

BSRBR-RA Web Portal Progress Report

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www.bsrbr.org

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SUMMARY

Recently, the British Society for Rheumatology Biologics Register for Rheumatoid Arthritis (BSRBR-RA) has been undergoing a major digital transformation. From **1st April 2019**, the study team (Section 1, page 3), based at the University of Manchester, moved away from the old paper data collection systems that have been in place for nearly two decades and transferred to a new secure, online portal.

The portal allows NHS hospitals participating in the study to view all of their patients' data, submit new data and have direct communication with the study team via the web system in an efficient manner. The new system allows clinicians and nurses, once appropriate R&D approvals are in place, to access the portal via the study [website](#) where online training is available to help navigate it. We are using a staged process (Section 2, page 4) to bring the 160 centres online.

The data that you have sent to us prior to April 2019 that was stored in the old system has been moved to the new portal. This was a mammoth task involving the transfer of 1000+ data fields, 30,000 individual patient records with an average of 8 years' worth of follow-up data per patient. Following this transfer, some data will need clarifying with centres in due course. There is no timeline on this clarification process and centres will be encouraged to complete this task only when they are able to do so. This will ensure that the quality of the BSRBR-RA data will become even better over time. For this reason, a staged approach to bringing centres on board was chosen so that they can receive the support they need.

Following a period of in-house testing, on the **30th June 2019** the team opened the portal to "Early Adopters" (n=64 centres; stage 1), classified as centres who had approached the BSRBR-RA team and expressed interest in using the system first (Section 3, page 5). The second stage, estimated to start December 2019, involves the BSRBR-RA team approaching engaged centres (approx. n=50) classed as those who have been actively recruiting or submitting follow-up data within the past two years, to sign up to the new system. The third, and probably the most difficult stage, will be to try to engage those centres who have not been actively engaging in the study in recent years (approx. n=46).

Initial feedback from centres has been good (Section 4, page 6) with nurses reporting the registration process being simple and the system easy to navigate. As with all new systems, we estimate it will take centres time to get used to the portal.

To promote the portal, the BSRBR-RA Team has worked with the BSR to approach organisers of future national and regional rheumatology meetings to allow the team to discuss and demonstrate the new system in order to reach as many centres/users as possible (Section 5, page 7).

Our in-house developers (1 x Senior Software Developer; 0.2FTE and 2 x Software Developers; 0.8 and 0.4 FTE respectively) continue to improve the agile development of the system (Section 6, page 8). The next steps will be working with you to find out what you would like to see in the portal in terms of output reports and other functionality. In the future, if funding allows, the aim is to build a similar system to allow patients to enter data relating to their arthritis online/via an app which would connect with the portal already launched.

Section 1: The BSRBR-RA Team

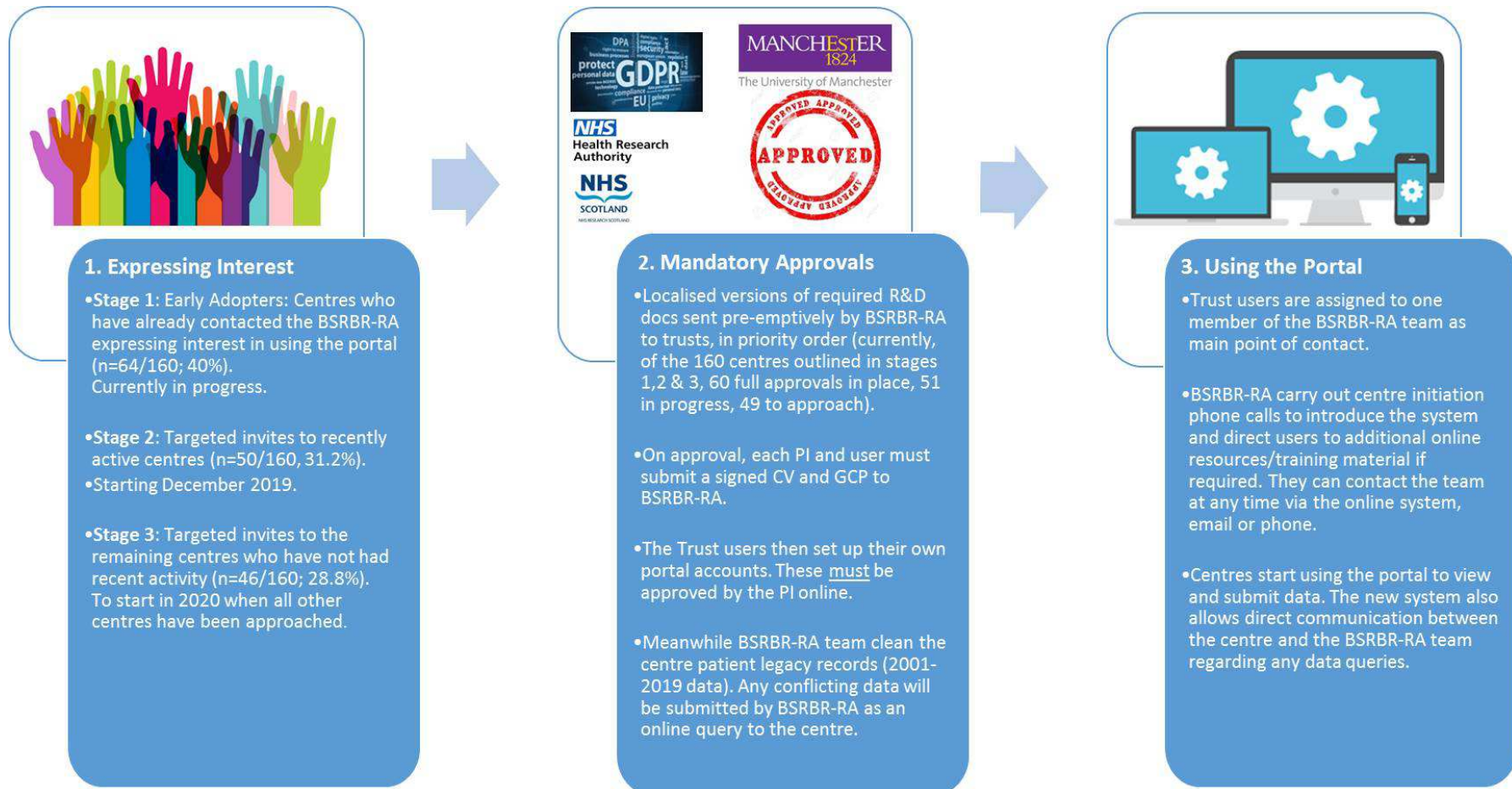
Our BSRBR-RA administration team is led by Michael and his team includes: Emma, Lisa, Vivienne, Jessica, Lizzy, Danny and Annouskha. Anthony is our R&D Project Co-ordinator and will be able to help your Trust with the necessary approvals required to start using the portal. Once your R&D department has approved the use of the portal, your site is assigned to one named member of our administration team as a primary contact to help you with the site initiation process and any queries and feedback you may have regarding the system.

Our pharmacovigilance team includes Sally, Anne, Lesley and Jenna and they will be able to assist with any queries relating to the data capture and reporting of serious adverse events, which is the primary aim of the BSRBR-RA.

Our IT team includes Hassan, Phil S and Phil B and they will be helping to develop the system over the coming months. We have built the system for you, so your feedback is very important.



Section 2: BSRBR-RA Portal Centre Joining Process



If you would like to start using the BSRBR-RA Portal and join Stage 2 users, please contact the team at biologics.register@manchester.ac.uk

Section 3: List of Early Adopters (Stage 1)

Centre	
Abertawe Bro Morgannwg University Health Board (now Swansea Bay University Health Board)	North West Anglia NHS Foundation Trust
Aneurin Bevan University Health Board	Northampton General Hospital NHS Trust
Ashford and St Peter's Hospitals NHS Trust	Northern Devon Healthcare NHS Trust
Barnsley Hospital NHS Foundation Trust	Pennine Acute Hospital NHS Trust
Betsi Cadwaladr University Health Board	Pennine MSK Partnership
Calderdale and Huddersfield NHS Foundation Trust	Queen Elizabeth Hospital King's Lynn NHS Foundation Trust
Cambridge University Hospital NHS Foundation Trust	Royal Berkshire NHS Foundation Trust
Cardiff and Vale University Health Board	Royal Bournemouth and Christchurch Hospitals NHS Foundation trust
Chesterfield Royal Hospital NHS Foundation Trust	Royal Free London NHS Foundation Trust
Croydon Health Services NHS Trust	Royal United Hospitals Bath NHS Foundation Trust
East Cheshire NHS Trust	Salford Royal NHS Foundation Trust
East Kent Hospital University NHS Foundation Trust	Sandwell and West Birmingham Hospitals NHS Trust
East Suffolk and North Essex NHS Foundation Trust	Sheffield Teaching Hospitals NHS Foundation Trust
East Sussex Healthcare NHS Trust	Sherwood Forest Hospitals NHS Foundation Trust
George Eliot Hospital NHS Trust	South Tyneside and Sunderland NHS Foundation Trust
Great Western Hospitals NHS Foundation Trust	St George's University Hospitals NHS Foundation Trust
Hampshire Hospitals NHS Foundation Trust	St Helens and Knowsley Teaching Hospitals NHS Trust
Homerton University Hospital NHS Foundation Trust	Stockport NHS Foundation Trust
Hull and East Yorkshire NHS Trust (now Hull University Teaching Hospitals NHS Trust)	Tameside and Glossop Integrated Care NHS Foundation Trust
Hywel Dda University Health Board	The Dudley Group of Hospitals NHS Foundation Trust
Kingston Hospital NHS Foundation Trust	The Princess Alexandra Hospital NHS Trust
Lancashire Care NHS Foundation Trust	The Rotherham NHS Foundation Trust
Lewisham and Greenwich NHS Trust	The Royal Liverpool and Broadgreen University Hospitals NHS Trust
Manchester University NHS Foundation Trust	The Royal Wolverhampton Hospital NHS Trust
Medway NHS Foundation Trust	Torbay and South Devon NHS Foundation Trust
Midlands Partnership NHS Foundation Trust	University College London Hospitals
NHS Fife	University Hospital Bristol NHS Foundation Trust
NHS Greater Glasgow and Clyde	University Hospitals Coventry and Warwickshire NHS Trust
NHS Lanarkshire	University Hospitals of Leicester NHS Trust
NHS Lothian	Weston Area Health NHS Trust
Norfolk and Norwich University hospital NHS Foundation Trust	Wirral University Teaching Hospital NHS Foundation Trust
North Middlesex University Hospital NHS Trust	York Hospitals NHS Foundation Trust

Section 4: Feedback from Early Adopters

"I have finally got access to the database and have entered my first patient. It looks good and is easy to navigate"

"I used the website for the first time for a follow up, yes all seems straight forward."

"I have just entered my first patient, and if I am honest I have found it is quite labour intensive! I actually had to do most of it on the paper forms and then put it on the database once I was back from clinic.

I guess it will get easier the more I do, and learn to navigate my way around."

"I have successfully logged on and submitted a test patient. I found the registration process straightforward. Upon 1st signing in, everything seems logical and easy to navigate."

"It might be useful to produce a blank follow up form with the required fields, in case people would prefer to first enter the data onto the paper CRF prior to then transferring to the web tool. As we deal with mostly online patient records and the data is in various places, it is sometimes easier to do it this way."

"We have done a few follow ups, which seems to be very easy and straight forward. We are getting used to database slowly and how to navigate around, but the SOPs are very useful and easy to follow to make sure we cover everything."

"I like the addition of the DAS calculator"

Section 5: BSRBR-RA Promoting the Portal: Strategy for 2019-2020



Section 6: Future Plans

