University of Birmingham Rheumatology Research Group (RRG)
Contents

Introduction to the Rheumatology Research Group (RPG) 03
Our Ongoing Research Projects 04
Rheumatology Research Group (RRG) - Staff Biographies 06
Lupus research - Interview with Dr John Reynolds 10
Behavioural research - Interview with Dr Marie Falahee 11
How are patients involved in our research? - The Rheumatology Research Patient Partnership (R2P2) 12
What's it like being a patient research partner (PRP)? Interview with Elspeth Insch 14
Useful links 15
Acknowledgements 15
Introduction to the Rheumatology Research Group (RRG)

Who we are

The Rheumatology Research Group (RRG) at the University of Birmingham is a substantial multidisciplinary team of over 75 staff, including academic/clinical rheumatologists, general practitioners, biological/behavioural scientists, allied health professionals, MSc/PhD students and patient research partners. The RRG works closely with University Hospitals Birmingham (UHB) and Sandwell and West Birmingham Hospitals (SWBH).

Traditionally, diseases are studied in isolation, e.g., a researcher only studies rheumatoid arthritis and nothing else. However, we are interested in looking at a range of different diseases, including rheumatoid arthritis, Sjögren’s syndrome and systemic lupus erythematosus and discovering if their causes have something in common with each other. This will give us a better understanding of the diseases we study and could lead to more significant scientific breakthroughs in the future.

What we do

The overarching aim of the Rheumatology Research Group is to improve clinical outcomes for those with, and at risk of developing, rheumatoid arthritis (RA), Sjögren’s syndrome (SS) and systemic lupus erythematosus (SLE).

We do this by developing diagnostic tests, drugs and therapies to predict, prevent and reverse the causes and effects of disease.

Other research aims include:
- Predicting the course of disease from the earliest stages of symptoms
- Comparing common traits across a range of inflammatory diseases and using these as a way to identify potential treatments
- Understanding how patient beliefs and behaviour affect clinical outcomes

Specialist areas and achievements

- Our research has demonstrated the importance of early treatment for RA
- We have pioneered the use of ultrasound to guide biopsies of inflamed joints
- We have identified new cell types in the joint—some that come from the blood and some which originate in the joint—that play fundamental roles in regulating the switch to persistent disease in patients with arthritis
- We have identified a cell that controls the involvement of salivary glands in people with Sjögren’s syndrome
- Our work in bone biology has identified a new interaction between cells that determines if bone is made or destroyed
- We have developed methods to analyse blood, urine and joint fluids, which have allowed us to predict the effectiveness of RA drugs and the progression of early arthritis
- We have shown the level of side effects that people at risk of developing RA would tolerate in return for a treatment to reduce their risk of RA
- Our patient research partners have played important roles in the projects which have led to these important discoveries and we are very grateful to them for their significant contributions
Our Ongoing Research Projects

Biomedical Research Centre - BRC

The National Institute for Health Research funds a number of Biomedical Research Centres (BRCs) across the UK. In 2017, Birmingham was awarded £12 million for a BRC exploring a range of inflammatory disease themes, including inflammatory arthritis, sarcopenia (loss of muscle mass & strength) and gastroenterology.

The aim of the inflammatory arthritis theme of the BRC is to improve outcomes for people who have (or are at risk of developing) rheumatoid arthritis and Sjögren’s syndrome. Diagnostic tests, drugs and cell-based therapies are being developed to predict, prevent and reverse the causes of disease.

There are a number of patient involvement groups linked to the BRC, including representatives from the Rheumatology Research Patient Partner group (R2P2), liver and ageing.


Research into Inflammatory Arthritis Centre - RACE

This Versus Arthritis UK-sponsored project is partnership between the University of Birmingham, the University of Glasgow, Newcastle University and University of Oxford, which aims to speed up the progress towards finding a cure for rheumatoid arthritis.

RACE aims to identify:
- Why rheumatoid arthritis begins
- Where it starts and why it attacks the joints
- Why it persists
- Whether we can develop new treatments

It will do this by:
- Bringing together researchers from four leading universities
- Recruiting the best young scientific minds
- Engaging with patients to guide our research

www.race-gbn.org

Arthritis-Therapy Acceleration Programme - A-TAP

The Arthritis Therapy Acceleration Programme (A-TAP) is an exciting new concept funded by the Kennedy Trust for Rheumatology Research. It brings together the Universities of Birmingham and Oxford and seven NHS partners across the Midlands and Oxfordshire. The A-TAP will support and develop new treatments for arthritis based on the underlying causes of inflammatory disease (including rheumatoid arthritis, Sjögren’s syndrome, inflammatory bowel disease and spondyloarthritis).

One of the key objectives of the A-TAP is to match the right drug to the right disease indication early in drug discovery. We collaborate with industry partners for A-TAP studies, with a focus on repurposing drugs, combination therapies and new experimental drugs. We are also developing basket trials - a clinical trial in which one drug is tested in more than one disease.

We work with a number of inflammation patient groups and charities to encourage patients to enter clinical trials.

www.a-tap.ac.uk
www.ndorms.ox.ac.uk/a-tap
BIOFLARE – BIOlogical Factors that Limit sustained Remission in rhEumatoid arthritis

BIOFLARE is a research study funded by the Medical Research Council (MRC), investigating the causes behind ‘flares’ (or relapses) in patients with rheumatoid arthritis (RA). Within BIOFLARE, we ask patients with RA, in remission, whether they would like to stop their medicines. If they do, we assess them at intervals for 6 months after stopping treatment. When they initially stop their medicines, and again if they flare, we will also ask to take a sample of the lining of their inflamed joint in a simple procedure which does not require admission to hospital.

By comparing samples from patients who flare and those who don’t, we will be able to gain a better understanding of the pathways that trigger flare. In the longer term, this should allow us to develop treatments that prevent or interrupt flare, as well as to predict the patients who are most likely to flare, in whom it is less safe to stop treatment. We believe that this could lead to new treatment approaches for such patients, enhancing their quality of life and long-term health.

https://gtr.ukri.org/projects?ref=MR%2FN026977%2F1

POLARISE – Clinical trial

POLARISE is a clinical trial investigating the safety and activity of the use of a drug called ORBCEL-C™ in the treatment of patients with primary sclerosing cholangitis, rheumatoid arthritis, lupus nephritis and Crohn’s disease. The trial is seeking to investigate whether prescribing ORBCEL-C™ improves patient disease activity, physical function and quality of life.

The trial, which started in March 2020, will recruit 60 patients across these four diseases. RRG staff are working with the Midlands and Wales Advanced Therapy and Treatment Centres (MW-ATTC) to deliver the rheumatoid arthritis part of the POLARISE clinical trial. The MW-ATTC is a UK-funded initiative aiming to develop and deliver complex cell and gene therapies across the NHS.
Rheumatology Research Group (RRG) - Staff Biographies

**Professor Karim Raza**
Professor of Rheumatology (supported by Versus Arthritis) and Honorary Consultant Rheumatologist, Sandwell & West Birmingham Hospitals
Specialist area: Rheumatoid Arthritis

Karim is a rheumatologist and sees patients at City Hospital, Birmingham. His research is concerned with developing ways to make sure that people with RA, or at high risk of developing RA, are treated as early as possible.

**Professor Andy Clark**
Professor of Inflammation Biology
Specialist area: Rheumatoid Arthritis

Andy is a molecular biologist with a long-standing interest in how expression of inflammatory mediators is switched off, contributing to the resolution of inflammation.

**Professor Dagmar Scheel-Toellner**
Professor of Inflammation Research
Specialist area: Rheumatoid Arthritis

Dagmar’s major focus is the investigation of a type of immune cell in the joints of patients with rheumatoid arthritis. She is currently working on a new therapy targeting these cells, to develop a new treatment for inflammatory diseases.

**Professor Adam Croft**
Professor of Translational Rheumatology and Honorary Consultant Rheumatologist, Sandwell & West Birmingham Hospitals and University Hospitals Birmingham
Specialist area: Inflammatory Arthritis

Adam is a rheumatologist, interested in the management of early and treatment resistant inflammatory arthritis.
Dr Andrew Filer  
Reader in Translational Rheumatology and Honorary Consultant Rheumatologist, University Hospitals Birmingham  
Specialist area: Rheumatoid Arthritis

Andrew is a specialist in rheumatology and using ultrasound to look at the insides of joints. In arthritis, ultrasound allows us to see inflammation going on in real time in the joints, and is much more sensitive than examination using just the hands to detect that inflammation.

Dr Helen McGettrick  
Reader in Inflammation and Vascular Biology  
Specialist area: Rheumatoid Arthritis

Helen is interested in understanding the cells and molecules that control the movement of immune cells across blood vessels in health, and how these change in disease. She is also interested in how bone is formed and repaired in development, as we age and in response to injury.

Dr Ben Fisher  
Senior Clinical Lecturer in Rheumatology  
Specialist area: Sjögren’s Syndrome

Ben is a rheumatologist at the Queen Elizabeth Hospital and his research is concerned with measuring how active a patient’s disease is, and developing new treatments for Sjögren’s syndrome. He also seeks to understand what makes a person more likely to develop Sjögren’s syndrome or, rheumatoid arthritis, when others do not.

Dr Paola de Pablo  
Senior Clinical Lecturer in Rheumatology and Honorary Consultant Rheumatologist, Sandwell & West Birmingham Hospitals  
Specialist area: Rheumatoid Arthritis

Paola’s current research investigates whether new imaging technologies can help to diagnose RA earlier and assess response to therapy more accurately.
Dr John Reynolds
Senior Clinical Lecturer in Rheumatology
Specialist area: Lupus

John’s research looks at the affected tissues, such as skin and kidney, in patients with different autoimmune diseases to see if there are common features. This will help to redefine these conditions and develop new treatments. John is also interested in why some patients with lupus respond well to treatment and others do not.

Dr Amy Naylor
Versus Arthritis Career Development Fellow
Specialist area: Rheumatoid Arthritis

Amy’s research builds on recent discoveries that a specific type of blood vessel in the bone can drive bone formation. Understanding this further function could provide a new way to boost new bone formation and therefore improve bone repair and strength. The earlier we can treat patients with age-related or arthritis-induced bone damage, the better the long-term prognosis will be for the individual in terms of disability and mortality.

Dr Rowan Hardy
Arthritis Research UK Career Development Fellow
Specialist area: Rheumatoid Arthritis

Rowan’s research explores new ways of targeting existing long-term drug treatments for rheumatoid arthritis to minimise their negative side effects whilst maintaining their positive anti-inflammatory actions.

Dr Marie Falahee
Lecturer in Behavioural Rheumatology
Specialist area: Rheumatoid Arthritis

Marie’s research explores the ways in which people’s perceptions affect whether they accept treatments, keep taking them and the extent to which their condition improves. She is interested in improving the methods used to measure patient perspectives, and is a passionate advocate for actively involving patients in the research process.
Professor Caroline Gordon
Emeritus Professor of Rheumatology
Specialist area: Lupus

Caroline is interested in helping people with lupus to get diagnosed promptly and treated appropriately so that they have better quality of life and fewer complications from the disease and its treatment than people have had in the past. She has been involved in studies across the world to determine if people from different backgrounds are more likely to get lupus.

Professor Simon Bowman
Honorary Professor of Rheumatology
Specialist area: Sjögren’s Syndrome

Simon is a rheumatologist, based in Milton Keynes, focusing on primary Sjögren’s Syndrome. He has led a number of research projects and clinical trials in this area, both in the UK and Europe.

Professor Chris Buckley
Kennedy Professor of Translational Rheumatology
Specialist area: Rheumatoid Arthritis

Chris was the theme lead for the Rheumatology Research Group until June 2021. Chris’s research is focused on stratified pathology, which involves studying a range of inflammatory diseases in order to choose the right disease indication for the right drug.
Tell me about your research
I am a senior clinical lecturer in rheumatology, specialising in lupus. I look at the tissues affected by lupus (such as the skin and kidneys) in patients who have other inflammatory diseases to see if we can find common features. This will help us to redefine these conditions and develop new treatments.

What is your most important discovery, and why is this significant?
I suspect that my most important discovery is still to come. We are currently working on building a statistical model that will predict which lupus patients are likely to respond to particular drugs. If successful, this has the potential to change how we use certain drugs in the clinic. This is part of a national effort by both research groups and pharmaceutical companies in the UK to try to identify which patients are likely to respond to which drug.

What got you interested in this research area?
I think that it is always important to have a mentor, and it was Professor Caroline Gordon who first introduced me to lupus in the clinic and lupus research. Although lupus is an uncommon condition, it is life-changing for those it affects. Compared to some other conditions, we still know relatively little about what happens in the immune system and other cells in lupus patients, and why it affects different people in different ways.

What is your favourite aspect of your research?
Probably the variety. Although my focus is on lupus (and related conditions), I am involved with projects in which we study a small number of patients in detail, and larger national and international projects of 100s or 1,000s of patients. Collaboration with other researchers is always really exciting, especially when they have new skills or expertise to really push the research forward.

Why do you think it is important to look at other inflammatory diseases alongside your lupus research?
Lupus has lots of features which are also seen in other inflammatory diseases. We don’t yet know whether the immune system processes are the same or different in lupus compared to these other conditions. If we can study them together, we can move more quickly to identify new treatments that work across a range of different conditions.

What are your experiences of involving patients in your research?
As part of the MRC-funded MASTERPLANS project, we had a group of lupus patients and their carers working alongside us. Patient partners were present at every meeting and were involved in all aspects of the project, from designing the study to understanding the data and communicating the results. It is a privilege to be able to work with patients who are interested in research; in my experience they always think of things that nobody else has thought of and always ask the best questions!

What are your hopes for the future?
It would be wonderful to be able to prevent people from developing lupus, or to have a cure. I think this is a long-term goal. In the shorter term, I would hope that we can have better ways to identify which is the right treatment for each patient. A personalised approach to treatment like this should allow us to make patients feel better quicker with fewer treatment side effects.
Spotlight interview

Behavioural Research
Dr Marie Falahee

What is behavioural research?
Behavioural science investigates the factors that affect people’s actions, habits and decisions. My background is in psychology, so I’m particularly interested in how people’s beliefs and perceptions explain why they do what they do!

Why is behavioural research important within rheumatology?
There are many aspects of people’s behaviour that affect their health. For example, how quickly they seek help when they first develop symptoms; the extent to which they take their treatments; their lifestyle; their psychological-wellbeing, and so on. These are all important determinants of clinical outcomes for many diseases, but especially for musculoskeletal and autoimmune conditions. Understanding how to assess people’s experiences is also important to measure outcomes such as pain and fatigue, which are very important to patients.

What kind of research projects have you been involved with?
It’s well established that early treatment of rheumatoid arthritis (RA) results in much better outcomes for patients, and there’s increasing interest in the idea of identifying and treating people who are at risk of getting RA in the future, to try and stop RA from developing in the first place. I’ve been involved in several projects to investigate people’s perceptions about this approach, and the preferences of ‘at risk’ groups for preventive treatments.

I’m also involved in projects to investigate and address why many people don’t visit their GP when they first develop symptoms of RA until after the ideal time to start treatment has passed.

Another key area of interest for me is understanding how symptoms such as pain, fatigue, and depression evolve over time, before and after treatment.

What have been the key outcomes of your research to date?
My work on preferences for preventive treatments for RA is currently being used to inform international guidelines on how and when patient preferences should be incorporated into the development of new drugs. I’m also proud to have been involved in the development of information resources for people who may be at risk of developing RA in the future. For example, a brochure for patients to pass on to their relatives about RA and how to reduce risk of RA is now available through the National Society for Rheumatoid Arthritis (NRAS).


Can you talk about your own experiences of patient and public involvement/engagement?
I believe passionately that research is improved by patient involvement. Working with patient research partners is one of the most enjoyable parts of my job. Knowing that my research is important to them is hugely rewarding, and I’m never ceased to be amazed at how much our research, and our researchers, benefit from their input. Patient research partners also have an important role to play in helping us to communicate with the public about our research effectively. The more people know about our research, the more likely it is to have real impact, and result in real benefit for patients.
The Rheumatology Research Patient Partnership (R2P2) is a group of patients who support the work of the Rheumatology Research Group at the University of Birmingham. Patient research partners (PRPs) are actively involved in the research process, advising us about:

- what research we should be doing
- how should we be doing it
- how should we be sharing and using research findings

We believe that involving patients in our research helps us to ensure that it is relevant and efficient.

Our patient partners:

- support applications for research funding
- ensure that materials developed for patients are written in language that is clear and understandable
- give their opinions on patient priorities for research
- help us to design research studies that are ethical and acceptable to patients
- mentor the next generation of researchers through the Student Patient Alliance

How much time commitment does it take to be a patient partner?

That's up to you! Our patient partners choose to get involved when they are interested in particular projects/events, or when they have enough spare time. All patient involvement is always voluntary.

Will I be paid?

Sometimes we are able to offer payments/shopping vouchers in return for contributions to specific projects that have funds for patient involvement. Sometimes this is not the case and patient partners often contribute their time voluntarily. We always refund any travel and parking expenses.

Do I have to come to the University/Hospital?

Occasionally, researchers may invite you to attend a meeting at the University, or at a hospital site. Attendance is always voluntary.

There are also many opportunities to contribute via email, virtual meetings, telephone or by post if you prefer not to attend in person. All contact during the COVID-19 pandemic is conducted online or by telephone.

What else can I expect?

We encourage our researchers to provide you with feedback about how your contribution has made a difference. We also try to keep you informed about our research, and the impact of patient involvement, via regular newsletters, our website, and events for our patient partners. These events also give patient partners opportunities to get together and share their experiences.

Do I need to have any qualifications?

If you are affected by rheumatoid arthritis, Sjögren’s syndrome or lupus then you are welcome to join R2P2, whatever your education or background. We value the expertise you have because of your experience as a patient, relative, or carer.

Where can I find out more?

Check out our website www.birmingham.ac.uk/r2p2 and follow us on Twitter @R2P2_UoB

How do I get involved?

Contact Becky Birch for further information and details about how to join.

Email: r.birch@bham.ac.uk
Telephone: 0121 371 8115
Address: College of Medical and Dental Sciences, Research and Knowledge Transfer Office, University of Birmingham, Edgbaston, B15 2TT.
Please note

If you want to participate in rheumatology research (ie, receive new treatments through clinical trials), please speak to your doctor or rheumatology team.

If you want to get involved with how our rheumatology research is conducted (ie, working with researchers on grant applications, contributing to focus groups/ questionnaires etc), you may like to consider joining R2P2.
Spotlight interview

What’s it like being a Patient Research Partner (PRP)?

Elspeth Insch
Patient Research Partner
R2P2 – Rheumatology Research
Patient Partnership

How did you become a patient research partner (PRP)?
I’ve been a patient research partner for about four years. It all began on my first visit to the QE Hospital for an appointment with a lovely consultant called Andrew Filer. At that appointment, I felt able to ask him questions and get answers that I’ve not had before. He then said to me, ‘Why don’t you get involved with us in the rheumatoid arthritis department?’ I had absolutely no idea that patients were involved at all with research. I thought it would be interesting and stimulating, so I went for it.

What kind of activities have you been involved with?
I have been to a variety of meetings which are often very sociable, as well as informative and, at times, mentally challenging. I’ve been to lots of conferences, open days and events too. I also do proof reading for funding bids and journal articles and hope that ‘my’ researchers are successful. I’ve also been involved with a variety of representatives from different disease groups at the QE Hospital in Birmingham and have come to understand the exciting work that is being done. One of the things I have particularly enjoyed is working with a research student; that has been real fun.

I’m also involved in RACE (Rheumatoid Arthritis Centre of Excellence), which is a collaboration between Birmingham, Oxford, Glasgow, and Newcastle. I’ve met scientists from all four universities and it’s been an incredibly stimulating experience and really stretched my understanding and knowledge.

What has been the most rewarding thing about being a patient research partner?
I think the most rewarding thing is the feeling of being able to give something back. I’m really grateful for the help that I’ve had in overcoming my rheumatoid arthritis and stopping it from being as bad as it otherwise might have been. I’ve really felt valued which is nice.

How much time does it take to be a patient research partner?
As much time as you let it! Sometimes I’m really busy when I’m proofreading, particularly if it’s a very short deadline. You have the control and nobody ever seems offended if you say, ‘Sorry, I can’t do this at the moment’. And they’re always immensely grateful for our help.

How is being a patient research partner different to a clinical trial?
Being involved in clinical trials is different from being the sort of patient research partner that I am, but I would say to you, if you have an opportunity to be part of a trial, do it.

What would you say to someone who was considering being a patient research partner?
There’s plenty to do for someone who is considering being a patient research partner. People with all sorts of experiences are needed and you don’t have to have a scientific or academic background. There are many different roles we can play. You have control over your involvement, and you’ll find that you will feel valued and useful. You’ll gain knowledge and personal skills and you get to meet such nice people. So if you’re thinking about it, go for it!
Useful links

Rheumatology Research Group (RRG)
www.birmingham.ac.uk/research/inflammation-ageing/rheumatology-research-group.aspx

Rheumatology Research Patient Partnership (R2P2)

Research into Inflammatory Arthritis Centre (RACE)
http://race-gbn.org

NIHR Biomedical Research Centre Birmingham (BRC)
www.birminghambc.nihr.ac.uk

Twitter feeds

Rheumatology Research Group
@RRG_Birmingham

R2P2
@R2P2_UoB

College of Medical and Dental Sciences
@unibirm_MDS

Inflammation and Ageing
@InflamAge_UoB

Rheumatology research charities

Versus Arthritis
www.versusarthritis.org

National Rheumatoid Arthritis Society (NRAS)
www.nras.org.uk

British Sjögren’s Syndrome Association (BSSA)
www.bssa.uk.net

Lupus UK
www.lupusuk.org.uk

Fundraising

You can support research at the University of Birmingham through the Development and Alumni Relations Office (DARO):
https://www.birmingham.ac.uk/university/colleges/professional/daro/index.aspx

Acknowledgements

Thank you to John Rowland and family for their generous donation, which has enabled us to produce this brochure. John led the City Hospital rheumatology patient support group, and was a founding member and significant contributor to R2P2. John sadly passed away in 2017 and is deeply missed by us all.

Thank you also to our R2P2 patient research partners, who have contributed to the development of the content of this brochure. This brochure was supported by and presents independent research funded (or supported) by the National Institute for Health Research (NIHR) Birmingham Biomedical Research Centre at the University Hospitals Birmingham NHS Foundation Trust and the University of Birmingham (Grant Reference Number BRC-1215-20009). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

This brochure presents work that was funded/supported by Versus Arthritis (grant number 22072) via the Research into Inflammatory Arthritis Centre.