

## A website for citizen science for research purposes: the opinion of people with rheumatoid arthritis



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

Patients live with the condition on a daily basis. As a result, they have gained a lot of experience. This knowledge is a valuable addition to the knowledge that 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 between patients/citizens and researchers is called citizen science. To properly shape this collaboration, researchers and patients need a place to communicate with each other and where the research can be conducted. A website for citizen science seems to be a possibility for this.

To understand patients' wishes about research collaboration and to explore whether a digital environment is a good way to shape such a collaboration, we asked the opinions of people with rheumatoid arthritis. We first asked their opinions through interviews, and later through a digital survey, during the period from February to April 2021.

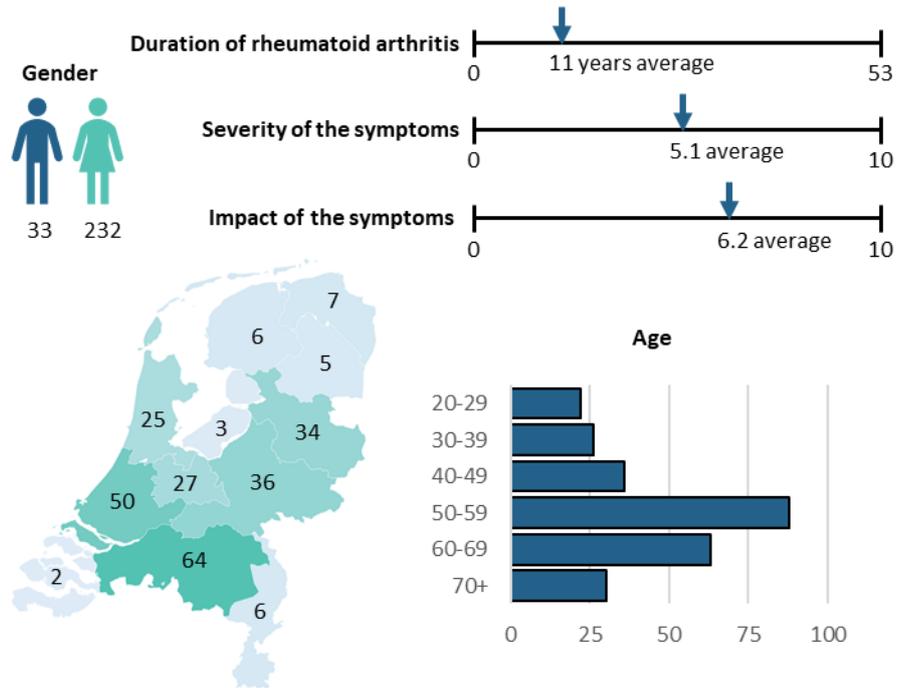
### Interviews

In 10 interviews we talked with patients. First about their ideas on topics related to arthritis that are important to them, relevant research topics, and then about their opinions regarding a citizen science website. We asked about reasons why they would use such a website, what they would like to be able to do on such a website, and what topics they would like to research in a citizen science project. These interviews helped to get a first impression and to create the survey. The interviews with patients were very valuable to prepare the survey, as it helped us to ask the right questions.



## Survey

The survey was distributed digitally over a four-week period via websites, social media, patient associations and by the Medisch Spectrum Twente. The questionnaire was fully completed by 265 people with rheumatoid arthritis. The picture on the right shows more information about the participants.



## A website for citizen science

There was great interest in a citizen science website; 233 patients (88%) found it interesting for themselves, and 257 patients (97%) found it potentially interesting for others.

Patients mainly want to use the website to view the results of studies (212 patients; 80%), to participate in research (192 patients; 72%), to exchange advice with others (167 patients, 63%), to suggest topics for research (105 patients; 40%), to start their own research (92 patients; 35%), and to create an overview of personal data (75 patients; 28%). Fifteen patients (6%) indicated that they would not use a citizen science website.

## User needs for a website for citizen science

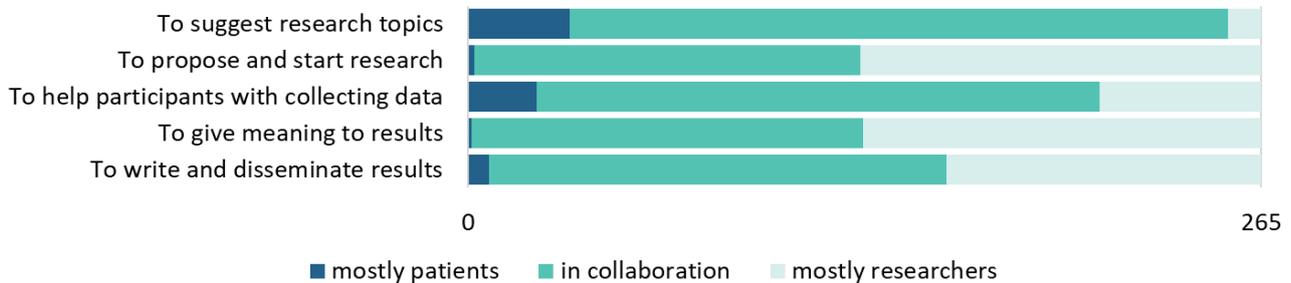
When asked about user needs for the website, the most frequently mentioned needs were that it should be user-friendly and accessible (90x), that the website should be secure and that the anonymity and/or privacy of participants should be guaranteed (57x), that the website should contain simple language and clear explanations (40x), and that the website should contain reliable information (23x).

## Types of research

Different types of research can be initiated through a website. Patients were most willing to participate in survey research (254 patients; 96%), research of short duration (199 patients; 75%), an interview (148 patients, 56%), or research of long duration with weekly data collection (128 patients; 48%). They were less willing to participate in research for which data from a smartwatch or activity tracker could be shared automatically (74 patients; 28%) or research of long duration with daily data collection (56 patients; 21%).

## Roles for patients and researchers

Research consists of various components and the tasks involved can be performed by both patients and researchers. The figure below shows that according to most patients, these tasks should be performed in collaboration, or else researchers should perform certain tasks.



## Research topic

The idea is that eventually multiple research projects can start on the website and run side by side. We will first start with a single research project, to test if the website works well and to possibly improve it. To determine the topic, we looked at both the number of times a topic was chosen, and the amount of money spent on a topic (everyone was allowed to divide 1000 euros between the different topics).

The topic that patients would most like to see research on was fatigue (61,445 euros; 202x), followed by nutrition (45,481 euros; 189x), prevention of rheumatoid arthritis (31,072 euros; 111x), pain (2,845 euros; 134x), stress (21,159 euros; 120x), exercise (17,567 euros; 118x), the weather (14,954 euros; 105x), sports (9,374 euros; 69x), daily schedule/activity level (9,139 euros; 66x), sexuality (5,679 euros; 40x) and support tools (3,085 euros; 31x).



## Conclusion and future steps

This study shows that people with rheumatoid arthritis that participated in our study are open to the idea of a citizen science website. On the website, research can be conducted, to which patients and researchers could contribute in various ways. In general, patients feel that the cooperation between patients and researchers is of added value. Patients propose that the first research on the future citizen science website focuses on fatigue.

In May and June people with rheumatoid arthritis and Citizenlab researchers will be collaborating to determine the functions of the website, what it should look like and the requirements it should meet. Subsequently, developers of Roessingh Research&Development will start to build the website. Hopefully the first research can start in the autumn of 2021.

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