

## Registry news for IBD teams



BSG 2019: Sarah, Stephen and Liz from the Registry team at BSG 2019 in Glasgow say good-bye after connecting with IBD teams and sharing information and tips to make the most out of our services.

## News

As the weather has warmed up, at least on some days, so has the pace of activity at Registry HQ.

Top of our list was getting out and about and meeting hardworking IBD teams and listening to your priorities. We have just had a very successful BSG 2019 meeting in Glasgow with our data surgery tutorials on the WebTool proving extremely popular.

The 2019 update of the IBD Standards and the BSG IBD Consensus Guidelines are landmark achievements in IBD, and were a highlight of the meeting for the Registry. We are proud to have played our part in the IBD UK alliance. More on BSG 2019 inside.

Finally, we are working hard on enhancing support for sites participating in the Registry, including an information pack for teams with tips on data upload and more general information on users' experience. These will be available over the later this year. We wish you all a happy summer and are at your service should you need us.

## Zessly safety study opens for interest

The IBD Registry is inviting IBD clinical teams across the UK to participate in a post-marketing safety study of patients using the infliximab biosimilar Zessly. This study is facilitated by the Registry on behalf of Sandoz Ltd, the manufacturer of Zessly. The purpose of the study is to track use of and reactions to the biosimilar in a cohort of IBD patients. Only clinical teams prescribing Zessly are eligible to participate, however the study is open to IBD teams from all parts of the UK whether or not they are already participating in the Registry. Participating centres will receive our newly upgraded online WebTool for PV data capture



and all necessary training materials. Study setup and data entry costs will be reimbursed. This is an observational study only, so no additional patient tests or monitoring will be required. Follow-up of patients in the study will continue into 2021. There is the potential the study may lead to further opportunities. If you are interested in participating in this study, for more information please email [pvsupport@ibdregistry.org.uk](mailto:pvsupport@ibdregistry.org.uk).

## Webtool upgrade - down time 17th July

We would like to give advance notice that the WebTool will be temporarily unavailable for the whole working day on **Wednesday 17th July**. This is to allow installation of key upgrades to the WebTool enabling pharmacovigilance (for clinical teams participating in our safety studies - currently Hyrimoz and Zessly).

The upgrade will also include some general updates to the wider service, which we will be detailing separately for all users. We expect to be live again at the end of the day and will confirm by email that the system is running. Please ensure that you are logged out of the system on the **17th July** and that you have saved any data you are working on.

### Forthcoming data submission deadlines

4th October 2019

10th January 2020

3rd April 2020

## IBD audit requirements Quality Accounts 2019-20

The IBD Registry is the listed provider for Quality Accounts with our Biological Therapies Audit. We will analyse your Trust's provided data (submitted to us quarterly) to compute the required KPI calculations and provide you with a Report that can inform your Trust's Quality Account. We are currently taking enrolments for 2019-20. Please contact us to enrol your Trust for our Quality Accounts service.

## WebTool Wizards

The good news for IBD teams is that the Registry will soon have a suite of relaunched Webtool Wizards to help users of the WebTool upload IBD patient information. While PMS user experience issues should be referred to CIMS, the Registry has also produced a Wizard for PMS users to ensure maximum support for IBD teams.

## Supporting studies

Are you planning a research study? The Registry has a UK wide, NHS approved, cloud infrastructure can be tailored for use by clinical teams for studies. We have supported two already with more in the pipeline. If you are interested please get in touch at

[support@ibdregistry.org.uk](mailto:support@ibdregistry.org.uk).

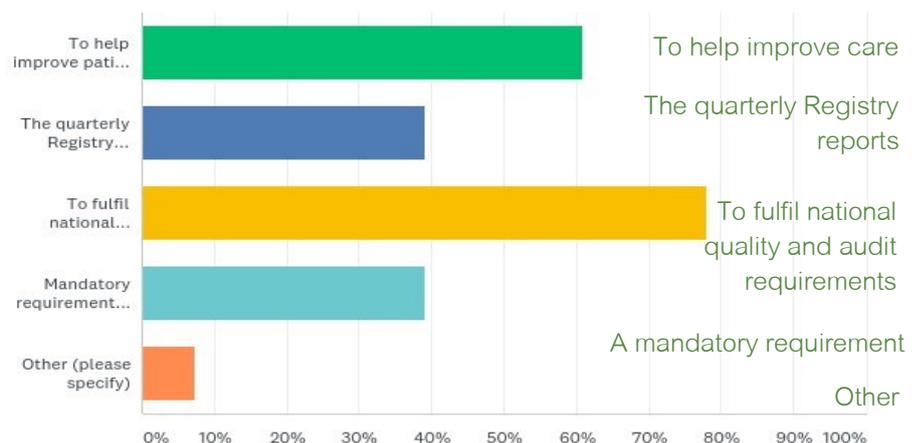
The BSG 2019 meeting is the most important event in our calendar for meeting our IBD teams. This year, in Glasgow, Registry staff and the executive team were out in force meeting our partners and IBD clinical teams from around the UK. A quick snapshot of some numbers gives a flavour of what we were up to over the three days:

- 40 conversations with clinical teams at our exhibition stand;
- Meeting five IBD teams interested in participating in the Registry;
- Undertaking eight tutorials with clinical teams with our expert tutors;
- Issuing two news statements – on the new IBD Standards and our Audit of Biological Therapies;

- Presenting one scientific poster on the Audit of Biological Therapies in IBD (more on the poster below);
- Issuing nine proactive tweets on topical BSG 2019 issues with a total of 10,626 viewings and 60 likes;
- Producing four information posters for our stand, including a focus on consent;
- Drinking numerous cups of free coffee.

For those who could not attend the BSG annual meeting, we have an open door to meet and a number of opportunities to visit your team over the coming months. We are planning to offer a programme later this year of multi-disciplinary team roadshows to meet as many people as possible who use the Registry.

## Survey: why do you participate in the IBD Registry?



The Registry recently commissioned an online survey of clinical teams who use the data capture systems. It was especially interesting to see your reasons for participating in the Registry: 61% said they participated to help improve patient care; 39% said it was to access the Quarterly Reg-

istry 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. More on the survey to come next time . . .



# 2019 IBD Standards

## IBD

## Consensus Guidelines

The launch of the new IBD Standards 2019 at BSG 2019, an update of the 2013 Standards, will provide a catalyst to drive quality in inflammatory bowel disease (IBD). The IBD Standards, produced by IBD UK, an alliance of 17 IBD patient and professional organisations, including the Registry and Crohn's & Colitis UK set out how high quality care should look for a patient at every stage of their journey from before diagnosis to long-term management. More information from Rukshana Kapasi below.

The IBD Standards were not the only piece of milestone guidance in IBD issued at BSG 2019 with the BSG IBD section launching a set of consensus guidelines for managing IBD in adults. The guidelines were presented by Dr Barney Hawthorne of the University Hospital of Wales, Cardiff, alongside Dr Chris Lamb of the Institute of Cellular Medicine, Newcastle University.

## New IBD Standards in focus



**IBD UK's Rukshana Kapasi explains what it means for IBD teams.**

The IBD Standards say what high-quality care should look like at every point of a patient's journey – from first symptoms, to diagnosis, treatment, and ongoing care; whatever their age and wherever they live in the UK. A well-managed IBD service is essential to delivering this.

Announced at the BSG annual conference, these 59 statements set out what good care and treatment looks like for patients with IBD, with the aim that every IBD service in the UK will work to meet these.

A new digital Benchmarking Tool has been developed to help with this, so that services can assess how they are doing against the IBD Standards and plan to improve. A new UK-wide Patient Survey will give people with IBD the opportunity to rate their experience of care, allowing patient experience to support the development of a service. This will provide an opportunity to push through real change, support with business

cases and make the case for additional resources needed.

Through this process, healthcare professionals and patients will be able to work together to improve standards of care for everyone with IBD across the UK. IBD UK needs the support of healthcare professionals to make the IBD Standards a reality by:

- Registering for the IBD Benchmarking Tool from 20th June
- Promoting the Patient Survey in your service from 8th July - we want to ensure a minimum of 10,000 people participate this year across all IBD services in the UK!
- Incorporating the Standards in your overall service design and work and making opportunities to discuss and raise awareness of the Standards at meetings, events and talks.

To see the full list of IBD Standards, register for the Benchmarking Tool and find more information visit: [www.ibduk.org](http://www.ibduk.org). For any questions or to request IBD Patient Survey flyers, e: [info@ibduk.org](mailto:info@ibduk.org)

Rukshana is Chair of IBD UK, Director of Health Service Development at Crohn's & Colitis UK and a Director of the IBD Registry.

The authors note they were informed by 2,379 electronic survey responses from individuals living with ulcerative colitis and Crohn's Disease, including patients, their families and friends.

The word count of the guidelines comes to an extensive 67,786 excluding references. The authors say the guidelines offer clinicians comprehensive, up-to-date guidance on indications for initiation and monitoring of immunosuppressive therapies, nutrition interventions, pre-, peri- and post-operative management, as well as structure and function of the multidisciplinary team, and integration between primary and secondary care. More information at:

<https://www.bsg.org.uk/resource/bsg-consensus-guidelines-ibd-in-adults.html>

## Support packs coming...

The Registry will shortly mail out hard copy support packs that include user guides for PMS or WebTool as well as useful documents such as patient consent forms and posters. If you would like a pack please email us at [support@ibdregistry.org.uk](mailto:support@ibdregistry.org.uk)

## Patient consent congrats to IBD teams

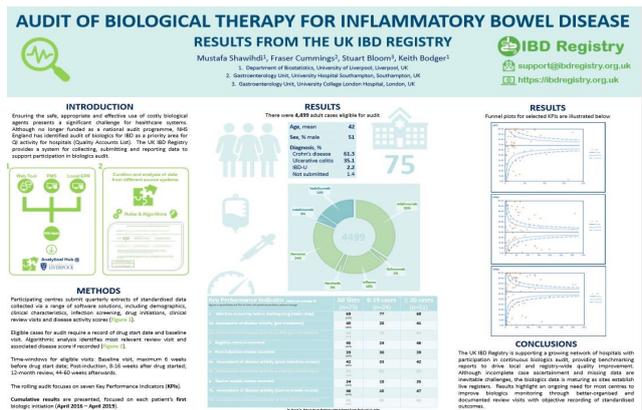
The Registry is moving towards gaining consent from all patients whose records are submitted to the Registry and is encouraging all clinical teams to gain patient consent. Eleven IBD teams have achieved consent rates of **more than 80%** of patients – thank you and special commendations from the Registry to these IBD teams:

- Watford General Hospital
- St Mary's Hospital (Isle of Wight)
- Poole General Hospital
- Buckingham Healthcare Trust
- Musgrove Park Hospital
- Bradford Royal Infirmary
- The Royal Liverpool University Hospital
- Kingston Hospital
- Basildon Hospital
- University Hospital of Wales
- Leighton Hospital

### Why the drive for consent?

Although we still have in place our Section 251 exemption from consent, the Registry has matured rapidly over the past year or so, and we need to mature our consent along with this. Our target is all new patients consented by July 2020, and so to see some clinical teams already achieving over 90% in July 2019 is very good news. The IBD Registry understands that IBD teams are busy, and that consent might seem 'just another thing to do'. To help, we are setting in place guides and user materials to help you with minimum cost to your time. Please get in touch and we will be delighted to assist.

## Registry poster— audit of biological therapies in IBD unveiled



The IBD Registry is delighted a poster presentation prepared by the Registry's Analytics Hub on an audit of Biological Therapy for IBD featured at BSG 2019. The poster summarises the results of the latest registry-based Audit of Biological Therapy for Inflammatory Bowel Disease. Dr Mustafa Shaihi, lead analyst at the Hub, extracted and analysed data from 4,499 adult cases of IBD, supervised by Dr Keith Bodger (Registry Academic Lead). The audit is a cumulative rolling type, focused on seven key performance

indicators and plays a crucial and ongoing role in measuring the quality of clinical care received by patients on these potent biological treatments. Although incomplete case ascertainment and missing data are inevitable challenges, biologics data is maturing as participating teams publish live registers and vital KPIs such as the 12-month review of a patient's biologic treatment are seeing a 64% growth in data captured and performance. Poster (PDF) [here](#)

## PMS User Group—update

The Registry is in the process of revamping the PMS User Group to ensure it provides as much support as possible to users. A forum structure where members can share ideas and tips is an option which the Registry is exploring. For those interested in more information please ask us to add your details to our contact list by contacting [support@ibdregistry.org.uk](mailto:support@ibdregistry.org.uk).

With our thanks for your continued interest in the IBD Registry

Liz Dobson  
CEO



Contact us T: 020 3393 3969 E: [support@ibdregistry.org.uk](mailto:support@ibdregistry.org.uk) Twitter @IBDRegistry

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