

Listening to nurses



Pic: Registry CEO Liz Dobson in discussion with Clinical Nurse Specialist Pearl Avery at the Registry stand at the LOGIC Nurse Education Day.

The Registry joined IBD Nurses on Friday 29th November at the LOGIC IBD Nurse Education Day in London. Registry CEO Liz Dobson chatted to specialist IBD nurse delegates at registration and in the lunch break. We gained some valuable insights into what nurses would like to see improve in data management to help them in their clinical practice. We also offered advice for anyone who wanted to 'deep dive' into any aspect of the WebTool data system. The day was rounded off with the Nurse Awards in the evening which Liz also attended. Huge thanks to event sponsors Tillotts for inviting us.

Complementing clinical data with patient reported outcomes

Uniquely, the Registry collects 'real world', clinically entered and validated data on an on-going basis to build up a picture of the IBD patient journey over time.

These insights can be used to help improve services and ultimately research. We have a long-held ambition to complement this clinical data with the patient perspective. To help achieve this goal, we had built into the Registry the means for Patient Reported Outcome Measurements or 'PROMS' to flow into our dataset.

We are delighted to report that the last upload of data by IBD teams in October saw the first ever patient-entered data flow to the Registry. This was made possible by IBD Nurse Specialist Pearl Avery and her colleagues at the Dorset County Hospital who have been working to connect a patient app to

their clinical data system. In that submission, they collected and uploaded 466 PROMS relating to 372 patients - the first 400 of many.

Please get in touch if you have experience of patient apps in IBD

There's already a wide variety of patient experience apps in use in the UK and, having piloted our first app, we are now commencing work on a project to integrate more patient apps - so offering an increasingly wide access net.

We are keen to learn more about apps in IBD so if you have experience of working with any (whether as a patient, clinician or other) we would be interested to know your thoughts. Please get in touch e: support@ibdregistry.org.uk

Realising quality improvement in IBD

The IBD Registry is a proud founder member of IBD UK, a consortium of 17 member organisations working to transform IBD care and outcomes in the UK.

The Registry has provided an on-going clinical audit for IBD care since 2016 and in 2019 this was joined by a complementary organisational audit developed by IBD UK in which clinical teams self-assess or "benchmark" their service through a 'Benchmarking Tool' against the new IBD Standards which were launched last year by

IBD UK. 84% of IBD clinical teams across the UK are now registered for the Benchmarking Tool. Alongside this, IBD UK initiated a patient survey which resulted in over 10,000 responses, meaning that IBD teams can assess themselves not only against the IBD Standards but also their patients' experiences to identify what is working well and where services could be improved.

The first IBD team Benchmarking assessment phase closes on 31st January so we encourage IBD clinical

teams to complete their self-assessments as soon as possible. The results of the IBD Benchmarking Tool will be publicly available in March 2020. Following this, a national report will be published, giving an overall picture of IBD care across the UK – a major milestone for all involved with or affected by IBD. If you would like any more information, please visit www.ibduk.org or e: info@ibduk.org More info on quality and standards is available on the Registry website <https://ibdregistry.org.uk/quality-standards/>

Taking stock over the decade

As the Registry approaches ten years since the concept of collecting real world information on the progress of people living with IBD, it is timely to look under the bonnet at the data collected so far. With over 60,000 records, the Registry is one of the largest IBD registries in Europe. Key to success has been collaboration with the University of Liverpool, AIMEs, IBD UK, Gut Reaction (the health data research hub for IBD) and not least the enthusiastic participation of so many IBD clinical teams serving their patients.

Our 60,000 records contain rich information on patients' progress which helps clinicians deliver better patient care:

- one third of the records hold information on multiple follow-up reviews
- nearly one half contain disease activity information
- 7,000 courses of steroids
- over 9,000 patients receiving mesalazine
- and 15,000 receiving azathioprine or 6-mercaptopurine

The changing use of biologics and biosimilars is reflected in the evolving choice of first line biological agent and in the transition from one biologic to another, which the Registry has been able to report for the first time (IBD Registry Annual Report, October 2019). This is an edited version of the article – the full version is available on our website at www.ibdregistry.org.uk

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We'd love your feedback on the annual report

As mentioned in a public mailing in October, we published the Registry's first ever *Annual Report on the Use of Biologics for Inflammatory Bowel Diseases*.

While the report is designed primarily for IBD clinical teams and based on data from England & Wales, we would be interested in feedback from other readers including patients and the general public.

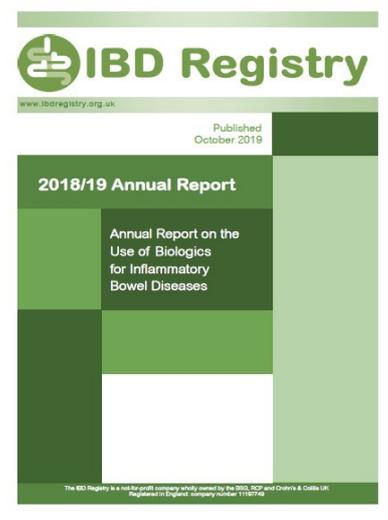
You can let us know by email:

support@ibdregistry.org.uk

You can download a PDF of the report (1.8MB) from our website:

[https://
ibdregistry.org.uk/2019/10/26/
first-registry-annual-report-on-the-
use-of-biologics-for-
inflammatory-bowel-diseases](https://ibdregistry.org.uk/2019/10/26/first-registry-annual-report-on-the-use-of-biologics-for-inflammatory-bowel-diseases).

Once again, thank you to all participating IBD clinical teams for their huge efforts in making this report a reality. If you have any questions or feedback, we would be keen to hear.



With our thanks for your continued interest in the IBD Registry

Liz Dobson
CEO



Dr Stuart Bloom
Medical Director