R2P2 newsletter

Issue 2, November 2015

Birmingham

Rheumatology Research

Patient Partnership

Welcome to the second edition of the R2R2 newsletter

Since the official launch of the Rheumatology Research Patient Partnership (R2P2) this time last year, patient research partners have continued to provide excellent support to the work of the Rheumatology Research Group at the University of Birmingham. A wide range of research projects have benefitted enormously from the contribution of patient research partners, including EuroTEAM and RAPID – updates on the progress of these projects, and information about exciting new projects and opportunities for patient research partners are included in this newsletter.

In recent months we have said a fond farewell to R2P2 coordinator Rebecca Stack, who has moved to take up a new post at Nottingham Trent University, and to our administrator Linda Briscoe. We wish them well in their new ventures, and in their place we welcome our new academic coordinators Dr Gwenda Simons and Dr Marie Falahee, with administrative support from Mrs Becky Birch. They have already been busy updating the R2P2 website and organizing the second R2P2 Annual meeting to be held on Thursday 26th November; you can find details of both in this issue.

The continued involvement of patient partners ensures the validity and quality of both research and clinical practice. This collaboration provides opportunities for patients and researchers to learn from each other, and to work together to improve outcomes for people who are affected by musculoskeletal disorders. Thank you to everyone who has been involved in the success of R2P2, we look forward to working together to build on this success in the coming year.

In this issue

Project Updates:

RAPID

The **RAPID** project will officially finish on the 30th of November 2015. It explores the perceptions of Rheumatoid Arthritis (RA) amongst members of the general public. The research is supported by the Dunhill Medical Trust.

Background

RA is a chronic condition which causes inflammation of the joints which can lead to joint destruction and has a profound impact on the lives of those suffering with it. Symptoms include joint pain, swelling and stiffness. Although early diagnosis and treatment of people with RA is likely to result in a better long-term outcome, people often delay seeking help for RA symptoms for around 3 months or more.

Obviously there are other sources which cause a significant delay between symptom onset and diagnosis and treatment, such as a long wait for referrals from GPs, but RAPID focuses on patient delay.

Where previous research has looked at illness perceptions and barriers to help seeking in patients diagnosed with RA (e.g. the DELAY project, see previous issue of the newsletter), the RAPID project investigates perceptions and knowledge of RA in the general public (i.e. people without RA), to understand what people might think and do when first confronted with the symptoms of RA.

Through interviews and a big postal survey the project has explored:

1) what members of the public know about RA
2) how they perceive this condition and
3) the triggers they may use to seek help from health care professionals.

Findings from the postal survey

The postal survey was sent out to 3400 persons over 18 years of age, and who did not have a diagnosis of inflammatory arthritis including RA. A total of 1088 people aged between 18 and 96 years completed the survey.

One of the aims of the survey was to understand the role of disease knowledge and symptom recognition in the decision to seek appropriate and timely medical attention. In order to do this we compared the respondents' reaction to symptoms of RA with those of Bowel cancer and Angina.

Respondents were presented with short symptom stories, depicting the symptoms of RA in several manifestations, angina and bowel cancer and asked to rate the seriousness of the symptoms and the urgency of medical attention. They were also asked to assign a cause to the symptoms.

Survey respondents were less likely to recognise the symptoms of RA as such and often assigned these symptoms to potential causes which are considered less serious or which people perceive cannot be changed (e.g. old age). This was especially the case when the symptoms depicted only included joint stiffness and pain in hands and wrists, but no swelling. On the other hand symptoms of bowel cancer and to a lesser extent angina were readily recognised and were considered to be more serious than those of RA (with and without swelling). Respondents would seek help faster for the symptoms of bowel cancer or angina compared to symptoms of RA.

Research in the past has shown that health campaigns can aid symptom recognition and convey the seriousness of the symptoms. This explains in part the findings of our survey as there have been high profile campaigns for both bowel cancer and heart disease. In addition to this, the benefit of early help seeking appears to be clear to most people for both cancer and angina (e.g. more chance that cancer will be cured or a heart attack prevented) as a result of health campaigns and we need to convey the benefits of early help seeking for RA symptoms in a similar manner.

People need to understand that RA is a serious illness which can manifest itself in a number of ways and which needs prompt action on the side of the patient in the first instance in order for patients with genuine RA symptoms to receive treatment within the window of opportunity.

Although the project will come to an end, we will continue to analyse data and publish articles **http://www.birmingham.ac.uk/ra-rapid**

A heartfelt thank you to all RAPID patient research partners

As the project is coming to an end, we would like to thank everyone who has been involved with RAPID in some shape or form. Your support has been extremely valuable!

This research is supported by The **Dunhill Medical Trust** [grant number R226/1111]

Project Updates: EuroTEAM

Background

EuroTEAM is a collaboration between researchers, companies, and patient research partners across Europe that is funded by the European Union until October 2016. The aim of this project is to develop efficient methods to predict the development of rheumatoid arthritis (RA) in people who have not yet developed the disease. The identification of individuals who are 'at risk' of developing RA will facilitate early diagnosis and treatment, and ultimately this will help to develop treatments to prevent RA.

Risk perception in people who may be "at risk" of developing RA

As well as identifying those "at risk", an important element of EuroTEAM that is being led by the University of Birmingham is to explore how people feel about potentially being "at risk", and how willing they would be to undergo tests to predict their risk of developing RA and to take preventive action. In order to achieve this we have conducted interviews across Europe with relatives of people who have RA, and with those who have early symptoms that suggest they may be go on to develop RA.

We are also developing strategies and tools to communicate with people who may be "at risk" about the development of RA and how to reduce their risk and ensure the best possible outcome.

Patient Involvement

Patient involvement is a key aspect of EuroTEAM, and a panel of nine Patient Research Partners (PRPs), including members of R2P2, has been established to support this project. PRPs are from the UK, Sweden, Estonia, Romania and Germany, who attend regular teleconferences and annual project meetings. So far, they have advised on interview schedules, analysis of interview data, validation of literature review findings, and have written articles about their experiences, presented at annual meetings, informed the development of informational resources and much, much more!

Findings from interviews

Many relatives of patients with RA were unsure of the extent of their own risk of developing RA. In addition, relatives felt that there was a need for more information and support specifically designed for family members of people with RA. The lack of support and information was suggested to have a number of effects, including family members not feeling able to communicate and support the person affected with RA.

Participants with joint symptoms that suggest they may be likely to develop RA in the future expressed a number of concerns, including their status as an "at risk" individual, worries about the future, and significant distress and lack of understanding about the results of predictive tests.

Information Resources

In order to address the needs identified in our interview studies, we have developed informational leaflets, both for relatives of people with existing RA and for individuals who have joint symptoms that suggest they may be at risk of developing RA in the future, based on our findings. PRPs have made a significant contribution to the content and format of these resources. We plan to conduct focus groups and experimental evaluation of these leaflets, and they will be made publically available soon on the EuroTEAM website, and through relevant organizations.

To find out more:

www.team-arthritis.eu

Euroteam is supported by the European Union under the grant agreement FP7-HEALTH-F2-2012-305549.

Researcher profile: Dagmar Scheel-Toellner

What is your name and what do you do?

My name is Dagmar Scheel-Toellner. I lead a research team that investigates the basic biological mechanisms of joint inflammation in patients with rheumatoid arthritis.

How did you train?

I initially trained as a pharmacist, and applying my current research into therapeutic strategies is still an important long-term aim in my work. After qualifying as a pharmacist, I went on to study for a PhD in Immunology and Pharmaceutical Biology. I moved to Birmingham to join the Department of Rheumatology as a Research Fellow, working with Mike Salmon and Janet Lord in 1994. During this time I researched the mechanisms keeping inflammatory cells alive in chronic inflammation.

How has your career progressed?

I was awarded a non-clinical Career Development Fellowship by Arthritis Research UK in 2004. In the following years I established my own research team and was promoted to Senior Research Fellow in 2007. The Career Development Fellowship was followed by an Arthritis Research UK funded Career Progression Fellowship, which led to a long term post. In October 2015 I was promoted to Reader in Translational Inflammation Research.

What are you working on at the moment?

I am closely collaborating with my clinical colleagues within the Rheumatology Research Group in their investigation of the early stages of the development of rheumatoid arthritis. Currently, a major focus of my work is the investigation of a novel group of pro-inflammatory B cells that my team has identified in the joints of patients with rheumatoid arthritis. We are now trying to work out whether these cells can be targeted to develop a new therapy for inflammatory diseases.

R2P2 Patient research partner profile: Sue Thomas

What is your name and what do you do?

My name is Sue Thomas, I've been diagnosed with Rheumatoid Arthritis since 2007, but happily at present I'm in remission. I used to teach in Further Education; work was a bit tough when my rheumatoid arthritis was playing up and I really feel for people who have to soldier on without much relief. I was one of the lucky ones: a particular combination of medication works well for me. This meant I could manage work till I retired and then keep very active. Now I spend some time looking after my grandchildren, some time volunteering and some time back in education – this time as a student.

Why did you want to become a patient partner?

I joined the Patient Support group at City Hospital soon after I was diagnosed and from there became involved in various projects as a Patient Research Partner. I have helped out at focus groups, commented on research proposals and discussed the format of questionnaires. I have particularly enjoyed being part of EuroTEAM which is looking at possible early interventions in rheumatoid arthritis. It is great to work with researchers, clinicians and patient research partners from different countries.

What do you think are the benefits of involving patient research partners in research?

The patient perspective is very important for researchers: they need to understand our priorities, our hopes and fears and our actual experience of disease. We don't have to be expert scientists – that's not our role! But a side benefit of being a PRP is that we do learn a bit more about the disease we live with. The main 'plus' though, is feeling part of the very significant work that's going on to tackle the causes and effects of these diseases so that more people can, like me, be put in remission or even have the disease halted before it takes hold.

Institute of Inflammation and Ageing

Rheumatology Research Group

Rheumatology Research Patient Partnership

New Project:
Mind the Risk

MIND THE RISK
Managing genetic risk information

Background

Recent advances in genetic science and technology have increased the possibility that the development and severity of diseases like rheumatoid arthritis can be predicted before any symptoms occur. This provides exciting opportunities to develop strategies for disease prevention, and facilitates early diagnosis and effective treatment.

It is therefore likely that in future years, more and more people will have opportunities to access information about their genetic makeup, and the likelihood that they will develop diseases. This raises important ethical concerns and questions about the management and evaluation of genetic information, both for health care providers and patients.

Mind the Risk is an international collaboration of researchers in philosophy, psychology, medicine, genetics, health economics and bioethics which aims to provide answers to these questions, and to support the clinical application of genetic risk information. The project runs from 2014-2020, and is funded by the Swedish Foundation for Humanities and Social Sciences.

First degree relatives (children and siblings) of patients with rheumatoid arthritis are more likely to develop the disease than other members of the general public. Therefore they are likely candidates for initiatives to predict the development of this disease, and for preventive interventions. However, patients may have considerable anxieties about approaching their relatives about their risk of rheumatoid arthritis, and relatives may vary in their willingness to engage with programmes designed to predict or reduce their risk of developing rheumatoid arthritis.

As partners in the Mind the Risk project, our aim is to understand the perspectives of both patients and their first degree relatives about the risk of rheumatoid arthritis, family communication about risk of rheumatoid arthritis, predictive testing, and preventive interventions. To investigate these issues, we shall employ a range of research methods, including qualitative interviews, large scale surveys, and choice experiments.

Opportunities for patient research partners

We would like patient research partners to be involved with a wide range of research activities, for example:

- Analysis of interview data
- Content and design of surveys
- Selection of attributes to be included in choice experiments
- Developing plain English summaries of research findings
- Presentation of findings to stakeholder groups and organizations

If you are interested in supporting this research, or would like more information please contact Dr Marie Falahee (m.falahee@bham.ac.uk)

Find out more:

www.crb.uu.se/mind-the-risk/index.html

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RIKSBANKENS
JUBILEUMSFOND
STIFTELSEN FÖR HUMANISTISK OCH
SAMHÄLLSVETENSKAPLIG FORSKNING

New project:

A link between the gut and the joints

Understanding the role of microorganisms in our intestines in the development of rheumatoid arthritis.

Our microbiome includes all the bacteria and other organisms that live inside our body. In fact, huge numbers of such organism live with us. Amazingly the human body hosts about 10 times more microbial cells (living for example in the intestine) than human cells!

Evidence is emerging that the microbiome in our gut, which is influenced by a range of factors including diet, influences both the development and course of conditions such as rheumatoid arthritis. For example is clear that the organisms in our gut can produce substances that cross into the blood and affect health.

Understanding this better will shed light on new approaches to treatment and to predicting outcome in patents with arthritis.

The Rheumatology Research Group has developed a collaboration with researchers at the University of Oxford, University College London and key groupings in the USA (New York University School of Medicine, Harvard School of Public Health and Icahn School of Medicine at Mount Sinai) to explore the microbiome in arthritis further.

We will keep you informed of results as they emerge.

Rheumatoid Arthritis Pathogenesis Centre of Excellence: RACE

RACE is a partnership between the University of Birmingham, the University of Glasgow and the University of Newcastle and is sponsored by Arthritis Research UK. The project is designed to speed up progress to find a cure for rheumatoid arthritis. It aims to identify why rheumatoid arthritis starts, where it starts, why it persists, and whether we can develop new treatments. It aims to do this by bringing together researchers from three leading Universities, recruiting the best young scientific minds, and engaging with patients to guide the research. Many of the researchers have already prepared posters and presentations for patients which are made available on the RACE website.

Find out more: www.race-gbn.org

News and Events

Updated website

Please take a look at our new look website. You can now find information about several local support groups on the website. Many people attending these groups are also members of R2P2. We have also added a section for researchers looking for involvement of patient research partners. http://www.birmingham.ac.uk/r2p2

New forms

Our researchers are now required to complete a request form (available on the R2P2 website) if they would like patient research partners to get involved in their project or grant application. On this form we ask researchers to provide details of the project and the involvement needed, and also to specify how they will provide **feedback** to patient research partners about the outcome of their involvement.

We also ask that all **new and existing patient research partners** complete an information form which makes sure that we are up to date with your contact details, and also that we know which kind of research activities you are interested in or have taken part in in the past. This information will help us to match patient research partners with projects that they will enjoy. If you have not completed a form recently, please let us know and we will supply you with a copy!

New Institute

Recently there have been some changes to the organisational structure of the College of Medical and Dental Sciences, at the University of Birmingham. As a result of these changes, most of the researchers that are involved in R2P2 are now members of the new **Institute of Inflammation and Ageing (IIA).** You can find out more on the IIA website: **www.birmingham.ac.uk/research/activity/inflammation-ageing**

New patient group at QE

A new rheumatology patient group has started at the new Queen Elizabeth hospital. For details of upcoming meetings please contact Fiona Maggs: Fiona.maggs@uhb.nhs.uk

Write for us!

If you have any items for the next newsletter and/or website, please let us know and we'll do our best to include it! This could be news items, details of upcoming events, photographs, or perhaps you could write about your experiences of being a member of R2P2, or of your involvement in specific projects. You may even have more creative ideas of your own! All contributions and feedback are very welcome. If you would like to get involved, please don't hesitate to contact Marie Falahee (m.falahee@bham.ac.uk) or Gwenda Simons (g.simons@bham.ac.uk).

Upcoming events

R2P2 meeting

The next annual R2P2 event will take place on Thursday the 26th of November at Hornton Grange (University of Birmingham campus), please contact Becky Birch for further information: r.birch@bham.ac.uk; telephone 0121 414 9249

Rheumatology patient group meeting at City hospital

27th of November at 1pm, speaker Dr Paola de Pablo on RA and gum disease.

For more information about the Rheumatology Patient Group at City hospital contact John Rowland:

drowland.home@virgin.net

RACE meeting

A meeting is planned for patient research partners involved in the RACE project during the afternoon of Wednesday 27th January 2016. More details to follow soon…

BSR 2016

The British Society of Rheumatology Annual Conference will be held on 26-28 April 2016 in Glasgow. Many of our researchers will attend and present their work, and patient research partners are welcome to attend and get involved.

www.rheumatology.org.uk