

Rheumatology Research

Academic Rheumatology Newsletter



March 2021

Welcome

It has been a long and challenging start to the year but with the vaccine rollout and lighter days we hope that this newsletter finds you with a little optimism.

Like so many, the team is still working from home with the odd essential trip into the office. Some research has been able to continue thanks to technology and in this newsletter we focus on the progress some of these studies and some of the research methods we use.

We also meet team member Chris Silverthorne who turned her expertise to health research when she was herself diagnosed with rheumatoid arthritis.

Get in touch

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GCA-PRO Study

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News

New study into nurse helpline

Dr Emma Dures, Dr Jo Robson and Dr Mwidimi Ndosu have been awarded funding from Above and Beyond, the charity that supports Bristol's city centre hospitals. The funding is being used to analyse information from a rheumatology nurse helpline. The researchers will

look for patterns to see who uses the helpline, how often and why. The helpline is an important point of contact for patients dealing with their rheumatic condition and our long-term aim is to see what further support might be needed. The project is being undertaken in collaboration with colleagues from Bristol, Bath and Weston.

Zoom coffee mornings



Members of the research team have been joining patients on online coffee mornings since November. The meetings take place every six weeks and have been arranged as part of the work of Bristol Bones and Joints. Bristol Bones and Joints is a group that brings together patients, researchers, health professionals and organisations that offer care and support from across Bristol and the region. By sharing knowledge and experiences it aims to help patients cope with health conditions that affect their bones and joints.

The coffee mornings are held on Zoom and are open to anyone. They are friendly and informal and conversation has included crafting, joint replacements, baking, GP appointments, vaccines, pets and local walks! If you would like more information or to join us please get in touch.

The FREE-IA Study



Patients with inflammatory arthritis often say that fatigue is one of the hardest symptoms to manage. The FREE-IA team (Emma Dures, Susan Bridgewater and Alice Berry) developed sessions for patients to discuss their fatigue and how to cope with it. In the long-term, the FREE-IA team want to test if the fatigue sessions are effective and reduce the impact of fatigue, but that requires a large scale 'randomised controlled trial' study. This FREE-IA study was to see if a large study is do-able, and if

so, how to plan it. The type of study is called a 'feasibility trial'. We worked with a small number of patients and health professionals to assess whether the idea is practical. This way, we do not spend time and resources on a study that might not be possible.

Though it was a small study the evidence is promising. Healthcare professionals were able to provide fatigue sessions to patients. The FREE-IA team were able to collect fatigue scores and questionnaires from patients and their responses suggest that the sessions were helpful. The team is looking forward to doing the next study.



Meet the Team

Chris Silverthorne, Research Associate

I am a chartered occupational psychologist and decided to move into health psychology after being diagnosed with rheumatoid arthritis. I have worked on various research projects in previous jobs, including in the areas of education, careers and the military. I love the process of investigating to answer questions, solve problems or to just discover facts, thoughts and possibilities. My favourite part of research is talking to people and really listening to what they say. With health research the best part is knowing that what we find out has the potential to help people learn to manage their health conditions and the effects of these on all areas of their lives – to help them to live their best lives.

GAPS II Study

GAPS II was the first project I worked on with the rheumatology research team. It involved talking to patients with psoriasis (an inflammatory skin condition). Patients with psoriasis are at a greater risk of developing psoriatic arthritis (an inflammatory arthritis characterised by pain, swelling and stiffness in the joints) and for which there is no definitive test.

The study looked at the potential benefits of bringing in a screening program to help ensure patients with psoriatic arthritis are diagnosed and treated as quickly as possible. Researching the patients' views was crucial to check that screening would be acceptable if it brought in as part of clinical care.

I spoke with 24 patients over the telephone, asking each patient the same questions about their experience of living with psoriasis and of screening. It was also important to give them flexibility to talk about relevant issues important to them personally and to express their ideas.

The study indicated that screening was viewed as a positive and reassuring experience. Patients particularly valued the fact that the screening appointments were not rushed and said they felt they were really being listened to – this was true for all patients whether diagnosed with psoriatic arthritis during screening or not. Many thanks to Jane Lord and Clive Owen, the patient research partners on GAPS II.

Psychological distress in rheumatology care settings

I am currently working on a project looking into psychological distress in rheumatology care settings. People with rheumatic diseases face challenges including pain, fatigue, flares of disease activity, dealing with complex medical treatments and making decisions about when to seek help with their symptoms. Research shows that people with rheumatic diseases can have higher levels of anxiety and depression compared to the general population. Health professionals report that patients experiencing psychological distress often need extra support and require more time. Patients' concerns can include health-related anxiety and difficulty accepting their diagnosis. However, we are not sure about the best support to offer.

I spoke with UK health professionals working in rheumatology and asked them how they support patients who are distressed and how they think psychological support might be best provided in future. Analysis showed that distress can be obvious or hidden and can cause issues for both patients and health professionals. Health professionals described the powerful link between physical and mental distress and the vicious cycle that can develop. They reported that patients' emotional wellbeing should consistently be given equal priority to their physical wellbeing during treatment and that psychological support should ideally be part of usual care. The next stage of the project will include using these results to develop a proposal for how to make access to psychological support part of routine care in rheumatology. We will be asking patients for their views at this stage. The patient research partners supporting this research are Caroline Swales and Kate Wilkins.

Jargon Buster – Qualitative Data

The type of information, or data, that Chris has been collecting through her conversations with research participants is known as qualitative data. Qualitative data is information in the form of words, pictures or audio files that cannot be counted, measured or easily expressed in numbers. When researchers analyse qualitative data they are exploring people's views and experiences on a topic.

If you would like to subscribe to this quarterly newsletter please email Jen Orme at RheumatologyResearch@uwe.ac.uk