Welcome to the BSRBR-RA study newsletter. This long-term study aims to find out how safe and effective new drugs prescribed in the NHS to treat rheumatoid arthritis are. We are primarily collecting data on biologic and biosimilar drugs, but as new treatments come to the market we hope to capture data on these too. Here is an update on how things are going in the study. Please visit our website for more information.

BSRBR-RA Participant Newsletter  
Winter 2016/ 2017

What is Re-Registration?
The BSRBR-RA groups patients into different cohorts depending on what RA therapy is being taken at the time of registration. This is to allow our researchers to make comparisons or note differences between the groups. Over time the groups have changed; some have closed having reached their recruitment target and new groups have been added with the addition of new biologics and biosimilars. Sometimes if you start a new therapy you may be eligible to move from one group to another.

Re-registration is the process of moving a participant to a new cohort. For example you may have been on the register for a while but have now started a biosimilar and, if you agree, can be moved into that group.

How it works and what it means for you
- The register will be informed of the change in your RA therapy by your rheumatologist.
- Your rheumatologist will ask if you mind being re-registered in a new BSRBR-RA group, provide you with information and ask you to sign the consent form to confirm this.
- Once re-registered you will see that your patient study ID number has changed and your follow up will restart. (This is because we want to collect data on how you are feeling from when you first start in the new group.)
- The follow up process will be exactly the same as before and you will receive a diary and follow up questionnaire when needed. (You will be asked for data at 6 month intervals for up to 3 years.)

Even if you are eligible to be re-registered you don’t have to and can continue to be followed under your original ID. So whether you are registered just once or more the BSRBR-RA appreciates all the information our participants provide us with!

BRAGGSS: Linked Registration
BRAGGSS stands for ‘Biologics in Rheumatoid Arthritis Genetics and Genomics Study Syndicate’. The main aim of this study is to evaluate the role of genetic and other variation in determining response to treatment. As the information collected is very similar, a ‘linked-route’ was set up for patients who are eligible to take part in both studies.

This means that linked participants will have first provided information to that study (which is shorter) before then continuing their follow up long term with the BSRBR-RA. BRAGGSS recruits participants before they start a biologic/biosimilar. It is only once they have started therapy and finished the BRAGGSS 12 months of follow up that they are transferred over and the BSRBR-RA begins to collect data directly from them.

If, however, the biologic/biosimilar therapy is stopped before the end of the 12 month period, follow-up on the BRAGGSS study will stop. The BSRBR-RA would then begin to collect the follow up data. We have done our best to make sure that these transfers happen smoothly but if you were a BRAGGSS participant who has unexpectedly started getting BSRBR-RA questionnaires please feel free to get in touch with us with any questions you have!
Anti-TNF therapy and the risk of heart attacks: Results from the BSRBR-RA

What was already known?
We know that people with rheumatoid arthritis (RA) are at higher risk of heart attacks compared to the general population. This can be partly explained by the increased inflammation seen in RA. There is evidence to show that biologic therapies (including anti-TNF therapies such as Humira or Enbrel) reduce joint inflammation but it is not known if these therapies reduce the risk of heart attacks in the medium term (3-5 years).
We used your data to find out if people receiving anti-TNF therapy were at an increased risk of heart attack compared to people with RA with similar symptoms receiving standard (s) DMARD therapies such as methotrexate. We linked with the Myocardial Ischaemia National Audit Project (MINAP) for further information on heart attacks.

What did we find?
A total of 14,258 participants were studied: 3,058 patients receiving sDMARD only and 11,200 patients receiving anti-TNF therapy. The majority of the participants were female and the average age was between 55-59 years.
Over 3-5 years of follow-up, the risk of heart attacks was reduced by almost 40% in participants who received anti-TNF drugs compared to those who received sDMARD only. We did not find any difference in the severity of heart attacks between the two groups. The median duration of treatment with anti-TNF therapy was 4 years.

Why is this important?
We found that patients treated with anti-TNF therapy over the medium term had a reduced risk of heart attacks compared to those who received sDMARD only. It is possible that this effect is related to suppressing the inflammation in general. It is reassuring to note that in those patients who experienced a heart attack, there was no difference in the severity of attack irrespective of whether they were treated with TNFi therapy or sDMARD only.

Hi.
My name is Joe and I’m a recent BSc (Hons) Biomedical Sciences graduate from The University of Manchester. Since finishing my degree, I have been working in the role of Project Support Officer for the BSRBR-RA as part of their graduate internship programme. My main responsibilities involve collecting and managing data. As well as liaising with the patients and healthcare professionals who contact the register. In addition to this, I work as one of the facilitators for the musculoskeletal research user group (RUG). I have benefited from the variety of training courses offered by the university. Specifically, the courses “Research Ethics: University & NHS” and “Project Management”.
My time at the BSRBR-RA has given me an excellent insight into clinical research and has provided me with a good grounding for a career in science. A personal highlight is the excellent work culture within the BSRBR-RA team. Every member of staff has been very supportive of me throughout my internship. Whether it be answering my questions or giving me a bag full of presents for my birthday.
I am very thankful for their efforts!

Useful Links
The National Rheumatoid Arthritis Society (NRAS) is an organisation whose aim is to provide information and support for people diagnosed with Rheumatoid Arthritis, along with their family, friends, carers, and anyone with an interest in RA. They have a free phone helpline: 0800 2987650 or you can look at their website for more information: www.nras.org.uk
The British Society for Rheumatology is an organisation supporting health professionals working in the field of arthritis; their web page has a section with information for patients: www.rheumatology.org.uk/Patient_Information
Arthritis Research UK is a charity which campaigns on behalf of people with arthritis and funds research into making a difference to the lives of people with arthritis: www.arthritisresearchuk.org

The BSRBR-RA is coordinated at the University of Manchester by study manager Dr Kath Watson who leads a team of around 15 people. The project assistants are available to answer any questions you have about the study. We are unfortunately unable to provide medical advice regarding your RA; for this, you should contact your rheumatology department.