

## IBD Registry Newsletter for friends Summer 2019

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The IBD Registry is a not-for-profit company wholly owned by the Royal College of Physicians, the British Society of Gastroenterology and Crohn's & Colitis UK



## Dear friends, welcome to our summer newsletter

To some, it may seem we've been quiet at the IBD Registry – but in fact we've been very busy 'behind the scenes'. We've grown our Registry staff team so that we can strengthen the level of support that we can give to IBD clinical teams across the UK. With the growing number and availability of biological treatments for IBD, we have started a pharmacovigilance system to support real world monitoring of these as part of routine clinical care. Since last year, we have been a partner in the revision of the IBD Standards and in the readiness for their release at the upcoming BSG 2019; this is a great piece of work that aligns naturally with our re-appointment by NHS England as the Quality Accounts provider for IBD for 2019-20. We could not do all this without the priceless backing of the BSG, RCP and Crohn's & Colitis UK, our three founding organisations. So, it has been a busy time, and we intend to keep up the pace! We look forward to meeting you, either at BSG 2019 or on a future occasion.



## BSG 2019 preview Taking the high road on data quality...



Teaser of poster submitted by the Registry at the BSG on results of an audit of biological therapy for IBD. See the whole poster at BSG 2019.

**BSG Annual Meeting 2019:** We'll have a full team at this year's BSG (SEC, Glasgow, 17 – 20 June), including CEO Liz Dobson, Medical

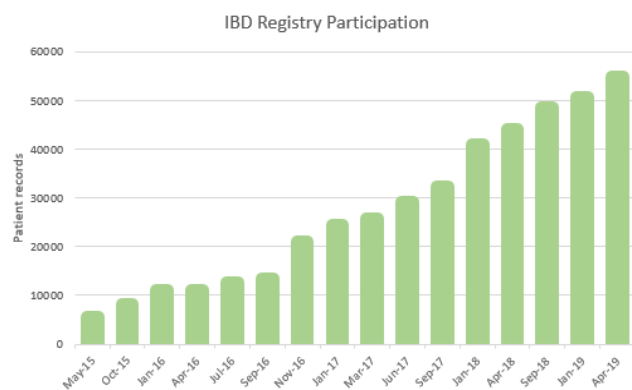
Director Dr Stuart Bloom, Academic Lead Dr Keith Bodger and Clinical Lead Dr Fraser Cummings. This year we are focusing on the role clinical data can play in the drive to improve the quality of IBD care. Liz will be speaking as part of the IBD Quality Symposium (11.00 – 12.30 Hall 1) on Thursday 20<sup>th</sup>.

We'll also be on hand in the exhibition area (**Stand 166**) all week to meet delegates and anyone interested in our work. Whether you have specific questions on our services, would like to discuss how we might collaborate on projects or would just like to say hello, we'd love to see you. Our stand will also feature

presentations and demos of our clinical support and data capture tools as well as manuals and new support packs for clinical teams. To help frontline IBD clinical staff, we'll also be running practical 'data surgeries' to help use the tools more effectively or as sample introductory sessions for new clinical teams wishing to join the Registry.

The Registry team are also delighted that the results of the Audit of Biological Therapy in IBD, prepared by Dr Bodger, has been selected as a poster and will be on display in the BSG 2019 poster zone. Please say hello at BSG or if not then follow us on Twitter [@ibdregistry](https://twitter.com/ibdregistry) and see updates on our revamped [website](https://www.ibdregistry.org.uk). Drop us a line if you would like to arrange a meeting at [support@ibdregistry.org.uk](mailto:support@ibdregistry.org.uk)

## We've reached almost 55,000 IBD records and rising...



Figures showing growth in number of patient records - now at almost 55,000 (April 2019).

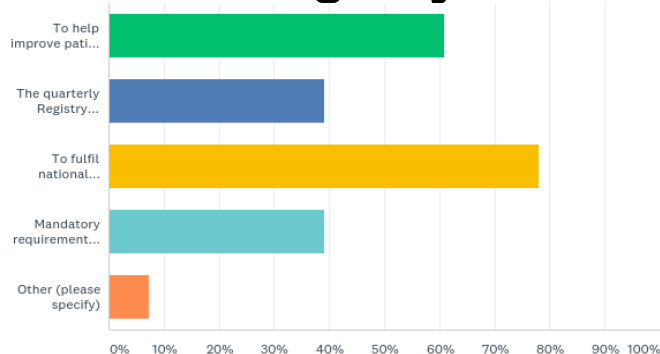
The IBD Registry has hit a grand total of almost 55,000 patient records with 83 IBD clinical teams around the country now participating in the Registry. The IBD Registry is now one of the largest registries in Europe for inflammatory diseases. We are delighted to welcome a host of respected IBD units who have recently signed up including Guy's and St Thomas' NHS Foundation Trust, Peterborough City Hospital, The Epsom Hospital, The Royal Shrewsbury Hospital and The Hillingdon Hospital.

## Quality accounts 2019

NHS England's Quality Accounts (QA) list the areas that health service providers must formally report on. The IBD Registry's Biologics

Audit has again been selected for IBD in the NHS England Quality Accounts List for 2019/20. Signing up with the Registry for your Trust's QA is now even simpler; contact us at [support@ibdregistry.org.uk](mailto:support@ibdregistry.org.uk) to find out more.

## Why do you participate in the IBD Registry?



The Registry recently commissioned an online survey of clinical teams who use the data systems. The results are still being analysed but an interesting indicator was the reasons for participating in the Registry: 61% said they participated to help improve patient care; 39% said it was to access the Quarterly Registry Reports; 78% said they participated to fulfil national quality and audit requirements and 39% said because it is a mandatory requirement e.g. direction from clinical audit team or lead consultant.

## Listening to what IBD patients say



IBD Registry team loyally sporting their corporate green clothing set up at St Mark's Hospital patient open day.

Although the Registry is not primarily a patient-facing organisation, we believe it is crucial that

our data services are built around the end goal of better treatment outcomes for people with IBD, empowering clinicians to achieve this goal, working with patient groups such as Crohn's & Colitis UK. That's why we were delighted to attend the patient open day in May for St Mark's Hospital at Northwick Park in London to explain our role in data quality, discussing topical issues such as patient consent and gauging opinion on how our information materials work, including our newly updated patient information leaflet. You can download our new patient information leaflet [here](#).

## Integrating data with the new IBD Standards

We are proud to be a committed core member of IBD UK, an alliance whose role has included producing the IBD Standards: guidelines for high quality person-centred-care in IBD. The revised Standards are an organisational benchmarking tool for NHS Trusts, and after months of work, it's great to see them being released as part of the upcoming BSG 2019. Within this work, the Registry has been exploring ways to integrate its existing captured data into the measurement element of the Standards wherever possible, so that clinical teams are saved from the burden of repeat data entry. More information on the IBD Standards will be announced by IBD UK at BSG 2019 on Thursday 20<sup>th</sup> June.

## Tracking biosimilar safety

The recent introduction of biosimilar treatments in IBD means that, as these treatments become more widely used by the NHS, the Registry has a pivotal role to play in the collection of crucial, on-going safety data as part of routine clinical

care. The IBD Registry will soon be facilitating several safety studies using our cloud-based Web Tool for data capture. Our first study will monitor the use of Hyrimoz, an adalimumab biosimilar. The second study will observe the infliximab biosimilar Zessly. The IBD Registry will receive funding to collect safety data and analysis, and participating NHS Trusts will be reimbursed for their time. The study is completely observational, and all patients will be asked to consent to their data being used as part of the study. Click [here](#) for more information.

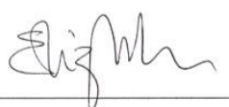
## Building our team at Registry HQ

We are delighted to keep up the pace of growth with some new staff appointments including a technical manager and a communications manager as we seek to meet the tasks ahead. We now have a full team at our Epsom HQ who are able to respond to clinical team queries and problems, help with technical issues and ensure we are communicating and building dialogue with our partners.

## Check out the IBD Registry website after our revamp

[www.ibdregistry.org.uk](http://www.ibdregistry.org.uk)

The Registry website has had a makeover. There is now a more intuitive format to help navigation and convey the information we believe patients, clinicians, the NHS, industry and the public all need to understand our work. We hope that you will notice a difference and we would welcome any feedback. Further improvements are planned in the coming months. See what you think [here](#).



Liz Dobson  
Chief Executive Officer



Dr Stuart Bloom  
Medical Director

With our thanks for your continued interest in the IBD Registry.

### Contact us

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