British Society for Rheumatology

Rheumatoid Arthritis Register

BSRBR-RA Study Newsletter

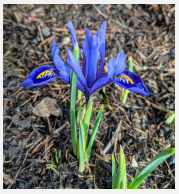
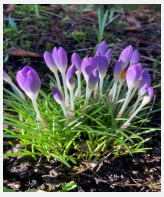
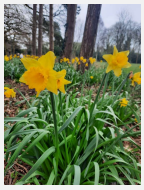
June 2021

As we move through 2021, we appreciate that the NHS remains under extreme pressure and are thankful for the new registrations and follow up data that you have provided for BSRBR-RA participants throughout this difficult period. The study remains open to new registrations and submissions of follow-up information.

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.

- The BSRBR-RA study team continue to work from home and are contactable via email.
- Participants can only be registered and followed up via the online database - unfortunately paper registration forms cannot be accepted due to remote working. **Training and tutorials** for the database are here: https://www.bsrbr.org/database/training-help/
- **75 NHS Trusts** are successfully submitting data using the online system – thank you for your support!

Recent Publications using BSRBR-RA data

- **Bechman et al.** "Is background methotrexate advantageous in extending TNF inhibitor drug survival in elderly patients with rheumatoid arthritis? An analysis of the British Society for Rheumatology Biologics Register".
- **Chadwick et al.** "Cervical screening uptake and rates of cervical dysplasia in the British Society for Rheumatology Biologics Register for Rheumatoid Arthritis".
- **Hamann et al.** "Early response to anti-TNF predicts long-term outcomes including sustained remission: an analysis of the BSRBR-RA".

COVID-19 Update

Please include reports of **any suspected or confirmed COVID-19 cases** for BSRBR-RA participants in the adverse events section of the next scheduled follow up. A Serious Infection 'Event of Special Interest' form should be completed for all serious events of COVID-19.

In the coming weeks you will see changes to the data collection forms at baseline and follow-up to collect detail around COVID-19 vaccinations (name of vaccine, date of first dose and second dose) as well as details of COVID-19 cases prior to baseline registration.

• Email: biologics.register@manchester.ac.uk • Twitter: @BSRBR_RA

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

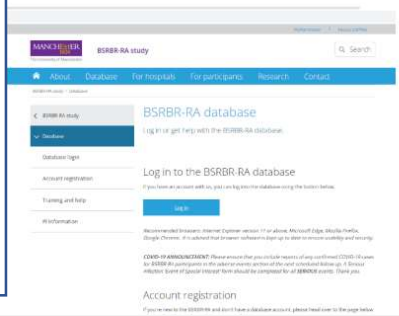
Person taking consent countersigns the consent form, posts a copy back to the participant and puts original form in the patient notes.

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.