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 the patient is 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). Our UK CRN ID is: 7302.

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.

FAQs

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

You can view a full list of patients currently registered to your centre when using the BSRBR-RA Online Database. If in doubt please contact the BSRBR-RA office to discuss further.

- **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 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.

- **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 under their current BSRBR-RA study number but this will result in some missing information (EQ-5D and HAQ and some clinical measures).

- **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 (under their current BSRBR-RA study number) as long as they don't withdraw from the study.

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