Editorial

Some very important changes are about to take place in the BSRBR.

With support to be provided by Pfizer (previously Wyeth) and Abbott, the Ankylosing Spondylitis Register that we have been discussing for several years is finally about to happen (see Update box for more information).

In addition, the companies supplying the three “classic” TNF alpha blocking agents, i.e. etanercept, infliximab and adalimumab have agreed to extend the follow-up period of assessment from the original five years at least until the end 2013 (ten years of follow-up for most of the original cohorts). The assessment will take the form of an annual request to the rheumatology team in charge of the patients taking these drugs asking them some very simple questions about whether they still remain on the drug, or if there have been any major side effects such as a myocardial infarction, infection or cancer and if the patient is still alive.

Another major development is that UCB Pharma have agreed to fund a biologics register for patients with rheumatoid arthritis to be treated with certolizumab pegol. We will be seeking to assess the five-year outcome (looking at particular the side effects) of 2000 patients and importantly, we will be seeking to compare these patients with a new comparison cohort of 2000 RA patients newly started on other TNF-α-blocking agents.

Finally, BSR is also in negotiations with Roche who are considering establishing a register for patients treated with tocilizumab.

Certolizumab pegol recruitment

Please don’t forget that patients newly starting certolizumab pegol (i.e. within the last six months) can now be recruited onto the Biologics Register.

If you inform us that a patient currently registered with BSRBR starts certolizumab pegol on one of the follow up forms, you will be posted all the forms required to re-register the patient us. Alternatively, these forms can be downloaded from BSRBR’s Manchester website and sent in with the follow-up questionnaire, or at any other time:

http://www.medicine.manchester.ac.uk/musculoskeletal/research/arc/clinical_epidemiology/pharmacoepidemiology/bsrbr/ in the health professionals section.

Update on Ankylosing Spondylitis biologics study

After a long gestation period, in January 2011 the final proposal for the British Society for Rheumatology AS Biologics Study was sent to Abbott and Pfizer, marketing authorisation holders for adalimumab and etanercept, the two biologics currently authorised by NICE for Ankylosing Spondylitis. These two companies already fund the Scotland and Ireland Register of Ankylosing Spondylitis (SIRAS) and are now seeking formal approval within their global parent companies.

A meeting of the AS community organised by Aberdeen, Manchester and Glasgow (3 members of consortium running the study) was recently held in Birmingham to consult on the core dataset and recruitment criteria and there is clearly great enthusiasm for the project. The establishment of a study, rather than a Register, reflects the objectives of the work and should simplify the process of adoption on to the NIHR Comprehensive Local Research Network (CLRN) and subsequent obtaining of support by participating centres.

The proposal is to recruit a cohort of 650 AS patients newly started on either adalimumab or etanercept and a second, comparison cohort of non-exposed AS patients.

If you would like to find out more, come and talk to us at the BSRBR stand (DG/22) at Rheumatology 2011 (12-14 April in Brighton) or drop in to meet Professor Gary Macfarlane and other members of the research consortium on Thursday 14 April from 09.15 to 10.00 in the Empress room at the Grand Hotel in Brighton.
This year sees the launch of the iQ initiative; a faculty-led educational programme initiated and funded by Pfizer, to support excellence in practice and the continuous professional development of healthcare professionals responsible for the care of patients with inflammatory disorders in the UK.

As part of this initiative, iQ Science comprises a series of cutting-edge scientific meetings for specialist consultants, led and developed in collaboration with a world-renowned faculty, exploring a range of exciting advances in each specialty, with particular emphasis on how the most recent scientific breakthroughs will impact on clinical practice. Furthermore, the content of the meetings has been designed to provide groundbreaking educational content with cutting edge technology, creating a unique learning experience. There are two iQ Science meetings currently planned for 2011:

**Translational Frontiers in Rheumatoid Arthritis: Biological, Technological and Clinical Advances**

- **Thursday 12 May**: 19:00 – 21:30
- **Friday 13 May**: 08:00 – 17:30

**Translational Frontiers in Psoriatic Arthritis and Ankylosing Spondylitis: Biological, Technological and Clinical Advances**

- **Thursday 16 June**: 19:00 – 21:30
- **Friday 17 June**: 08:30 – 17:00

For more information about these meetings, including an overview of the agenda and faculty, and to register your interest in attending, please visit [www.iq-education.com/Science](http://www.iq-education.com/Science)

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**BSRBR Landmark recruitment figure**

Thank you to Dr Lesley Hordon and the team at Dewsbury and District Hospital, who recruited the 20,000th participant to the BSRBR! This is a fantastic achievement and represents all the hard work put into the study across the UK over the last 10 years. Thank you all for your continued support of the study, and we look forward to the next successful decade!
New anti-TNF comparison cohort

We would like to thank Dr Hordon and her team for being the first rheumatology centre to approach the team to recruit patients to the new anti-TNF comparison cohort, to include patients with rheumatoid arthritis newly starting one of the original anti-TNF therapies (adalimumab, etanercept and infliximab). Patients recruited to this cohort will be eligible for accrual on the NIHR CRN portfolio, so if you are interested in contributing to this new cohort of patients, please contact kath.watson@manchester.ac.uk or katy.evans@manchester.ac.uk.

Tocilizumab cohort

Watch this space for details of a new tocilizumab cohort in BSRBR.
BSRBR Research Nurse Q&A

Ms Ursula Pattinson has worked as a research nurse for the BSRBR since June 2008, having previously worked in rheumatology departments across Greater Manchester. Part of her role for the BSRBR is visiting rheumatology sites within the North West to help set up systems for the identification, recruitment and follow-up of participants to the study; we asked her about how she maintains recruitment to the BSRBR as the study moves into its second decade.

How do you identify and recruit eligible patients for the BSRBR?

I currently help with the recruitment of patients newly starting (within the last six months) rituximab and certolizumab pegol to the study. As these drugs have different routes of administration, I have different methods of recruiting these patients:

Rituximab is administered on a Medical Investigation Unit rather than in clinic, so I rely on the staff within the MIU to let me know when eligible patients are due in so that I can send the potential participant the study information before the drug is administered. If I am unable to recruit them at the time of the first infusion, I will give them the information at the first infusion then ask if they are interested in participating in the study when they come back for the second infusion.

I also leave cohort details at the MIU, including the eligibility criteria for rituximab patients, my name and contact details, so that the staff there think of the BSRBR when any patient with RA is due to start rituximab and knows to contact me.

Recruiting certolizumab pegol patients is slightly different; I liaise with the nurses in the rheumatology clinics as to who may be eligible for the BSRBR when any patient with RA is due to start rituximab and knows to contact me.

How important is it that you have good relationships with the staff at each site you visit?

It is important that I establish good relationships with the relevant teams so that I can recruit patients to the BSRBR. I rely on the ward staff and staff in the rheumatology departments to contact me when they have a patient that might be eligible for the study coming into the ward so that I can travel to the sites to try to recruit the patients to the study.

I always ensure that the teams can contact me, and do what I can to get involved with the teams to get to know them better. Last summer I did a charity climb up Mount Snowdon with the team from Oldham to raise money for a local charity – it was hard work and an early start on a Saturday morning, but I did get to know the team better and had a lot of fun. I also make sure that people are aware of who I am at the RCN conference / BSR AGM and so forth so that I can promote the BSRBR.

What is your current focus?

The emphasis now is on getting the message out that we have started recruiting certolizumab pegol patients and trying to boost numbers as much as possible. It is always worth remembering that every participant recruited to the BSRBR – including those patients that were already on the study that we are able to re-register as a rituximab/certolizumab pegol patient if we are informed of the drug change within six months of the switch – are counted as new registrations on the UK CRN accruals database.