BSRBR-RA GUIDE TO RE-REGISTERING PATIENTS

WHAT IS RE-REGISTRATION?

Re-registration is the process of moving a BSRBR-RA participant who is already taking part in the register to a new cohort when starting treatment with a new RA therapy.

The BSRBR-RA groups patients into different cohorts depending on what RA therapy is being taken at the time of registration. This is to allow our researchers to make comparisons or note differences between the cohorts. When the register first started there were very few cohorts but more have been added as new therapies have come along.

Re-registering a participant means that both their clinical and patient follow up will begin again allowing us to collect more data. For example, we only capture patient reported data (HAQ and EQ-5D) for the first three years from registration, so it is really important we re-start follow-up to understand how they are responding to their new drug.

When a participant is re-registered, we inform the Clinical Research Network (CRN) that this is a new accrual for your hospital via a monthly upload to the Central Portfolio Management System (CPMS).

WHO CAN BE RE-REGISTERED?

Any rheumatoid arthritis patient starting an eligible biologic, biosimilar or JAK inhibitor for the first time who is currently participating can be re-registered for that drug. The eligibility checker on our website can tell you which therapies are currently eligible for re-registrations (www.bsrbr.org).

WHEN SHOULD PATIENTS BE RE-REGISTERED?

Ideally, we would ask that you re-register a patient as close to them starting the new drug as possible, but within 24 months of the switch at the very latest. It is also a good idea to re-register a patient when completing a patient's current follow up form to prevent gaps in data.

If we receive a clinical follow up form with details of an eligible drug start, without the corresponding re-registration forms, the BSRBR-RA will send out a switch pack asking you to re-register the patient.

HOW TO RE-REGISTER

1. **Ask the patient if they are happy to be re-registered. Ask them to read the participant information sheet and transparency information sheet. If they agree, complete the consent form.**

2. **Have the patient complete a HAQ and EQ-5D.**

3. **Complete the Short Baseline Questionnaire.**

   ** If you do not know the patient's current study ID you can find this out by contacting the office.**

4. **Send the completed forms to the BSRBR-RA.**

   You can do this using our pre-paid envelopes, if you need some extras email the office and we can send you some

5. **We will process the forms and the patient will be assigned a new study number, any follow up forms will now be sent with the new study number. We keep both records linked in the database.**

FORMS

All the necessary forms can be found on our website for downloading & printing or obtained by contacting the office.

- Short baseline questionnaire
- Patient information sheet
- Transparency information sheet
- Patient consent form
- Health assessment questionnaire - HAQ
- Patient baseline EuroQol

If you are intending to re-register a large number of patients (e.g. your trust has decided to move all Enbrel patients to Benepali) we may be able to help by providing the necessary forms that have been pre-populated with some of the information we already have. Please email us for details.

FAQ

- **How do I know if a patient is already on the register or find out their BSRBR-RA study number?**

Please phone or email the office to check. We can provide a full list of patients currently registered to your consultant/hospital or check any individual records as needed.

- **Do I have to re-register a patient and what happens if I don't?**

Although we would like you to re-register all eligible patients where possible it is by no means mandatory. Where a patient is not re-registered they will simply continue their follow up as if was before under their original BSRBR-RA study number but this will result in some missing information (EQ-5D and HAQ and some clinical measures).

- **The patient has already stopped the new drug should I still re-register them?**

Yes, the information on patients who stop or change drugs soon after starting a new therapy is just as important as those that continue on a drug.

- **Does a re-registration count towards our CRN accrual in the same way a new patient does?**

Yes all registrations count including re-registrations. Our UK CRN ID is: 7302

- **This patient has already been re-registered, can I do it again?**

Yes, as long as the patient is starting an eligible drug for the first time and is happy to re-consent again. We already have patients who have participated in the register for a long time and have been part of a number of different cohorts.

- **The patient does not want to re-register, what now?**

It is essential that patient consent for re-registration is given. If you have approached a patient and they have declined re-registration, follow up will continue as long as they don't withdraw from the study. You can indicate on their next follow up form that the patient is NOT for re-registration, which means we will not send you a request to do so.

CONTACTS

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