

2026 Spring

Participant Newsletter



British Society for
Rheumatology

Rheumatoid Arthritis Register

Celebrating 25 Years



A word from...

PROFESSOR KIMME HYRICH
BSRBR-RA CHIEF INVESTIGATOR



Dear Reader,

I'm writing this on what is the hottest day of the year so far. It feels a long time since we had our 25 years of the BSRBR-RA celebration at our annual rheumatology conference in Glasgow, at a much cooler and windier time of the year, but it was only a few months ago. These celebrations allowed us to reflect on some of the greatest impacts of the register, such as giving us a better understanding of how best to use biologics and a better oversight at how often adverse events do occur. We have shown that biologics are a very effective treatment for most but not all people living with severe arthritis, and for some it will take a lot of trial and error to find the best drug for them. But along side this, serious side effects are very rare, which has been very reassuring. Enjoy reading our most recent update and as always, do contact us if you have any questions or even ideas for our national register.

Kimme



The BSRBR-RA turns 25!

Since its very beginnings in 2001, the BSRBR-RA study has been a unique collaboration between The University of Manchester, the British Society for Rheumatology and the pharmaceutical industry.

Over the years, the study has had a wide impact on the rheumatology world, answering many important questions about biologics, biosimilars and other targeted therapies. These have included questions about increased risk of serious infection and cancer and about how similar biologics and biosimilars really are. We are incredibly proud of all that we have achieved over the years.

The data has contributed to:

- 110 academic study papers that have discovered much to help rheumatologists know which the best therapies are to prescribe for individuals. [Some of our lay summaries can be found on our website.](#)
- Real change to the way products are prescribed
- Training of new doctors
- Collaboration with similar international studies to find out even more about risks of rare outcomes

We still have much that we want to find out, including patient reported outcomes and quality of life data. For new participants to the study, we send follow up questionnaires to find out how they feel and how their rheumatoid arthritis affects their everyday lives. All we need for this is an email address to send the questionnaire to.

We will be celebrating this milestone over the next 12 months, so look out for us on Instagram ([@bsrbr_ra](#)) and for updates to our website - <https://bsrbr.org/for-participants/>

PATIENT-PROVIDED DATA

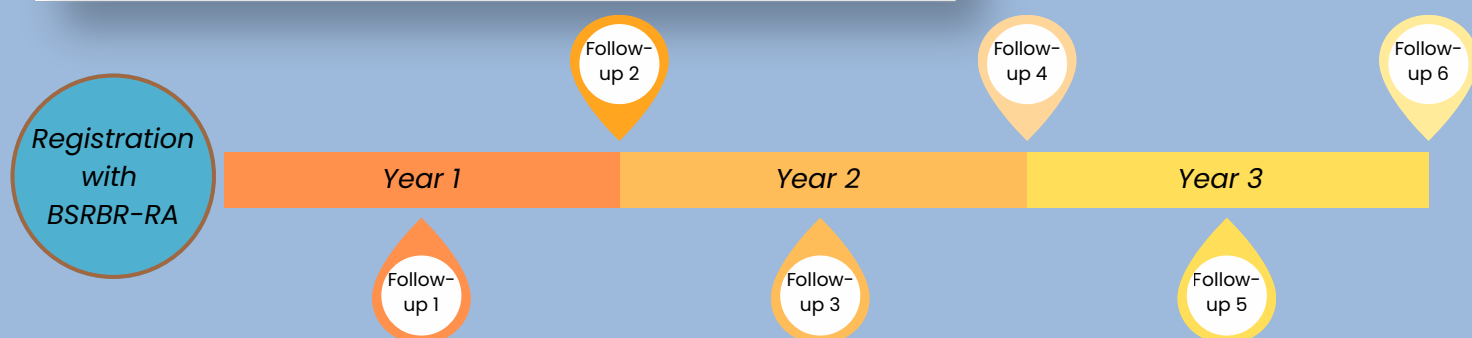
In Spring 2025 the BSRBR-RA study reintroduced patient follow-up through our new online patient questionnaires.

When your hospital first registers you with the study, they will ask you to complete some questionnaires:

- A Health Assessment Questionnaire (HAQ)
- EuroQoL-5D (EQ5D)

If you have consented to participate in patient follow-up and have provided your email address, you will receive these questionnaires as well as a Work Disability Questionnaire, again every six months, for three years.

This is entirely optional, and you can opt-out at any time.



Why this information useful?

Patient-reported data are essential in helping us to understand the impact that rheumatoid arthritis has on day-to-day living, and how ability/ disability may change when starting biologic targeted therapies.

How is participant data used?

All incoming data is checked for quality and accuracy.

The data is then grouped together in a 'dataset'. This is anonymised and no one can be identified. Researchers analyse the data to answer important questions about rheumatoid arthritis – the impact it has on your health and quality of life and the effects of different treatments.

There have been over 100 publications using BSRBR-RA data. Read some of our [lay summaries](#) to find out more key findings.

Your Data Journey

For more than 20 years, the BSRBR-RA has been able to address questions about the safety of medicines for rheumatoid arthritis (RA) thanks to the dedication of our study participants and NHS contributors.

This is how your data helps.

1



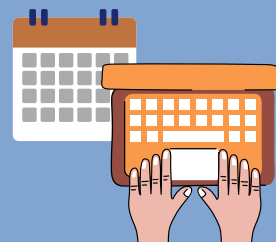
Joining the study

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.

Follow-up

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

You will also be contacted periodically via email by the BSRBR-RA study team, with a reminder to complete online questionnaires about your health (if you have consented to participate in this way).



2

3



Data checking and coding

The data are checked by the study team to make sure that they are complete. Any new illnesses that have been reported are coded into categories.

Drug safety

Capturing data on any new illnesses helps to monitor drug safety over the long term. This is important as biologic and targeted therapies are relatively new; tracking this data helps to ensure the health and well-being of patients.



4

5



Analysis

Researchers analyse the rich dataset to answer important questions about RA, such as the impact of the disease on quality of life and the effects of different treatments. Building this knowledge helps clinicians to more effectively prescribe biologic and targeted therapies to achieve maximum benefit with minimum risk.

Information and Guidance

Your data helps to guide the way drugs are prescribed, contributes to how doctors are trained and helps better inform drug information leaflets and product labelling. The more we understand RA and the therapies available to treat it, the better results we can hope to achieve.



6

Read some of our key publications at <https://www.bsrbr.org/research/lay-summaries> or scan the QR code.



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www.bsrbr.org

“Real-world evidence shows body weight has minimal impact on tocilizumab effectiveness”



DR MAN FUNG TSOI
University of Manchester

What was already known?

Tocilizumab is an established and effective treatment for rheumatoid arthritis (known as RA) and can be administered straight into the blood stream (intravenous) or under the skin (subcutaneous). The dose of tocilizumab is different depending on which route is administered. When given intravenously, the dose is adjusted based on the person’s weight to ensure an appropriate amount of drug is received.

When given subcutaneously, the formulation received is a fixed dose regardless of the person’s weight. Previous evidence on whether body weight influences how well a treatment works (i.e. clinical response) has been mixed, and no large real-world study has explored this in depth.

This study looked at three main things:

- ① Whether bodyweight affects how well tocilizumab works after 6 months of treatment.
- ② Whether bodyweight affects how long patients remain on tocilizumab (known as treatment persistence), an indicator that the treatment is working for the patient, depending on the route of administration.
- ③ How long patients remain on the treatment after switching from intravenous to subcutaneous, and whether this is related to bodyweight.

What was discovered?

The study looked at 2612 patients with RA starting tocilizumab, in either the intravenous or subcutaneous formulation, who had no prior exposure to the drug. Among these patients starting subcutaneous tocilizumab, higher body weight was only weakly associated with a poorer clinical response after 6 months of treatment, and this effect was unlikely to be clinically meaningful. No association was observed for those starting intravenous tocilizumab.

Body weight also did not affect how long patients remained on tocilizumab for either route, nor how long patients remained on therapy after switching from intravenous to subcutaneous.

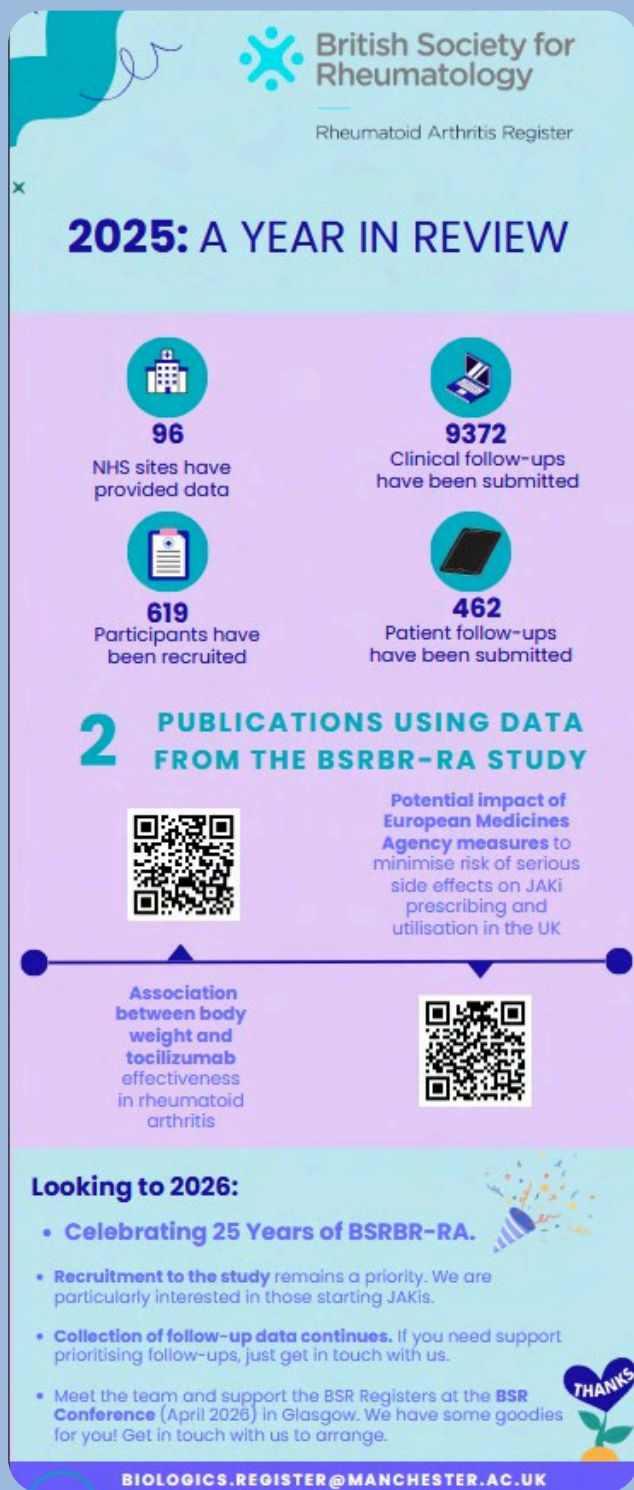
Why is this important for patients?

Although patients with higher body weight may experience a slightly reduced initial response to the subcutaneous formulation of tocilizumab, the effect is minimal and has no influence on how long they remain on the drug. Importantly, body weight had no impact on the effectiveness of intravenous tocilizumab or on treatment continuation for either route, offering reassurance that this therapy is suitable across body sizes.

Whilst minimal, these findings could highlight the value of closer monitoring in heavier patients starting subcutaneous therapy. Importantly, it could encourage shared decision-making and supportive conversations about healthy weight management—which can improve overall rheumatoid arthritis outcomes and long-term health.

Read the full text online

<https://doi.org/10.1093/rheumatology/keae500>



Review of 2025

2025 was another good year for BSRBR-RA. As always, we are very grateful to the participants who provide data, especially those who have completed follow up questionnaires.

BSRBR-RA are proud to have had a wide impact, with results having answered many important questions.

With questions still to be answered, we continue to need your support!

Our publications this year

- Potential impact of European Medicines Agency measures to minimise risk of serious side effects on JAKi prescribing and utilisation in the UK.
- Association between body weight and tocilizumab effectiveness in rheumatoid arthritis.

Thank you for supporting the BSRBR Rheumatoid Arthritis Register.

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EMAIL

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WEBSITE

www.bsrbr.org