Newsletter #3 – April 2025

# REMORA2 Patient Newsletter

## Welcome

Welcome to our third REMORA newsletter. How time flies!
Spring is here at last; the daffodils are coming out, and we anticipate that, for some of us, pain will improve with the warmer weather.
An interesting study undertaken by The University of Manchester, Cloudy with a Chance of Pain, in 2016, which analysed 5.1 million pain reports, found that days with a higher humidity, lower pressure, and stronger winds are more likely associated with high pain days which, in turn, can help us to prepare for the bad days.

This finding was only possible because people like us reported back to the researchers. We hope that you enjoy the short video within this newsletter, and we would love to hear how you are getting on. You can update us via the helpline, and, as they say, 'Keep Reporting!'

**Items in this edition include:**
- An introduction to the Research Associate for digital inclusion
- A patient report, providing feedback on their REMORA2 experience so far
- The latest key reminders about the study and the app

**Designed with patients for patients**

**Karen & Paul**
**Co-Leads of the REMORA2 Patient Panel**

**Top Tip:** **Track as often as you like. It doesn't have to be daily, but the more you track, the more your clinician can monitor changes.**

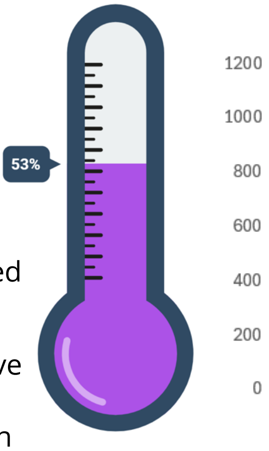
## REMORA2 web survey

Each participant in the REMORA2 trial is sent a link to complete the online web survey every 3 months, starting from when you joined the study and again at 3, 6, 9 and 12 months.

At the start of the study, we worked closely with our patient partners, who advised us what information was important to them and which questions should be included, to help us understand the impact of Rheumatoid Arthritis on our patients.

The more information you provide will help us to see whether technology, like the REMORA app, can help improve your day-to-day life and the number of times you need to see your doctor.

It doesn't matter if you haven't completed or finished any questionnaires that you have been sent so far. Any information you give us through the online survey is really important. So, help us by completing any remaining questionnaires that you receive in the future. This short video explains the importance of the web surveys. Watch here.



**Our REMORA2 thermometer shows the percentage of web survey responses received so far. Please help us to increase this total!**

# Meet the team: REMORA2 Researcher

My name is Josh Behan-Devlin, and I am the Research Associate for digital inclusion on the REMORA2 study. I have recently completed a PhD in social work, where I examined every-day uses of digital technology by social workers and people who use social care services following the Covid-19 pandemic. Prior to this, I worked as a social worker in Trafford, Greater Manchester.

The digital inclusion work stream on REMORA2 aims to develop our understanding of the reasons why people can't or don't want to use the REMORA app. This is important for us (and other teams investigating similar healthcare technologies) to ensure that the benefits of the REMORA app can be enjoyed equitably by all patient groups. I've really enjoyed (and felt rather privileged!) getting to speak to such a diverse range of patients through the interviews I've conducted so far – so thank you for your involvement in REMORA2.

## Anonymous Patient Report

"I was very excited to hear about the REMORA study at a clinic appointment. Once I expressed my interest, I registered onto the study and found the instructions about downloading the app clear and straightforward.

I started by filling in the questionnaires, which were a little daunting, but I believe these are important, and I have just completed my second survey. Having forgotten what I included in the first questionnaire, it will be interesting to see if there are any differences.

As for completing the app, it takes about 30 seconds! The difficulty I have is remembering to do it, so the text reminders are very useful. Interestingly, I have already noticed consistencies, in that I almost always have a very low level of pain (apart from the flares), and I constantly suffer from fatigue and don't sleep very well. It's made me realise that while I wait for my next appointment, I can adjust my lifestyle to try to help. I also find the diary useful, just to note anything I have been doing when I experience a flare. This will be beneficial at clinic because I always forget the bad days.

I will definitely persevere, and I know that help is available via the contact/helpline email, if I need it. I like the fact that I can also contact one of the patient partners, rather than a member of the research team if I want to. I also wonder how other patients are getting on and would be interested in hearing about their experiences!"

## Key reminders

**I've started, so I'll finish…later!** We're pleased to announce that web surveys no longer need to be completed in one sitting. Progress can now be saved to allow you to finish later if you wish.

**Web surveys now open for six weeks.** The completion window has been extended to provide more time to submit your surveys.

**App news:** A new app update is available in stores for all users. Please do update your app when you have the chance.

**Remember:** Are you in the tracking group but haven't downloaded the app yet? Don't worry, you can still take part. Details of how to access the app can be found in your welcome email, or just contact the team at remora2@manchester.ac.uk and we'll be happy to help!

**And finally…don't forget** to tell your clinician that you are part of REMORA!

## Get in touch

If you have any queries about the REMORA2 study or you are experiencing any issues, please email **remora2@manchester.ac.uk** or call **0161 306 2000** to reach the University of Manchester study team.