



IBD audit programme 2005–2017

Review of events, impact and critical reflections

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About this document

This report was prepared in January 2018 by:

Dr Ian Arnott, clinical director of the IBD programme and consultant gastroenterologist, Western General Hospital, Edinburgh.

Susan Murray, programme manager, Audit and Accreditation, Royal College of Physicians, London.

About the IBD audit programme

IBD programme team

Dr Ian Arnott, clinical lead, IBD audit programme,

Ms Kajal Mortier, IBD project manager, Audit and Accreditation Unit, RCP

Ms Susan Murray, IBD programme manager, Audit and Accreditation Unit, RCP

Ms Aimee Protheroe, IBD programme development manager, Audit and Accreditation Unit, RCP

Healthcare Quality Improvement Partnership

The national IBD audit programme is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit Programme (NCA). HQIP is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices. Its aim is to promote quality improvement, and in particular to increase the impact that clinical audit has on healthcare quality in England and Wales. HQIP holds the contract to manage and develop the NCA Programme, comprising more than 30 clinical audits that cover care provided to people with a wide range of medical, surgical and mental health conditions. The programme is funded by NHS England, the Welsh Government and, with some individual audits, also funded by the Health Department of the Scottish Government, DHSSPS Northern Ireland and the Channel Islands.

The Royal College of Physicians

The Royal College of Physicians (RCP) is a registered charity that aims to ensure high-quality care for patients by promoting the highest standards of medical practice. It provides and sets standards in clinical practice, education and training, conducts assessments and examinations, quality assures external audit programmes, supports doctors in their practice of medicine, and advises the government, the public and the profession on healthcare issues.

UK inflammatory bowel disease (IBD) programme

The UK IBD programme aims to improve the delivery of care for people with IBD through effective measurements against standards and feedback to providers.

Document purpose	To provide a review of the IBD audit programme activities from inception in 2005 to December 2017.
Title	IBD audit programme 2005–2017. Review of events, impact and critical reflections
Author	On behalf of the IBD audit programme at the Royal College of Physicians
Audience	Audit and quality improvement community Funders – Health Care Quality Improvement Partnership, Health Foundation Key stakeholders involved through the programme’s life IBD hospital teams across the UK This may also be of interest to people living with IBD and patient support groups.
Description	Reviews the IBD programme’s key activities, achievements and impact over 12 years
Supersedes	All other reports published on behalf of the IBD audit programme as listed below
Related publications	<p>National clinical audit of biological therapies. UK inflammatory bowel disease (IBD) audit. Adult report. September 2016.</p> <p>National clinical audit of biological therapies. UK inflammatory bowel disease (IBD) audit. Paediatric report. September 2016.</p> <p>National clinical audit of biological therapies. UK inflammatory bowel disease (IBD) audit. Adult report. September 2015.</p> <p>National clinical audit of biological therapies. UK inflammatory bowel disease (IBD) audit. Paediatric report. September 2015.</p> <p>IBD Standards Group, 2013. <i>Standards for the healthcare of people who have inflammatory bowel disease, IBD standards, 2013 update.</i> www.ibdstandards.org.uk</p> <p>Mowat C, Cole A, Windsor A <i>et al</i>, on behalf of the IBD Section of the British Society of Gastroenterology. Guidelines for the management of inflammatory bowel disease in adults. <i>Gut</i> 2011;60:571–607.</p> <p>National Institute for Health and Care Excellence, 2008. Technology appraisal 163: <i>Infliximab for acute exacerbations of ulcerative colitis.</i> www.nice.org.uk/guidance/TA163</p> <p>National Institute for Health and Care Excellence, 2011. Technology appraisal 187: <i>Infliximab (review) and adalimumab for the treatment of Crohn’s disease.</i> www.nice.org.uk/guidance/TA187</p> <p>National Institute for Health and Care Excellence, 2015. Technology appraisal 329: <i>Infliximab, adalimumab and golimumab for treating moderately to severely active ulcerative colitis after the failure of conventional therapy (including a review of TA140 and TA262).</i> www.nice.org.uk/guidance/TA329</p> <p>National Institute for Health and Care Excellence, 2015. Quality standard 81: <i>Inflammatory bowel disease.</i> www.nice.org.uk/guidance/QS81</p> <p>Royal College of Physicians, 2014. <i>Experience of inpatients with ulcerative colitis throughout the UK.</i></p> <p>Royal College of Physicians, 2014. <i>National audit of inflammatory bowel disease (IBD) service provision. Adult report.</i></p> <p>Royal College of Physicians, 2014. <i>National audit of inflammatory bowel disease (IBD) service provision. Paediatric report</i></p> <p>Royal College of Physicians, 2014. <i>National clinical audit of inpatient care for adults with ulcerative colitis.</i></p> <p>Royal College of Physicians, 2014. <i>National clinical audit of inpatient care for young people with ulcerative colitis.</i></p> <p>Scotland leading the way a national blueprint for inflammatory bowel disease in Scotland. www.alliance-scotland.org.uk/download/library/lib_5773c0b293b3e/</p>

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Foreword

Throughout the rounds of the IBD audit, the programme was fully supported by many stakeholders who were keen to ensure the success of the programme and actively promoted our work. We acknowledge the kind support of the patient charity Crohn's and Colitis UK (CCUK) who frequently and without question supported us through their own communications in promoting our messages to engage hospital teams to participate in the audit.

The IBD audit has seen a wholesale change in the way that IBD is approached and managed in the United Kingdom. This has been driven by data that the clinical teams who participated have entered and I sincerely thank them for their efforts. This work has supported a continued effort to improve services and develop a better experience for their patients. Although we have seen substantial improvements there remains work to be done and I hope that the IBD audit has served as a catalyst for the development of a culture of quality improvement within IBD teams in the UK. Further efforts will be supported by the IBD registry, IBD UK and the British Society of Gastroenterology and I wish them every success in the years ahead.

Dr Ian Arnott

Executive summary

Background

Inflammatory bowel disease (IBD) includes ulcerative colitis (UC) and Crohn's disease (CD); these are chronic conditions that involve inflammation of the gut. Symptoms can be erratic or constant and include pain, cramps or swelling in the abdomen, bloody diarrhoea, weight loss and extreme tiredness. Treatment varies and includes medical and at worst surgical interventions. People of any age can get IBD, but it is usually diagnosed between the ages of 15 and 40.

In 2003 it was evident that the prevalence (currently estimated at 300 per 100,000 of the UK population) was increasing, that there were no standards for care or national data that evidenced the provision of care, and, despite it being a chronic condition, that it had been excluded in the National Service Framework.

When did the IBD audit start?

In 2004 recognition that this was a population that had been significantly overlooked prompted initial funding from The Health Foundation 'Engaging quality initiative' to fund two rounds of a national audit on IBD. This was the start of the national UK IBD audit programme that was later funded centrally by the NHS and achieved many improvements in IBD care for over 12 years.

Objective and aims

From the outset the IBD audit programme's main objectives were to improve the quality and safety of care for IBD patients throughout the UK. The key aims were to assess the structure and organisation of care and the processes and outcomes of care delivery, enable trusts to compare their performance against national standards, facilitate an intervention strategy to improve quality of care and develop a sustainability programme to maintain quality of care.

Data collection

We captured data on inpatient care, inpatient experiences, primary care services, organisational care and biological therapies. Over time our methodology altered; for example, from round 2 data collection was widened to capture data on children and adolescents, which meant that every patient in the UK could be audited and we could get a fuller picture of quality of care across all the population groups. The methodological rigour of data collection was changed from retrospective to prospective data collection and by the end the programme had moved from multiple aspects of snapshot data to longitudinal data collection and there was more emphasis on facilitated quality improvement (QI) initiatives.

Participation in the national audit

Our audits achieved participation rates from hospitals across the UK that increased from 76% at the start to >95% by the end. While we were working with a very engaged community who were motivated to make improvements in IBD care, we also benefitted from a number of initiatives to prompt hospital teams to participate in the audit. These included a 365 day telephone and email helpline, monthly newsletters, letters to chief executives at the start of each round of the audit, and email prompts at key points of data collection, to name only some. Links with national initiatives in England (Quality Accounts), NHS Scotland, and NHS Wales (National Clinical Audit and Outcome Review plan) and the listing of nationally agreed key performance indicators with the CQC also proved to be very effective in prompting participation in the audit.

Results

The first round of audit results published in 2007 provided evidence of a wide variation in the quality of IBD care. By the final round, the audit programme was able to demonstrate many improvements. Listed below are only a few of the most notable ones:

- a decrease in adult mortality during admission from 1.54% (2008) to 0.75% (2014)
- an increase in the number of patients seen by an IBD nurse during an unplanned admission from 27% (2010) to 48% (2014)
- a decrease in the time from diagnosis to initial treatment with biological therapies from median 4.5 years (2011) to 3.8 (2016) (adult data) and 1.2 years (2012) to 0.9 years 2016 (paediatric data).

More of the results and impact can be found in chapter 5 of the main report and within all the published reports since 2007–2016. (www.rcplondon.ac.uk/projects/ibd-programme)

Quality improvement initiatives

After each round of results we used a number of initiatives to help teams make improvements in patient care. These included national action plans based on key findings from each report with supporting slide sets, letters to chief executives, peer support site visits, and instant feedback from audit tools, including the most recently developed data visualisation tools embedded into the IBD Registry web tool.

In the last few years we have adopted an even more interactive approach and have set up regional workshops with action planning focused on QI. Most recently we have run a 6-month IBD Quality Improvement Collaborative via the RCP QI hub, which has involved eight teams across the UK adopting a local QI project and meeting together at least three times to learn QI methodology and share learning experiences. Participants have found the ‘time out’ allowed for teams to meet together and plan their interventions particularly useful.

Transitioning the IBD audit to the IBD Registry

After five rounds of IBD audit, the programme was commissioned to transition the audit to the IBD Registry. This has been a 2-year project that has involved working closely with the IBD Registry project team not only to share skills in data collection and QI methodology but also to transfer the biologics audit to the IBD Registry and support the development of data visualisation tools for their web tool.

What next for IBD?

The IBD Registry is the main programme now for collection of longitudinal data and is moving towards a subscription model. Participation rates are increasing and the IBD Registry needs public backing and support to ensure its long term viability.

Key reflections

We have observed many improvements in the care of IBD, which is due to the audit and also to other national initiatives such as the development of the IBD Standards (CCUK) and the NICE quality standards, together with the BSG and the NICE national guidelines and technology appraisals. Furthermore we have learnt much during this time and our key reflections include the following: engaging participation in data collection takes time; stakeholder input is critical to steering the direction of the programme; instant reporting of results is becoming more important but IT developments always take longer than

anticipated; and finally, it would have been better if we had moved to planning a sustainable model for data collection and QI much earlier on.

Conclusions

The IBD audit has been a truly national audit, including participation across England, Wales, Northern Ireland and Scotland. It has had the benefit of over 12 years of funding and in that time has demonstrated many improvements in patient care; this has been a very cost-effective programme. Future audit programmes would be advised to develop their programme so that they can respond promptly to emerging clinical questions.

We hope that the IBD community, including the BSG, CCUK and IBD Registry, will build on the learning that we have experienced together and become supported nationally to develop into a properly established programme.

Recommendations

Clinical

- Important areas of care that have not improved include the provision of psychological and dietetic services to patients, treatment of anaemia, and earlier escalation of treatment for outpatients. Stakeholders should work with IBD hospital teams to help facilitate improvements in these areas.

Strategic

- The IBD Registry needs to embrace further a philosophy on QI and proactively facilitate teams to use QI methodology to improve patient care.
- The IBD Registry need to be supported by the IBD community and other healthcare initiatives to become successfully established as a subscription model. The registry should continue to engage with Quality Accounts and other national drivers.
- The IBD community, including BSG, CCUK, IBD UK and the IBD Registry, should work together to plan a programme that has a long term sustainable future with a central platform for communicating with the clinical community and patients. They should also forecast on where IT developments are likely to lead and, most importantly, build on the increasing knowledge emerging on how to help hospital teams continue to make sustainable improvements in patient care.
- Future audits need to be able to respond promptly to emerging clinical questions.
- The government needs to invest for the long term in national audit and empower programmes to make long term plans that are committed from the outset to developing enduring and sustainable models for improving care.

1. Background

The UK IBD audit, since its inception, has sought to improve the quality of care of people with inflammatory bowel disease (IBD). IBD encompasses ulcerative colitis (UC) and Crohn's disease (CD), long-term conditions that involve inflammation of the gut. UC only affects the colon (large intestine) while CD can affect any part of the digestive system, from the mouth to the anus. People of any age can get IBD, but it is usually diagnosed between the ages of 15 and 40. The estimated prevalence is around 300 per 100,000 of the UK population. The most common symptoms include pain, cramps or swelling in the abdomen, bloody diarrhoea, weight loss and extreme tiredness. Symptoms can be mild or severe and can be consistent or erratic, affecting people's social and psychological wellbeing. The varying presentations means that treatment varies according to presentation – but can include dietary and lifestyle changes, medications and if necessary surgery.

Medical treatments include aminosalicylates or mesalazines and immunosuppressants, such as steroids or azathioprine or if necessary biological therapies, which are specific antibody-based treatments given by injection or intravenous infusion that target a specific part of the immune system. Between 30–50% of people treated with medications do not improve and will require surgery, which in many cases results in patients having a stoma, which is extremely invasive and life changing.¹

1.1 How and why the UK IBD audit was initiated

IBD is a lifelong condition – there is no cure. The symptoms are potentially severe and debilitating, and are not necessarily visually apparent to the outside world. This is a population who are at risk of being overlooked in their requirements for continued improvements in the provision of their care and in 2003 this was especially apparent. At that time there was concern that IBD 'had been ignored' from the National Service Framework, despite IBD being a recognised chronic disease with an average of around 27,000 admissions per year due to exacerbation of the disease, increased death rate around time of surgery and demonstrable variation in mortality. The British Society of Gastroenterology (BSG) had developed guidelines² that covered all the clinical aspects of the management of IBD, and there was a 'Service and Standards of Care' document³ based largely on consensus. There had been some small audit studies but these were of limited generalisability. With the influence of a strong patient agenda it was made evident that people with IBD were not being managed as well as they could be and there was a belief that improved care was possible.

1.2 Duration and funding of the programme

The evidence of the poor quality of care that people with IBD were experiencing influenced the Health Foundation as part of their Engaging with Quality initiative to fund the first two rounds of the UK IBD audit (2004–2008). This was to be the start of 12 years of a national audit and quality improvement programme that was subsequently commissioned by Health Care Quality Improvement Partnership (HQIP) with funding from the NHS for a further nine years.

2. Overview

2.1 What the programme measured

Between 2005 and 2017, the IBD audit programme assessed the quality of several aspects of IBD care including:

- inpatient care
- the experience of inpatients
- the organisation of IBD services in hospitals
- the experience and understanding of GPs treating patients with IBD in primary care
- the efficacy, safety and appropriate use of biological therapies in the treatment of IBD.

All of these apart from the experience of GPs (assessed via primary care questionnaires) were repeated in subsequent rounds of data collection and therefore comparisons of changes in patient care were enabled. A summary of each round of audit is displayed below in Table 1.

Table 1. A summary of IBD care audited across 5 rounds from 2005–2017

The table shows the aspects of care that were audited with the years taken to conduct each round of audit. Note the dates do not refer to the period of data collection.

UK IBD audit 2005–2017	Round 1*† (2005–2007)	Round 2† (2007–2009)	Round 3 (2009–2012)	Round 4 (2012–2014)	Round 5 (2014–2015)	Transition (2016–2017)
Organisational audit	✓	✓	✓	✓		
Inpatient care audit, CD	✓	✓	✓			
Inpatient care audit, UC	✓	✓	✓	✓		
Inpatient experience questionnaires, CD			✓			
Inpatient experience questionnaires, UC			✓	✓		
Biological therapy audit			✓	✓	✓	✓
Primary care survey			✓			

*Adult services only this round

† Combined organisational and inpatient care audit reports were produced

Table 2. Reports produced across rounds of audit from 2005–2017

UK IBD audit 2005–2017	Round 1** (2005–2007)	Round 2+ (2007–2009)	Round 3 (2009–2012)	Round 4 (2012–2014)	Round 5 (2014–2015)	Transition (2016–2017)
Organisational audit	1 national + 202 site-level	1 national + 210 site-level	2 national + 227 site-level	2 national + 204 site-level	–	–
Inpatient care audit	As above	As above	2 national + 221 site-level	2 national + 188 site-level	–	–
Inpatient experience questionnaires	–	–	1 national	1 national + 109 site-level	–	–
Biological therapy audit	–	–	1 national	4 national + 317 site-level	2 national + 168 site-level	2 national + 196 site-level
Primary care survey	–	–	1 national	–	–	–

* Adult services only this round

† Combined organisational and inpatient care audit reports were produced

2.2 Overall programme objectives and aims across rounds (2005–2017)

From the outset in 2004, the IBD audit programme had a clear objective to improve the quality and safety of care for IBD patients throughout the UK. This objective was the focus for all the subsequent rounds of audit and QI that were conducted. The following sections outline the core aims for each round.

2.2.1 Round 1 (2005–2007) and round 2 (2007–2009)

The specific aims of the initial four year programme were to:

- assess the current structure and organisation of care for IBD
- assess the processes and outcomes of care delivery in IBD
- enable trusts to compare their performance against national standards
- identify resource and organisational factors that may account for observed variations in outcome
- facilitate, develop and institute an intervention strategy to improve quality of care
- repeat the audit to prove that change has occurred
- establish measures that healthcare services can use beyond the study to compare quality of IBD services
- develop a sustainability programme to maintain quality of care.

2.2.2 Round 2 (2007–2009)

While the core aims for rounds 1 and 2 remained the same, an important development in round 2 was the decision to widen the scope of data collection to include children and adolescents, who represent a considerable part of the IBD population. This decision increased the scope of the audit programme by 100%, which meant that every patient in the UK could be audited and would enable the community to better understand the quality of care provided for people with IBD across all the different population groups.

2.2.3 Round 3 (2009–2012)

From round 3 central funding from the NHS was granted, and while the core objectives specified for rounds 1 and 2 were maintained, the central funding had big implications for how the audit was run. In round 3 the scope of data collection expanded to include assessing patient experiences while in hospital, primary care involvement and treatment for IBD with biological therapies. The intention was to capture a wider perspective of the quality and experiences of patient care.

Note: For rounds 1–3 data was collected on patients with UC and CD.

2.2.3.1 Organisational audit and IBD Quality Improvement Project (IBDQIP)

A key component of rounds 1 and 2 was the collection of the organisational audit data which had been collected within the same tool that captured inpatient care. After round 2 the organisational data items were not included in the inpatient care audit tool; instead a separate and very different audit tool, IBDQIP, was developed, with an emphasis on directly facilitating hospitals to make improvements. The data items were directly aligned against the newly developed national *Standards for the healthcare of people who have inflammatory bowel disease* published 2009 and updated in 2013⁴ and the tool was developed on an IT platform based on the JAG endoscopy accredited system, which was conceptually very recognisable to IBD teams. This audit differed from the other audits as the data was not derived from individual patient data, but from service level data that involved services meeting as a team to assess their service and using the web-based tool to respond to a series of statements. Once services completed their assessment, they were provided with an instant dashboard showing their results in comparison to national outcomes. The tool also included a facility to develop a local improvement action plan and a link to a resource section containing a wide range of examples of good practice. This aspect of the audit in round 3 was funded by the Health Foundation, but after round 3 the IBDQIP tool was formally adopted into round 4, funded this time by the NHS. Many hospitals reported the benefits of this tool, in particular the facility of instant feedback to sites, which showed them automatically how well they were meeting the national standards. The publication of the findings from this audit in round 4 prompted the development of the first report specifically for patients, which was developed in collaboration with CCUK and supported the publication of *My Crohns and Colitis Care*.⁵

2.2.3.2 Biological therapy audit

During the third round of the audit there was recognition that biological therapies (infliximab and adalimumab) were an increasingly widely used form of treatment for people with IBD. While these are potentially life changing drugs for people with IBD, there was little evidence on the efficacy and safety of these drugs. Since there were a number of unanswered questions surrounding these drugs, in September 2011 the biological audit was initiated, with the vision of capturing longitudinal data on many aspects of patient safety that clinical trials would not address. The objective was to collect prospective, continuous, pseudo-anonymised data that could eventually provide longer term linkage with cancer registries. The timing of the commissioning of the biologics audit was not in alignment with the other elements of the audit and so a separate audit tool was developed on a different IT platform. The specific aims are listed below.

The biological therapy audit aimed to assess:

- the appropriate use/prescribing of biological therapies (adalimumab and infliximab)
- the efficacy of biological therapies
- the safety of biological therapies
- patients' views on their quality of life at defined intervals throughout their use of biological drug therapies.

2.2.3.3 PANTS

Between March 2013 and July 2016 the Personalised Anti-TNF Therapy in Crohn's disease study (PANTS) (www.pantsdb.co.uk) was conducted in parallel with the biologics audit. This was a 3-year prospective uncontrolled cohort study investigating primary non-response, loss of response and adverse drug reactions to infliximab and adalimumab in patients with severe active luminal CD. Several of the data items for the PANTS study matched the data items of the biologics audit and since many hospitals (approximately 70) contributed clinical data for the PANTS study, hospital teams were advised that if they entered data for the PANTS study that the relevant matching data items for the biologics audit would be shared with the project team at the RCP and included in the biologics annual analysis and reporting. This avoided hospital teams doing double data entry and communicated a collaborative approach on data collection to the IBD community.

2.2.4 Round 4 (2012–2014)

In 2012 the IBD audit was successful in its bid for a further 2-year contract extension on the national clinical audit outcomes programme (NCAPOP). A specific aim was to ensure high participation rates of >90% of IBD hospital teams across the UK. This time round data was only collected on patients with UC and not CD, so as not to overburden sites with too much data collection. The focus was a continued collection of data on multiple aspects of care as per round 3, excluding primary care but continuing with the biologics audit, and this time round the IBDQIP tool became the data collection tool for the organisational audit. This continuation in many aspects of IBD patient care enabled even further comparisons in quality of care across rounds.

2.2.5 Round 5 (2014–2015)

In round 5 the only audit that continued data collection and reporting was the biological therapies audit. The remaining scope of the work was to facilitate IBD hospital teams to make improvements in patient care through a series of regional QI workshops and site visits.

2.2.6 Transition (2016–2017)

The primary aims during this period were to complete a final round of data collection for the biological audit and to facilitate its transition to the IBD Registry. Furthermore the programme team were commissioned to support the embedding of QI initiatives via the IBD Registry to ensure some long term sustainability in supporting continued improvements in patient care. The aims included the development of data visualisation tools and implementation of QI training for IBD teams in the form of IBD collaboratives delivered via the RCP QI hub.

2.3 Methods of data collection an overview across rounds 1–5

All acute hospital IBD teams across the UK were invited to take part in the each round of the audit. The detailed methodology for each of the rounds of data collection can be found in each of the annual reports (www.rcplondon.ac.uk/projects/ibd-programme). Below, the key changes in the methodology are reported for each round.

In rounds 1–3, cases were identified based on ICD10 diagnostic codes at discharge. The last 20 UC and 20 CD patients for the defined period of data collection were selected retrospectively. Data was submitted via a web-based data entry system.

2.3.1 Changes for round 2

The data sets for inpatient care for adults and organisation of IBD services were adjusted moderately in line with the newly published standards.⁴ Data sets for the collection of child and adolescent data were

developed from round 2 onwards. This ensured that the IBD audit addressed the entire population of IBD patients.

2.3.2 Changes for round 3

As this round included additional data collection from patients on their experiences and from GPs, the web tool was enlarged to include the collection of this additional data. For each complete inpatient admission audited, an inpatient and GP questionnaire were generated by the UK IBD audit web tool. These questionnaires were sent to patients or GPs who could either self-report directly into the web tool or alternatively return the completed questionnaires to the RCP, where the data was entered by a coordinator onto the web based data entry system. Use of a unique cross reference code on the questionnaires allowed for anonymised linkage of questionnaire data with clinical data.

2.3.3. Changes for round 4

In rounds 1–3, data was collected retrospectively on 20 patients with UC and 20 patients with CD. From round 4 this was no longer considered an appropriate approach, as this was not necessarily representative of the population and there was a risk of missing outliers. The methodology changed to prospective data collection, on the first 50 patients admitted with UC during the specified period of data collection. For 50% of IBD services, this number represented 100% of their case load. Moving to prospective data collection also meant that data entered on patients identified at admission was less susceptible to clinical self-selection and bias and improved the quality of data entered. The data set was also altered in parts to allow a greater focus on some aspects of outpatient care that had been received prior to admission to hospital.

For the biologics audit, data was entered on a separate web based data entry system. Feedback from sites at that time indicated that the requirements for data entry were too onerous. In response, the programme team worked to minimise the mandatory data fields for the biologics audit web tool.

2.3.4 Changes for round 5

For this round the main focus of data collection was on the continued collection of biological therapies. Feedback from sites following round 4 prompted further refinements to the biologics audit web tool. This time the web tool also included a dashboard that provided teams with instant feedback on the completeness of their patient-entered data. This successfully prompted teams to complete the required data items.

3. Ensuring successful engagement and participation in audit

3.1 Levers to promote engagement in the IBD audit

Throughout all of the rounds of the IBD audit programme, promoting and facilitating engagement in data entry from IBD hospital teams across the UK was an important aspect in ensuring the success of the programme. The following methods supported continued engagement in the audit.

From the first round, all IBD hospital teams were invited to participate and register to take part. Key individuals were approached from each hospital; a lead clinician, lead surgeon, and a lead from the clinical audit department. The chief executives were alerted by letter. Hospital teams that registered were provided with an appropriate login, password and help booklets. Throughout the life of the audit programme a telephone and email helpdesk was provided and frequently used.

Structured communication plans were devised for each round, which included monthly newsletters and email prompts at key points of data collection. For rounds 3 and 4 additional prompts were developed, such as posters for wards to alert patients about the audit and slide sets for the teams entering the data which outlined in detail how and where to enter the data.

From round 3, national levers prompted participation and the audit was listed on Quality Accounts. Direct funding from NHS Scotland provided a further lever and in Wales, inclusion in the National Clinical Audit and Outcome Review plan also supported participation.

In 2014 a specific set of key performance indicators (KPIs) were agreed for monitoring biological therapies. These acted as further prompts to ensure complete data entry. These are also listed with the CQC.

3.2 Participation rates across rounds

As a result of the various initiatives to prompt data entry, participation rates of IBD hospital teams across the UK increased across all the rounds of audit from about 76% at the first round to about 98% by round 4. It was noted that even without specific national levers such as Quality Accounts in rounds 1 and 2 there were reassuring levels of participation in the audit, which reflected the IBD community's desire to ensure improvements in IBD care were achieved. Later on, in rounds 3–4, it became more challenging to increase participation rates as the extent of data input was large and too onerous for some hospital teams, who would require more prompting to enter the data. However, by 2012 the IBD audit was well established and the benefits of contributing to national data collection to measure the quality of care were well known, and this had a significant influence in ensuring ongoing participation in the audit. The tables below example the increasing participation rates across rounds. Note for some audits the site numbers reduced as hospitals got together to submit data jointly.

Table 2. A summary of the participation rates (by the numbers of patient entered data) across rounds for inpatient care and biologics audit. (Please note the number of sites decreased as some hospital teams were merged.)

Round	1	2	3	4	5	6	Trans
Inpatient care audit, adults							
Hospital sites submitting data (n)	212	235	198	190			
Patients UC	2767	2981	3049	4359			
Patients CD	2914	315	3122				
Inpatient care audit, paediatric							
Hospital sites submitting data (n)		20	23	32			
Patients UC		248	176	298			
Patients CD		440	342				
Inpatient experience							
Adult questionnaires returned			2027	1484			
Paediatric questionnaires returned			167	66			
Organisational audit							
Adult sites		207	160	142			
Paediatric sites		33	23	24			
Biologics audit							
Adult sites with data included in analysis (n)			99	114	158	159	161
Patients UC			62	184	281	412	903
Patients CD			426	1026	1509	1943	1766
Patients IBDU			22	33	33	41	53
Total patient data entered per round (n)			510	1243	1823	2396	2722

4. Methods for stimulating improvements in care

A report was written after each round of audit containing both national data and site-specific data for each site that participated. The following interventions supported teams to make improvements in care.

4.1 Rounds 1–4 (2006–2014)

A number of improvement tools were used, as set out below.

- Slide sets with summary results (local and national) and key messages from each round of audit were produced for each IBD hospital team to support dissemination of results.
- A letter was sent to the chief executive of each trust, highlighting the key findings and the priorities for improvement.
- From round 3 onwards, all the reports contained a specific action plan outlining the key priorities for improvement.
- 23 peer support site visits with members of the steering group were organised after the first round of audit. These visits involved supporting hospital teams to develop action plans that were specific to their sites, based on the key findings from their site audit reports.
- Regional workshops were run at the end of round 1 and 3 and during round 5. Specific aims were to engage IBD teams to participate in the audit, review the key results and draft model 'action plans' for IBD services. These model action plans were then made accessible via the internet with adaptable reference documents such as care pathways, model business cases for IBD nurses and patient information leaflets.

4.2 Round 5 (2015)

After completion of round 4 it was recognised that there needed to be better mechanisms to facilitate improvements in patient care.

Therefore, in 2015 the programme team ran eight regional action planning/QI workshops. The agendas were developed with a specific focus on QI methodology and time was allotted to enable hospital teams to actively develop action plans on their priority areas for improvement, where possible using local data resulting from the audit. These proved to be highly successful in prompting teams to implement changes. Many hospital teams explained that the greatest benefit of these regional meetings was the time and space that they offered to take 'time out' and plan as a team their priority areas/aims for improvement.

After the conclusion of regional workshops, the IBD teams were offered the opportunity to receive peer support visits; six hospitals took up this opportunity. For each of these visits a patient representative, a lead clinician, a nurse and a member of the IBD programme teams attended and provided peer support. These proved to be very effective in enabling local support from respected peers and provided the opportunity through team discussion to drill down to the more unique problems hospital teams were experiencing. These visits were followed up with a formal letter to the chief executive and the medical director to encourage support for local improvement goals.

4.2.2 Data visualisation (2016–2017)

During the transition phase (March 2016–December 2017), the biologics audit was transferred to the IBD Registry. Data visualisation tools have been developed to give instant feedback on key performance indicators for biological therapies. Only hospital teams using the IBD Registry web tool currently have access to this facility and anecdotal reporting indicates that the instant feedback is helping hospital teams to more actively manage their patients. It is intended that this tool will be developed for the

other data entry systems of the IBD Registry and will be an important tool in ensuring continued improvements in patient care.

4.2.3 Quality Improvement training (2017)

The outcomes of the audit findings have been clearly reported in many formats such as annual reports, slide sets and more recently data visualisation tools on the IBD Registry web tool (<http://ibdregistry.org.uk/>). However, it has become evident that provision of outcome data, together with active engagement with hospital teams to help them make improvements (such as regional workshops) is very effective in ensuring improvements can happen. In response, the programme team have further extended this level of engagement and, together with the QI hub at the RCP, have recently facilitated eight hospital teams to complete a detailed six-month QI training course run as an IBD collaborative using the Institute for Healthcare Improvement's 'Breakthrough collaborative model' (www.ihl.org/). This programme has involved three one-day learning events which build skills in planning and implementing QI projects that will have a long term sustainable impact.

5. Impact of the IBD audit

5.1 Summary of impact

The IBD audit has been a truly national audit with participation across the UK in England, Wales, Northern Ireland and Scotland. Funding for the audit has been in the region of £2.3 million over 12 years and, with data captured on over 20,000 patients with IBD, this equates to approximately £115 pounds per patient in the audit. To emphasise this further, with a national patient population of approximately 300,000, this equates to £7.60 per person, which does not capture likely savings made on patient care as a result of improvements hospital teams have made. The audit has made a significant difference; it has been proven to demonstrate good value for money and is significantly cheaper than running clinical trials that do not necessarily capture the same levels of comparative data over long durations. The overall impact is reported below.

5.1.1 National – Evidence of national improvements in the quality and outcomes of care

- Decreased adult mortality for UC during admission: 1.54% (2008) to 0.75% (2014).
- Increase in number of patients seen by an IBD nurse during an unplanned admission: 27% (2010) to 48% (2014).
- Increased prescription of prophylactic heparin during inpatient care: 73% (2008) to 90% (2014).
- Increase in the number of hospital sites with an IBD nurse: 56% (2006) to 86% (2014).
- Increase in the number of sites with a specific gastroenterology ward: 67% (2006) to 95% (2014).
- Decreased time from diagnosis to initial treatment of biological therapies: from median 4.5 years (2011) to 3.8 (2016) (adult data); from 1.2 years (2012) to 0.9 years 2016 (paediatric data).
- Decreased frequency of surgery prior to biologic treatment 2012: 36% (2012) to 15% (2016) (adult data); 25% (2012) to 8% (2016) (paediatric data).
- Increase in the number of IBD specialist pharmacists: 47% (2010) to 59% (2014).

5.2.3 System – Additional benefits

- The results of the first rounds of IBD audit prompted the development and publication of the IBD Standards in 2009 and the update in 2013.⁴ This was coproduced between patients (CCUK) and healthcare professionals and universally adopted by the IBD community.
- Results of subsequent rounds of the IBD audit were mapped against the national standards so that hospital teams could benchmark their performance. This effected many improvements, as outlined in 5.1.1.
- The Biologics audit report 2016 provides evidence that the safety and efficacy of the biosimilar infliximab is equivalent to that of the original infliximab. Universal adoption will enable greater cost savings.
- The programme supports the British Society of Gastroenterology IBD section working group in identifying next tranche of quality indicators, currently covering pre-treatment screening for biological therapies.
- The programme supports the IBD Registry to become established as a national register for the long term collection of data on people with IBD (see Chapter 6).
- The programme collaborates with the UK IBD Registry, British Society of Gastroenterology and patient charity Crohn's and Colitis UK in promoting a culture of continued QI in the IBD community.
- In 2017 IBD UK formed as a new strategic partnership and QI group that will work together to ensure improvements in quality of care are delivered through the IBD community.
- The programme was the catalyst for informing the development of the NICE quality standard for IBD.

5.2.4 Local – How the programme stimulates local quality improvement

2006–2016	25 national audit reports over five rounds of data collection
2006–2017	>16 RCP-led IBD AUDIT regional action planning workshops
2006–2016	>30 peer support hospital visits
2016	IBD programme engages 191 hospital teams to take part in transfer of the IBD audit to the IBD Registry
2017	‘Learning from hosting’ workshops lead to publication of <i>Effective Events for local quality improvement following national clinical audit</i> ⁶
2017	Eight teams, including 25 hospital professionals, sign up to and take part in a 6-month QI training course at RCP QI hub
2017	IBD audit supports six Registry roadshows and promotes the roll-out of data visualisation, a tool to facilitate QI on IBD Registry web tool.
2017	First reports from IBD nurses (July 2017) on benefits of instant reporting from data visualisation tools in informing them on their use of biological therapies

5.2.5 Public – How the project is used by the public and the demand for it

- Active collaboration with Crohns and Colitis UK, including joint publication of IBD audit summary report supported by *My Crohn’s and Colitis Care* patient guide⁵ in 2015.
- Publication of key audit data is used to inform patient choice.
- Results from IBD audit reports enable and empower patients to challenge levels of care.
- IBD audit data supports IBD Patient Panels in evidencing the need for improvements of care.
- IBD audit data raises the profile of IBD patients and contributes to improved public understanding of the disease.
- IBD audit data supports Crohn’s and Colitis UK research and health service development work – eg IBD nurse campaign.
- Prompted and informed development of international audits in the Netherlands, Australia and New Zealand.

6. Transition

6.1 Transition – why and what it involved

In 2015 the IBD programme applied for a further round of funding via the National Clinical Audit and Patient Outcomes Programme (NCAPOP) – this time with a focus on auditing outpatient care. HQIP as commissioners of the work informed us that NHS England Medical Directorate had decided that the IBD audit programme would be decommissioned over a two-year transition, during which the biologics audit would be transferred to the IBD Registry and a culture of QI should be embedded within it.

The following sections in this chapter describe what happened during that process.

6.2 The IBD Registry

The IBD Registry is a receptacle of longitudinal data on people with IBD with the potential to link with other national data systems such as Hospital Episode Statistics (HES). The intended benefits are that a greater understanding on the longevity and disease processes of IBD can be captured and utilised for care monitoring and research purposes.

6.3 Planning for the transition of the IBD audit to the IBD Registry

While the community positively recognised the opportunity for a transition phase, there was a disparity between the function of the audit, which had always been to facilitate improvements in patient care, compared to that of the IBD Registry, which was to provide a systematic process to capture the data needed to facilitate QI which others would then do. Priorities for key deliverables for a transition were eventually agreed and this included the transfer of the biologics audit to the IBD Registry, the development of data visualisation tools onto the IBD Registry Web tool, and a series of QI training for IBD teams. (The details of these are described earlier in chapter 4.7.)

6.4 What was achieved in the transition phase?

We were keen to build on the excellent working relationships built up with IBD teams across the UK that the programme team had developed. During the transition, our methods and systems for working with hospital teams were shared with the IBD Registry programme team. For example, one of our first initiatives involved inviting IBD teams to register for transition to the IBD Registry programme. The response to this was very positive, with over 170 sites registering and consenting to be involved in the transition phase. Following this, the programme team facilitated the development of detailed registration packs that supported hospital teams in signing up to use either the IBD Registry web tool or the IBD Registry patient management system. This would later prove to be an essential initiative in engaging hospital teams to transition their data entry from the IBD audit biologics web tool to the IBD Registry platform of their choice.

We also supported the appointment of an IBD Registry project manager and contributed to the development of the role specification, job description and interview selection.

However, the primary aim of the transition year was to transfer the delivery of the biologics audit to the IBD Registry. This required working with an IT provider working for the RCP and another working for the IBD Registry to ensure data entry items from the biologics audit mapped to the IBD Registry. By the end of February 2017, following a significant communications initiative with the added support of CCUK, many hospital teams independently agreed and transferred their biologics data to the IBD Registry and have since continued to enter data on the IBD Registry systems.

We have discussed earlier in chapter 4 that one of the key aims in the transition phase was to embed a culture of QI further into the IBD Registry. The initiatives included the development of data visualisation tools that provide instant feedback on key performance indicators for hospitals entering the data onto the IBD Registry web tool. Anecdotal evidence indicates that hospital teams find these summative tools helpful for reviewing how well they are managing patient care. The next stages include developing resources for hospital teams to think further about how they implement improvements based on the data that is reported to them; these resources will be embedded into the IBD Registry web-based platform and communicated in the IBD Registry monthly newsletter.

The final stage of the transition involved running a second round of the IBD QI collaboratives in 2018. The benefit is that this will expand further the IBD community's knowledge on QI methodology and develop champions for QI who can share and disseminate their shared learning to the wider IBD community.

6.5 Developing and supporting a sustainable future for the IBD Registry

The IBD Registry planned to move to a subscription-funded model to ensure a sustainable future for the work. After market research on its potential value to users, a subscription package was initiated in March 2017. Hospital sites were invited to subscribe to the IBD Registry with specific charges for participation in return for certain outputs. This included access to data visualisation tools initially only on the IBD Registry Web tool and to annual reports on biologics key performance indicators. Initial response to this is encouraging (80 sites have signed up so far).

The future of ensuring continued improvements in the care of people with IBD currently lies primarily with the IBD Registry, which is now in its early days of becoming a self-funded programme. There are risks that hospital teams will opt out or not buy into the IBD Registry subscription model due to budget constraints. This leads to a risk that the quality of patient care will not be monitored in a way that enables reliable comparison of the data nationally. The IBD Registry should be supported as much as possible over some considerable time to become properly embedded. A key learning from the IBD audit is that it takes time to become recognised and established through iterative refinements and adaptations in response to the ongoing changes in the NHS population.

It is hoped that the work we have done to start to embed a culture of QI into the IBD Registry will have a lasting impact via the data visualisation tools, the first wave of the IBD QI collaborative and a second wave to follow in 2018. Our experiences as a programme team have been underpinned by the RCP Audit and Accreditation unit's knowledge and expertise in conducting national audits and QI methodology. Going forward the IBD community should where possible embrace within their costs the RCP's expertise in these areas as an essential resource.

7. Reflections

7.1. Critique – of what did not improve so easily and why

Since the inception of the IBD audit programme in 2004 there has been a significant change in the practical care of people with IBD. The arrival of biological therapies has had an immense impact on the medical treatment. There has also been a vast change in the organisation of IBD services; increases in the number of IBD nurses and the introduction of telephone helplines and gastro-specific wards are some of the main changes. This audit identified the need for improvement in the provision of psychological and dietetic services to patients, improvements in the treatment of patients with anaemia and greater escalation of treatment from outpatient admissions. We noted from our active QI activities that clinical teams found these areas more challenging to prioritise and achieve improvements in. In our view this is because clinical teams are not able to easily address these issues in isolation. The application for resource is frequently unsuccessful and the opportunity to promote these issues as national problems is a priority. We therefore recommend that in the immediate future these areas of improvements identified by the audit are addressed by stakeholders working together across the wider healthcare system.

7.2 What did we learn?

In view of what was and was not accomplished, we reflect on our key learnings from the audit.

7.2.1 It takes time....

The lengthy duration of the IBD audit programme (12 years), with five rounds of audit and a transition phase, has been one of its key attributes and has enabled many opportunities for reflection and improvement, not only in the processes of data collection but also in the processes for facilitating teams to make improvements in patient care.

A key learning has been that it takes time for participants in audit to learn to engage with the process of data entry, respond to results and make improvements. This is evidenced by the increasing engagement in participation, which increased from 76% to 98% across rounds and could be a key learning point for the IBD Registry.

7.2.2 Stakeholder engagement

During each round of the audit programme, we hosted 3–4 steering group meetings a year that were supported by lead specialists in gastroenterology, surgery, pharmacy, dietetics and nursing, together with patients and representatives of the patient charity CCUK, from across the UK. The group, chaired by a lead clinician, would actively contribute from either an adult or paediatric perspective on the direction and outputs of the IBD audit programme. This included defining the scope and design of each round of audit, ensuring local hospitals were aware of the phases of data entry, evaluating and supporting dissemination of the programme outputs, and supporting peer support visits and regional and national action planning QI meetings. The patient representatives significantly influenced the design and impact of the audit and their support was vital. Over the duration of the programme we learnt the importance of actively engaging patients in the design and outputs of the audit and of inviting them to contribute their patient experiences at regional workshops –these real life sharing of experiences really impacted and re-motivated IBD teams to implement improvements in patient care. It is common now to ask IBD teams to engage patients in their improvement projects, and increasingly the set-up of patient panels in hospitals are proving to be very influential in communicating the patient experience and positively affecting improvements. Feedback of site-specific data is also important, and this gives sites a sense of personal ownership of data. This is an important mechanism to support continued engagement across rounds. This is also supported by regional meetings. As a consequence the broad spectrum of

stakeholder engagement from across the UK ensured the IBD community were able to feel part of the process, which as a result ensured the high levels of participation.

7.2.3 Capturing good quality data – reducing selection bias

Within chapter 2 we describe our various methods of data collection and we reflect on the challenges we tackled to improve the quality of the data captured, such as the steer away from retrospective to prospective data collection after round 4 to help reduce selection bias. Furthermore, we learnt that large sets of data collection, as with the biologics audit, presented significant difficulty for hospital teams who would then disengage with data collection or revert to other methods to simply the process for them at the risk of reducing the quality of data. For example, some sites reported that they would only enter patients into the biologics audit that had the most easily retrievable data items from hospital notes or only enter data on the minimum numbers required to be considered adequate participation for the audit. This type of selection bias raised concern around the validity of the data reported and our learning is to carefully consider the methodology of data entry and facilitate hospital teams as best as possible, as we did with our constant refinements to the biologics audit tool.

7.2.4 Technology

In addition to minimising the biologics data set, improving information technology enabled the programme team to develop support tools which provided instant feedback to hospital sites on the status of their data entry to the biologics audit. This was via a dashboard that showed sites how many patients they had entered into the audit and the proportion of patients for whom they had completed data entry. The concept of providing instant electronic feedback proved to be very beneficial, not only for showing data entry status for the audit but for presenting key findings, as we also learnt from running the IBDQIP tool. The evidence of the benefits of instant reporting was also clear from other audit programmes, with the result that by the end of the transition phase, 2017, the programme team had embedded data visualisation tools onto the IBD Registry web tool. The opportunity for more instant reporting will support future audits to move away from a lengthy 2–3 year cycle of audit – design, collection, analysis and reporting – to the provision of more instant results and prompts to make earlier improvements in patient care.

However, it needs to be stressed that despite advancing capabilities in technology, working to embed IT systems during the life of the audit programme has also presented significant delays at numerous times. The programme evolved to have as many as three different platforms for data entry, using three different IT providers, largely due to the capacity and capability of the web developers, and admittedly this added to the complexity of delivering the programme. In hindsight, if there had been an overall long term plan for delivering the programme then this might have been avoided.

There were also at times significant delays in developing the technologies at various points along the programmes cycle. Most recently, the IBD Registry web tool took longer than expected time to complete its full development which delayed the transition of the biologics audit to the IBD Registry and then the implementation of the data visualisation tools.

If these barriers had been more easily overcome, we would have been more likely to realise the optimum possibilities IT systems can provide – such as patient-entered data. Our learning is that it takes a long time to set up good IT systems, that these require lengthy iterative processes that need to be built in at the outset, and that IT delays should be managed as a project risk, with contingency plans identified where possible. The real challenges of data governance should also not be underestimated and this was an aspect that changed markedly over the rounds of IBD audit. Future audits will also need to address the issue of patient consent and it is our opinion that all patients should now be consented from the outset, allowing a transparent and more engaging exercise.

7.2.5 Clinical teams are becoming busier and have less time to support audit and improvements

We recognised that working environments since 2003 have changed and hospital teams were becoming increasingly stretched in their ability to support improvements in patient care. Evidence of this was the increasing difficulty that we had encountered with organising site visits in round 5 in 2016, a total of five, in comparison to round 1 in 2005, when there were 23 peer support site visits.

After round 4, the priorities of the commissioners (HQIP) changed from further detailed data collection to more active engagement with hospital teams to facilitate them to make local improvements based on their data in the audit and other emerging priorities (see chapter 4). IBD teams reported that the biggest advantage of the regional workshops and IBD QI collaboratives was the space and time out to meet and work in teams to plan improvements outside of the hospital environments.

Continued initiatives such as the instant reporting and feedback from data visualisation and hosting of regional meetings in the working day will most likely be important in ensuring continued engagement in improving patient care.

7.2.6 Drivers in facilitating improvements

Over the duration of the programme other external national developments occurred that increased the emphasis on improving the quality of patient care. These included not only the development and update of the IBD Standards in 2009 and 2013 led by the patient charity CCUK,⁴ but also several developments from NICE, which included two clinical guidelines for UC⁷ and CD,⁸ NICE Quality standards for IBD,⁹ and a number of technology appraisals.¹⁰⁻¹²

The value of having a national audit as part of the National Clinical Audit and Outcomes Programme (NCAPOP) and being listed on Quality Accounts cannot be underestimated in its value in alerting hospital teams to the importance of participating in the audit and the benefits of audit to improving patient care. This was a feature for the IBD audit from round 3, and evidence of a spike in calls to our helpdesk every year in spring from hospital teams checking that they had entered adequate data into the audit highlighted the influence that Quality Accounts currently has on motivating hospital teams to participate in national audit in England. This is something that the IBD Registry would benefit from being included on going forward.

Notably, the IBDQIP tool that was used for the organisational audit in a number of pilots and from round 4 proved to be a very effective tool for alerting teams to the areas where they needed to make improvements. There are many reports from hospital teams that this was the most effective tool in persuading senior managers on where services needed to be improved. We recognised IBDQIP has considerable value and have debated at length if we should have re-invigorated this tool during the transition. After each round of debates we have concluded that this is an excellent tool for driving improvement and that there is a place for it going forward, but the outputs need to be modernised and it has to be aligned with the IBD community's future strategy for QI.

7.3 Critique – Did we achieve as much as we could have done?

A health improvement programme that runs for 12 years will inevitably experience many changes and challenges to adapt and much of this learning is re-told in the earlier chapters.

The IBD audit has had a generous and lengthy phase of funding – initially from the Health Foundation and then from the NHS. It has facilitated many improvements in care and demonstrated a significant impact.

With the benefit of hindsight, we think it would have been beneficial to have conducted fewer rounds of inpatient care audits (four in all). Although we did audit primary care services, we should have adopted a more holistic approach to auditing IBD care much earlier on and negotiated more strongly to conduct an outpatient care audit sooner.

We did apply at round 5 for funding for an outpatient care audit, but instead two years of funding for a transition to the IBD Registry followed. This was not a surprising outcome in a climate of austerity and given the valid perception that patients with IBD were now receiving satisfactory levels of care – as depicted in the biologics audit.^{13,14} However, the key findings of the inpatient care audit 2014 showed that increasing numbers of IBD patients were being treated as outpatients and early evidence indicated that the quality of care in outpatients was below standards, resulting in avoidable re-admissions to the NHS, which is costly and contribute further to overcrowding in hospitals. This is a particular challenge for the paediatric population, who are mostly treated as outpatients, and again exemplifies that we should have conducted fewer inpatient care audits and moved quicker to capturing outpatient data. If technology had allowed, we had aspired to trialling patient-entered data in the outpatient setting.

It could also have been beneficial to have progressed more quickly to a sustainable model; part of the delay was due to waiting for the IBD Registry to become ready, but it too encountered a number of barriers to implementation. At the onset of the transition phase their web tool was still in development and it still had a small number of actual users, although we did assist them to improve on this significantly during the transition (see section 6.4).

Our learning is that an earlier and open dialogue with funders, 5 years in advance of programme conclusion, to plan to implement a long-term sustainable infrastructure for the IBD programme, would have been helpful and could have put the programme in a more likely position to succeed.

7.4 Conclusions

- The IBD audit has demonstrated dramatic changes in IBD care and has been a central to that change.
- It has demonstrated excellent value for money.
- The change in methodology to prospective continuous data collection takes time and requires a change in culture. Sites require support through this process and this is helped by ensuring data sets are efficient and effectively supporting local QI.
- We encountered many IT challenges, and the IBD Registry and other similar programmes need to be aware of the delays that can be incurred when planning future developments.
- Ideally we would have been commissioned to develop a long term sustainable model for auditing IBD and facilitating QI at an early stage.

7.5 Recommendations

Clinical

- Important areas of care that have not improved include the provision of psychological and dietetic services to patients, treatment of anaemia, and earlier escalation of treatment for outpatients. Stakeholders should work with IBD hospital teams to help facilitate improvements in these areas.

Strategic

- The IBD Registry needs to embrace further a philosophy on QI and proactively facilitate teams to use QI methodology to improve patient care.

- The IBD Registry need to be supported by the IBD community and other healthcare initiatives to become successfully established as a subscription model. The registry should continue to engage with Quality Accounts and other national drivers.
- The IBD community, including BSG, CCUK, IBD UK and the IBD Registry, should work together to plan a programme that has a long term sustainable future with a central platform for communicating with the clinical community and patients. They should also forecast on where IT developments are likely to lead and, most importantly, build on the increasing knowledge emerging on how to help hospital teams continue to make sustainable improvements in patient care.
- Future audits need to be able to respond promptly to emerging clinical questions.
- The government needs to invest for the long term in national audit and empower programmes to make long term plans that are committed from the outset to developing enduring and sustainable models for improving care.

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