

The views of people with rheumatoid arthritis about controls and the potential role of the HandScan



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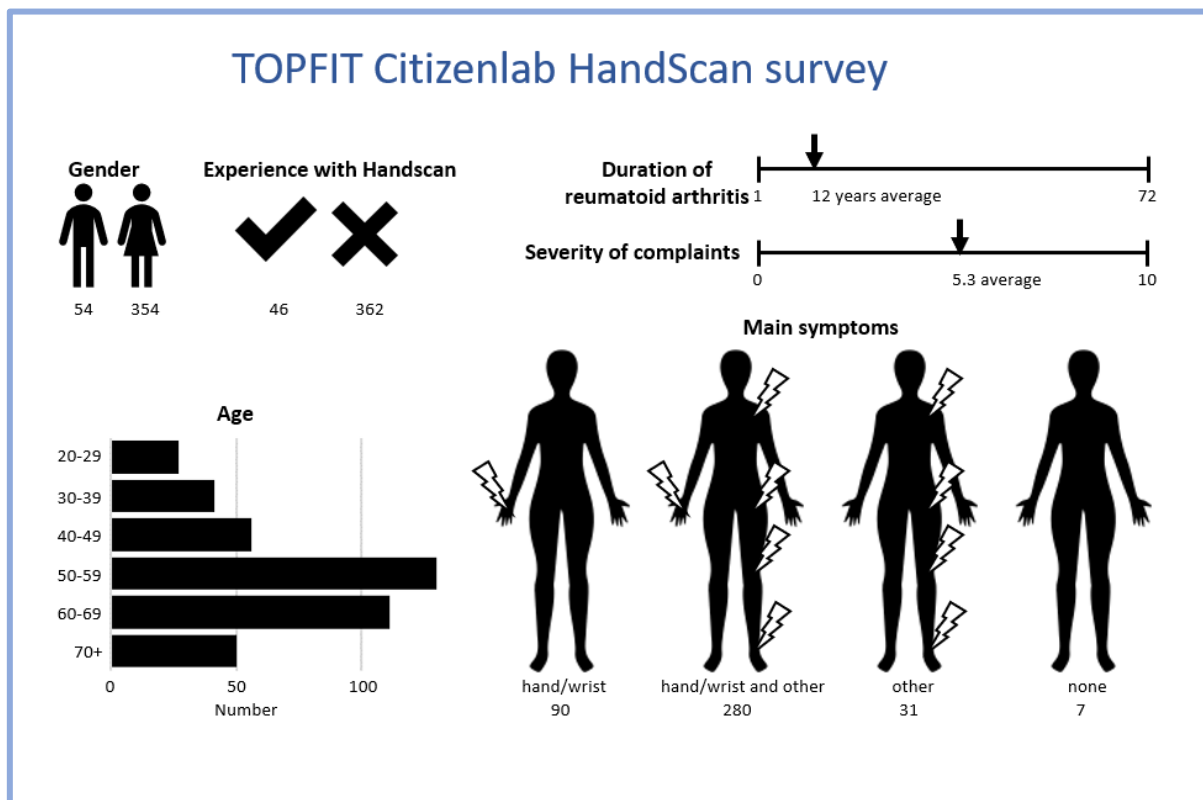
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Inflammation of joints is one of the main problems of rheumatoid arthritis. It is important to keep the inflammatory activity as low as possible. This is now mainly done by medication. To choose the right medication and dosage, it is important to know how much inflammation is currently present and how severe this inflammation is.

In 2020, as part of the TOPFIT Citizenlab, we conducted a survey. We asked about the current practice to monitor inflammatory activity of rheumatoid arthritis. In addition, we investigated whether a new device - the HandScan - could be a valuable addition to the monitoring process.

Participants

The survey was distributed digitally through social media, patient associations and by the Maxima Medical Center. 408 people with RA completed the questionnaire in full and sent it to us. You can see who these people were in the image below.



Monitoring

Most participants had 1 to 4 hospital appointments a year for their rheumatoid arthritis, and almost all (91%) were satisfied with the number of appointments. They were generally satisfied with how often blood tests or physical examinations were performed. However, almost half (41%) said they would like more frequent imaging tests (such as X-rays, ultrasounds, CT scans or an MRI).

In general, healthcare professionals clearly explained the results of blood tests, physical examinations, and imaging tests. Participants reported that they understand these outcomes. Participants indicated that they generally trust the results of the tests and understand what the results may mean for their treatment. They also indicated that there is often sufficient opportunity and time to ask questions. Participants were less positive about their own knowledge of the current state of their RA; of all participants, 27% did not rate this as sufficient.

Just over a quarter (28%) would like to receive more information from their practitioner. This could include more explanation about the current status and test results, but also additional information. For example, about possible other medication that is more effective or has fewer side effects, but also about other types of treatment. Nutrition and exercise are good examples of this. Also, some would like to know more about other complaints than inflammation that may be present, such as fatigue and pain.

Participants rated their role in making treatment decisions as an average of 8.1 out of 10. Only 6% gave this process a failing grade (score of 5 or lower). The main reason for being satisfied or dissatisfied was the cooperation and communication between the doctor and the patient.

HandScan

The HandScan is a new device that uses light beams to determine if inflammation is present in the hand and/or wrist and how severe it is (see figure). Almost all respondents (95%) saw a small or large added value of the HandScan to monitor inflammatory activity. The main reason for not seeing an added value was that these participants themselves had complaints of joints other than those in the hand or wrist. The added value is seen mainly because the HandScan can clearly determine the location and severity of inflammation. Participants prefer to have imaging with the HandScan at all (47%) or some (42%) of the appointments.



When given the choice between an examination with the HandScan or a physical examination, about 1 in 3 chose the HandScan, 1 in 3 chose physical examination and 1 in 3 indicated they had no preference if the results were the same. Participants could elaborate on their choice; here 10% indicated that they would prefer to have both examinations done. The choice for the HandScan was mainly because it was seen as more reliable and objective and as a more pleasant examination. Physical examination was chosen mainly because participants also had many complaints of joints other than in the hand and wrist. Participants who did not have a preference indicated that both had advantages and disadvantages and that they would like the choice to depend on the specific complaints at that time.

Those who were already familiar with the HandScan generally saw a greater added value of the HandScan than those who relied only on the description given in the survey. They also had more confidence in using the results of the HandScan examination for choices around treatment. However, people who were already familiar with the HandScan were not more likely to choose the HandScan over a physical examination; this was similar for both groups.

Participants who indicated that they would like more imaging examinations have less insight into their disease than those who feel that enough examinations are taking place. Therefore, they see a greater added value of the HandScan and indicate that the HandScan should be used more often.

Conclusion and future

This study shows that people with rheumatoid arthritis are generally satisfied with the way inflammatory activity is now monitored (before COVID-19). In addition, people seem to see an added value of the HandScan. At the moment the HandScan is being used in a few hospitals for scientific research and/or in healthcare. In the future, further research is needed to find out whether patients and healthcare professionals are satisfied with the HandScan and whether it benefits the quality of care. It should also be investigated whether the use of the HandScan can be cost-effective.

In the future, the Citizenlab would like to initiate further research in collaboration with people with rheumatoid arthritis on topics of interest to them.

For more information or to participate in future research, please contact us: r.wolkorte@utwente.nl