IBD Registry

www.ibdregistry.org.uk

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2018/19 Annual Report

Annual Report on the Use of Biologics for Inflammatory Bowel Diseases

The IBD Registry is a not-for-profit company wholly owned by the BSG, RCP and Crohn's & Colitis UK
Registered in England: company number 11197749

Foreword

This is the first Annual Report on the data submitted to the IBD Registry as part of the rolling National Audit of Biological Therapies and is a milestone in the Registry's journey as an independent not-for-profit organisation serving those affected by or working in the field of inflammatory bowel diseases (IBD).

Ensuring that IBD clinicians have the most comprehensive information possible on the disease journey of their patients is a key objective of the Registry.

So, although this report's purpose is to consolidate in one place annual changes and trends across a basket of key performance indicators used in our Biologics Audit, we hope that it also gives a sense of how clinical and data management in IBD has been changing for the better in recent years.

Crucial information for clinicians treating patients (for example, biologic drugs' start and stop dates, clinical markers of disease activity) is increasingly being captured at the point of care rather than retrospectively, with the associated benefit of a more complete picture of the patient's progress.

Technological changes, coupled with recent developments in regulations governing capture, storage and use of patient data, have opened opportunities for advances in care for patients with IBD. We are currently exploring the possibility of capturing patient-entered data via phone- and computer-based apps that can upload data directly to the Registry's database. This patient-supplied dataset will complement the clinical dataset and result in richer information for the benefit of patients without the burden on IBD teams of capturing the data.

The report focuses on progress during the calendar year 2018 with comparative data from 74 IBD clinical teams in England & Wales participating in our rolling audit. The report also makes references to a larger clinical dataset captured by the Registry which aims to provide a longitudinal (on-going) picture of the care received by people with IBD over time. We hope the results and commentary prove of interest to clinicians and others involved in managing IBD, as well as to the 500,000 people living with the disease in the UK.[1]

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Finally, the IBD Registry would like to thank all those who have contributed to making this report a reality; above all, our partner IBD clinical teams around the country who provided the information on which the report is based.

Dr Stuart Bloom, Medical Director

Note: data periods

IBD teams upload data to the Registry at the end of a quarter typically in the first week of the following month. The data for a quarter is referred to by its upload month. So, 'January 2019' refers to the data captured to the end of December 2018 and uploaded in the following week/ten days.

Contents

Executive summary

Key findings

The IBD Registry has created and developed a number of data platforms and tools that support the continuation of the national clinical audit of biological therapies and the wider goal of creating a national register of people of all ages with IBD.

- **Number of IBD teams**
  The number of clinical teams in England and Wales delivering care to people living with IBD and which submit information to the Registry has grown year on year – from 62 to 74 during 2018, a 19% increase.

- **Number of patient records**
  The number of records submitted to the Registry grew by 28.3% in 2018 from just under 40,000 to 51,000 - a healthy growth (see Figure 2). From January to July 2019 there has been a further increase in the number of records submitted, resulting in almost 58,000 patient records held by the Registry at time of publication of this report.

- **Key Performance Indicators**
  The Key Performance Indicators (KPIs) of the national audit, which were designed to reflect safety in initiating biologic therapy and monitoring of efficacy during a course of treatment, show consistent improvement in each of the seven measures over the period under review. (See page 18 for details).

- **Review visit data**
  Data recording review visits at three and twelve months (two of the seven KPIs), while increased from the previous period, is still only 39% and 33%, respectively, suggesting more focus on these key areas is needed.

- **Use of biosimilars**
  Use of biosimilars and drugs acting on non-antiTNF pathways is increasing (see page 20 for details).

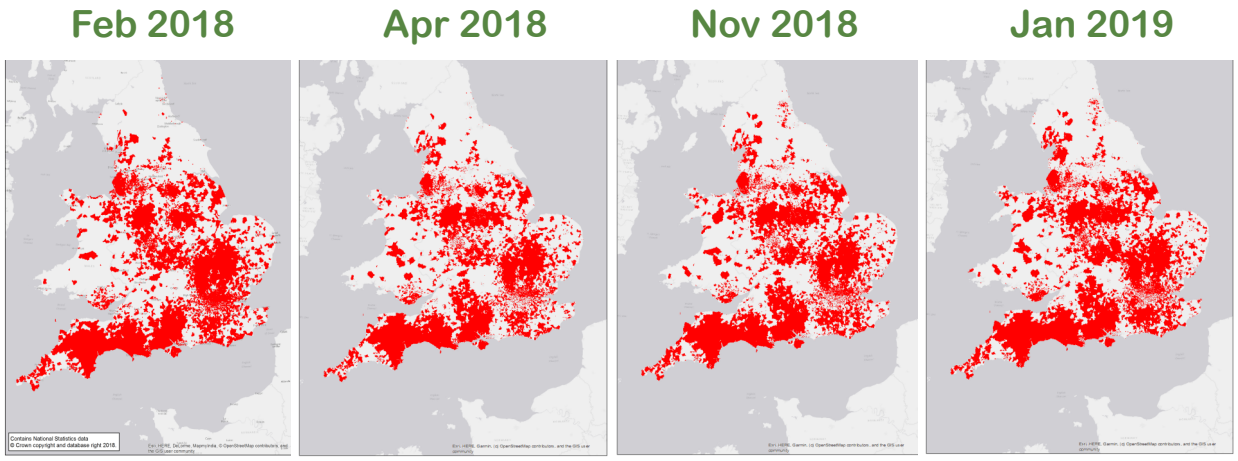
- **Duration of steroid use**
  Duration of steroid use is highlighted by both the NICE guidelines and the new BSG guidelines. In an exploratory analysis of the duration of courses of oral steroids, where the Registry has received both start and stop dates, 27% of courses were for longer than 12 weeks. There is also some preliminary evidence that course length is shortening.

- **Small number paediatric results**
  The number of patient records of people under 16 years continues to rise. The numbers in this age group with IBD in the UK is fortunately small; this means that the records from individual sites providing a paediatric service, other than a few, are often too small for analysis, comparison and reporting. Small number results, especially when reporting on a site-level basis, are required to be suppressed to avoid accidental re-identification of individuals. The Registry wishes to avoid reports for our specialist paediatric services containing too many suppressed data entries; we are undertaking a project to address this in 2019-20.

Note: full numbers used in the commentary text other than percentages will usually be rounded to the nearest whole number. Tables and figures will usually show a precise numeric value when available.

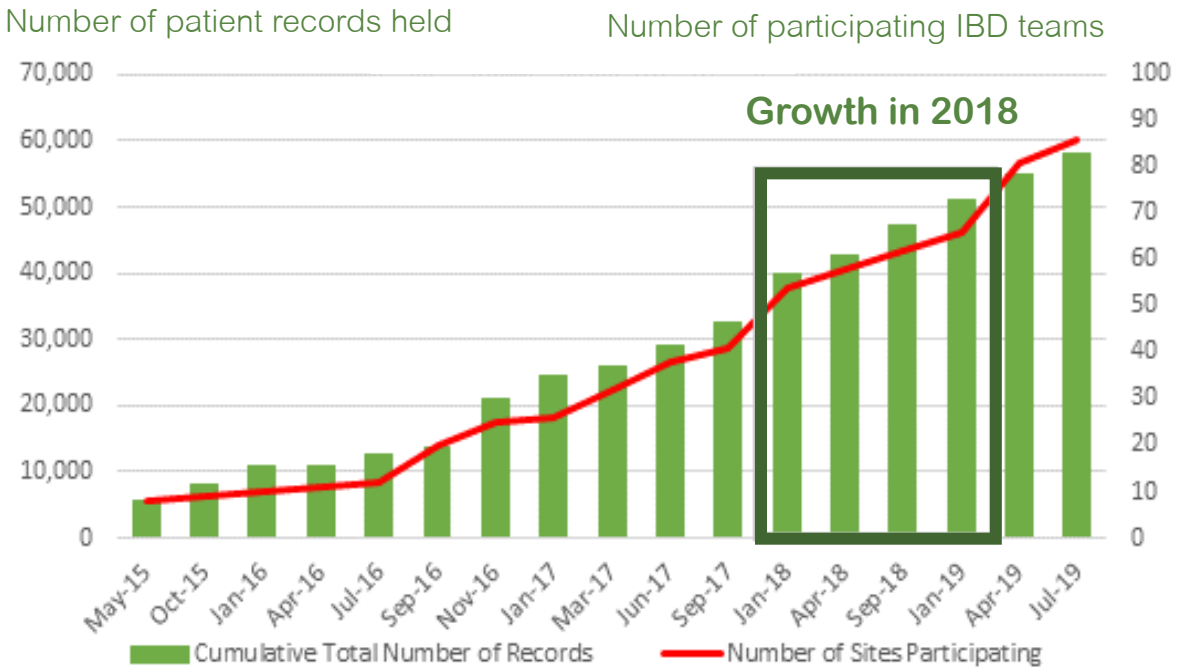
Figure 1: Geographical distribution of residence for registered cases

Number of participating IBD teams: Number of electronic patient records:



62 39,748 | 65 42,542 | 70 47,088 | 74 50,982

Figure 2: Growth in electronic patient records held by the Registry and number of participating clinical teams



Recommendations for IBD teams

IBD teams are to be congratulated on the improvements across all domains of the Key Performance Indicators (see Table 3 on page 18) for patients starting biological therapy. Focus on the following areas in the coming year will help improve patient care and, given the high albeit falling cost of biologic treatments, also allow improved management of health economies.

- **Improve capture of clinical data at point of care.** One time data capture without duplication of effort has long been a key aspiration of the Registry project (and we now note that this is a goal of the NHS Long term Plan*). This idea, while universally attractive, is still difficult to achieve with the current state of electronic health record systems but a small number of sites have demonstrated that entry of the key registry dataset is possible during the clinical encounter. Recognising that many units will take some time to enter this level of data for the majority of their patients, we recommend units concentrate over the coming year on entering a core dataset on their patients starting with their patients on biologics and including start and stop dates and disease activity at each visit, with the aim of creating an informative prospective longitudinal (on-going) cohort.

- **Redouble efforts on patient consent.** The Registry from its earliest days has aspired to having patient consent to hold the pseudonymised patient data. September 2020 sees the expiry of the Registry's exemption from being required to hold consent and the full implementation of the national opt-out allowing patients to opt out of their confidential information being used for research and planning (see page 11). It takes seconds to record the Registry's consent items and our experience shows most patients agree to give consent. With these two fundamental events fast approaching, we strongly encourage IBD teams to do all they can to seek consent from all their patients for their pseudonymised records to flow to the Registry. New initiatives in this area are underway to support IBD teams and patients; the Registry can advise on ways to achieve high consent rates while minimising the workload for teams.

- **Ensure all patients on biological therapy have a clinical review at initiation of therapy.** All patients starting a biological therapy for the first time or changing a biological therapy should have a review within the six weeks preceding the start date documenting the reason for the biologic and recording a disease activity index. Evidence that this review took place should be submitted to the Registry. For patients who have not received a biological therapy before (biologic naïve), evidence that the recommended pre-treatment

*NHS Long Term Plan

www.longtermplan.nhs.uk/

**See page 11 for more on Consent, the Section 251 exemption and the expiry of the exemption in 2020.

screening tests have been performed should also be submitted.

- **Ensure all patients on biological therapy receive post-induction and annual reviews.** In line with key clinical guidelines, all patients starting a biological therapy for the first time or changing a biological therapy should have a documented post-induction review at around twelve weeks and again at twelve months after therapy begins. Evidence that these reviews took place should be submitted to the Registry to demonstrate continued treatment is safe and appropriate.

- **Ensure all patients have a disease activity index to measure their progress on biologics.** Recording of sequential disease scores is reported in less than half of patients receiving biologics. The Registry's Data Submission Framework is designed to accommodate a variety of clinical recording practices. It can capture the Harvey Bradshaw Index for Crohn's disease, the Simple Clinical Colitis Activity Index (SCCAI) and modified UCDAI for Ulcerative Colitis; as well as the Physician Global Assessment (PGA) score for both diseases. Clinicians should document a disease activity index at the post-induction review and ideally at each visit while on biologics; at a minimum we recommend a year after treatment with a biologic begins and annually thereafter.

- **Consistently record stop dates for courses of biologic treatment.** When sites do not submit stop dates of biologic therapies the analysis of follow-up data assumes the patient continues to receive the drug. This can cause the percent of patients appropriately seen for follow-up reviews to be underestimated. IBD teams are urged to record consistently the stop dates of courses of biologic therapies to avoid this risk of apparent under performance. In addition, this will enable an additional goal of the audit to be achieved – allowing switches in biological therapy to be reported in future (see page 22 for early results in this area).

Recommendations for the IBD Registry

Alongside recommendations for IBD Teams, we felt we should also give ourselves a set of recommendations from our growing experience in managing the audit and in producing this report.

The data submitted by IBD teams depends on the processes and systems we provide to them, and we want to do all we can to make the process simpler and the tools easier. We thank IBD teams who have alerted us to some of the issues that they have come across, and also for their patience as we seek to resolve them.

The Registry recognises the need to improve user experience. While in many instances we are not the provider of the clinical systems, we can see it is our interaction with those system providers that can make a real difference to the clinical teams' experience of the Registry. We have listed some of the actions below and have styled them as 'Recommendations for the Registry'. These recommendations have either been fully implemented or are high priority work in progress.

- **Make it simpler for IBD teams recording patients on biologics.** The Registry are already working on simplifying the process for recording the data needed for a patient starting on biologics. From analysing the data combined with clinical user feedback, we can see that fewer fields (meaning fewer 'clicks' on a screen) are needed than originally envisaged to record key events. An example is the current requirement to enter a review event type ('initiation', 'three months' or '12 months') as well as the date of the review; as our data management advances, we see that we only need the date of the event, and we can impute the review type from that. By combining simple changes like this, we hope that we can speed and smooth the recording of this key data.

- **Initiate a feedback system for every participating IBD team's data upload.** Recording of data and ensuring compliance with information governance requirements such as the drive for patient consent are significant calls on time for clinical staff. As such IBD teams deserve better feedback on the outcomes of their data capture activities. The Registry will seek to provide bespoke feedback for each participating IBD team to help them optimise their data performance and minimise errors in data capture.

- **Improve guidance to IBD teams on effective data capture.** As we meet IBD teams around the country, we have learnt some users find the process for recording medications unclear or confusing. The Registry will seek to ensure the recording process is simplified and more logical and we are already working on clear guidance on such matters e.g. imprecise dates.

- **Provide clear guidance for IBD teams in the drive to increase consent rates through patient consent at point of care.** We recognise the efforts by IBD teams across England & Wales that are already

resulting in improved rates of patient consent. However, more needs to be done to ensure we reach our target of 100% of data held with the consent of the patient. The Registry will support all IBD teams with practical tools such as ensuring copies of consent forms are available and providing guidance on how to obtain consent with minimum outlay of clinical time. We are piloting an e-consent option and see this as a key focus in supporting IBD teams.

- **Improve usability issues of the tools.** We are already working on improving performance and are already building in the clinical worklists asked for by IBD teams. Confusing or unintuitive interfaces of the data entry systems erode the quality of the Registry's data. Entering the data can be frustrating and burdensome for IBD teams. We will seek to resolve issues as quickly as possible.

What clinicians recommend to us*

"Compatibility with our patient data software is key."

"Log helpline calls, allow us to track patients on immunosuppression and biologics, including screening and to enable blood monitoring. Allow a local audit."

"… a system that enables rapid upload of data. One way to address this would be to remove a lot of the mandatory boxes so as much data can be filled in but should there be gaps (e.g. when a patient is transferred to your service and you may lack some background information) it doesn't hinder data upload."

"Make [the WebTool] more friendly for users; so we don't duplicate data and keep leaving the page, [and] easier to cancel/change data."

"[The tool] needs to work alongside our existing systems to generate patient letters and to avoid additional admin tasks (no time). Synthesis with other systems such as ICE to import blood results etc would be particularly helpful."

"If data that is missing/required could be highlighted - e.g. an alert for missing KPI data at the point of entry onto the Webtool would be helpful - instead of after an unsuccessful data upload to NHS Digital."

"We don't have problems with the tool it's just that we don't have time to do it."

Note:*Quotes taken from responses to the IBD Registry survey of participating clinical teams May 2019.

Background

Context

It is estimated that more than half a million people in the UK live with the inflammatory bowel conditions Crohn's disease and Ulcerative Colitis[1]. With onset in the first decades of life and with no cure, the diseases present a huge burden to people who are affected by them. Healthcare teams and the economy of the country also bear a heavy cost, with commentators in recent years estimating an average spend of £3,000 per patient per year* by the NHS - excluding the cost of treating complications and loss of productivity[2].

Management of these conditions was revolutionised twenty years ago when the first anti-TNF drug was approved for the treatment of Crohn's disease. Since then, the indications for their use have widened, additional anti-TNF drugs have become available and biologic drugs acting on different parts of the inflammatory pathway have been introduced. Most recently, the expiration of the patent on Humira (the adalimumab originator) in October 2018 has opened the way for a wide range of less expensive but equally potent biosimilars, transforming treatment patterns in a way that is rapidly unfolding. These drugs, though effective, carry a risk of serious adverse effects that can be mitigated by appropriate screening of the patient before, and monitoring during, biologic treatment.

History of the IBD Registry's involvement in the clinical audit

For more than a decade, until 2016, the Royal College of Physicians' (RCP) Inflammatory Bowel Disease Programme oversaw a series of audits of the delivery of care to people with IBD and, from 2012 to 2016 supported a continuous audit of the safety, efficacy and appropriate use of biological therapies in the UK. From 2017, data collection transitioned from the RCP to the IBD Registry, which had been established in 2013 within the British Society of Gastroenterology (BSG) to provide the first ever UK-wide repository of pseudonymised IBD adult and paediatric data for prospective quality assurance, audit and research. The Registry seeks to capture items of relevance as a by-product of the patient-clinician interaction, as far as possible at the point of care. In early 2018, the Registry was incorporated as an independent not-for-profit company owned by a partnership between the BSG, Crohn's & Colitis UK and the RCP.

Launch of the Registry Biologics Audit

IBD teams participating in the earlier UK IBD audits managed by the RCP were supported to upload to the Registry the data they had accumulated during their years of participation. The IBD Registry Biologics Audit is a continuation of the previous audit and became part of the IBD Registry Programme from January 2017.

***Note: Cost**

In 2012 the national IBD audit estimated the cost of IBD to be £3000 per person per year but did not include the cost of treating complications.

The seven key performance indicators (see page 18) were devised based on recommendations in the final RCP report. The Registry encouraged IBD teams to participate through the development of data capture tools that provided clinical management functionality. Participation in the audit was also stimulated by its inclusion in the Healthcare Quality Improvement Partnership (HQIP) Directory of Quality Accounts that requires Trusts providing IBD services to publish their participation in their annual Trust Quality Account public report.

The data process

IBD clinical teams across the UK capture information across many domains to define the local IBD population; describing the disease characteristics of each patient, their management (including medication, surgery, hospital admissions), and measuring patient outcomes. Information recorded by the clinical team is uploaded securely each quarter to an approved data "safe haven" (currently NHS Digital), where patient identifiable data is pseudonymised. This pseudonymised data is then transferred securely to the Registry itself, where it is reviewed and analysed by the Registry's Analytical Hub based in the Biostatistics Department of the University of Liverpool. Participating IBD teams are provided with quarterly analyses of their information to stimulate reflection and promote service improvement initiatives, with rolling performance against the KPIs included in reports created for subscribers.

Patient consent

The Registry espouses a fully consented model for the accumulation of patient information. In the early years of establishing the Registry, the Confidentiality Advisory Group, an independent health body which advises the Secretary of State on the use of confidential patient information, provided a temporary exemption from the requirement for patient consent under Section 251 of the NHS Act 2006.

The exemption was considered necessary to enable IBD teams time to establish systems to acquire patient consent as they manage the task of entering patient information at the point of care. The approaching end of this exemption in September 2020, together with the implementation of the national opt-out for patients (from secondary uses of their health data) in March 2020 is the reason for urging clinical teams to embed patient consent within their processes. The IBD Registry is committed to offering patients the opportunity to consent formally to submission of their data. Progress towards this objective is one of the Audit KPIs.

Note: pseudonymisation of data

The UK Information Commissioner's Office describes pseudonymisation as "a technique that replaces or removes information in a data set that identifies an individual." The EU General Data Protection Regulation defines pseudonymisation as: "the processing of personal data in such a manner that the personal data can no longer be attributed to a specific data subject without the use of additional information, provided that such additional information is kept separately and is subject to technical and organisational measures to ensure that the personal data are not attributed to an identified or identifiable natural person."

Source: www.ico.org.uk

Note: national data opt–out

Patients have the right to prevent their confidential patient information being used for purposes other than their care and treatment. This right is known as a national data opt-out. If a patient chooses to opt out, health and social care organisations such as the Registry are required to apply the opt-out by March 2020.

Source: www.nhs.uk/your-nhs-data-matters/

The Biologics Audit

Aims and scope

Aims of the Biologics Audit

Patient perspective

All patients with IBD receiving biological therapy should be adequately screened before initiation and the safety and effectiveness of the therapy reviewed post-induction and each year. Patients should be asked to consent to their data being submitted to the Registry.

Clinical team perspective

The IBD Clinical Team should have a safe, efficient and secure electronic system for recording and accessing the key demographic and clinical data on all patients receiving biological therapy. The team should be resourced to ensure the minimum data is routinely entered.

Management and governance perspective

Trust management and Commissioners should be able to review key demographic and clinical data on the use of biological therapies on a regular basis to assure quality and value for money. They should have access to national benchmarking on key indicators at least annually.

Scope of data collection

Data collection for the biologics audit has been reduced to the minimum necessary to report the key clinical indicators which are compliant with the European Crohn´s and Colitis Organisation (ECCO) guidance on pre-treatment screening and compliance with NICE recommendations for follow-up review of patients receiving biological therapies*. All patients starting or receiving biological therapy for IBD since April 2016 should be included. Data collection is prospective and continuous with quarterly uploads of data to the Registry. As Health Boards in Scotland and Northern Ireland have different arrangements for the submission of data to alternative data safe havens, the Registry population is, at present, limited to people living in England and Wales (Wales has its own National Welsh Clinical Platform, but it also can submit to the Registry via NHS Digital acting as the data safe haven).

The data collected for submission includes a minimum of patient identifiable information to enable linkage by NHS Digital of the Audit data to routine Hospital Episode Statistics (HES) and other national health data sets; these identifier fields are removed and replaced by NHS Digital as part of the process of pseudonymisation.

Information governance

The Registry dataset includes patient-identifiable demographic data to be uploaded to NHS Digital. As part of the process for each site joining the Registry, the Trust's Caldicott Guardian must confirm that the Trust has authorised submission of this data, which allows NHS Digital to grant access to their Clinical Audit Platform.

Note: *Guidelines

ECCO:

www.e-guide.ecco-ibd.eu/interventions-therapeutic/anti-tnfs#crohnsdisease

NICE:

Crohn's disease: management (full guideline). NICE, 2019. www.nice.org.uk/guidance/ng129/evidence

Ulcerative Colitis: management (full guideline). NICE, 2019 www.nice.org.uk/guidance/ng130

Key performance indicators*

The KPIs were originally chosen by the RCP's Transition Steering Group to focus on the findings and recommendations in the IBD biological therapies audit report published in September 2016. (www.rcplondon.ac.uk/biologics)

The aim has been to keep data entry to a minimum by focusing on three key points in a patient's biologics treatment – initiation on first biological therapy (since April 2016 – the cessation of the RCP biologics audit), post- induction review and 12-month review.

Collecting this data enables the IBD Registry to fulfil the audit and quality improvement role it has taken over from the IBD programme at the RCP and report on these key aspects of clinical safety and effectiveness.

Pre-treatment checks

- For patients who have not received a biologic before, were they screened before starting treatment? To be reported as complete, pre-treatment screening includes Chest X-Ray, hepatitis B and C, HIV and TB testing
- Was a formal assessment of disease activity recorded at the point the decision was made to commence a biological therapy?
- Is there a record of Registry consent being discussed with the patient?

Post-induction review

At approximately three months after the date of the initial treatment:

- Did a post-induction review take place?
- Was a formal assessment of disease activity recorded at this time?

12-month review

At approximately 12 months after the date of the initial treatment:

- Did a 12-month review take place?
- Was a formal assessment of disease activity recorded at this time?

*** Note:** please see Table 3 on page 18 for the key performance indicators.

Results

Adults - pre-treatment screening by type

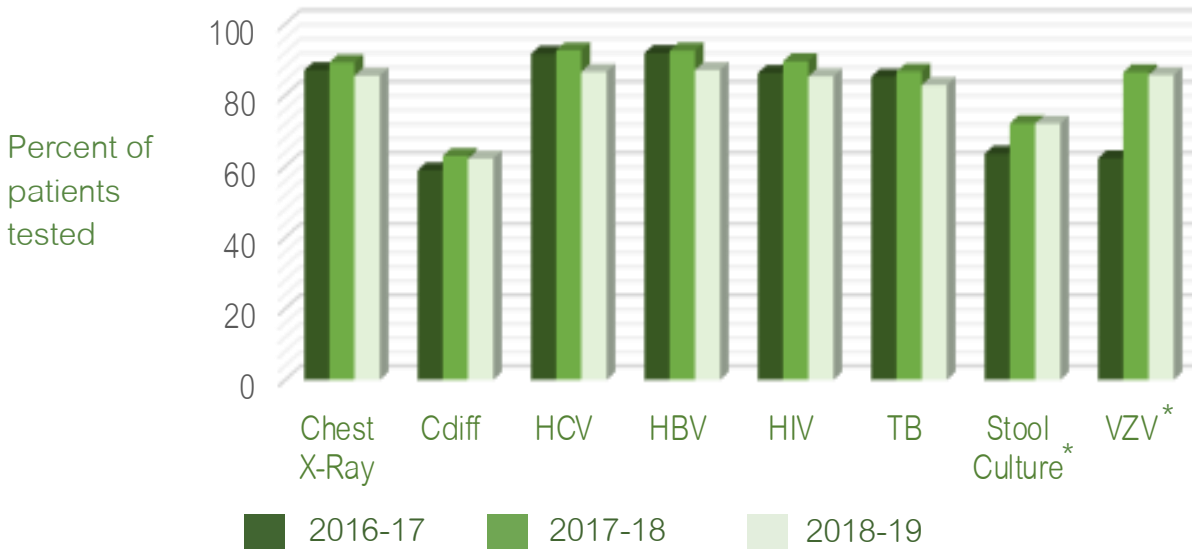
A key quality element formally assessed by the Biological Therapies Audit is the undertaking of and recording of pre-initiation screening tests. These are captured in their entirety in KPI-1.

KPI-1 asks: **Was the patient screened before starting on a biological therapy?**

The recommended screening tests are Chest X-Ray, HCV, HBV, HIV and TB. To fulfil this KPI, all five screening tests must be recorded as having been performed or not indicated; and entered on the data capture system within the six weeks preceding the initiation of the biologic treatment. KPI-1 is applied only to patients who are biologics naïve with a recorded drug start date. Note: HIV is not required for paediatric reviews. The cumulative national figure indicating completion of pre-treatment screening of biologics naïve patients is 69.2%, based on data up to January 2019. We have looked more deeply into the data to comment on this figure, notably examining year-on-year periods. We note that the completion results for the tests taken individually are much higher, suggesting that screening is undertaken more widely than the KPI-1 might suggest at first view. The Registry holds a rich data set with a greater number of biologic screen tests, so we investigated this further, as follows:

Every biologic event in our dataset noted as having naïve status recorded was linked to a time period. We then identified patients in these events and checked how many of them had their screening status recorded as either done or positively recorded by the clinician as not required to be done (not indicated). We did this for each screening test.

Figure 3: Screening tests for biologic-naive patients - comparison by period



*Note:

Non-mandatory screen tests

Table 1: Screening tests for biologic-naive patients, comparison by period - actual numbers

Screening test	2016-17	2017-18	2018-19
Chest X-Ray	970	1,592	1,579
C. Diff *	656	1,123	1,149
Immunity HCV	1,021	1,653	1,599
Immunity HBV	1,023	1,652	1,608
Immunity HIV	961	1,598	1,575
Immunity TB	949	1,547	1,531
Stool culture*	708	1,287	1,330
Immunity VZV (for chicken pox)*	694	1,543	1,583

We observe that the completion results for the tests taken individually are indeed both higher, and consistently undertaken across the periods analysed. This suggests that screening is undertaken more widely than might have been realised. This may be due to multiple factors mostly related to the KPI-1 selection criteria that include:

- Every patient should have a drug start date recorded (from April 2016 onward)
- Naïve status recorded
- All the guideline recommended screening test elements (Chest X-Ray, HCV, HBV, HIV* and TB) recorded as YES or NOT INDICATED and recorded within six weeks of drug start date.

Reviewing the results and keeping these criteria in mind, it seems that disparity between the lower overall KPI-1 score and the high completion record of the individual tests reflects both the high hurdle that all five biologics screening tests must be done and recorded, together with the real-world challenges of full data recording in a busy IBD clinic. Omitting to record even one essential component will cause the screening to be excluded in the analysis for a site's KPI-1, and so may artificially lower the completion figure. We encourage teams to make sure that these required elements are recorded in full, along with naïve status and initiation date of treatment.

*Note:

Non-mandatory screen tests

Results

Adults - national aggregate data

The tables in this section provide an overview of the whole population of adults with IBD whose records have been submitted to the Registry up to January 2019 and then report on the delivery of biologic treatments. The tables include cumulative data held at the beginning and end of 2018.

Figures 4 and 5: Proportion of patients with Crohn's disease, Ulcerative Colitis or IBD unclassified

Figure 4: Jan 2018

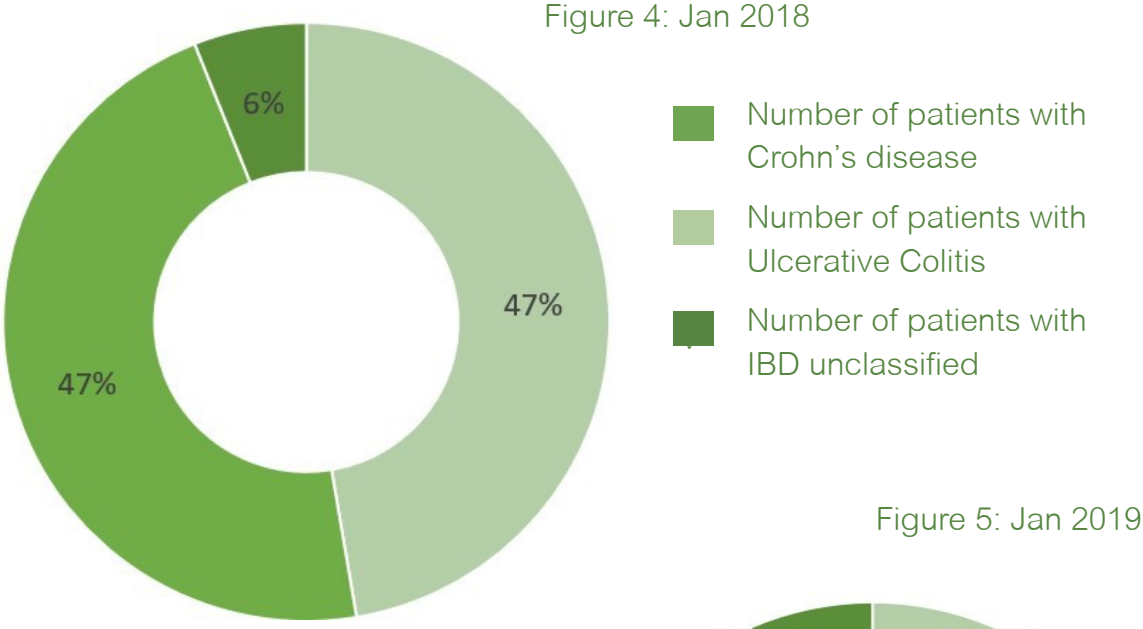


Figure 5: Jan 2019

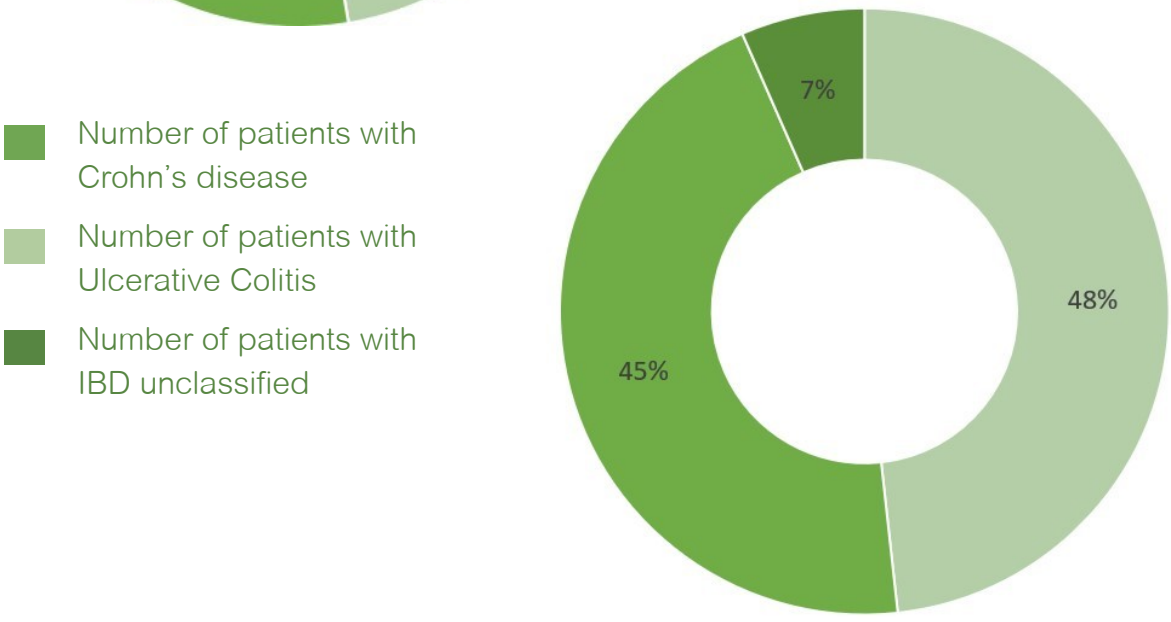


Table 2 shows the demographic changes of the whole IBD population held by the Registry at January 2018 and January 2019. Note the Biologics Audit data is a subset of this whole dataset.

Table 2: Key demographic data for the whole Registry

Registry demographics	Cumulative to January 2018	Cumulative to January 2019	Increase or decrease
Number of participating IBD teams	62	74	⇧
Total number of patients	37,475	47,169	⇧
Number of patients with Crohn's disease	17,745	22,762	⇧
CD proportion male	0.47	0.45	·
Number of patients with Ulcerative Colitis	17,479	21,308	⇧
UC proportion male	0.52	0.51	·
Number of patients with IBD Unclassified	2,251	3,099	⇧
IBDU proportion male	0.45	0.44	·
Median age of patients (years) - all diagnoses	48	48	⇨
Number of consenting patients (%) - all diagnoses	7,213 (19%)	12,262 (26%)	⇧

Results

Adults - national aggregate data

Table 3: Summary of Biologics Audit KPIs

Cumulative national aggregate performance in the seven KPIs at the beginning and end of the current audit period.

Key performance indicators for all biologic starters (except KPI 1)	Cumulative to January 2018	Cumulative to January 2019	Increase or decrease
KPI 1* - complete pre-treatment screening [number of biologic naïve]	59% [n = 1186]	69% [n = 1671]	⇧
KPI 2 - disease activity assessment at initiation [number of all starters]	27% [n = 2286]	39% [n = 4174]	⇧
KPI 3 - Registry consent	34%	44%	⇧
KPI 4 - review at 3 months	24%	39%	⇧
KPI 5 - disease activity assessment recorded of those reviewed at 3 months	21%	40%	⇧
KPI 6 - review at 12 months	22%	33%	⇧
KPI 7 - disease activity assessment recorded of those reviewed at 12 months	28%	43%	⇧

*Note: KPI 1

KPI 1 is applicable only to patients who are starting a biologic for the first time (this is called 'biologic naïve'). The denominator for KPI-1 is numbers of biologic naïve patients. This is much lower than the number for all new starters which is the denominator for KPIs 2-7. The denominators are given as [n=].

Table 4: Remission rates on biologic treatment in Crohn's disease

Cumulative information since April 2016 of the time to initiation of first biologic treatment in patients with Crohn's disease, for whom disease scores were available at follow-up, the percent in remission.

Crohn's disease**	January 2018	January 2019	Increase or decrease
Median time from diagnosis to start of first biologic (years)	3	3	⇨
Proportion male	0.46	0.47	·
Remission rate at 3 months	62%	68%	⇧
Remission rate at 12 months	69%	59%	⇩

Table 5: Remission rates on biologic treatment in Ulcerative Colitis

Cumulative information since April 2016 of the time to initiation of first biologic treatment in patients with Ulcerative Colitis, and, for those with a disease score recorded at follow-up, the percent in remission

Ulcerative Colitis**	January 2018	January 2019	Increase or decrease
Median time from diagnosis to start of first biologic (years)	3	3	⇨
Proportion male	0.60	0.57	·
Remission rate at 3 months	75%	69%	⇩
Remission rate at 12 months	Not available	78%	·

**Note: remission rates

Remission rates are based only on the sub-group of cases with both a record of a visit and a disease activity score at that time-point. Recording of these scores is recommended.

Results

Use of biologic treatments

We have been reviewing Registry data to see if we are able to show clinical teams their patterns of biologics use over time: for example, their move from the originator molecule (e.g. 'Remicade') to the newer biosimilars and switches from one drug class to another. Our Registry dataset is real-world data which presents issues of completeness of data collection in presenting such reviews.

A notable example is the weaker recording of drug stop dates; however, the dataset is robust enough to show both the choice of first drug and subsequent sequencing. This analysis can only be performed at national level.

Table 6 shows a summary of the choice of biologic treatment for Crohn's disease and Ulcerative Colitis in 2018 for those adult patients included in the audit. Figures 6 and 7 show the share of each agent as a proportion of patients for each disease.

Table 6: Reported choice of biologic agent in 2018

Reported choice of biologic agent* in 2018	Crohn's disease	Ulcerative Colitis	IBD unclassified
Golimumab	8	59	<8
Adalimumab**	790	299	38
Inflectra	319	235	26
Remicade	<8	11	<8
Remsima	286	204	10
Ustekinumab	102	<8	<8
Vedolizumab	198	218	12
Not specified	4	9	<8
Total	>1,707	>1,037	>86

**** Biosimilars and adalimumab**

The data does not show any biosimilars equivalent to the originator molecule adalimumab. This is because the reporting period preceded the introduction of these biosimilars.

***Note on names of drugs**

Where a molecule does not yet have any equivalent biosimilar available, the report refers to the molecule's generic name. Where there is a biosimilar equivalent to the originator molecule, the report refers to the commercial name to avoid confusion.

Figure 6: Reported choice of biologic agent for Crohn's disease in 2018

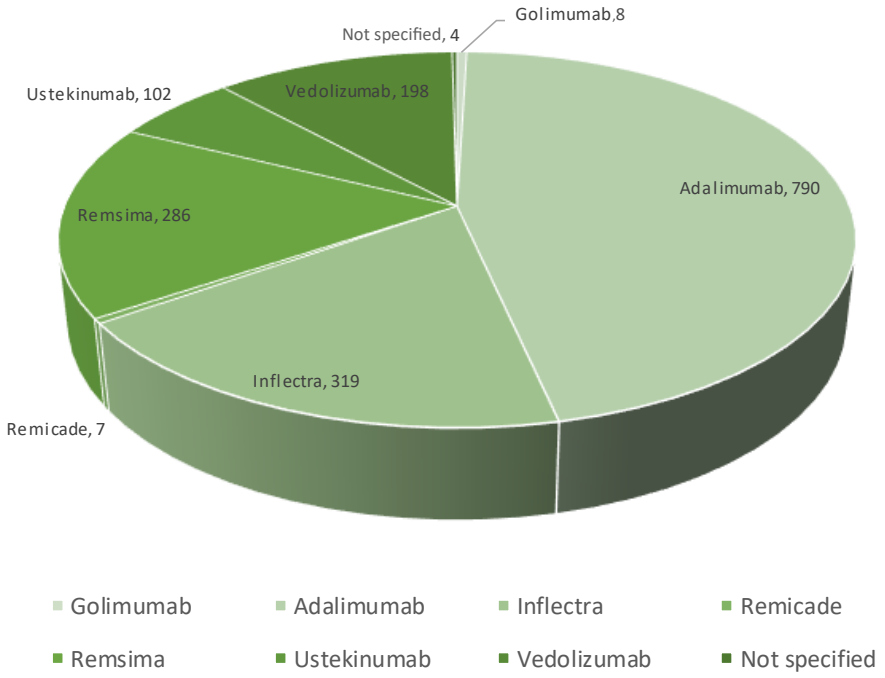
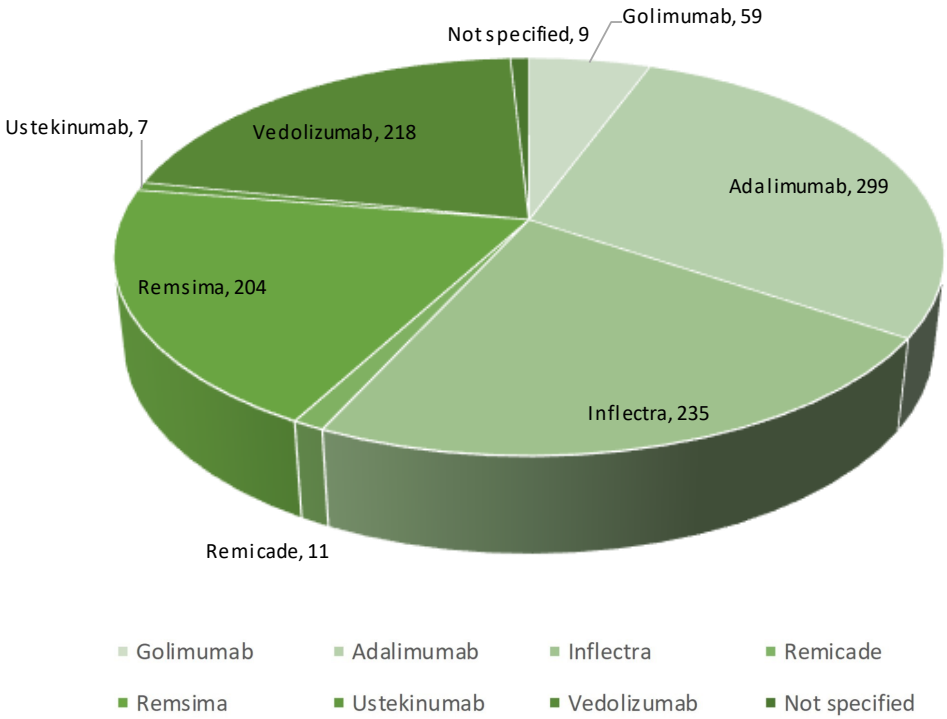


Figure 7: Reported choice of biologic agent for Ulcerative Colitis in 2018



Results

Use of biologic treatments *continued*

Table 7 and the related graphs (Figures 8 and 9) show that, according to Registry records, 7,751 patients had a drug start date for a biologic recorded any time after April 2016. After that 'first' drug initiation date, all subsequent biologic drug changes were tracked for individual patients.14.4% of cases 'changed' to a new drug between that 'first' initiation and April 2019 (some changed several times).

Table 7: Records of patients who 'changed' to a new biologic between the 'first' drug initiation and April 2019

Drug Name	No evidence of drug change	Evidence of drug change
Golimumab	128	42
Adalimumab	2,582	303
Inflectra	1,031	234
Remicade	182	54
Remsima	1,506	388
Ustekinumab	170	5
Vedolizumab	1,038	88
Total no. patients 7,751	6,637 (85.6%)	1,114 (14.4%)

Although available in the UK in late 2018, patients receiving adalimumab biosimilars are not reported in these analyses but will be included in future Registry reports.

The table and charts on changing biologic treatments are an exploratory analysis of this important data. With participating IBD teams focusing on recording drug stop dates and the reason for stopping we hope to provide richer analysis in future reports.

Figure 8: Change or no change from 'first' drug within the time period?*

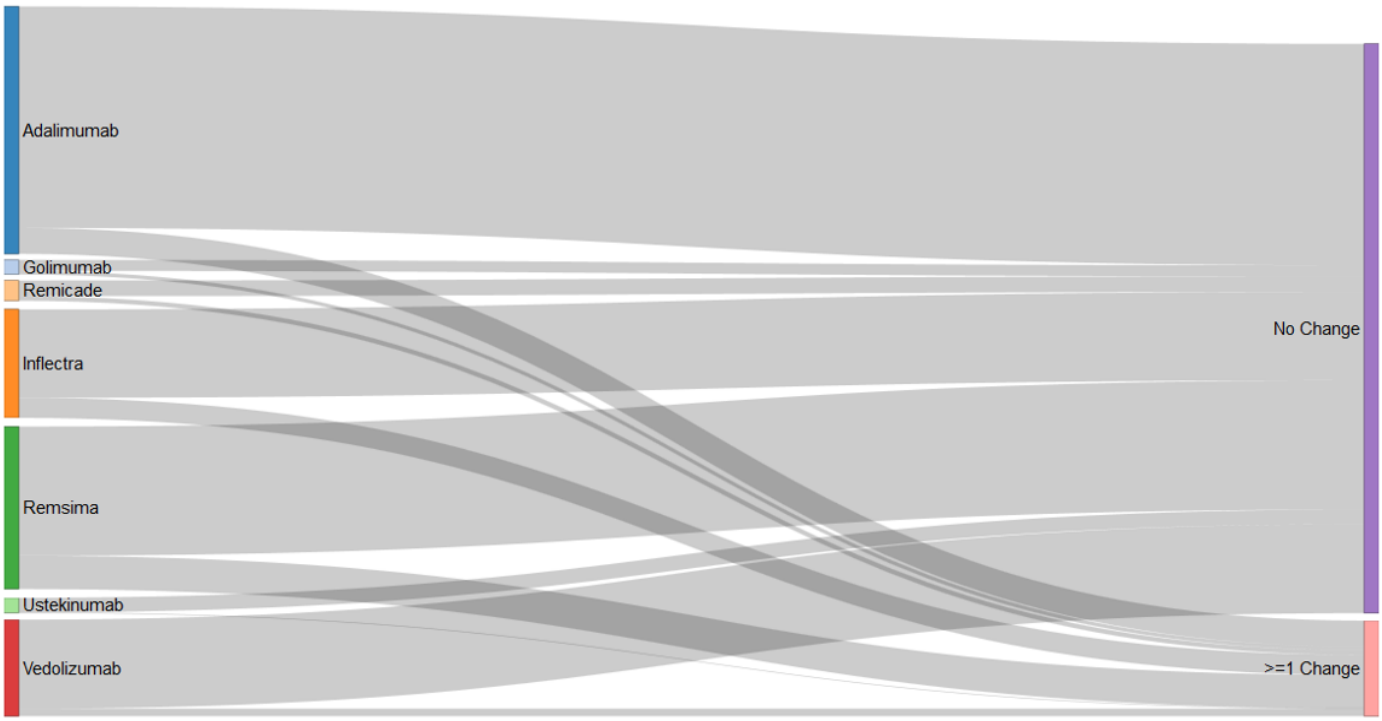
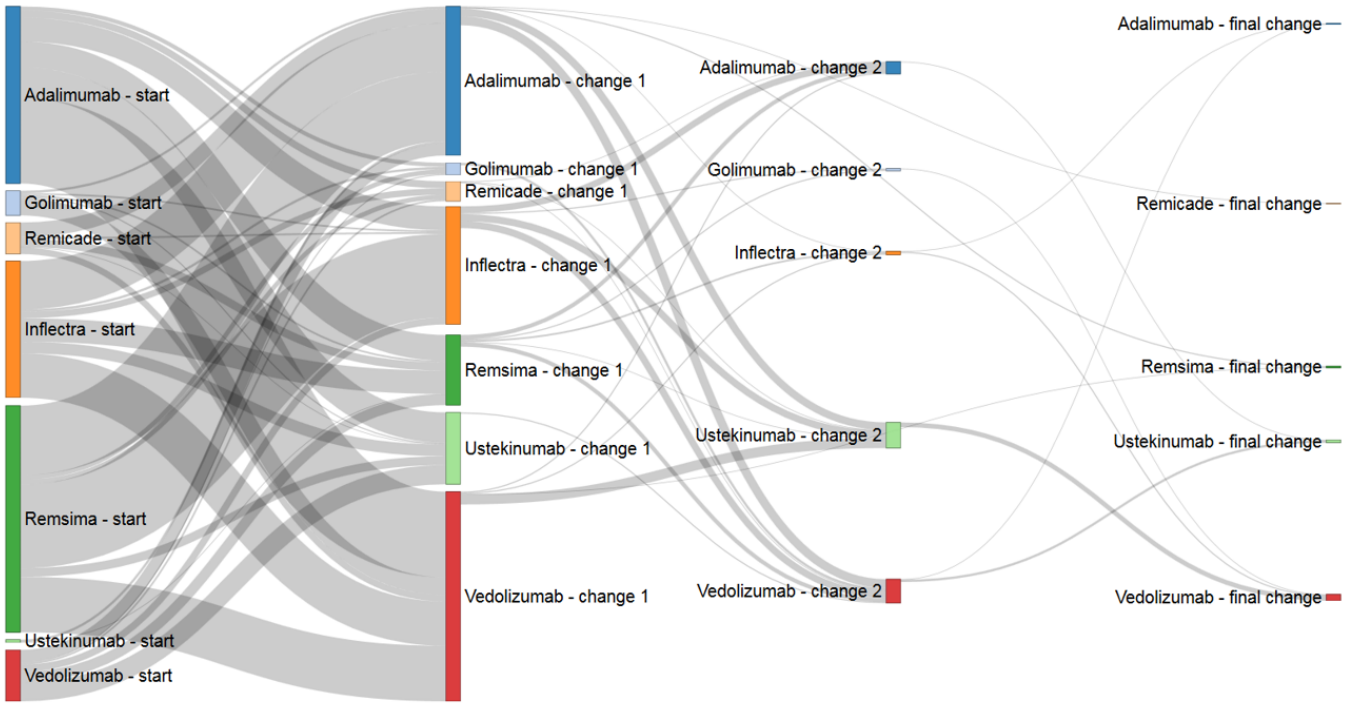


Figure 9: Patterns of changes in biologics



*Note: choice of first line biologic agents is evolving and has become increasingly diverse as a wider range of biologics have become available.

Results

Paediatric - national aggregate data

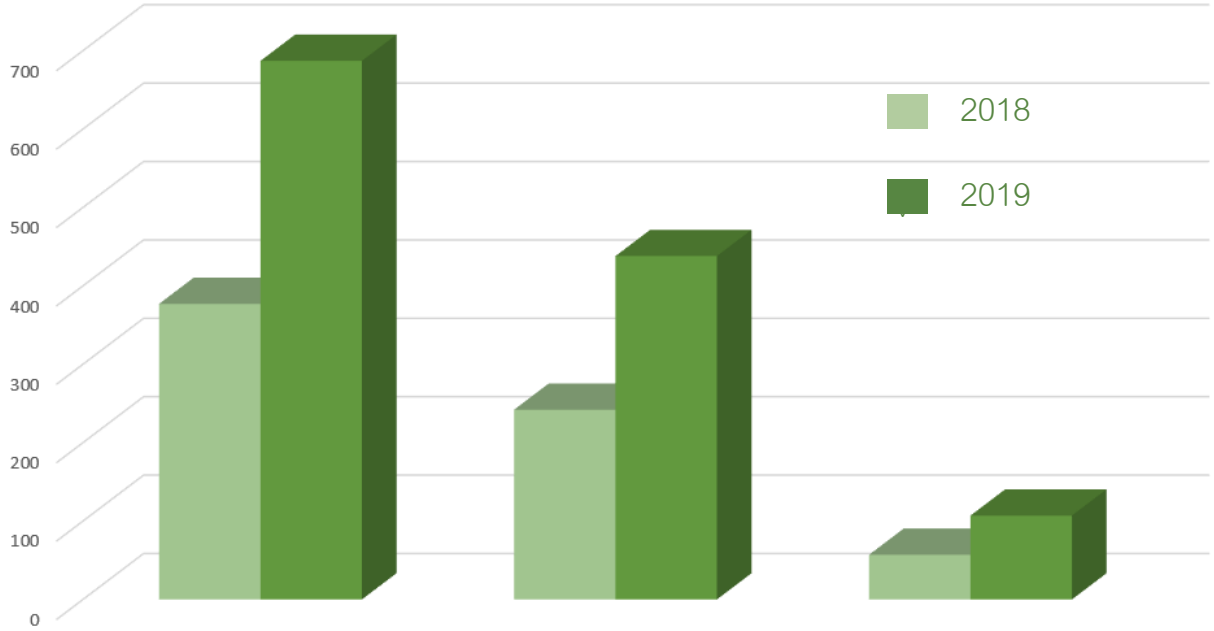
Table 8 provides an overview of the whole population of children and young people (less than 16 years old) with IBD whose records have been submitted to the Registry. Table 8 below includes cumulative data held at the beginning and end of 2018. The numbers at the two dates are not strictly comparable because the definition of a paediatric site was refined during 2018 to include only sites with a designated paediatric IBD service, rather than including records from patients under 16 years submitted by all sites.

Note: this is the whole Registry paediatric population. The Biologics Audit data is a subset of this whole dataset.

Table 8: Children and young people (less than 16 years old)

Registry demographics	January 2018	January 2019	Increase or decrease
Number of participating sites	21	11	Different inclusion criteria
Number of patients with Crohn's disease	377	687	⇧
Number of patients with Ulcerative Colitis	242	438	⇧
Number of patients with IBD Unclassified	57	107	⇧
Median age of patients (years)	13	15	⇧
Number of consenting patients (%)	16%	17%	⇧
Number of patients recorded as starting a biologic	158	155	Different inclusion criteria

Figure 10: Paediatrics: number of patient records held by the Registry January 2018 and January 2019



Number of patients with Crohn's disease 2018 and 2019

Number of patients with Ulcerative Colitis 2018 and 2019

Number of patients with IBD unclassified 2018 and 2019

In a specialist area such as paediatric IBD, low numbers of patients are inevitable. Because we are required to suppress small numbers we have not reported the key performance indicators for paediatric sites in the National Audit of Biological Therapies. We are exploring ways to enlarge our collection of data on this important patient group, and so provide our analytical support to the IBD teams who care for them.

Results

NHS Trust / IBD team level data

Tables 9,10 and 11 on pages 27-29 show key data reflecting participation in the IBD Registry since its inception for individual IBD teams treating patients. The number of patient records uploaded is a simple indicator of Registry participation by an IBD team's NHS Trust. However, it should be noted that recently-joined Trusts will have low numbers of uploaded patient records. Paediatric teams will also have low numbers by virtue of their smaller pool of patients.

Note: Tables 9,10 and 11 on pages 27-29 show key data reflecting participation in the IBD Registry since May 2015 for individual IBD teams treating patients - tables with assistance from NHS Digital.

Table 9: Participating Trusts with the Registry

Participating NHS Trusts A-M	Duration of participation (to nearest year) >*	Most recent upload of data
Aintree University Hospitals NHS Foundation Trust	3	Jul-19
Ashford and St Peter's Hospital NHS Foundation Trust	1	Jan-19
Barking, Havering and Redbridge University Hospitals NHS Trust	4	Jul-19
Barts Health NHS Trust	4	Apr-19
Basildon and Thurrock University Hospitals NHS Foundation Trust	1	Jul-19
Bedford Hospital NHS Trust	2	Jul-19
Betsi Cadwaladr University Health Board	2	Jul-19
Bolton NHS Foundation Trust	2	Jul-19
Bradford Teaching Hospitals NHS Foundation Trust	3	Jul-19
Brighton and Sussex University Hospitals NHS Trust	2	Jul-19
Buckinghamshire Healthcare NHS Trust	1	Jul-19
Cambridge University Hospitals NHS Foundation Trust	3	Jul-19
Cardiff & Vale University Health Board	2	Jul-19
County Durham and Darlington NHS Foundation Trust	1	Jul-19
Cwm Taf Morgannwg University Health Board	3	Jan-18
Dartford and Gravesham NHS Trust	2	Apr-19
Dorset County Hospital NHS Foundation Trust	4	Jul-19
East and North Hertfordshire NHS Trust	2	Jan-19
East Kent Hospitals University NHS Foundation Trust	1	Jul-19
East Sussex Healthcare NHS Trust	2	Sep-18
Epsom and St Helier University Hospitals NHS Trust	1	Jul-19
Frimley Health NHS Foundation Trust	1	Jul-19
Gateshead Health NHS Foundation Trust	1	Sep-18
George Eliot Hospital NHS Trust	2	Jul-19
Great Western Hospitals NHS Foundation Trust	1	Jul-19
Guy's and St Thomas' NHS Foundation Trust	1	Apr-19
Hampshire Hospitals NHS Foundation Trust	1	Jul-19
Harrogate and District NHS Foundation Trust	2	Jul-19
Homerton University Hospital NHS Foundation Trust	2	Jul-19
Isle of Wight NHS Trust	1	Sep-18
King's College Hospital NHS Foundation Trust	1	Jul-19
Kingston Hospital NHS Foundation Trust	2	Jul-19
Liverpool University Hospital NHS Foundation Trust	3	Jul-19
London North West University Healthcare NHS Trust	2	Jul-19
Luton and Dunstable University Hospital NHS Foundation Trust	4	Jul-19
Maidstone and Tunbridge Wells NHS Trust	3	Jul-19
Manchester University NHS Foundation Trust	3	Jan-18
Mid Cheshire Hospitals NHS Foundation Trust	1	Jul-19
Milton Keynes Hospital NHS Foundation Trust	1	Jul-19

*Note: some Trusts have provided data for longer than the four years time span in tables 9,10 and 11.

Results

Table 10: Participating Trusts with the Registry

Participating NHS Trusts N-Z	Duration of participation (to nearest year) >*	Most recent up-load of data
Norfolk and Norwich University Hospital NHS Foundation Trust	1	Jul-19
North West Anglia NHS Foundation Trust	2	Jul-19
Northampton General Hospital NHS Trust	3	Jul-19
Northern Lincolnshire and Goole Hospital NHS Foundation Trust	2	Apr-19
Nottingham University Hospital NHS Trust	1	Apr-19
Poole Hospital NHS Foundation Trust	3	Jan-18
Portsmouth Hospitals NHS Trust	1	Jul-19
Royal Berkshire NHS Foundation Trust	2	Jul-19
Royal Cornwall Hospitals NHS Trust	2	Apr-19
Royal Devon and Exeter NHS Foundation Trust	3	Jul-19
Royal Free London NHS Foundation Trust	2	Jul-19
Royal Surrey County Hospital NHS Foundation Trust	2	Apr-19
Royal United Hospitals Bath NHS Foundation Trust	1	Jul-19
Salisbury NHS Foundation Trust	1	Jul-19
Sandwell and West Birmingham Hospitals NHS Trust	1	Jul-19
Sheffield Teaching Hospitals NHS Foundation Trust	2	Jul-19
South Warwickshire NHS Foundation Trust	2	Jul-19
Southport and Ormskirk Hospital NHS Trust	2	Jul-19
St George's University Hospitals NHS Foundation Trust	1	Jul-19
St Helens and Knowsley Teaching Hospitals NHS Trust	2	Jul-19
Surrey and Sussex Healthcare NHS Trust	1	Apr-19
Tameside and Glossop Integrated Care NHS Foundation Trust	1	Jul-19
Taunton and Somerset NHS Foundation Trust	1	Jul-19
The Hillingdon Hospitals NHS Foundation Trust	1	Apr-19
The Rotherham NHS Foundation Trust	3	Jan-18
The Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust	2	Jul-19
The Royal Wolverhampton NHS Trust	3	Jul-19
The Shrewsbury and Telford Hospital NHS Trust	1	Jul-19
Torbay and South Devon NHS Foundation Trust	4	Jul-19
University College London Hospitals NHS Foundation Trust	4	Jul-19
University Hospital Southampton NHS Foundation Trust	4	Apr-19
University Hospitals Birmingham NHS Foundation Trust	1	Apr-19
University Hospitals Coventry and Warwickshire NHS Trust	2	Jul-19
University Hospitals of Derby and Burton NHS Foundation Trust	1	Apr-19
University Hospitals of Morecambe Bay NHS Foundation Trust	2	Jul-19
University Hospitals of North Midlands NHS Trust	2	Jan-18
University Hospitals Plymouth NHS Trust	3	Jan-18
West Hertfordshire Hospitals NHS Trust	2	Jul-19
Whittington Health NHS Trust	1	Jul-19
Wrightington, Wigan & Leigh NHS Foundation Trust	3	Apr-16
Yeovil District Hospital NHS Foundation Trust	2	Apr-19

Table 11: Children and young people's services*

Participating paediatric departments*	Duration of participation (to nearest year) >**	Most recent upload of data
Alder Hey Children's NHS Foundation Trust	3	Jul-19
Barts Health NHS Trust	4	Apr-19
Birmingham Women's & Children's NHS Foundation Trust	4	Apr-19
Cardiff & Vale University Health Board	2	Jul-19
Great Ormond Street Hospital for Children NHS Foundation Trust	2	Jul-19
London North West University Healthcare NHS Trust	2	Jul-19
Luton and Dunstable University Hospital NHS Foundation Trust	4	Jul-19
Maidstone and Tunbridge Wells NHS Trust	3	Jul-19
Norfolk and Norwich University Hospitals NHS Foundation Trust	1	Jul-19
Royal Devon and Exeter NHS Foundation Trust	3	Jul-19
Royal Free London NHS Foundation Trust	2	Jul-19
Sheffield Children's NHS Foundation Trust	1	Jul-19

Table 11 shows key data submitted to the IBD Registry since its inception for participating sites providing specific services for children and young people with IBD.

Note: Data for Sheffield Children's Hospitals NHS Trust is not included in the earlier paediatric analyses as their first submission of records was in July 2019. In 2019, the Registry is embarking on a specific initiative to encourage wider participation from Trusts providing paediatric services.

*Note: the title and heading for Table 11 were revised after initial publication to make clear the table refers to paediatric departments rather than NHS Trusts.

**Note: some Trusts have provided data for longer than the four years time span in tables 9,10 and 11.

Data - what to take away

Evidence of improvements in patient care and treatments

Each indicator measured in the biologics audit has improved during 2018.

Biological therapies are powerful drugs. Their use is inevitably accompanied by the risk of adverse reactions. Appropriate pre-treatment screening can minimise the risk to patients. Therefore, it is particularly encouraging to see the reporting of the completion of pre-treatment screening continues to rise and is likely to exceed 90% in the latest cohort of biologic starters.

The benefit of an intervention (in this case administration of a biological therapy) can only be determined if the target (disease activity) is measured. Participating sites are to be congratulated in submitting data that shows a near doubling of the recording of disease activity scores in patients reviewed post-induction and at twelve months. This closer focus on measurement means patients are likely to be treated more effectively and more cost effectively.

Following the same theme of disease activity, we analysed the recording of these key measures across our whole Registry population not just those receiving biologics. We found a record of multiple follow ups, with an average of five 'contact events' per patient (a total of 83,630 contact events across this population). Almost 35,000 (42%) of these contact events had a disease activity score associated with them.

This is a welcome result to see and IBD teams are to be commended for this achievement. Tracking disease activity in this longitudinal manner allows real insight into how patients are responding to treatment.

More broadly, the Registry now holds records of more than 10% of the IBD population of England and Wales. Analysis of this increasingly rich dataset will reveal trends in use of drugs and other aspects of patient care that will inform better and new approaches to improve the lives of those living with IBD.

How to record data more effectively – guidance from what we have learnt

The IBD Registry-based audit is unique in seeking to collect and analyse standardised data from a range of software solutions and local systems, in contrast with traditional audits that rely on the entry of data onto a stand-alone, singular website or audit tool. Given the diversity of local systems, constant evolution of electronic records and differing pace of digital transformation across hospitals, there are inevitable challenges in capturing standardised data for audit. Variable local interpretation and use of data fields and a range of software-related factors can create anomalies in the data that flows to the Registry. The processing of data for audit reporting is constantly evolving as we identify and account for anomalies and variations across sites and systems of data collection. In order to maximise IBD team submissions for the biologics audit, this report has emphasised a number of priority areas for data collection.

We suggest the following steps:

- Record diagnosis and disease classification in all newly diagnosed patients.
- When a patient begins or changes a biological therapy, record one initiation review, noting accompanying drugs for IBD and record a disease score – a Physician Global Assessment would suffice.
- If the patient has not received a biologic before, record which pre-treatment screening tests have been performed.
- Between eight and sixteen weeks after initiation of a biologic, record a post-induction review and record a disease score.
- At around 12 months after starting a biologic, record a review and a disease score.
- If a patient stops a biologic, record a review, a disease score and the reason the drug was stopped.

And beyond biologics...

- Seek Registry consent from all newly diagnosed patients.
- Record courses of steroids, taking care to enter stop dates when the course has finished.

Other observations

Beyond biologics

As well as data on biological therapies, the Registry holds data on a number of concomitant medications. There are 7,500 records of patients on aminosalicylic acid (5-ASAs), almost 12,000 on azathioprine or 6-mercaptopurine and 4,500 on oral steroids. For clinicians and patients alike, steroids have been a focus of attention because of adverse effects associated with long-term use. Registry data on prolonged steroid use (defined as continuous therapy for more than three months) is shown below in Figure 11. Where we have received a stop date for a course of steroids, prolonged use occurs in 27% of courses.

Figure 11: Oral steroids: course length of steroids reported to the Registry (April 2016 - July 2019)

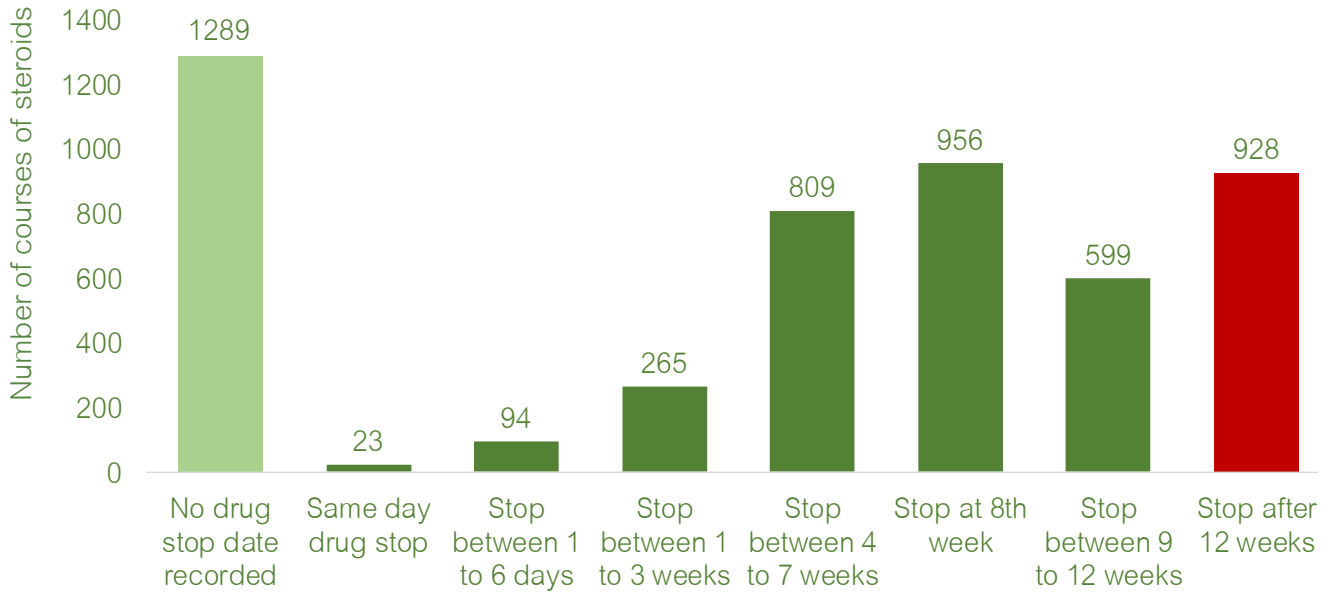
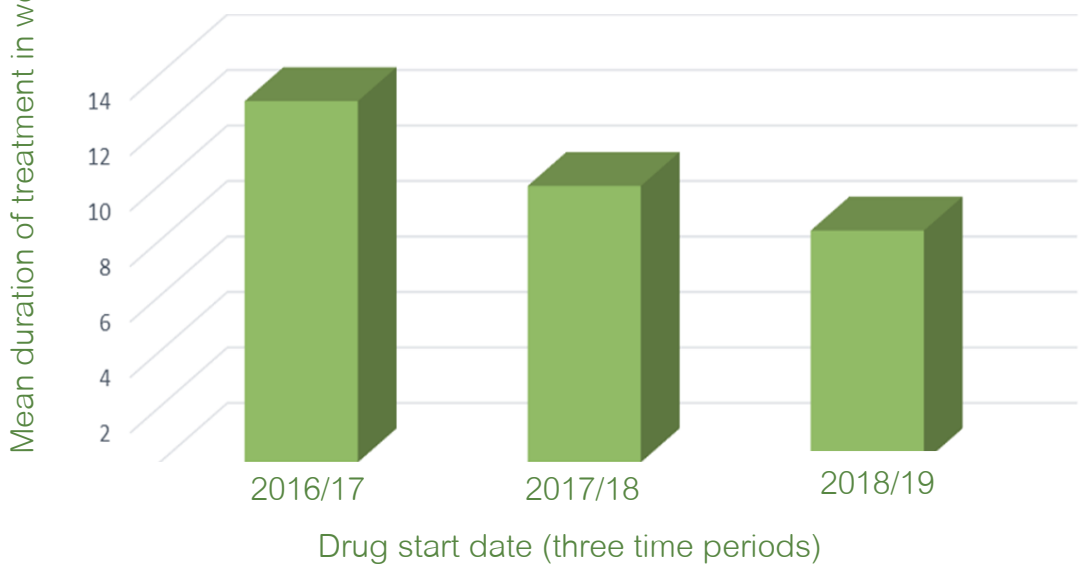


Figure 12: Duration of courses of steroids reported to the Registry in three time periods



Preliminary analysis of data received over three successive years suggests IBD teams are now using shorter courses of steroids; this will be investigated in more detail in future reports.

For future reports we are looking to include more in-depth analysis of concomitant medications and to include use of bone protection while patients are receiving steroids.

Future vision

The way forward

Collecting data

The Registry recognises that provision of a data capture tool incorporating clinical management functionality, increases the complexity of the screens used by clinical teams entering information and does not always provide at point of care the information the clinician requires. As a result, despite IBD teams being encouraged to capture Registry data in real time, we see that a number of teams have chosen to record information for the Registry and the National Biologics Audit as a 'back office' activity.

Taken with the move towards hospital-wide electronic health records (eHR), the Registry is investing significant effort in being able to receive information for the audit from diverse sources, including locally held spreadsheets, research databases and whole hospital eHRs, with the key goal being to enable greater data capture with reduced effort for local IBD teams.

Consent

Gaining consent from every patient is progressing, but at insufficient pace to meet the goal of 90% by September 2020, when the current exemption granted by the CAG expires. The Registry can apply for an extension to this date but has also embarked on a project to collect consent from patients via one or more apps and patient portals. With the increasing availability of specific IBD-targeted apps we believe this is a fruitful area in which to engage.

Patient reported outcomes

The collection of longitudinal data on the progress of patients is of fundamental value in informing changes in IBD care and therefore to the Registry. Clinical teams record information for the Biologics Audit 12 months after starting therapy, but the Registry believes many patients will recognise the value and have the ability to record their own information (current medication; modified disease score; PROM) on an app or portal from where the information can flow securely to the Registry, so enhancing the breadth of information and relieving the burden on hard-pressed clinical teams. Work is on-going in this area, supported by an independent grant from an industry partner.

Goals and partnership

New audit goals

Biological therapies have been the focus of UK audits for the last eight years, in which time they have evolved from expensive and narrowly available to almost commonplace with widened choice of treatments. Alongside this change in biologics, there remains a focus on longer established treatments, such as steroids. Interest has been expressed in auditing the time taken from referral to diagnosis of IBD and to revisit the use and duration of steroid therapy. The Registry's dataset includes items that measure these aspects of patient care and is working with groups including the BSG IBD section to investigate how best to provide the platform for these additional audit questions.

The Registry sees value in informing quality improvement initiatives by reporting a greater depth of information on patients newly diagnosed with IBD and is consulting on taking this forward.

Collaboration with IBD UK

In 2019 IBD UK a partnership of organisations, including the IBD Registry, launched updated standards for the care of patients with IBD. The IBD Registry is pleased to be both an integral and founding partner of IBD UK. The Standards define what quality care means for IBD patients at every point in the patient journey, including from pre-diagnosis to in-patient care to ongoing care. The 2019 version is the first update for six years. The initial IBD Standards were launched in 2009, after the first audit of IBD Services in 2006 by the Royal College of Physicians. This highlighted large variations in standards of care. The Standards were updated in 2013 and are the foundation for the 2015 NICE quality standard on IBD.

Alongside the 2019 Standards, a website has been created to provide a platform for patients to participate in a survey of the care they receive. The website also enables IBD teams to participate in an organisational audit to assess their service against the new standards. With our established IBD data collection network, the Registry has a special role to play in these standards, providing the measuring and monitoring element in support of the defined Standards. Our goal is to provide, using our existing data collection processes, as much standards-aligned information to participating sites as possible, thereby saving clinical teams the burden of multiple data entry.

The Registry sees this benchmarking activity as complementary to continued participation by IBD teams in the Registry, particularly as information submitted by sites to the Registry will inform their responses to the organisational audit.

Concluding remarks

We would like to thank participating hospitals for helping us progress in our aim of using a range of local IT systems for routine collection of clinical data, and embedding this data in large scale audit and quality improvement. We think that this approach will enable us to move away from traditional audit methods of duplicated data entry, stand-alone audit tools and retrospective extraction of information.

The Registry is committed to supporting local teams to establish better ways to collect a standardised IBD dataset and to identify and solve the inevitable challenges of cleaning, normalising and reporting on the data. This report provides evidence for the feasibility of registry-based audit and an increasing maturity of the data.

The scope of this report has been primarily on the use of Biologics for IBD in the period 2018-19, with the focus being on the KPIs established for the Biologics Audit. The report also provides evidence that the dataset that we are collecting allows more in-depth analysis than the subset of medications that is biologics available for analysis. We as a Registry intend to use this newly maturing depth and width of data to provide increasingly useful information back to clinical teams to support them in their drive for better, safe care for patients.

For further information

To keep up to date and informed of our work, please sign up to our regular public newsletter by emailing:

support@ibdregistry.org.uk

You can also follow us on Twitter @ibdregistry

If you are a member of an IBD team not yet participating in the Registry and would like to find out more, please contact us for an informal discussion. One of our experts will be delighted to explain how we can help you and ultimately help IBD patients in your care. Our full contact details are on the back page.

Glossary and references

Glossary

Text accessibility

This report is primarily aimed at healthcare professionals and uses terms that may only be familiar to these readers. However we hope some patients and others may also be interested in information contained in this report. To make it more accessible, we have added a glossary of terms here.

Anti-TNF - or Tumour Necrosis Factor inhibitor is a drug that suppresses the body's response to TNF, which is a part of the body's response to inflammation.

Biologic naive - describes a person who has not received any biological therapies before.

Biosimilar - a *biosimilar* is a biological medicine highly similar to another already approved biological medicine (the 'reference medicine' or originator).

eHR - electronic health record. A computer system used in hospitals and other healthcare settings that holds the full medical record and is more accessible than paper medical notes.

Longitudinal - in the context of patient care means long term or follow-up.

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1 Molodecky NA, Soon IS, Rabi DM, et al. Increasing incidence and prevalence of the Inflammatory Bowel Diseases with time, based on systematic review. Gastroenterology 2012;142:46–54.

2 Ghosh N and Premchand P A - UK cost of care model for inflammatory bowel disease 2015 Frontline Gastroenterol. 2015 Jul; 6(3):a 169–174

Contributors

Thank you to all our participating IBD teams whose daily efforts serving IBD patients and safely recording relevant health data have enabled us to publish this report.

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This report was produced by the IBD Registry's Analytical Hub, working in partnership with the Department of Biostatistics, University of Liverpool.

About the IBD Registry

The IBD Registry is a not-for-profit company established by the British Society of Gastroenterology, the Royal College of Physicians and Crohn's and Colitis UK. The Registry seeks to transform outcomes for patients, clinicians and health organisations by providing detailed IBD information to facilitate greater understanding, treatment and care of people with IBD. As our dataset matures, we continue to expand the breadth and depth of analysis. Our aim is to provide clinicians with information to support planning of services and to improve the care provided to patients.

IBD Registry

2018/19 Annual Report on the Use of Biologics for Inflammatory Bowel Diseases

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