

## Fatigue in rheumatoid arthritis: shaping research together by people with rheumatoid arthritis and researchers



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

Rheumatoid arthritis is a chronic condition. Although much research is being done on it, not everything is known and people with rheumatoid arthritis still frequently have questions. That is why we, as researchers, started talking to people with rheumatoid arthritis about research. One of the topics that people with rheumatoid arthritis want to do research on is fatigue.

To carry out the research, we have developed a **citizen science website** together with people with arthritis. On this website, the knowledge and expertise of people with arthritis and that of researchers are brought together. People with arthritis can provide data about their arthritis. In this way, they can hopefully gain more insight into their condition themselves. In addition, they can share this data with researchers, for scientific research.

### Research on fatigue in rheumatoid arthritis

The first study on this website is about **fatigue** and the various symptoms and activities that may be associated with it. This topic was suggested by people with rheumatoid arthritis. The researchers then searched the **scientific literature** for symptoms and activities that may be associated with fatigue. They also spoke with a **rheumatologist**. Based on the available information, a **list of symptoms and activities** was drawn up that can help provide insight into the occurrence of fatigue. These include physical and cognitive activities or sleep, but also pain and stress. The idea is that on the website data on these symptoms and activities will be collected data for the study.

### Group conversations

This list was then presented to people with arthritis. For this purpose we held group conversations. A total of 20 people with arthritis took part in the group conversations, divided over 3 sessions. Also 3 researchers participated in each discussion. The discussions took place digitally via Zoom and lasted one and a half hours per conversation.

In the group conversations, various topics were discussed, including:

- **Which symptoms and activities are interesting to collect data on;** for example, fatigue, pain, and activities in a day. These should be outcomes that participants can easily measure and report themselves.
- **How this data should be collected;** for example, mentioning activities in a diary, or wearing a smartwatch.
- **How long you would need to collect data** to be able to discern a clear pattern for yourself.
- **How much time participants are willing to spend each day** to collect the data, and how long the period is over which they want to do this.

## Outcomes

Based on the interviews, a final list of questions was drawn up that will be used in the study. It was also decided how long the study will take.

## Measuring symptoms and activities

A distinction is made between data collected on a daily basis and data collected on a one-off basis.

Eight questions will be asked **daily**:

- **Fatigue:** by means of an average grade for the day on a scale of 0-10. *This was seen by participants as a simple way of describing fatigue. It was indicated that fatigue can also vary throughout the day, but participants do not want to provide data more than once a day.*
- Has there been a **peak in fatigue**? If so, what do you think caused it? *Participants indicated that sometimes an attack of fatigue can occur that is so severe that it is impossible to function properly. This is often not long-lasting, but is very important in understanding the pattern of fatigue. To learn more about these peaks, participants are also asked what they perceive to be the possible triggers for the peak.*
- **Pain:** by giving an average grade for the day on a scale of 0-10. *This was seen by participants as a simple way of describing the pain. Previous research suggests that fatigue and pain are related.*
- **Stress level:** using an average grade for the day on a scale of 0-10. *This was seen by participants as a simple way of describing stress. From previous research there seems to be evidence that fatigue and stress are related.*
- **Activities:** 4 types of activities were identified, and for each type the participants were asked how many hours they had spent doing these in the past 24 hours. The types of activity are physical activity, cognitive activity, rest and sleep. *A distinction between heavy and light physical activity was first devised, but the participants found this a difficult distinction to make and one that can vary greatly from person to person. Cognitive activity (tasks that require thinking or concentration) was seen as very important. This is often not included, but can lead to great fatigue. Participants also wanted to see the influence of resting, because resting does not always seem to lead to a reduction in fatigue.*

In addition, more questions are asked **once at the start of the study**:

- **General information:** This includes age, gender, duration of the arthritis and level of education. *This information is used to describe who has participated in the study.* Participants are also asked about medication use and changes in medication, and the joints where most complaints are experienced. *Participants indicated that different medications seem to cause more or less fatigue. Changing medications also seems to influence fatigue. In addition, it was indicated that complaints in different parts of the body can lead to different levels of fatigue, depending on the influence on daily activities.*
- **Fatigue:** This is assessed once using a comprehensive 20-question questionnaire. This is the BRAF, which is specifically aimed at fatigue complaints in people with arthritis. *The questionnaire distinguishes between physical fatigue, cognitive fatigue, emotional fatigue and fatigue in daily life.*
- **Depressive and anxious feelings:** This is assessed with a 14-question questionnaire, the HADS. *Previous research clearly shows a link between depressive feelings and fatigue. It is therefore important to include this information in the study.*
- **Activity pattern:** The SQUASH questionnaire is used for this. *This questionnaire gives a general picture of a person's activities.*
- **Self-efficacy:** The ASES questionnaire is used. *Self-efficacy is a measure of the feeling of control that someone thinks he/she has over dealing with arthritis and the associated symptoms.*
- **Quality of life:** To better understand the impact of rheumatoid arthritis and associated fatigue on quality of life, the EQ5D questionnaire asks about the quality of life experienced by a person.

### Duration of the survey and daily time commitment

Participants indicated that **participation should be easy** and the daily questionnaire should be very short. Completing the daily questionnaire should be easy using **a phone or tablet**, and preferably **within 2-3 minutes**. Therefore, it was decided that the daily questionnaire should consist of 8 questions. Each answer consists of either indicating a score on a scale from 0-10 (fatigue, pain and stress), or entering a number between 0 and 24 hours (activities). Only in the presence of a peak in fatigue will a short textual explanation be requested. With this, the daily questionnaire is expected to take 2-3 minutes.

Participants had different opinions about the duration of the survey. Some indicated that it would not be a problem to complete such a daily questionnaire for a year, others thought 2-3 weeks was the maximum achievable. As participants indicated that 3 weeks of data would be necessary to recognise any patterns in themselves, we opted for **a 3-week survey**. In doing so, we hope to have found a balance between the burden on participants and the relevance of additional data to the study. We hope to be able to offer those interested the opportunity to continue keeping track of their data even after 3 weeks.

## Conclusion and future steps

By bringing together the knowledge and expertise of people with arthritis and researchers, we have been able to shape the research as best as possible. **We would like to continue this collaboration.**

### Sport Data Valley

At this moment the website is being developed and the questionnaires are being put on the website. For this we are making use of the Sport Data Valley platform. Sport Data Valley has been developed by various universities and other research institutes. It is meant to collect data for research in a safe and reliable way. We think this is an important point of attention for a website, and that is one of the reasons why we partnered with Sport Data Valley. Up to now, Sport Data Valley has mainly focused on sports research. We are currently working with Sport Data Valley to find out how this platform can be expanded for research into health and well-being. This does mean that the first research into fatigue in arthritis will take place on the Sport Data Valley platform, and therefore in an environment with an emphasis on sport-related outcomes.

### Next steps

The planning is that the research can **start in the first quarter of 2022**. In the meantime, we will test the website with people with arthritis, and make sure that the questionnaires are as easy to fill in as possible.

We have also discussed our research with, among others, ReumaNederland and ReumaZorg Nederland. Both are positive about this research and we will stay in contact with these parties.

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

