Newsletter #1 – October 2024

REMORA2 Patient Newsletter

Welcome

Welcome to our first REMORA2 patient newsletter and thank you for joining the REMORA2 study! Like you, we have Rheumatoid Arthritis (RA) and are part of a patient panel working to make sure the study benefits everyone.

Items in this edition include:

- Information about our patient panel (the REMORA2 Patient and Public Involvement and Engagement Group) and details about how you could join us.
- How to access help from our patient support group.
- A story from Dorothy, another RA patient, about how she manages day-to-day.
- An introduction to the research leads on the study.
- A reminder of what to do if you need help with the app, top tips for participating, and details about how to get in touch with the study team.

We recognise that everybody is different, so let us know what you think of the newsletter, whether you'd like to share your patient story, and what you'd like to see in future editions.

Thanks again for being part of the study!

Karen & Paul
Co-Leads of the REMORA2 Patient Panel

Join our Patient and Public Involvement and Engagement Group

Patient and Public Involvement and Engagement (PPIE) is about working with people who use healthcare services and community members to develop research processes and share research findings. The REMORA2 study team work closely with our patient partners and is using feedback from the members of our PPIE group, who each have lived experience of RA, to inform the research.

Click here to find out more about current members

Want to be more involved? We're now looking for two new members to join our PPIE group – get in touch at remora2@manchester.ac.uk if you'd like to find out more.

REMORA2 patient support group

Our REMORA2 patient support group is made up of PPIE group members living with RA who are working alongside our research team. They're available to answer any questions you might have about the trial, using the app or responding to the web surveys.

Please get in touch at **remora2@manchester.ac.uk** or on **0161 306 2000** if you'd like a support group member to contact you. Please note – our patient partners are unable to give medical advice.

Living with rheumatoid arthritis – Dorothy's story

I've been living with RA for 15 years now and wanted to share some of the ways I've tried to care for myself, and how the REMORA2 study can help with capturing and monitoring symptoms and providing information into the research study that will benefit other RA patients in the future.

When you have an 'invisible' disease like RA, you must realise that people only see you as they see themselves, as someone who can do anything they put their mind to. But when you have a disease like RA, you must decide what you want or need to spend your time and energy on.

When I wake up, I check in with myself and set expectations based on how I'm feeling and what I have to do that day. What's my morning stiffness like? How is the pain and fatigue today? Am I experiencing a flare? Managing everyday tasks when you can hardly open your hands or put one foot in front of the other can challenge you on a daily basis.

I have found that the following things have helped me

Finding adaptations and taking my time:
During a flare, I bought a larger handled electric toothbrush, and this is now part of my daily routine.
Making life easier by pacing myself with housework, buying frozen or ready prepared veg, and I batch cook using a slow cooker.

Finding activities that ease the pain, help me relax, and keep muscle tension at bay:
I've started crochet again – it was incredibly painful to begin with but gradually the pain in my hands eased and I felt more relaxed.
Using a hydro pool to help ease my aches and pains (local gym). I go to a special Pilates class tailored to people with physical problems – you might want to check with your local council to see if there's one in your area.
Listening to music to lift my spirits.
Meditation, not for everyone, but it helps me.

I've found that being more in tune with my body and wellbeing in general has helped me adapt to living with RA – knowing when I can do more and when I need to go easy on myself makes a big difference. I try not to tire myself out too much as fatigue is a big problem with RA.

How taking part in REMORA2 can help you and others with RA

As patients, our clinic visits are often many months apart, and so it can be difficult to remember how symptoms have varied or to make sure we report flares and other important, often painful, events. The daily, weekly and monthly questionnaires on the REMORA app capture these symptoms over time and this information is automatically available to our hospital doctors and nurses to review with us when we meet.

This includes difficulties faced with showering, dressing and travel and the discomfort or ability to cope. This information is collected through the web-based surveys. The REMORA2 team worked with their patient partners to put together a set of questionnaires to provide a bigger picture on the impact of RA on the quality of life and use of healthcare by patients with RA. Taking part in the REMORA2 study and completing the quarterly web surveys is just as important as providing information through the app.

Designed with patients for patients

Meet the REMORA2 Co-Lead Researchers

Professor Will Dixon and Dr Sabine van der Veer are the co-leads of the REMORA2 study. Will is a consultant rheumatologist at Salford Royal Hospital and a Professor of Digital Epidemiology at The University of Manchester. Sabine trained as a health informatician at the University of Amsterdam and is now a Senior Lecturer at The University of Manchester.

REMORA2 has been designed to explore how patient-generated data, such as information on symptoms and quality of life, can be used to improve the care and outcomes of people living with long-term conditions. It is the first study of integrated symptom tracking in any disease area in the UK and is only possible because of your help and support – so thank you!

Key reminder

For patients using the app, the more you're able to track your symptoms, the more data there will be to review at your clinic visits. Please don't worry if you miss a day here or there though, simply pick it up again when you can. And don't forget – when you go back to the hospital, tell your clinician you're taking part in the REMORA2 study!

Top tip

After your welcome email, whenever the REMORA2 team send you an email, we also send you a text to let you know an email has been sent. If you haven't received the email, please check your junk folder just in case any emails haven't made it into your main inbox!

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.