

REMORA2 Patient Newsletter



Happy New Year

Welcome to the seventh REMORA2 newsletter. My name is Catherine, and I am a PPIE volunteer for the REMORA2 project. I have been part of the team for 10 years now, and I feel proud to be involved in the project, which I truly believe is making such a positive impact on improving care for those with Rheumatoid Arthritis (RA).

I first started with RA thirteen years ago, and it took almost 12 months before I was diagnosed. However, from that point on, I have had fantastic care, medication, and support to get my life back on track. My appointments are annually now, and it's important to track my RA symptoms in between visits, as without it I would forget the 'ups and downs' in my condition over the year.

It's been a harsh start to the year with the snow and extremely cold temperatures, and I know for some of you - me included - the cold weather increases my pain, stiffness and fatigue. Another good reason to track symptoms, as external factors can impact your condition.

It's so easy to not track when things are going well, but if we don't, it's difficult to get that important picture of symptoms over time that helps you and your Rheumatologist make important changes or decisions regarding your medication and condition. The trial only has three months left, so let's make a New Year's resolution to track, complete the last survey, and support the team and ourselves in getting insights into our symptoms to help with continually improving the quality of care.

Items in this edition include:

- Introduction to the REMORA2 trial statistician
- Information about what happens next as we approach the end of the trial

Catherine, Member of the REMORA2 Patient Panel

Final Chance to Win a £50 Voucher in Our Survey Prize Draw!

Thank you to everyone who has taken the time to complete the survey so far. Your feedback is invaluable to REMORA2!

We're pleased to announce that the **second prize draw has now taken place**. Three more lucky winners have been randomly selected and will receive their Love2Shop vouchers via email shortly.

If you weren't selected this time, don't worry, **there's still one more chance to win!** Our final prize draw is coming up soon, with three £50 vouchers available to win. To enter, simply complete the 12-month survey and opt in to the prize draw at the end.

If you haven't received your invitation to complete the last survey, just let us know by emailing remora2@manchester.ac.uk and we can re-send it. **Good luck and thank you once again for your ongoing support!**



Ask your doctor or nurse to check your progress since your last visit

Meet the Team: REMORA2 Trial Statistician



I'm Colin Everett, and it's great to be working with you on REMORA2. Before joining the team, I spent 14 years with the University of Leeds Clinical Trials Unit, where I worked on trials in heart disease, Primary Sjögren's Syndrome, diabetes, and even writing more effective letters to people. No, that last one isn't me making stuff up: I lead a trial on cover letters to encourage more responses to postal surveys.

My job is to bring all your data together and make sense of what difference symptom tracking in RA can make. As well as merging the data, I'll be keeping an eye out for any inconsistencies and sending them back to the REMORA2 data manager for review. At the end, I'll help write up the reports to ensure we have a clear description of what was done, what we found, and what it all means.

I can't do this without you taking the time to complete the web surveys, so thank you for taking the time to do this!



Entering the Final Stages of the Trial – What Happens Next

As we approach the last phase of the trial, here's what this means for you:

- If you were in the tracking group, once you reach around 15 months from activating the app, your REMORA app will automatically switch off. Some of you may notice that this has already happened!
- At this point, there is **no need to continue tracking symptoms**. You should also receive an email from us explaining what happens next. If you don't receive this email, please let us know and we can resend it.
- Although the app will stop collecting data, you will still be able to open it for a short period. If you've been using the personal diary and find it helpful, you're welcome to continue adding entries for your own use during this time.
- For patients in our usual care group, once you have completed the last web survey, we will send you an email to confirm you have completed the trial.
- **Please note:** When the REMORA2 study ends, the app - including the diary - will no longer open. Before this happens, we'll email you to let you know that closure is approaching. We'll give you time to save anything from your diary and provide guidance on how to delete the app.



If you have any questions about the next steps, please get in touch!

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.