

Rheumatoid Arthritis Register

## **BSRBR-RA Newsletter**

**JAN 2019** 

## **Your Diary**

**Many** patients ask how to fill in their diary so we have listed a few things below to help when filling it in.

When we send your follow up form, we will ask that you return your diary from the **previous** 6 months so with the Follow-up "1" form (which you will receive 6 months into the study) you need to return Diary "0".

We ask for: New referrals over the last 6 months.

We don't need: Ongoing referrals for know conditions (e.g. a new referral for your RA) or treatment referrals (e.g. hearing aid clinics).

We ask for: Any new overnight <u>hospital admissions</u> you have had. This includes admissions for RA flares and A&E visits that result in you <u>staying overnight</u>.

**We don't need**: <u>Planned</u> hospitalisations for surgery (e.g. knee replacement due to RA).

**We ask for:** Drugs prescribed for new illnesses/conditions (e.g. antibiotics for a chest infection).

We don't need: Change of doses for ongoing medications (e.g. increased dose of methotrexate).

If you lose your diary don't worry, you can request a new one from the office or print off a new copy from our website bsrbr.org (remember to add your study ID or name).



## **Changing Therapies**

On occasion we are contacted by patients who think we have sent them questionnaires in error because they have stopped their biologic, biosimilar or other targeted therapy. This is not the case. Participants who have stopped or changed their therapy are just as important as those who remain on the drug. The main aim of the BSRBR-RA is to monitor the long-term effect of these drugs which includes the time after a treatment has been stopped.

We will send you forms to complete about your health for 3 years but we will follow you via your rheumatology team at the hospital for longer. All the data you and your rheumatology team provide is important; whether you have been taking biologics, biosimilars or other targeted therapies for any length of time, be it 2 weeks, 2 years or longer. If you want to know more about our findings you can visit the <u>research section of our website</u> which includes many accessible versions of publications that have been produced recently from BSRBR-RA data.

## **Useful Link**

We work closely with our colleagues at NRAS (National Rheumatoid Arthritis Society) who provide support and advice for people living with RA. You can find helpful information and more on their website.

www.nras.org.uk





The BSRBR-RA is coordinated at the University of Manchester. Our staff are available to answer any questions you have about the study. We are unfortunately unable to provide any medical advice regarding your rheumatoid arthritis (or other rheumatic condition) so for this, you should contact your rheumatology team at the hospital.

Have a question? Contact us! Tel: 0161 275 1652/7390 Email: biologics.register@manchester.ac.uk





