

YOUR Members' Magazine!

NEWSRHEUM



nras

National Rheumatoid
Arthritis Society

**AUTUMN
2023**



New SMILE-RA Module on Exercise has been launched!

UPDATED BSR
PREGNANCY IN RA
GUIDELINES PUBLISHED
.....

'ARTHRITIS DOESN'T
STOP ME...'
.....

WELLBEING
AND JIA
.....



Emma-Jayne Adams
& Mary-Ann Palmer

Patient and Public
Involvement members

NHS Remote Monitoring in Rheumatoid Arthritis Service Trial

King's Health Partners Rheumatoid Arthritis Remote Monitoring Service

The idea of monitoring patients remotely was born from recognising and acknowledging that waiting times in clinic were getting longer, with patients 'in flare' waiting longer than they should be seen, whilst some patients were attending clinic when well. The Rheumatology Service at Guy's and St Thomas's Trust (GSTT) were keen to explore innovations in practice regarding digital monitoring between appointments to gain helpful information on patient health and potentially free up clinic capacity to focus on those that need more support. Being co-designed with RA patients attending GSTT, the trial kicked off in January 2019 with the first four patients, Melanie Martin as Digital Lead for the project, Toby Garrood as Clinical Lead, King's Improvement Science (KIS) as evaluation partner, and collaborative support from the Health Innovation Network (HIN) to scale the remote monitoring service across Lewisham & Greenwich NHS Foundation Trust and King's College Hospital NHS Foundation Trust. To date, the service has been rolled out to over 2000 RA patients.

Although at different stages of our lives, we both understand what it's like to live with RA, with Emma-Jayne being diagnosed in 2004 during her early 20s and Mary-Anne more recently in 2018

Overview of Service

Consenting RA patients receive a monthly text message to their mobile phone.

Text includes a link to a secure online patient survey.

Survey contains 7 questions regarding the patient's health over the past week in relation to their RA disease activity.

Questions cover emotional and physical well-being, with patients providing a score out of 10 for each question.

Answers generate a summary score which, on completion, is added to a graph line chart which shows the patient's scores over the last year/inclusion period.

Open text box towards the end of the survey allows patients to provide additional information to the Digital Pathway Coordinator (DPC) directly, to support survey answers, or to ask questions/seek support.

Scores and additional information are reviewed by the DPC and any concerns are flagged to the RA Clinical Team. The DPC can also text the patient with guidance, e.g., to advise the patient that they should contact the clinical team – providing contact details, when needed.

Regular reminders are sent to the patient until the survey is completed.

Perspective of the two key patient partners

How did we get involved in the RA-RMS project team?

We were involved in the trial before joining the project team. In 2019 after routine consultations at Guy's Hospital in London we were both asked whether we would be interested to trial a new digital monthly RA remote monitoring service (RA-RMS), which aimed to track our RA symptoms and well-being.

The opportunity to be part of the review of this service seemed to arise at the right time for both of us, Emma-Jayne just having decided to move on her from her 20 year career in finance to pursue her passion for nutrition, and Mary-Anne having taken early retirement from a career in risk management. In August 2021 all patients on the trial were advised of two opportunities on the project team. After submitting a letter of interest for the role, highlighting our backgrounds, relevant experience and skills which could potentially support the project, there was an informal interview – with our roles being confirmed in early September 2021.

Although at different stages of our lives, we both understand what it's like to live with RA, with Emma-Jayne being diagnosed in 2004 during her early 20s and Mary-Anne more recently in 2018. We also both have experience of projects in the corporate world and concerns about patient care, so this project piqued our interest. We both felt we could be involved in the discussions surrounding our future treatment and hopefully make a valuable contribution.

Is your appointment when you need it?

Many of us have sat in a busy waiting room in the Rheumatology Department, patiently waiting for our appointment. When you are well this can be frustrating, with busy lives and so many others not doing so well and in need of attention the appointment can feel unnecessary – potentially for both patient and clinical staff. It's when you are experiencing a flare, are experiencing intolerable side effects of a medication or another urgent reason that you need clinical support but with increasingly busy clinics, it is not always easy to get an appointment. Our experience of remote monitoring to date has been positive, as being monitored monthly as part of this trial, we have felt that we have the support of the clinical team.

A vital connection

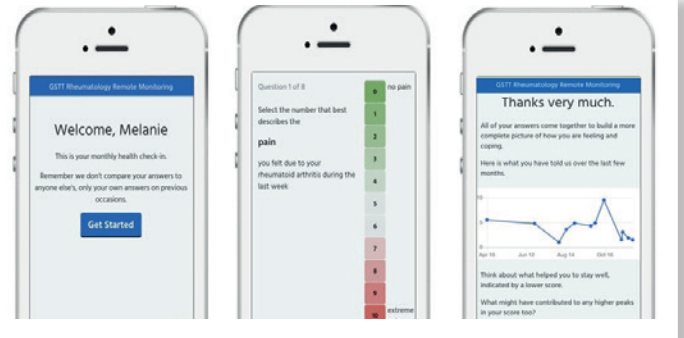
During the pandemic, when we felt quite isolated whilst shielding, the RA-RMS was a vital connection to our clinical team, providing reassurance that we were still being monitored and help was there should we need it. Being a 2-way connection, when Emma-Jayne (despite shielding) contracted COVID-19 and was unable to obtain urgent guidance through the normal channels, she contacted the team directly via the text message function and got the support (and vital antibodies infusion) required.

Time to reflect

Although the survey only takes a few minutes at most, taking the time each month to sit and think about our own health and well-being rather than being swept along with life and just 'getting on with it', it has given us the chance to reflect and take stock. The small graph which is generated once the survey is completed has helped us to see how the summary score and disease have fluctuated, supporting self-management by helping to flag potential patterns and connections to, for example, periods of stress or changes to nutrition. All may seem obvious to some but 'in the moment', when flaring, it may not always be clear.

The project team

In addition to those mentioned earlier, the project team comprised Rheumatology Clinical staff, KIS Patient and Public Involvement coordinators (PPI) and Ailsa Bosworth, representing NRAS. Everyone was incredibly welcoming and patient especially as we tried to get up to speed with the various project documents, terminology and research theories being used. Naturally, the team evolved over time as people moved roles, which occasionally slowed momentum but the sense of positivity, inclusion and commitment remained constant.



The results from both the questionnaires and interviews suggested that patients were extremely positive about the RA-RMS, with some patients noting that they believed that they were being much more closely monitored as a result.



NHS Remote Monitoring in Rheumatoid Arthritis Service Trial *continued*

Our input

As patients with 'lived experience' we were encouraged to get involved as much as we could. We helped structure workshops, questionnaires and 1:1 interview questions for both patients and clinical staff, supported the interpretation and coding of results (giving the patient's perspective) as well as reading and commenting on the draft report. We also wrote blogs for the KIS and HIN websites to provide insight into our experience, hoping to encourage other patients, not just with RA, to get involved with other patient initiatives taking place. Before we got involved with this project, we certainly weren't aware of the many patient involvement opportunities to have your say and make a difference.

Patient results

The results from both the questionnaires and interviews suggested that patients were extremely positive about the RA-RMS, with some patients noting that they believed that they were being much more closely monitored as a result. Whilst some were not fully aware of the two-way functionality, there were also concerns raised that due to the introduction of patient-initiated follow-up pathways (PIFU) the survey may lead to appointments being cancelled and patients going for long

periods, possibly years, without a face-to-face clinical appointment. To date, there are no plans to use the survey results for this purpose and the results suggest that patients feel that they can get appointments when they need them. However, for stable patients moving onto PIFU pathways, this service provides the clinical team with additional information about how patients are doing between appointments. Most patients were overwhelmingly positive about the trial service and see this as a positive addition to their patient care.

Communication

As is often the case, communication was a key area where there are lessons to be learned. Clinicians, particularly those in the smaller sites, were not as positive about the service, suggesting that they were not fully involved in the development and roll-out. With around 2000 patients now using the service, patient communication clearly providing details of what the service is, its functionality, and how the results can be used by both the clinical team and patient are essential. Communications regarding changes to functionality, approach to treatment/monitoring and news of further rollouts are the next priority.

As for us, with the report finished our job is done although we hope to continue to contribute to future developments and be part of the wider PPI team.

Sex hormones and RA remission

It probably won't come as a surprise to hear that hormones could play a role in rheumatoid arthritis (RA). Women are approximately three times more likely to develop RA than men, and common times for women to develop the condition include after giving birth and around the onset of menopause.

A study published in 2022 has now also suggested that hormones could play a part in remission rates, as well as disease onset.

The NORD-STAR study was a controlled trial of early rheumatoid arthritis, covering Denmark, Finland, Iceland, Norway, Sweden, and the Netherlands. The study looked at 4,474 patients and separated them into groups. 2,817 were post-menopausal, 202 were early post-menopausal, 1,021 were premenopausal and 414 were perimenopausal. Analysis showed that the patients in the perimenopausal group were less likely to achieve remission than those

in the premenopausal group. In both the perimenopausal and early post-menopausal groups, significantly higher remission rates were seen when patients were receiving hormone treatment.

This analysis adds to the weight of evidence pointing to periods of hormonal change being important factors for women not just at the point of diagnosis, but in their treatment journey with RA and points to ways to help women in these groups to achieve remission.

