

Rheumatology Research

Academic Rheumatology Newsletter



January 2020

Welcome

Happy New Year and welcome to the first Rheumatology Research Newsletter! The Rheumatology Research Team is employed by University of the West of England (UWE) but located in the Rheumatology Department in the Bristol Royal Infirmary. Being close to the Rheumatology Department means that we can maintain close contact with the clinicians and patients who work and live every day with rheumatic conditions. Patient involvement is vital to our work so this newsletter has been designed to keep you up to date about who we are, what we're doing and how you might get involved.

The team is made up of researchers with a range of backgrounds, including medical, nursing, physiotherapy and psychology. Our focus is on understanding what outcomes are important to patients and the social and emotional effects of living with rheumatic conditions. This includes looking at ways to support self-management and dealing with fatigue. We work with Patient Research Partners who join our project teams to provide insight into the experience of living with rheumatic conditions. If you would like to know more, please get in contact.

Get in touch

Email
rheumatologyresearch@uwe.ac.uk

Telephone
0117 3427415

In future editions

Meet the team - Patient Partners

Current Research Projects -
The FREE - IA Fatigue Study

Anatomy of a Research Project

News

OBE Recognition

We are very happy to report that **Professor Sarah Hewlett** was recently awarded an OBE for 'services to people with arthritis and to nursing research'. Some of you will recognise Sarah who led the UWE Rheumatology Research Team for many years. Sarah gained an international reputation for her work on fatigue and making sure that patients' views and experiences were at the heart of her research. Sarah was a fantastic mentor and colleague and the OBE reflects her outstanding contributions.



Fellowship Awarded



Dr Alice Berry has been awarded an 18 month Launching Fellowship. The fellowship is funded by the Bristol, North Somerset and South Gloucester Clinical Commissioning Group. Currently, some people with musculoskeletal conditions take part in NHS physical activity programmes. Alice would like to understand what happens after these programmes finish and whether people go on to use community services. The idea is that this work will help Alice to plan for a larger study to support people to stay physically active in the community. Congratulations Alice – we look forward to hearing more!

CURRENT RESEARCH PROJECTS

Nordic Walking Intervention for people with Inflammatory Rheumatic Diseases

This project was led by Melissa Domaille, who came research through her role as a physiotherapist in the Rheumatology Department. It was funded by University Hospitals Bristol Research Capability Funding and supported by the hospital's charity Above and Beyond. The project aimed to address two important issues. The first is that patients with rheumatic conditions can find it hard to stay physically active, especially when they experience pain and fatigue. The second is there are limited resources in healthcare, and we need to find new ways of supporting patients to become physically active. One possible solution is tailored Nordic Walking.

(continued overleaf)



Nordic Walking is a whole-body activity which involves using two specially designed poles. It combines walking with core and upper body conditioning, and it can be suitable for a wide range of abilities. Melissa and the team developed a Nordic Walking programme tailored to patients with rheumatic conditions.

The patients who took part attended an initial training session in a small group to learn the basic Nordic Walking technique. This was followed by 10 group sessions for one hour a week over 10 weeks. The sessions took place on the Downs in Bristol. We chose the Downs because it is a flat, grassy public space, with a café, toilets, reasonable parking and public transport.

The tailored Nordic Walking was different to a standard group because we had a physiotherapist to hand, and patients could choose their own pace and distance rather than being part of single group walk. We had a central 'base camp' with chairs for patients to rest whenever they needed to. The group had a warm-up and cool-down together and re-grouped 2-3 times during the hour's session.

We had so much positive feedback! Most patients attended 8 out of 10 sessions and no one dropped out of the study. Afterwards, all 24 patients attended either a focus group or interview to tell us about their experience. Patients emphasised how much they enjoyed the sessions and how they felt better after taking part. They liked learning a new skill and being with other patients with similar health conditions. They liked being in a group with a wide range of abilities and the adaptable routes let them pace themselves without risking over-doing it or holding other patients up. This meant that they still attended on days when they were not feeling as good because they could modify how much they did. Improved balance and posture were two of the main physical benefits reported.



“with the Nordic poles you're more balanced and the posture is very much better. I could walk faster in the end and a longer distance”.

We know that physical activity is beneficial, but it is very challenging to keep it up. We believe that this tailored Nordic Walking might help patients with rheumatic conditions to keep physically active in the long-term. Running the programme in a public space seemed to empower patients to continue and we know that at least 10 out of the 24 patients have bought their own poles. Friendships developed over the 10-week programme. Lots of the patients met to Nordic walk together after the study finished and they are still meeting more than a year later.

Steroid PRO

This study led by **Dr Jo Robson**, Consultant Rheumatologist at the BRI, is exploring how steroids affect patients and the impact they have on their quality of life.

The team is currently looking for patients to interview who have a rheumatic disease (for example rheumatoid arthritis, lupus, vasculitis or gout) and have taken steroids in the last two years. You need to be over 18 years old to take part.

If you would more information please contact RheumatologyResearch@uwe.ac.uk



Meet the Team

Dr Emma Dures, Associate Professor of Rheumatology and Self-Management at UWE and a chartered psychologist, leads the Rheumatology Research Team. Emma's current research projects include investigating a brief intervention for fatigue, exploring patients' experiences of getting a diagnosis of psoriatic arthritis and starting treatments, and looking at the support that is available to rheumatology patients who experience a high level of distress. Emma and the Rheumatology Research Team are supported by Jen Orme.

If you would like to subscribe to this quarterly newsletter please email [Jen Orme](mailto:Jen.Orme@uwe.ac.uk) at RheumatologyResearch@uwe.ac.uk