

BSRBR-RA Newsletter

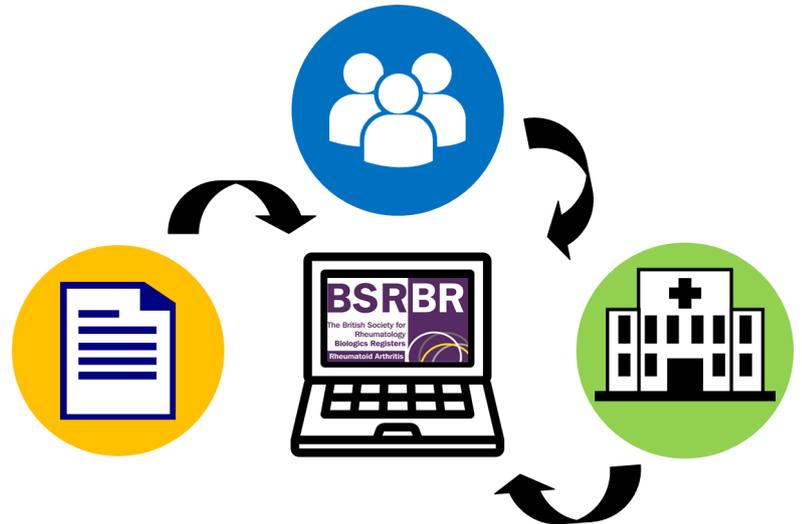
Summer 2018



Welcome to the BSRBR-RA study newsletter. We send this to participants who are involved in this important research and aim to provide information on the Register, updates on how things are going, what we have found out so far and what we hope to find out in the future.

Data Linkage at the BSRBR-RA

Thank you for your continued participation in the study. The data that we collect from participants or their doctors can be enriched by linking to other national healthcare databases such as those held by NHS Digital (such as healthcare data from the Office for National Statistics, ONS). This means that we can be informed when health events happen that we might have not previously known about via participants or the hospitals.



The current BSRBR-RA participant information sheet has full details of what is involved in linking to other national healthcare databases. If when you joined the study, you signed version 8 of the consent form (dated 19/10/2016) or any subsequent version you will have already seen this information. However if you joined the study before this time, then you may want to read further details around this linkage.

To find out more:

- Visit our website: www.BSRBR.org
- Read the current information sheet (Version 9: 17/Jul/2017) available on our website, from your rheumatology team or from the BSRBR-RA study team.
- Or if you have any further questions please contact the BSRBR-RA team who will be happy to advise you. (0161 2751652, biologics.register@manchester.ac.uk)



What if I decide I don't want to take part anymore?

Please remember that you are able to withdraw from the study at any time, should you wish to do so, and this will not affect your standard of care in any way. Not every withdrawal needs to be complete. For example, you can choose not to fill in forms yourself but have your rheumatology consultant continue to provide the study with information on your health. Again all the options can be found on our website or just contact us at the office.

Thank you once again for your participation.

Where can I find information about the Register?

Our website has undergone a long overdue redesign and update which includes the new shorter & easier address: www.BSRBR.org

The website has lots of **information** about the study and our research. You can download a copy of the participant diary (if you ever lose one), find copies of our newsletters and even quick summaries of our most recent results.

If you are a social media user you can keep up to date by following us on **Twitter** and **Facebook**; just search for **BSRBR-RA** and follow us. You can also access our **blog** from the website and get all our contact details too.

Protecting Your Data

You may be aware that new **data protection** laws have been recently introduced in the UK, known as the General Data Protection Regulation (GDPR). It is important that you know how we use your personal data and what your rights are under the law; a new '**transparency sheet**' has been developed to explain this further.

You can view this at our **website** or if you would prefer a paper copy you can get this from your rheumatology team the next time you are at hospital. If you have any questions about this please do not hesitate to contact the office and we will be happy to help.

BSRBR-RA Research Findings

Lymphoma and treatment with TNF Inhibitors

It is known that patients with Rheumatoid Arthritis (RA) have a higher chance of developing lymphoma (a type of a blood cancer) compared with the general population. Patients with RA are often treated with a type of drug called a TNFi (Tumour necrosis factor-alpha inhibitor) which targets parts of the cells in the body to reduce inflammation. This type of treatment is known as a "*biologic*" therapy, because of how it is made.

It was unknown whether treatment with a TNFi for RA would increase the risk of developing lymphoma. The research team at the BSRBR-RA looked at the numbers of lymphomas that were developed in two groups of people within the study, to see if there was a difference between the two:

Group 1

Number of lymphomas developed in patients with RA who were treated with TNFi therapy.

Group 2

Number of lymphomas developed in patients with RA who were treated with traditional DMARD (Disease Modifying Anti-Rheumatic Drugs) therapy.

Reassuringly, after taking the differences in the groups of patients in to consideration, the results showed that there was no evidence of a higher chance of developing lymphoma in those being treated with a TNFi compared with those being treated with traditional DMARDs.

Should you wish to read this scientific paper in full, the text can be found online here:
<https://www.ncbi.nlm.nih.gov/pubmed/27502891>



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