



Improving quality in IBD services

UK inflammatory
bowel disease audit

February 2016

Foreword

It gives me great pleasure to write the foreword to this report, which summarises the process and outcomes from a series of eight regionally based inflammatory bowel disease (IBD) service improvement workshops, organised by the IBD Programme team during 2015. You will see from the report that there was some variation in the themes that emerged from the different workshops, but the active participation and enthusiasm of the IBD community was consistent throughout. As such, we hope that this report serves as testimony to the amazing commitment of the IBD community to improve services for their patients throughout the UK.



The IBD programme was established over 10 years ago with the aim of improving the quality and safety of care for people with IBD throughout the UK. The initial emphasis was to audit the quality and care and services offered to patients and to shine a light on the variation that existed. The first round of UK-wide audit took place in 2006 and the four rounds that have now been completed have shown substantial improvements in care over time. The programme has steadily evolved to encompass a wider range of quality improvement measures, and the energy surrounding the IBD programme has supported the development of national standards for IBD care and helped establish quality IBD care as a key component of local healthcare delivery. Further information about the work of the IBD programme can be found at www.rcplondon.ac.uk/ibd.

Despite the undoubted success of the IBD programme, it is clear that there is an ongoing need for continued improvement in the care of people with IBD in order to maintain sustainable, effective and cost-efficient services. The IBD workshops were developed to help address this need by creating an opportunity for services to reflect on their local performance data, develop quality improvement skills and to meet together to share experience.

It was my great honour to have been able to chair a number of the workshops and to witness at first hand the drive and enthusiasm from attendees to work within the often challenging climate of the NHS to improve their local service for the benefit of their local patient population. We hope that the report captures some of the energy of the workshops, while also providing a useful summary of the workshop process and helping to disseminate the shared learning gained from the participation of the real experts in IBD service provision – the UK IBD community.

Clinical director, IBD programme quality improvement
Clinical Effectiveness and Evaluation Unit
Royal College of Physicians

What is this report about?

The inflammatory bowel disease (IBD) programme was established over 10 years ago with the aim of improving the quality and safety of care for people with IBD throughout the UK. The initial emphasis was to audit quality and care to show variation, but through four rounds of audit the programme has steadily evolved to encompass a wider range of quality improvement measures.

This report has been written to summarise the regional service improvement workshops conducted by the IBD programme team in 2015. We hope that it will serve as a helpful overview of the process, summarising the content and feedback from the workshops and also sharing successes and experiences of IBD teams as they work to develop their services.

This report has been written for the IBD teams involved in the regional workshops, for people with an interest in their outcomes, and also for quality improvement teams who may be considering conducting a similar process.

Thank you

We would like to express our sincere appreciation to the IBD teams and patient representatives who took part in the workshops and site visits, and to the organisations that supported their delivery.

Commissioned by:



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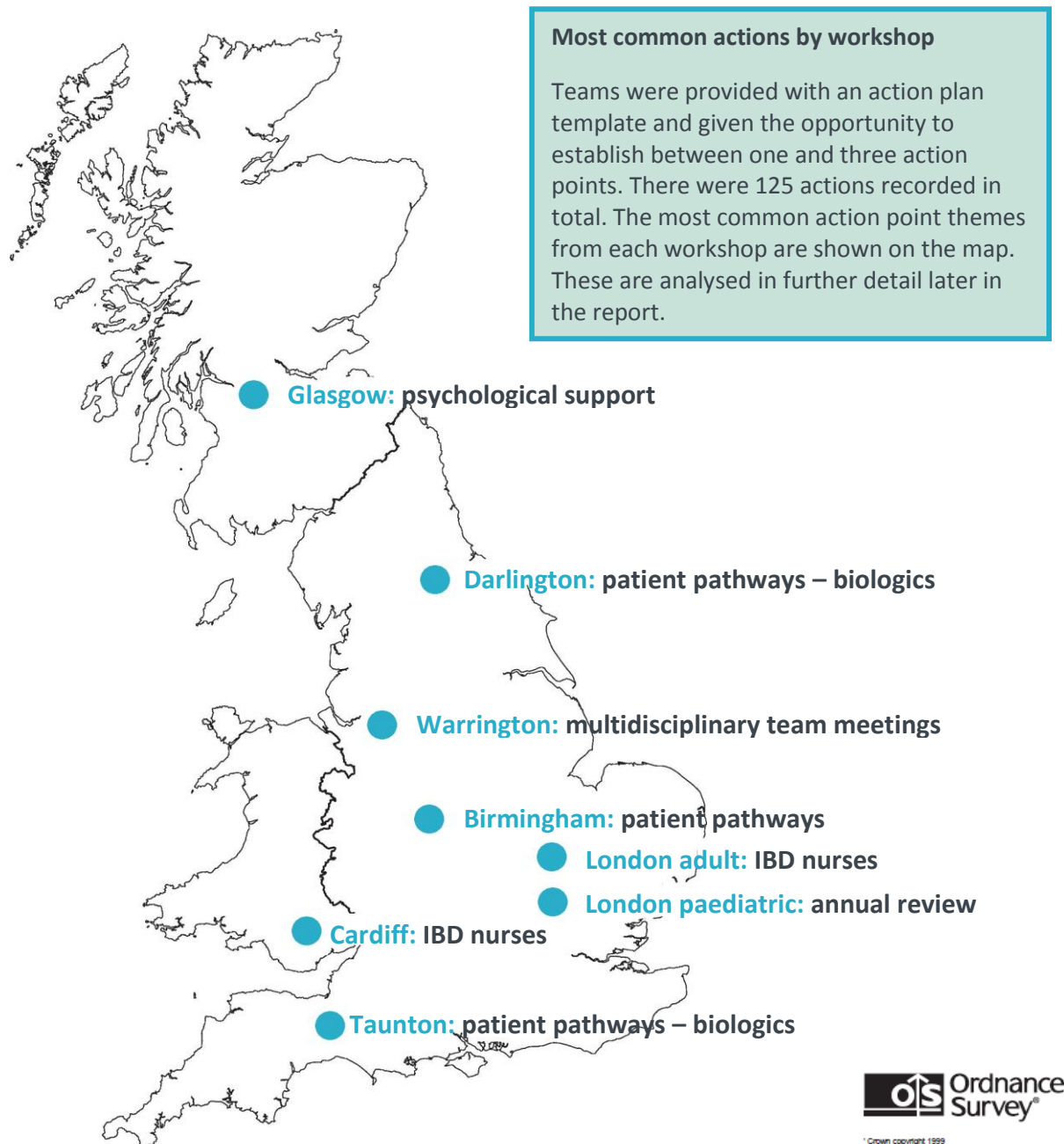


Workshops

Throughout March 2015, seven workshops were held throughout England and Wales, with one further workshop held in Scotland in September 2015.

The overall aim of the workshops was to provide IBD teams with dedicated time away from day-to-day practice to review their service and plan for necessary improvement, with the following specific objectives:

- to reflect on their service using their own data to identify areas for change
- to network with colleagues to share expertise and examples of best practice
- to leave the workshop with an action plan to implement and evaluate improvement in their IBD service.



The workshops

Invitations to the workshops were circulated to the IBD healthcare community through existing contact lists, newsletters and articles in relevant publications 6 months prior to the date of the workshop. Several reminders were reissued in the months and weeks leading up to the workshops. Online registration was open to both participants and non-participants in the previous work of the IBD programme.

To get the most value from the workshops, attendees were recommended to register along with other members of their IBD team. Ideally a team would consist of the IBD lead for the organisation, an IBD or gastroenterology specialist nurse, a manager responsible for the gastroenterology services, any allied healthcare professionals with an interest in IBD, for example a dietitian or pharmacist, and an improvement or data specialist, for example local clinical audit or quality improvement staff.

The agenda was tailored to meet any specific needs of the local audience, but each covered core elements including a quality improvement presentation sharing simple methods to implement and demonstrate change, a patient's perspective, a summary of pertinent findings from the IBD programme and the future work plan by an IBD programme clinical director. Time was protected within each agenda to allow for reflection, networking and sharing of best practice, as well as action planning by IBD teams.

An example of an agenda is available to download from <http://bit.ly/1PCBv5I>

To prepare for delivery of the workshops, the IBD programme team, including its clinical director, underwent a tailored facilitation training session as a team. The training ensured that the objectives of the workshop were built into each individual agenda item and that the team were focused on directing attendees accordingly. Each workshop was led by one of the IBD programme clinical directors and chaired by a clinician from a local hospital to ensure that the content was relevant to the region. The IBD programme team facilitated the workshops (averaging three facilitators per workshop) and managed registration, distributed roaming microphones for open discussion sections and facilitated breakout groups at flipchart stands.

Copies of completed action plans were taken during the closing presentations and attendees were informed that they would be followed up to collate progress with actions in 6 months' time. Four continuous professional development points were awarded to delegates for their participation and these certificates were exchanged for the return of evaluation forms at the end of the workshop.



Dr Ian Shaw, introducing the workshop to attendees in Birmingham on 6 March 2015.

The workshops in numbers

8 regional workshops were held in England, Wales and Scotland

84 trusts and health boards were represented, with 18 attending multiple workshops

This equates to: **67/139** trusts in England

22 paediatric trusts / health boards (**15/25** of the specialist centres)

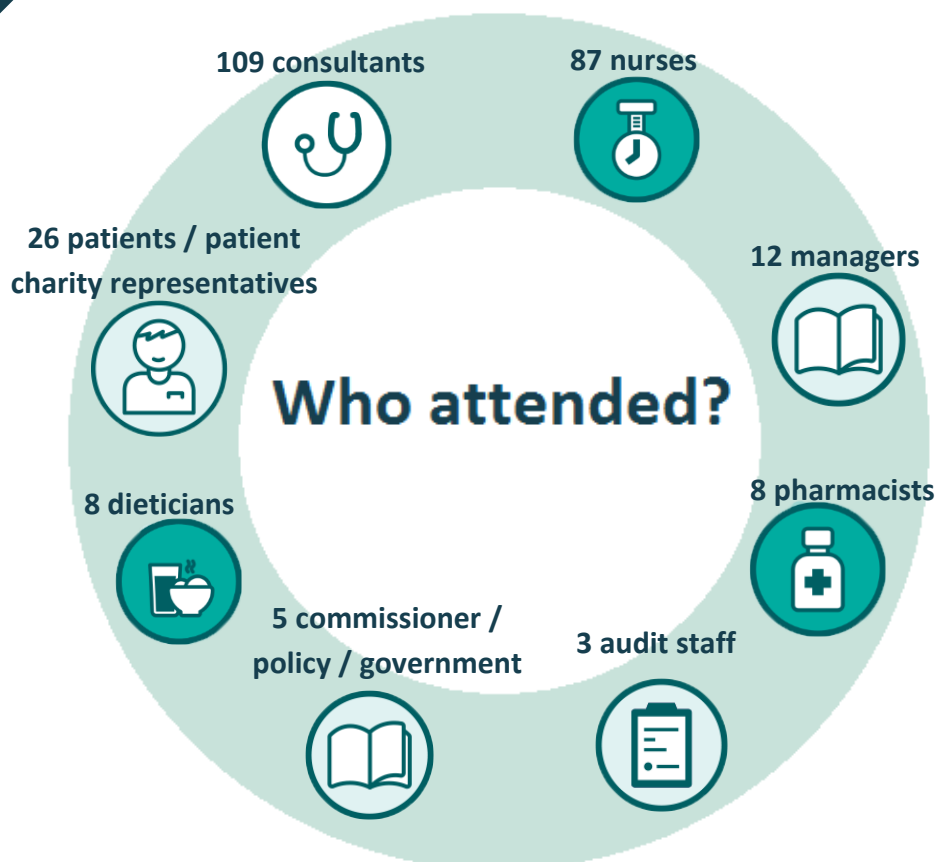
5/7 health boards in Wales

8/14 health boards in Scotland

Sites were encouraged to attend as a team: **69** trusts / health boards attended as part of a team (two or more attendees)

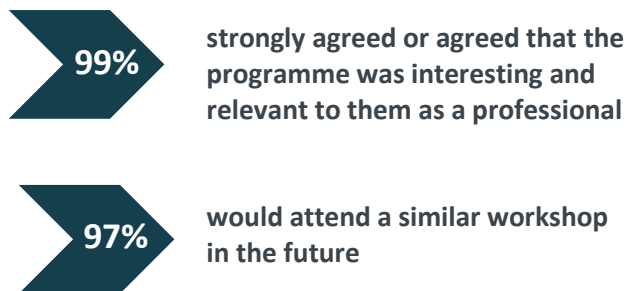
33 trusts / health boards had one IBD team member attend

258 delegates attended the workshops. The attendees comprised:



A detailed breakdown of each individual workshop can be found at <http://bit.ly/1PCBv5I>

What did they think?



'**Very helpful** to focus on objectives and action planning for service development'
'**Excellent** afternoon of **shared learning**'
'A very helpful meeting, **learned a lot** from my other colleagues and their services'
'Good speakers and a **very productive** day'

Best bits

- 1 Networking
- 2 Time away from hospital to talk and forward thinking with teams about quality improvement
- 3 Action planning

The quote below is from Denise Cann, who provided her perspective as a patient, IBD service user and as a volunteer on the Crohn's and Colitis Support Line at the Birmingham, Darlington and Taunton workshops.

'It was a pleasure – and a privilege – to be able to attend three regional workshops, to talk about an aspect of care which means a great deal to me, and which is central to the quality of the clinical relationship. Not only has my own experience demonstrated this, it has been reinforced by hearing the experiences of many on the Crohn's and Colitis UK Support Line for over 20 years.

That aspect is *communication*, and that is exactly what these days were about for me. They were opportunities to share, to listen, to learn, and to hear of the work that goes on with care and commitment. It was a valuable insight. There were a number of consistencies, eg recognition of the need for easier access to psychological support. The day was a joining up of writing, coming from real places, from people who really understood the issues.

To be able to continue such times would be of great value. Sadly, Support Line callers speak of bad experiences of care. Continuing such days could be part of the process of sharing good practice, to listen to needs, and to lift standards of care.'

Denise Cann
Patient representative

Five most common action themes

Teams were provided with an action plan template and given the opportunity to establish between one and three action points. The template enabled individual actions to be broken down into achievable steps using the principles of SMART: specific, measurable, attainable, realistic and timely. IBD teams were asked to put their action plan into motion following the workshop and were informed that they would be followed up to assess progress 6 months after the workshop.

The action plan template is available to download from <http://bit.ly/1PCBv5l>

During analysis, the 125 individual action points recorded at all of the workshops were grouped into 24 themes. The table below shows the five most frequently recorded action plan themes that emerged across all of the workshops, when combined.

Action plan themes	Number of action points
Patient pathways (This included biological therapies, diagnostic, inpatients, pregnancy, standardised care, policy / protocol and shared care pathways)	22
IBD nurses	16
IBD Registry / database	9
Patient panel / group	9
Multidisciplinary team meeting	8

The quote below is from Claire Munro, communications lead for the IBD Registry, who attended the Scotland workshop in Glasgow on 18 September 2015.

‘The IBD audit regional workshops were really well received by clinical teams, and the one I attended was extremely useful. We felt it would make sense to use a similar model for a series of registry workshops, not least because – as the audit and registry teams work increasingly closely to bring the projects together – the registry meetings formed part of a continuum of information and support for IBD clinical teams.

The collaboration with the audit team was invaluable, especially being able to review the action plan themes from the workshops, which enabled us to get a sense of local priorities and allowed us to shape our agenda appropriately.’

Claire Munro
IBD Registry communication lead

The following table demonstrates the 125 individual action points created at the various workshops and the themes into which they were later grouped.

NB The London adult and London paediatric workshops are listed as London (A) and London (P), respectively.

Action plan theme	Individual action point	Workshop
Patient pathways – biologics	Biological pathway	Birmingham
	Pathway for biologics use in ulcerative colitis maintenance	Birmingham
	Improve timeliness of biologic patients’ review	Birmingham
	Access to treatment monitoring for patients on biologics	Darlington
	Home infliximab infusions (service)	Darlington
	Virtual biologic review service	London (A)
	Improve biologic monitoring	Taunton
	Improve biologics data	Taunton
	Management of biological therapies	Taunton
	Biosimilars	Taunton
	To decide appropriateness of a biologics MDT	Warrington
Patient pathways – diagnostic	Reduce diagnostic waiting time by improving diagnostic pathway by using faecal calprotectin testing with consequent cost savings	Birmingham
	Development of IBD pathway for use in primary care	Birmingham
	Checklist for patients diagnosed with IBD at endoscopy and to start appropriate treatment	London (A)
	Early assessment of patients under 40 to differentiate between IBD and IBS	London (A)
	Reduce diagnostic wait	London (P)
	Dexa scanning – improving monitoring where appropriate	Taunton
Patient pathways – inpatients	Inpatient service	Warrington
Patient pathways – pregnancy	GP guidelines – pregnancy pathway	London (A)
Patient pathways – standardised care	Pathways to standardised care	London (A)
Patient pathways – policy / protocol	Delivering safe immunosuppression care	Birmingham
Patient pathways – shared care	Shared care with primary care	London (A)
IBD nurses	More IBD nurse specialists	Birmingham
	Cross-cover for IBD nurses	Darlington
	Need a third IBD nurse	London (A)
	IBD nurse to meet IBD standards of 1.5 WTE	London (A)
	No gastroenterology clinical nurse specialist	London (A)
	More IBD nurses / increased hours	London (A)
	All inpatient should see the IBD nurse in line with IBD standard A1 (1.5 WTE IBD nurse per 250,000)	London (A)
	Second IBD nurse	London (A)
	Increase number of IBD nurses	London (A)

	Insufficient IBD nurse support	London (A)
	IBD nurse	London (P)
	IBD nurses	Wales
	Improving IBD nurse service	Wales
	More IBD nurses	Wales
	Improving inpatient care by IBD nurse review	Warrington
	Second IBS nurse	Warrington
IBD Registry / Database	IBD Registry	Birmingham
	Implementation of IBD Registry	Birmingham
	IBD Registry	Birmingham
	Database development	Darlington
	To improve use of Infoflex as a data collection tool for IBD patients	London (A)
	IBD database	London (A)
	Implementation of IBD Registry	London (A)
	Database	Taunton
Patient group / panel	IBD database	Taunton
	Patient support group	Birmingham
	Create IBD patient panel / contacts	Darlington
	Increase patient involvement through service development	London (A)
	Increased patient involvement to shape IBD services	London (A)
	Patient involvement in service improvement	London (A)
	Set up patient panel	London (A)
	Improve patient perspective of inpatient care	London (A)
	Patient panel	London (P)
MDT	Patient panel	Warrington
	To ensure that IBD MDT is minuted, attended and used for biological annual reviews	London (A)
	Establishment of MDT clinics – reconfiguration of service	London (A)
	Improve MDT	London (A)
	Setting up regular dedicated IBD MDT	London (A)
	IBD nurse services	Wales
	IBD MDT	Wales
	More organised IBD MDT meetings	Warrington
Access to care	MDT	Warrington
	Improve access to rural localities	Taunton
	Emergency admission pathway	Birmingham
	Early specialist review	Birmingham
	Access for patients to consultant when required on urgent basis	Darlington
	Improve access to specialist IBD services for newly diagnosed IBD	Taunton
	New IBD diagnosis	Taunton
	Reorganising IBD provision	Wales

Psychological support	Access to psychological support	London (A)
	Psychological support	London (A)
	Psychological support to IBD patients has been poor historically	London (A)
	Psychological support	Scotland
	Psychological support for IBD	Taunton
	Business case to employ a psychologist for IBD	Birmingham
	Psychology input	London (P)
Patient education	Patient education	Birmingham
	IBD patient website	Darlington
	Structured patient education	London (A)
	Provide patients with a self-management plan	London (A)
	Self-management program	London (A)
	Written info on service	London (P)
Dietetic / nutritional support	Dietetics / nutritional support	Birmingham
	Have dietician available for clinics/appointments as and when needed	Darlington
	To have improved access to dietetic support	London (A)
	Dietetic service	London (P)
	Nutritional team	Wales
IBD surgery	Negotiate more space on lower GI surgical lists for IBD patients	London (A)
	Get more surgical involvement in the care of IBD patients	London (A)
	Improve surgical pathway	Taunton
	Semi-urgent outpatient clinic / surgery	Taunton
	Timely access to surgery	Wales
Annual review	Create annual IBD plan	Darlington
	Annual review	London (P)
	Comprehensive consultant annual review	London (P)
	Establishment of annual formal review process	London (P)
Drug monitoring	Tailoring drug doses to patient response and optimising maintenance	Darlington
	All patients prescribed oral steroids should be on bone protection	London (A)
	To ensure bone protection for all patients discharged on oral steroids	Wales
	Azathioprine induction / monitoring	Warrington
Transition	Development of transition of care protocol	Birmingham
	Establish adolescent clinic	London (A)
	Creating more transition clinics	London (P)
	Transition process	London (P)
Clinic	Set up iron deficiency clinic and infusion service	London (A)
	Expansion of current virtual clinic	Wales
	To set up a biologics clinic	Warrington
Clinic – assessment	Scheduling IBD clinics	London (A)
	Time and space to do quality assessment	London (P)

	Dedicated IBD clinics / timely follow-up	Taunton
Communication	Family IBD day	London (P)
	IBD intranet pages	Taunton
Guidelines – assessment	Guidelines for acute severe UC and scoring system	London (P)
	Guidelines for acute severe UC and scoring system	London (P)
Pharmacist	Implement specialist pharmacist role	London (A)
	Having access to a pharmacist for IBD patients	London (A)
Service assessment	Undertake local audit	Wales
	IBD QIP – complete	Warrington
Admin support	Admin support for IBD service	London (A)
Adolescent clinic	Adolescent clinic	London (A)
Data manager	Data manager	London (P)
Immunisation	Immunisation of IBD patient	Warrington
Research	Publish research	London (P)

The quote below is from Jackie Glatter, health and public service development manager for Crohn's and Colitis UK, which was represented at each of the workshops.

'It was great that the IBD programme incorporated a patient perspective from the outset and recognised the importance of ensuring that a patient-centred approach is integral to quality improvement and service development, planning and delivery. IBD patients attended the regional workshops alongside members of the clinical and management teams. This demonstrated a commitment by IBD services across the country to involving patients as partners throughout the process.

Involvement in the IBD programme has further informed Crohn's and Colitis UK's health service development work, part of which offers support to IBD services to deliver the IBD Standards from a patient perspective. Our patient engagement officer is available to provide guidance and practical support to individual services on methods and approaches to effectively involve patients in service improvement.'

Jackie Glatter

Health and public service development manager for Crohn's and Colitis UK

Follow-up

Webinars

Three months after the workshops, webinars were held to allow participants the opportunity to share the progress of their action planning, to discuss any barriers that they had encountered, to explore solutions and ideas with other IBD teams, and to be provided with general support. The approach was to allow an open platform for discussion, with the webinar lead guiding conversation through the successes and issues of those participating.

A webinar for paediatric services was held on 11 June, and two for adult services were held on the 12 and 17 June 2015. A total of 10 organisations were represented, with participants focusing on the methods of increasing participation in, and the regularity of, multidisciplinary team meetings. Participants shared the issues that they were having in executing their action plans, and others who had experienced similar issues shared ways in which they had overcome similar barriers to change.

Hospital visits

Following completion of the workshops, 10 hospital visits were offered both to IBD teams who attended the workshops and to those that had not been able to attend. The visits were primarily intended to be supportive of the requesting hospital's IBD team, providing an opportunity to share ideas and solutions on priority topics, determined by the local IBD team. The visiting team would typically consist of at least one consultant gastroenterologist and an IBD nurse who were members of the Royal College of Physicians (RCP) IBD programme steering group, along with a member of the IBD programme project team. However the visiting team was adapted on each occasion to meet the needs of the requesting hospital. A pharmacist, Crohn's and Colitis UK staff member, patient representative, and non-steering group consultants and nurses with an interest in the visits, also attended.

While the agenda for each visit was adapted to suit each individual IBD team, each visit consisted of the following core elements: a presentation from the hospital's IBD clinical lead, a brief tour of the clinical area (ward and/or clinic) and then a period of discussion with the visiting team. The visits concluded with the offer of a RCP branded letter being written by the visiting team and sent to the chief executive officer of the organisation, to raise awareness of any issues identified on the day.

'These visits provide benefit to patients with IBD on a number of levels – highlighting the achievements and challenges of the host team within the organisation and obtaining external, independent and supportive advice from the visiting team. I am also struck by the amount I learn from fellow members of the visiting team and from host team's services.'

Alan Lobo

Professor of gastroenterology, University of Sheffield

Evaluation

Six months after the March 2015 workshops, a survey was sent to all IBD teams who had completed an action plan asking them to evaluate their progress. From the 61 surveys sent out, 30 IBD teams returned completed surveys.

Workshops

- 74%** strongly agreed or agreed that their participation in an IBD audit regional workshop had **helped improve their IBD service**
- 63%** considered the actions that they had created at the regional workshops as **one of the factors in the changes made to their IBD service** in the last 6 months
- 74%** of those who were already working towards actions prior to the workshops said that the content on the day **supported and/or assisted their improvements** over the last 6 months

Action plans

From the **30** returned surveys, **67** action points had been evaluated:



18 out of 67 actions had been **completed**

Action theme	Number completed
Patient pathways – biologics	5
Patient group / panel	3
IBD nurse (review of service)	2
Annual review	1
Dietetic / nutritional support	1
IBD Registry	1
IBD surgery	1
MDT	1
Patient education	1

How did they do it? **Click here** to see case studies from teams who completed actions

- 13** out of 67 actions were **in progress and on time**, but due after the date of the evaluation
- 27** out of 67 actions were **in progress with the original timeline extended**
- 9** out of 67 actions had were reported as **not started**

The most common action themes recorded as not having started or as having had their original timeline extended were:

Action theme	Not started	Original timeline extended
IBD nurse	2	6
IBD Registry / database	1	5
Patient pathways (including diagnostic, biologics, policy / protocol, inpatient)	1	4
Patient group / panel	1	2
Patient education	1	2

The most common reasons for a lack of progress in teams who had not started their actions or who had extended their original timelines are shown below:

- 11** other departmental targets
- 9** lack of staffing
- 8** waiting on approval or input from others (management, IT)
- 7** lack of funding

‘The workshops are very useful for **driving the service forward**; the aim is to keep on track. We now have psychological support for IBD patients which we did not list in our original priorities; however this is a **huge move forward**.’

‘We took **other lessons** from the meeting that were not reflected in the original action plan; namely audit tool for nurse workload planning and the development of a streamlined biologics pathway.’

Webinars

The 3-month webinars, which were designed to be an open and flexible forum for discussion, had a limited uptake. We believe that this web-based approach works best when either:

- participants are already familiar with one another and are joining a webinar with clear idea of what will be discussed and who else will be online, or
- a webinar is used to disseminate information or demonstrate a specific topic, such as the demonstration of a new web tool or presentation of information in a slideset.

When the IBD programme team has run webinars in the past using the more structured formats described above, they have been both well attended and well received. Those that did join the webinars on this occasion, however, did experience benefit from having done so.

‘Involvement in the webinar was **very interesting**, finding out information regarding how different hospitals were operating and the dilemmas they may be encountering.’

Hospital visits

At the time of writing this report, the hospital visits were still underway. To date, five visits have been delivered and anecdotal feedback suggests that these have been valued very highly by the IBD services that have been visited, and have proven to be an effective way of engaging services with their executive team.

Coordinating the visits proved difficult within a relatively short time frame; it was particularly challenging to find mutually convenient dates for both the requesting team and attending team members. While the process is time-consuming, we believe that the value, summarised in the two case studies below, outweighs the effort required.

‘The IBD programme site visit provided a unique opportunity to have an external review of our local IBD service. It consisted of an initial presentation outlining our current practice, a tour of the medical day unit facility, and a discussion on how to implement several improvements to the service. This was followed up by a letter to the chief executive of the health board summarising the recommendations made.

The visit proved to be a very constructive exercise, enabling us to review our own facilities and methods of working, and exchange new ideas with the IBD programme team. Using their experiences from other sites, we gained several suggestions on how to develop the service and also on how to instigate these changes. The subsequent letter to the chief executive has added substance to these recommendations and has helped us to make progress in appointing a new IBD clinical nurse specialist.’

James Berrill

Consultant gastroenterologist, Royal Glamorgan Hospital

‘Attending the London regional workshop really energised the conversation between our IBD team and management about what could be achieved for patients with the correct team. The executive management team are now engaged in the development of our IBD service. There are operational barriers which we will need to overcome, but having the executive team support our goals is a huge achievement.

I believe that the workshops and their follow-up are an effective way of encouraging the improvement of quality in services. The letter sent after our site visit has involved and engaged executive team members, including the medical director and CEO, in agreeing to plans for a second IBD nurse. The visit was also a huge morale boost for and acknowledgement of the work of the IBD team to date.’

Monica Bose

Consultant gastroenterologist, Princess Alexandra Hospital

Summary

8 regional workshops attended by **258** delegates from **84** trusts and health boards.

125 individual action points were recorded and grouped into 24 themes. The five most common action themes were:

- 1 patient pathways – biologics, diagnostic, inpatients, pregnancy, standardised care, policy / protocol and shared care
- 2 IBD nurses
- 3 IBD Registry/database
- 4 patient panel / group
- 5 multidisciplinary team meeting

It was encouraging to see the number of IBD services that have begun to implement change in a relatively short space of time, with 27% of actions completed and 60% in progress.

13% of actions had not been started at the time of the evaluation; the majority of these delays were due to resource issues and/or other departmental targets.

Although the uptake of the webinars was limited, those who dialled in found the exercise helpful as an opportunity to air concerns, which the wider group could then focus on and explore possible solutions. On reflection, the IBD programme team would not run webinars as a means of follow-up on action-planning workshops.

Feedback from participants of the hospital visits was overwhelmingly positive, and two services have shown encouraging progress in their plan for second IBD nurses. The site visits have proven to be a successful way of engaging executive teams with their IBD services.

How did they do it?

The case study below is from King's Mill Hospital, which **established a patient support group**.

'Establishing a patient support group was on our agenda as a service we wanted to provide before the regional workshop but until that point we had no firm ideas about achieving it. By networking at the meeting we were able to talk to a Crohn's and Colitis UK representative and other members of the workshop to gain ideas. From there I contacted Crohn's and Colitis UK directly, who were able to put me in contact with the neighbouring Crohn's and Colitis UK group, who were very supportive in our ambition to set up a more local patient support group. From there, I simply booked an available room at my hospital and set a date. I spoke to several patients and invited them to come along and the neighbouring Crohn's and Colitis UK group advertised the date on their Facebook page. On the day, we had around 15 patients participate, which was more than I had hoped for. We are hosting our second meeting shortly and I feel it has been a great success. The barriers to change were more perception rather than actuality, as it was very simple to do in the end. The workshop definitely helped in providing direction.'

Chris Murfitt

IBD clinical nurse specialist, King's Mill Hospital

The team at University Hospital of North Tees created an **annual IBD plan** and established a more **robust IBD nurse cross-cover**.

'One of our actions was to create a more robust IBD nurse cross-cover. Our challenge was staff going on maternity / long-term leave and impending retirements. We held a trust-wide meeting with IBD nurses, managers and consultants to agree on a plan of action and gained trust support for additional cross-cover.'

Our second action point was to create an annual IBD plan. We began by developing a large (>20 page) action plan listing all standards/requirements from the various national guidelines and audits. We held an IBD team meeting to discuss and to divide up the work. We have had fortnightly progress updates since, and the plan is now down to 1 page.'

Matt Rutter

Consultant gastroenterologist, University Hospital of North Tees

The team at Dorset County Hospital **improved the monitoring of patients currently receiving biologics.**

'We wanted to improve the monitoring of our patients currently receiving biologics. The main barrier in implementing this change was time and funding, but we were able to take advantage of the trust's and local clinical commissioning group's (CCG's) desire to switch from Remicade to Inflectra. This allowed us to enter into a gainshare arrangement to cover nursing hours for the increased monitoring needed to manage the switch safely, fulfilling a need already identified by the IBD nursing service.

The main barrier in implementing this change was time and funding, but we were able to seize an opportunity to overcome this by collaborating with our trust pharmacy and the CCG in a gainshare arrangement which allowed us to increase our nursing hours from 1.4 WTE to 2 WTE on a permanent basis, therefore allowing us to see each patient at every infusion of infliximab. In addition to this IBD nurses have just taken over the ongoing prescribing of adalimumab, which will allow us to have more control over blood monitoring and disease assessment in this patient group.

We were aware of the need for this change before the regional workshop but no action had been taken; attending the workshop allowed us to focus on this particular problem. When looking at the ongoing development of a service, there is in my experience a wish list of things you want to improve, usually driven by audit results and related to the IBD Standards or NICE guidance. The workshop got us to think what was achievable from this list.'

Pearl Avery
IBD clinical nurse specialist, Dorset County Hospital

The team at University College Hospital (UCH) London developed a structured patient education programme for IBD patients.

‘Prior to the workshop we had already identified that provision of group education for patients with IBD was lacking. I had been in the process of trying to arrange a group education session on diet in IBD but had not yet achieved this. The workshop supported us to achieve this action by providing a structure and deadlines for review which helped to motivate us and drive things forward.

We were able to successfully implement this action point by holding an IBD education open day organised by our IBD nurses Heather and Lisa. Crohn’s and Colitis UK and the Prince’s Trust attended, and refreshments were kindly provided by Coloplast. The programme was developed to provide education on various topics related to IBD care. The speakers were invited primarily from the UCH IBD team and one external speaker. A lecture theatre was booked within the UCH education centre alongside a breakout area where we had education stands with educational literature available for patients to take away.

Barriers to implementing this action included acquiring available space to hold the education day, advertising, organising and the costs incurred in delivering this. It was also difficult to gauge numbers of possible attendees as we did not request confirmation of attendance. We overcame most of our barriers by organising the day several months in advance. This ensured that the presenters had plenty of time to prepare and that there was adequate notice for both staff and patients ensuring good availability. Overall the action was successfully achieved and the feedback from patients was positive. We plan to run this study day now on an annual basis and will aim to improve the day based on any constructive comments that were received.’

Katie Keetarut

Senior IBD dietitian, University College Hospital London

The team at New Cross Hospital established dietetic support within their IBD service.

'The first step was to invite the dietetic team to attend the workshop in Birmingham; the aim was to have them engage as part of our IBD team. To get them involved, we used the findings of the organisational audit to help show that this was area of importance as well as part of the IBD Standards. The dietetic link was then able to bring this back to their manager for discussion and an action plan was developed. We also brought our findings from the audits to our organisational quality assurance meeting and they were impressed with the team's goal of achieving and maintaining the IBD Standards. They fully supported the plan of IBD dietetic support and this allowed the implementation of an IBD dietitian's clinic to run alongside the IBD clinic.

Running as a trial for almost 12 months now, the biggest barrier has been funding and we are currently facing this issue again so there is discussion about a further business case to be submitted. The clinic is not being used as much as anticipated and therefore we will need to liaise with dietetics about how best to continue.

The key points in establishing dietetic support are:

- Involve dietetics in the development early, let them have ownership of the plan
- Present key findings and relation to NICE standards to your organisational quality group
- Be amenable to how this clinic/support should run to allow for best uptake and utilisation.'

Matthew Brookes and Robert Nordon

Consultant gastroenterologist and IBD nurse specialist, New Cross Hospital

The team at University Hospitals Coventry and Warwickshire **recruited a second IBD nurse and audited their telephone helpline.**

‘Before the workshop we had just one full-time Band 7 IBD clinical nurse specialist (CNS). She was working to full capacity and although the service clearly needed to be developed further she was unable to carry it forward.

Since the workshops a business case was submitted for 1.5 Band 6 IBD nurses and a full-time Band 6 was appointed. Once the new IBD nurse was appointed, an audit of telephone calls to the nurse-run helpline commenced. All calls are logged and categorised into flare ups, drugs, results or other.

The audit is ongoing but outcomes so far have showed that the helpline has reduced clinic capacity, consequently freeing up clinicians’ time and reducing waiting times for patients. It has also enabled patients to be treated faster resulting in a better response time. The Trust is also able to charge the CCG for calls.’

University Hospitals Coventry and Warwickshire NHS Trust

The team at Brighton and Sussex University Hospital have been sharing their **business case for a specialist pharmacist** since they presented at the London adult workshop.

‘Our newly established IBD team presented the innovative service provision we implemented in Brighton at the London adult workshop.

The workshop provided opportunity to share ideas and identify gaps in our own service provision but also allowed us as presenters to showcase our innovative drug monitoring service provided by the pharmacist and how we manage anaemia. We were able to share our experience and several units have contacted us since for support in developing similar services by sharing our business case.

The day is useful time spent to concentrate on, benchmark and advance our services as well as networking to improve patient care across the region. The IBD audit has proved to be the most useful tool to advance our service for these sometime very ill patients and the workshop helped focus my team on this aim whilst being able to share practices with other service providers.’

Anja St Clair-Jones

Lead pharmacist digestive diseases centre, Brighton and Sussex University Hospitals NHS Trust

What would we do differently?

Just as we asked teams to reflect and evaluate their progress, the IBD programme team also reflected on our learning over the course of this quality improvement initiative.

Timing

Seven of the workshops were delivered over the course of 1 month; we would suggest that anyone delivering such a series of workshops should do so over a longer period of time. The complexity of arranging venues, couriers, attendees and speakers at different locations is a high-risk strategy unless there are a substantial number of team members involved or elements are outsourced to others.

A longer time frame would also benefit the follow-up processes; for example, we feel it would be valuable to undertake a further survey of progress against actions after 12 months.

The hospital visits proved challenging to organise within the originally intended 3-month period – arranging dates and times that were mutually convenient for both the hospital being visited and the visiting team members, with a sufficient notice period for busy healthcare professionals.

More scientific approach to the hospital visits

It would be helpful to take a more scientific approach to hospital visits, ie one that would aim to determine whether participation in such an approach does result in an improvement to IBD services. With more time available, we would have conducted a hospital visit with a group of IBD teams that do not participate in the broader work of the IBD programme and compared them with a group of IBD teams that do participate in the work of the IBD programme. It would also be helpful to do the same with IBD teams that did or did not attend a workshop.

Adapted agenda for workshops

The core elements of the agenda for each of the workshops were updated and improved using learning from those delivered before; this was done to create more positive and productive outcomes. We would suggest allocating significantly more time to action planning from the start, as it became evident – both anecdotally and through analysis of the evaluation forms – that IBD teams found this to be one of the most important and beneficial aspects of the workshops. Doing so would allow IBD teams to take full advantage of the opportunity to leave their usual workplace and have dedicated, uninterrupted time to plan with their colleagues and peers. The use of non-hospital venues for the delivery of such workshops is also highly recommended.

What next?

For IBD teams

- Continue to implement your action plans! The feedback from the workshops and the survey has been encouraging, and we don't want you lose momentum. Six months is a relatively short period of time to make and see significant change, so we ask that you continue to strive to complete your actions. Keep us informed of your successes and any barriers to improvement as you progress this work. If you require any assistance, please contact the IBD programme team: **ibd.audit@rcplondon.ac.uk**
- Networking was listed as one of the highlights of the regional workshops, and we would like to keep this going. If you would like to know more about any of the case studies in this report, or if you would like to be put in touch with a team who is working towards similar action to you, please contact us and we will aim to get you connected.
- The team at Crohn's and Colitis UK can provide guidance and support on involving patients in service development, including setting up a patient panel. They can also work with you to bring the patient perspective to specific quality improvement projects, for example, to increase IBD nursing provision. You can get in touch at **ppr@crohnsandcolitis.org.uk**
- Most of the following resources are not IBD specific, but contain useful learning from other settings and may be of help to you as you implement change going forward:
 - **The IBD quality improvement project resource store: www.ibdqip.co.uk/KMS**
Provides IBD-specific sample presentations, policies and guidelines, case studies and patient information collated from IBD teams across the UK.
 - **Healthcare Improvement Scotland: www.healthcareimprovementscotland.org**
Produces a range of resources, from evidence-based reports to best practice and improvement guides.
 - **Institute for Healthcare Improvement: www.ihl.org**
An online open school that teaches the basics of quality improvement.
 - **The Health Foundation: www.health.org.uk**
A charity that aims to test innovations and see what works, to build skills and knowledge, and to develop and share evidence on what works and why.
 - **Follow CHAIN on twitter: https://twitter.com/CHAIN_network**
CHAIN stands for Contact, Help, Advice, Information and Network – an online support network for people working in health and social care.

For the IBD community

- The IBD programme team, the IBD Registry and the British Society of Gastroenterology will continue to work to improve quality in IBD services by focusing on the five most common action themes identified in this report.

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