British Society for Rheumatology

Rheumatoid Arthritis Register

BSRBR-RA Study Newsletter

Spring 2023

As we move into 2023, we appreciate that the NHS remains under constant pressure due to covid, flu and other winter infections. The cost of living and public sector strikes are also putting immense pressure on our healthcare systems. Despite this, we are thankful for the new registrations and follow up data that you have provided for BSRBR-RA participants throughout this continuing difficult period. The study remains open to new registrations and follow-up data which can be entered using our online database.

As an observational study, the data we receive are obtained from clinical case notes so we are appreciative of any data that you are able to provide at any time that is possible to do so, however many months down the line this may be.

- **100+ NHS Trusts** are successfully submitting data using the online system – thank you for your support!
- Please access our online BSRBR-RA database training and help.
- Spring 2023 **Monthly Online Training** Session Dates:

Wednesday 29th March; 1-2pm Refresher
Thursday 30th March; 2-3:30pm Study Overview
Tuesday 23rd May; 9am-10.30 Study overview
Thursday 25th May; 2pm - 3pm - Refresher

Contact: biologics.register@manchester.ac.uk

Latest Publications using BSRBR-RA data

You can read the full article by clicking on each link

- **Zhao et al** "Effectiveness of sequential biologic and targeted disease modifying anti-rheumatic drugs for rheumatoid arthritis".
- **Lauper et al** "Effectiveness of TNFi, abatacept, IL6i and JAKis in 31,846 patients with rheumatoid arthritis in 19 registers from the "JAK-pot" collaboration ".
- **Taylor et al.** "Demyelinating events following initiation of TNFi therapy in the British Society for Rheumatology Biologics Register in Rheumatoid Arthritis".

BSRBR-RA Publications – Plain Language Summaries

Plain language or 'lay summaries' for all of our recent publications are now available on our website. We are also hoping to move towards infographic summaries in the near future so watch this space! https://www.bsrbr.org/research/

British Society for Rheumatology

Rheumatoid Arthritis Register

22 YEARS ON

MANCHESTER 1824

The University of Manchester

Recruitment

30,400
Registrations

2,900
Re-registrations
(for additional CRN Accrual)

Drugs	People exposed
JAKi	2,000
Biosimilars	8,000
Originators	22,000

Remember: The CRN might offer temporary help if you are low on resource

Data

284,500
Follow-up visits

Baseline data on **16** comorbidities

220,000
DAS28s completed

119,000
HAQs completed

Adverse Events

145,000
Adverse events reported

50,000
Serious adverse events reported

223,000
Person years of follow-up

Online Database

102
NHS sites online

600
Rheumatology staff using the database

15,100
Total messages exchanged between study team and site research staff

181
Rheumatology staff attended online training

To book onto online training, email: biologics.register@manchester.ac.uk

Publications

97
Scientific publications using the rich BSRBR-RA data

Increasing number of plain language summaries explaining the findings of BSRBR-RA publications

www.bsrbr.org/research/lay-summaries/

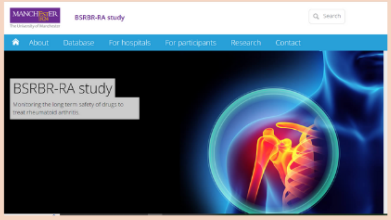
31
BSRBR-RA publications led by external academic researchers

Data Access

- Highly encouraged!
- Many great research questions remain
- What are your ideas?
- Apply for your own dataset or work with the BSRBR-RA team who can explore analysing the data on your behalf

For further details:
www.rheumatology.org.uk/practice-quality/registers

Find out more...



www.bsrbr.org
biologics.register@manchester.ac.uk

Remote Consent

There may be times when you identify eligible participants to approach for BSRBR-RA, but who may not be seen in clinic during the 6 month window for recruitment after the new therapy has started. In these cases, it may be appropriate to use a 'remote' method of consenting participants. These differ slightly for patients who are new to the study and for those who are current patients but are being re-registered in a new cohort - outlined below.

If you need any POSTAGE STAMPS for remote consent please get in touch, - we have a supply of these that can be posted out.

Remote consent for participants who are <u>new</u> to the study

Step One

Person taking consent posts Outreach Study Material to potential study participant.

Document	Download from
BSRBR-RA Outreach Consent Invitation Letter	Section 3 https://bsrbr.org/hospitals/research-development/documents/
Information Sheet	https://www.bsrbr.org/hospitals/data-collection/baseline-information/
Consent Form	
Transparency Sheet	
HAQ	
EQ5D	Not available on website - please contact the team for a copy.

Step 1 and Step 2 can be done in any order.

Step Two

Person taking consent phones the potential participant to explain the study and answer any questions.

Step Three

Study participant signs the consent form and posts it back to the hospital, along with the HAQ and EQ5D

Step Four

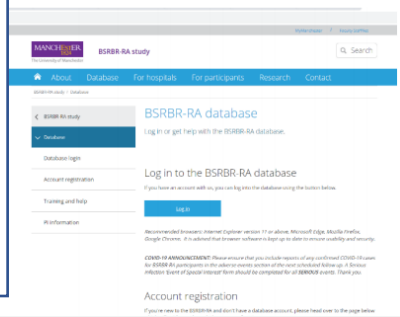
Person taking consent countersigns the consent form, posts a copy back to the participant and puts original form in the patient notes.

Step Five

Study participant can be registered in the online portal.

Please remember to upload the consent form.

If you don't have a DAS-28 for when the participant started therapy, please use the closest pre-biologic score from the patient notes.



Remote consent for re-registration of existing BSRBR-RA participants

Step One

Person taking consent posts the documents for outreach consent for re-registration to the study participant:

Document	Download from
BSRBR-RA Outreach Re-consent Covering Letter (Switchers)	Section 3 https://bsrbr.org/hospitals/research-development/documents/
Information Sheet	https://www.bsrbr.org/hospitals/data-collection/baseline-information/
Consent Form	
Transparency Sheet	
HAQ	
EQ5D	Not available on website - please contact the team for a copy.

If the participant has any questions about re-consenting, they can contact the research team on the details provided within the letter.

Step Two

Study participant signs the re-consent form and posts it back to the hospital, along with the HAQ and EQ5D.

Step Three

Person taking consent countersigns the re-consent form, posts a copy back to the participant and puts original form in the patient notes.

Step Four

Study participant can be re-registered in the online database after a switch request has been made in the original Study ID. Please remember to upload the re-consent form.

If you don't have a DAS-28 for when the participant started therapy, please use the closest pre-biologic score from the patient notes.