

# R2P2 Newsletter Summer 2018



**Birmingham**

**Rheumatology Research**

**Patient Partnership**

## *Welcome to the 2018 edition of the R2P2 newsletter*

We are extremely pleased to welcome you to the 2018 edition of the Birmingham Rheumatology Research Patient Partnership (R2P2) newsletter. R2P2 facilitates the active involvement of patients in the work of the rheumatology research group at the University of Birmingham. A number of people affected by rheumatoid arthritis, Sjögren's Syndrome, Lupus and other musculoskeletal conditions have already joined R2P2.

We see the involvement of patients and members of the public in research as essential to ensure it is relevant, appropriate and efficient. Patient involvement holds the key to a brighter future – innovation, validation and collaboration in health service research.

For further information, please visit us on <http://www.birmingham.ac.uk/R2P2> or contact us directly:

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Dr Gwenda Simons – Researcher	<a href="mailto:g.simons@bham.ac.uk">g.simons@bham.ac.uk</a>	0121 371 3235
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This is the first issue of the R2P2 newsletter for some time, and there are likely to be things we can do differently. If you have any feedback on the content or format, please don't hesitate to contact Becky.

If you have any items for the next newsletter, (e.g. upcoming events) please let us know and we'll endeavour to include it!

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# Rheumatology Research Patient Partnership (R2P2) Summer Lunch

Liberty Room, Winterbourne House  
Thursday 19<sup>th</sup> July 2018

## Schedule

### Feedback session (12-1pm)

- Welcome (Marie Falahee and Gwenda Simons)
- What's new in the rheumatology research group? (Karim Raza)
- Introduction to the BIO-FLARE study (Berny Dyke)
- Update on the 'Mind the Risk' study (Marie Falahee and Imogen Wells)
- The importance of shared understanding (Richard Lehman)

### Lunch (1pm-1.30pm)

### Informal discussion (1.30pm-3pm)

Suggested topics include:

- How do we measure up against standards for patient involvement in research?
- How to give feedback on a lay summary
- Patient priorities for rheumatology research
- Patient involvement in researcher training
- Patient involvement in academic meetings and conferences
- General Q&A

Feel free to suggest other topics on the day!

Our guests are welcome to stay on after the meeting and explore the historic house and beautiful botanic gardens at Winterbourne.

## Save the date!

All R2P2 members are welcome to attend our summer lunch on Thursday 19<sup>th</sup> July 2018 in the Liberty Room, Winterbourne House. This will be a great opportunity to catch up with everyone and for us to thank you to you for your continued involvement and support for the research carried out by the Rheumatology Research Group. You are welcome to stay on after the meeting and explore the historic house and beautiful botanic gardens at Winterbourne.

If you'd like to join us on 19<sup>th</sup> July, please contact Becky Birch on 0121 371 8115 or [r.birch@bham.ac.uk](mailto:r.birch@bham.ac.uk), highlighting any specific dietary requirements you may have.

**About the venue:** Winterbourne House is an Edwardian historic house set in beautiful gardens. We have booked the Liberty room for this event, which is located at the second floor and accessible by lift. There is parking at the house, including a number of blue badge spaces next to the main entrance. Bus 98 (from New Street / city centre) stops right outside the house and the train station (University) is a 10-15 minute walk away across campus.

Winterbourne House and Garden,  
University of Birmingham,  
[58 Edgbaston Park Road](https://www.winterbourne.org.uk),  
Edgbaston, Birmingham, B15 2RT

<https://www.winterbourne.org.uk>  
0121 414 3003



## Project Update: BEACON cohort



On Wednesday 23rd May 2018, we celebrated the last 6 years of progress in BEACON, the **Birmingham Early Arthritis Cohort**. Patients from this cohort take part in research conducted by members of the rheumatology research group. Several R2P2 patient research partners will have contributed to one or more research projects which fall under the remit of BEACON and during the celebratory series of talks, Dr Marie Falahee gave an excellent overview of patient and public involvement and engagement within BEACON.



The event was attended by clinicians, scientists, patients from the BEACON cohort, members of R2P2 and other interested parties. Besides Marie's talk there were talks and project updates from clinicians and scientists. Jackie Cobb gave an excellent overview of BEACON from a research nurse perspective. Besides this participants enjoyed talking over a cuppa and a celebratory piece of cake!

## Project Update: RACE



A team of R2P2 members have been working with the researchers involved in our Arthritis Research UK Rheumatoid Arthritis Pathogenesis Centre of Excellence (RACE) to develop our research strategy for the coming years, and to write a lay summary of our application for funding to renew RACE for a further 5 years. We have yet to hear whether this application has been successful so watch this space!



RACE is a collaboration between rheumatology researchers in three Universities (Birmingham, Glasgow and Newcastle) and if our renewal application is successful we will be joined by a fourth partner, the University of Oxford. Our aim is to speed up progress towards finding a cure for rheumatoid arthritis. Patient research partners from each University have been supporting RACE since it began, and came together at a successful and enjoyable patient conference last year to discuss our research priorities and identify challenges and opportunities for patient involvement in scientific research. The proceedings of this event have now been published in the journal *Musculoskeletal Care*. We hope there will be lots of similar RACE events and activities happening soon, so look out for notices and get involved!

You can find out more about RACE research here <http://www.race-gbn.org/> and you can follow us on Twitter [@Racegbn](https://twitter.com/Racegbn)

## Public/Patient Involvement & the NIHR Birmingham Biomedical Research Centre (BRC): How we work together

  
Birmingham Biomedical Research Centre *National Institute for Health Research*

### What is the Birmingham BRC?

The National Institute for Health Research (NIHR) has provided funding to the Birmingham Biomedical Research Centre (BRC) to create a multidisciplinary centre of excellence. The BRC will strive to reduce the time taken to translate scientific discoveries into new treatments for patients with inflammatory and autoimmune joint, muscle, bowel, and liver diseases.

The BRC is building on the outstanding clinical research infrastructure in Birmingham to carry out studies in groups of patients with inflammatory disease in which we are:

- Exploring the processes that drive these conditions, focusing on those that are shared between different diseases
- Developing new biomarkers that will allow us to select the best new treatment for each patient
- Testing new treatments that switch off or re-calibrate the overactive immune system that underpins these diseases

### How are patients involved?

The BRC is committed to involving patients and members of the public as research partners at all stages of research.

Members of R2P2 have been, and will continue to support the research of the BRC. Look out for opportunities to get involved in R2P2 emails and mail-outs! One of our members represents us on the BRC management committee. Two other patient involvement groups are also supporting the BRC; the Liver & Gastroenterology Reference Group and the newly established Sarcopenia Group.

The BRC will provide exciting opportunities in the future for the 3 patient involvement groups to come together, make new friends and learn from each other.

### Meet the NIHR BRC Patient Involvement & Engagement Manager!



Laura Chapman has experience of championing diversity and inclusion from a career in Human Resources and

conducting research with the public on readability / usability of Patient Information Leaflets for medicines. Her experience as a patient with a chronic disease for over 20 years has led to personal involvement in research, and to a desire to involve and engage others in research on a larger scale.

Laura will work with us to ensure our approach to patient involvement is effective, widen access to public involvement and increase our membership. She will also organise public engagement events to share the work of the BRC and the contribution of our patient research partners with the wider public.

Laura will be attending our summer event on 19<sup>th</sup> July at Winterbourne House, so do come along and say hello!

### Where can I find out more?

Contact Laura on 0121 371 8486 or [laura.chapman2@uhb.nhs.uk](mailto:laura.chapman2@uhb.nhs.uk)

[www.birminghambrc.nihr.ac.uk](http://www.birminghambrc.nihr.ac.uk)

### R2P2 on Twitter!



As of June 2018, we now have a dedicated R2P2 Twitter account, [@R2P2\\_UoB](https://twitter.com/R2P2_UoB), which we hope will help us to connect with a wider network of rheumatology patients. If you have a Twitter account, please follow us and interact with us!

## Project Update: Mind the Risk

Over recent years there has been a lot of research interest in finding ways to predict who is likely to develop rheumatoid arthritis in the future, and developing treatments that could reduce someone's risk of developing rheumatoid arthritis. Several members of R2P2 have been working with Dr Marie Falahee to develop a survey study to explore people's opinion about tests that predict someone's risk of developing rheumatoid arthritis in the future. The survey also looks at how likely people with rheumatoid arthritis are to pass on information to their relatives about their risk of developing rheumatoid arthritis. There are two versions of the survey, one for patients with rheumatoid arthritis and one for their relatives. Recruitment for the Min the Risk survey is well underway in local hospitals. Our patient research partners have made a huge contribution to this study. For example, as a result of their input we:

- Changed the content and design of the survey, omitting difficult questions and spreading the questions out to make the survey easier to read. We also included space for respondents to write in their own words how they feel about the issues raised in the survey.
- We split the survey for patients into two halves, so respondents can take a break if they want to. We also included table of contents to inform respondents what kind of questions are included in the survey so that they can decide in advance whether they want to complete the survey.
- We are approaching patients during visits to clinic, rather than by mail, so that they have an opportunity to raise any concerns with a member of their healthcare team.
- We are not approaching patients who have been recently diagnosed with rheumatoid arthritis, who are coming to terms with their own diagnosis and treatment.
- We developed a lay summary of a grant application to Arthritis Research UK to fund a PhD student to support this study.

We're delighted to report that this application was successful and now funds our PhD student Imogen Wells! Imogen recently completed a Masters degree in Health Psychology at the University of Bath. Imogen is looking forward to working with our patient research partners to develop effective ways to share the findings of the survey with members of the public when it is complete.

**A huge thank you to those patient partners who continue to support Mind the Risk!**



**PhD student Imogen Wells**