2024 Spring

Participant
Newsletter

In this issue...

- **Meet our researchers**

- **Latest research news**

- **Results of the National Rheumatoid Arthritis Society survey**

The BSRBR-RA study tracks the progress of people with rheumatoid arthritis (RA) who have been prescribed biologic (including biosimilar) and other new therapies in the UK to monitor the long-term safety of these drugs. It is one of the largest prospective observational studies of patients receiving these drugs in the world, with over 30,000 participants registered since it started in 2001.

www.bsrbr.org

Podcasts

Listen to Professor Kimme Hyrich and Dr Kath Watson discuss the BSRBR-RA study, its history and how it continues to grow as an invaluable dataset.

Listen here

Talking Rheumatology Spotlight
Ep 21. BSR Rheumatoid Arthritis Register (BSRBR-RA)

https://www.buzzsprout.com/1972494/12894952

A word from...

**PROFESSOR KIMME HYRICH
BSRBR-RA CHIEF INVESTIGATOR**

Dear Reader,

It gives me great pleasure to introduce our Spring 2024 participant newsletter. The team at the BSRBR-RA continue to work very hard to ensure we are using your healthcare data safely, securely and accurately to ensure that the safety of the newer rheumatology therapies is being monitored. In this edition, you can find a link to the British Society for Rheumatology (BSR) Talking Rheumatology podcast, where we discuss the history of the study. You can also meet one of our new researchers, Zixing Tian. We have the results from our recent NRAS research priority survey as well as a discussion on our most recent knowledge about infection risk.

I hope you enjoy this newsletter. You can find more information about all of our publications and activities online at www.bsrbr.org.

Kimme

Meet our researchers...

Zixing Tian
University of Manchester

Please introduce yourself!

My name is Zixing Tian, I am an epidemiologist with a research focus on rheumatoid arthritis (RA). Before I joined BSRBR-RA, I conducted research in nutrition epidemiology.

What do you do at the BSRBR-RA?

I am a researcher interested in RA, its treatment, and other co-existing health conditions, e.g. diabetes (known as comorbidities). Rather than conducting lab-based research, my research is based purely on the analysis of the BSRBR-RA data that you provide.

The data I am using is observational, meaning we don't intervene by assigning treatments. This approach provides an understanding of RA and its treatment across a diverse range of individuals with the disease. It reflects how these drugs are being prescribed for RA in NHS rheumatology clinics.

What is your current research focus?

I am focused on analysing data to see if people with RA receiving one treatment have a lower risk of developing comorbidities or adverse events compared to those receiving another treatment.

Many of these comorbidities or adverse events take years to develop or be diagnosed. Therefore, long-term follow-up datasets are necessary to answer these questions. Data from the BSRBR-RA is one such dataset!

Why is participant data important and how does it help in your research?

As mentioned, certain comorbidities or adverse events associated with treatment may take years to appear, showing the importance of ongoing follow-up. The BSRBR-RA began recruiting people with RA in 2001 and is still following these people and recruiting new patients over 20 years later. With this long-term follow-up data, I am able to understand the impact of comorbidities and adverse events associated with different treatments in individuals with RA. We hope this knowledge will help patients and clinicians make decisions about which therapies are best for them.

Latest research news

'Evaluation of serious infections, including Mycobacterium tuberculosis, during treatment with biologic disease-modifying anti-rheumatic drugs:

does line of therapy matter?'

Dr Kim Lauper
University Hospitals Geneva
Published in Rheumatology, Sept 2023

What was already known?

Biologic disease modifying anti-rheumatic drugs (bDMARDs) have shown to be associated with an increased risk of infection, particularly in the first 6 months treatment.

This analysis, performed by Dr Kim Lauper (a rheumatologist who used BSRBR-RA data for her PhD), looks to find out whether the occurrence of serious infections and active tuberculosis differs depending on which biologic drug is used to treat RA.

What was discovered?

The analysis was conducted using data collected between 2009 and 2018 in the BSRBR-RA study across seven biological DMARDs. Findings show that the risk of serious infections remains consistent across the lines of therapy and that changing biologics is not associated with any change in infection rates.

Analyses such as this are an important resource for clinicians and patients when considering treatment options and help us to understand the long-term impact of these drugs.

Please visit our website for further information about the study, including more research results.
www.bsrbr.org/for-participants

Once you consent to be involved in the study your hospital will register you on the study database where you will be assigned a unique ID number.

The hospital periodically sends the BSRBR-RA team information (taken from your hospital records) about any changes to your medication, your arthritis, and if you have experienced any new illnesses.

This data is collected for the duration of the study. The current end date is September 2028, though this may be extended further if additional funding is obtained.

The data that we have already collected from our participants' hospitals is enhanced by **linking** to other national databases such as NHS England (previously known as NHS Digital). This means that we can be informed of some adverse events that we might have previously not known about for people taking part in the BSRBR-RA study.

For example, if one of the participants registered on our study develops a cancer, then we will be informed of that via a notification from the national cancer register via NHS England. If a participant passes away, we will be informed via a notification from the national death register via NHS England.

More details about data linkage can be found on our website:
https://www.bsrbr.org/for-participants/linking-data

Future research

NRAS survey results –
Which questions are most important to you?

In 2023, we launched an online survey in collaboration with the National Rheumatoid Arthritis Society (NRAS) to find out which topics were most important to people living with RA.

Thank you for such a wonderful response! Over 1000 people participated within the first hour.

The survey proposed a series of questions and asked participants to rate those that they considered most important to them, helping to guide future research.

We would love to hear from you if you have any questions you would like to see answered, or any other suggestions for our research.
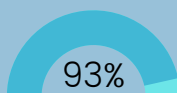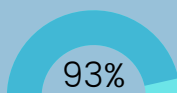
biologics.register@manchester.ac.uk

Top 5

Percentage of responses
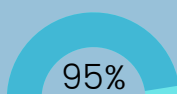
95% What is the best drug for me as an individual?
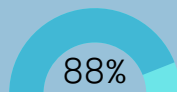
93% How will my treatment affect my physical function, such as doing day-to-day tasks or going out with friends/family?

93% How does treatment affect my quality of life, such as my social life, my condition and my happiness?

92% What is the risk of developing side effects or other illness on my treatment?

88% What is the relationship between rheumatoid arthritis and other co-existing health conditions or diseases?

https://nras.org.uk

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