, what it should be able to do and what kind of research should be done on it. In addition, together with people with arthritis we have designed the first research project that will take place on the website. Information and results of that process can be found [here](#). Based on these steps, Share Data Valley was started, where the first research will take place soon. Share Data Valley consists of a homepage, which explains the research, and a secure environment where the data is collected and can be viewed. In order to check whether this environment meets the wishes and requirements of the future users, and to see where we need to provide more information and explanation, we have entered into dialogue with them via interviews.

### Interviews

A total of 10 people with rheumatoid arthritis participated in the **interviews**. Two researchers were present during these interviews. The interviews took place digitally via Zoom and lasted one and a half hours per interview. The landing page and the Share Data Valley website were viewed together. In the interviews, we asked about the perceived user-friendliness among the participants and what their needs and wishes were with regard to the research and the functionalities of the Share Data Valley website. In addition, we looked at the questionnaire that will be used for the research, to hear what the needs, wishes, and experiences were of the participants.

## Outcomes

A lot of information was collected during the interviews. This will all be taken into account when improving the website and when explaining the survey. Below, we list the most important findings.

### Motivations for participation in research at the Share Data Valley website

First of all, people were asked in the interviews why they would participate in research on the Share Data Valley website. Many different motivations were mentioned. A common theme was to **participate to increase knowledge about arthritis or to help others**. These motivations included: to **contribute to research** into arthritis, to **raise awareness** of fatigue as an important symptom, to **help researchers**, and to **help the next generation**.

Another theme that was mentioned by a number of participants was taking part in the research out of **interest and curiosity**. They mentioned that they liked to participate so that they could learn what is going on in the world of arthritis and fatigue, and also to see what other participants have to say about arthritis and fatigue. A number of participants also said that they **enjoy taking part in research**.

The final theme that was mentioned was participation to **gain insight** into their own symptoms and to discover patterns in their chronic condition. Some participants indicated that they would like to participate so that they could get an overview of, for example, their **exercise pattern**. Finally, one participant mentioned that it is also valuable to **take the collected data** to a medical specialist, such as a rheumatologist.



Landing page Share Data Valley

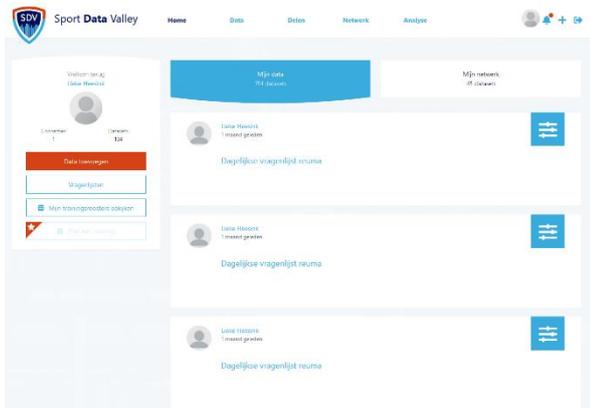
### Landing page Share Data Valley with explanations and background information

On the Share Data Valley homepage, people can find information about the study and explanations on how to apply, how to track data and share them with researchers, and how to view your own data. From the landing page you can click through to the secure part of the website where the data is collected.

Some of the participants indicated that they were satisfied with the **user-friendliness** of the landing page. They mentioned, among other things, that the landing page is has a good lay-out, is clear and makes it easy to understand what the research is about. Participants who saw points for improvement mentioned, among other things, that blocks with information were not in the right place or were unclear, that it was not clear that you could scroll down on the website and that it was

not clear to them that this was the landing page of the survey. They thought this was the page where the questionnaires had to be filled in.

Regarding the appearance of the homepage, people mentioned its **pleasant colour, easy to read letters** and clear structure. However, there were also participants who found the letters on the landing page **harder to read** and that you should give users the option of turning the website **lighter or darker** (because there are participants who may have impaired vision due to medication).



*Website of Share Data Valley where the research will be conducted*

Share Data Valley Website where the research will be conducted

After people have read the information about the research on the landing page, they can go to the secured part of the Share Data Valley website to participate in the research. This part of the website is part of Sport Data Valley, built for secure collection of sports-related data. During the interview, participants could try this out.

A number of people indicated to be satisfied with the user-friendliness of the website. They found the website **well-organised** and **clear**. Participants also found it attractive that the website **works well on a mobile or tablet**. In addition, there were people who saw room for improvement in the user-friendliness. They mentioned, among other things, that sometimes a lot of clicking (or scrolling) is required to get to the right page/place, which can be difficult for someone with arthritis.

Regarding the appearance of the website, people thought it had a **dynamic look** and a **clear layout**. There were also participants who thought that the website contained **(too) much information** and **(irrelevant) buttons**, which sometimes made it look busy and cluttered. There was also some confusion about the Sport Data Valley (the website aimed at collecting sports data) functions that were built into the website but are not used for the research with people with arthritis. This caused some confusion about some functions. Finally, participants were divided about the language and tone that should be used on Share Data Valley. Some wanted a businesslike and formal tone and others preferred an informal tone, because they felt this better suited the idea of researchers and participants working together.

Questionnaire on Share Data Valley

Finally, we reviewed the questionnaire together. Participants could try it out during the interview. In general, people said it was **easy** to fill in the questionnaire. They think they **do not need much time**

to fill it in daily. Participants who were less satisfied indicated that dragging the dot on the line to give a score for, for example their fatigue, was sometimes quite difficult (see image).



In terms of appearance and layout, participants found the questionnaire clear, easy to read and the questions were generally clear. They also liked the fact that there is a button next to the questions for extra information. This makes it clearer what, for example, cognitive activity means. Finally, participants also liked the fact that they could easily fill in the questionnaire on their mobile phones.

Activiteit: Hoeveel uur van de afgelopen 24 uur heeft u besteed aan cognitieve activiteiten?



0    0

Uren    Minuten

Benoem hier het aantal uren waarin u cognitief actief was. Denk hierbij aan vergaderingen of taken voor school/werk waarbij u veel moet nadenken, lezen of puzzelen, etc. 

Als u tegelijkertijd fysiek en cognitief actief was (bijvoorbeeld een intensief gesprek voeren tijdens een wandeling), mag deze bij beide categorieën meetellen.

*Extra explanation appears when someone clicks on the information-button.*

## Conclusion and future

The information obtained from the interviews will be used to improve the website and the research. It will also be used to expand and improve the information and explanations on the Share Data Valley landing page.

When all improvements have been made, we will start collecting data with a small group of people with arthritis by means of the questionnaires. This group will be asked to keep track of the data for a week. If this has gone well, we will broaden the research. At that time we will ask a large group of people with arthritis to fill in a questionnaire every day for three weeks.

For more information or participation in follow-up studies, please contact us at [r.wolkorte@utwente.nl](mailto:r.wolkorte@utwente.nl).