



# Organisational

## National audit of inflammatory bowel disease (IBD) service provision

UK IBD audit

Executive summary report

September 2014

Prepared by the Clinical Effectiveness and Evaluation Unit at the Royal College of Physicians on behalf of the IBD programme steering group



Adult

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## Foreword

The first round of UK inflammatory bowel disease (IBD) audit took place in 2006–08 and demonstrated considerable variation in service provision. Much has changed since this time. IBD services have seen substantial, real and sustainable improvement and the UK IBD audit itself has undergone much development. While this has delivered higher quality, it undoubtedly places additional pressures on the clinical teams who continue to collect and submit the data. The future therefore brings challenges to deliver an effective, cost efficient, relevant and acceptable audit.

The first round of UK IBD audit examined inpatient care of 40 adults with inflammatory bowel disease (IBD) at each site, along with the organisation and structure of IBD services. Paediatric services were included in round 2 (2008–10) and biological therapies and inpatient experience were added in round 3 (2010–12). Round 4 (2012–14) has seen substantial changes to methodology, with the prospective collection of data for up to 50 patients with ulcerative colitis per site and the adoption of the IBD quality improvement project (IBDQIP) tool for the assessment of organisation of services and to drive quality improvement. The audit has assessed patient outcomes more thoroughly in terms of disease activity, quality of life, patient-reported outcome measures and patient experience.

The progress of the UK IBD audit has been supported by the development of the service standards for patients with IBD. This was led by the patient organisation, Crohn's and Colitis UK, and the standards serve to complement, underpin and inform the recent quality standard for IBD published by the National Institute for Health and Care Excellence (NICE).

However, there continue to be aspects of care that need improvement. It is clear, particularly from this round, that this is true of some aspects of therapeutics. It is also important that we tackle areas that are harder to change, for example the provision of dietetic and psychological support, as well as addressing aspects of care that have not previously been assessed, such as outpatient care and colon cancer surveillance.

Further rounds of the UK IBD audit will continue to drive improvement. The challenge for the IBD community is to engage the support necessary to allow this to continue. We must think of smarter, more efficient ways of working and it is vital to allow clinicians to help patients as efficiently as possible. Increased engagement with patients is essential and adoption of new technologies, such as those being driven forward by the IBD Registry, will support this process. It is also vital to put a greater emphasis on quality improvement and the IBDQIP is an important step to help clinical teams implement change in what is already a time-poor environment.

The single and most heartfelt thanks must go to the clinical teams, who continue to give their time selflessly to enter data to the UK IBD audit.



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## Executive summary

### Background

Ulcerative colitis and Crohn's disease are the two main forms of inflammatory bowel disease (IBD). They are lifelong, chronic conditions that follow an unpredictable relapsing and remitting course. The current prevalence of IBD in the UK is unknown, but studies from the developed world have shown rates as high as 0.5%,<sup>1</sup> meaning that over 300,000 people in the UK are likely to be affected.

The main symptoms include abdominal pain, bloody diarrhoea, fatigue, loss of appetite, weight loss, abscesses, fistulas, rectal bleeding, swollen joints, mouth ulcers and eye problems, all of which can contribute to a poor quality of life. Effective multidisciplinary care can offset relapse, prolong remission, treat complications and improve quality of life. Medical costs associated with the care of IBD can be comparable to those for major chronic diseases, such as diabetes mellitus and cancer. Research from 2006 showed the annual average cost per patient to be as high as £3,000 per year, giving a likely overall annual cost to the NHS of £900 million based on current estimates of prevalence.<sup>2,3</sup> However, the cost may now be considerably higher, given healthcare inflation and the rise in use of biological drugs.

This report examines the quality of adult IBD services throughout the UK. Participating services were asked to report the status of their own service as at 31 December 2013. The quality of a service is assessed against the *Standards for the healthcare of people who have inflammatory bowel disease* ([www.ibdstandards.org.uk](http://www.ibdstandards.org.uk)).<sup>4</sup> The UK IBD audit provides the widest view of current service provision for patients with IBD. Through the collection of these data, the audit seeks to improve all aspects of care for people with IBD in the UK. Reports published in June 2014 addressed the quality of inpatient care and inpatient experiences of patients with ulcerative colitis and can be viewed at [www.rcplondon.ac.uk/ibd](http://www.rcplondon.ac.uk/ibd).

### Key message

This work continues to be widely supported by the healthcare community, with 87% (142/163) of UK trusts and health boards participating in this current round. This reflects a strong ongoing willingness and desire amongst the IBD healthcare community to improve services for patients.

The results offer many positive messages, including: a further increase in the number of specialist IBD nurses available to patients; improved dietetic services; greater provision of specialist transition support for children moving to adult services; over 90% of services now having some form of multidisciplinary meeting to discuss complex IBD cases; two-thirds of services participating in research; and high levels of participation in the national pouch registry.

However, closer analysis of the results shows that service provision remains variable, with 27% of services reporting that they have the full cohort of core IBD team members advocated by the IBD Standards. Arrangements for multidisciplinary meetings are often ad hoc and there has been a small, but concerning, fall in the number of services reporting that they are able to see relapsing patients within 7 days. Furthermore, the desired expansion in local IBD database systems has not yet materialised, and the results highlight an ongoing need to improve patient-centred care: variable provision of pain services for inpatients; few services involving patients in service planning; limited availability of formal education sessions for patients and their families; and disappointingly few services able to offer psychological support to their patients.

Importantly, although this report does show definite improvement in a number of aspects of IBD service provision, the current results serve to highlight the need to give IBD care formal recognition within healthcare services and for the UK IBD audit to continue to drive change and improve standards of care. It is therefore vital that policymakers, service commissioners, NHS managers and healthcare professionals continue to support this work.

## Key findings

- 1 The opportunity for patients to benefit from **IBD specialist nurse support** continues to increase, with 86% (148/173) of services now having at least some provision. However, provision remains variable, with 37% (64/173) of services meeting the recommendation by the IBD Standards to have 1.5 whole-time equivalent (WTE) IBD nurses.
- 2 The provision of **nutritional support** for patients with IBD remains mixed. 23% (40/173) of services still have no access to specialist dietitian input and only 67% (116/173) of services have 0.5 WTE dietitian or more, as advocated by the IBD Standards. Furthermore, only 61% (105/173) of services reported that at least 90% of their IBD inpatients undergo a basic nutritional risk assessment during their admission.
- 3 91% (157/173) of services now hold some form of IBD **multidisciplinary team (MDT)** meeting, where complex IBD cases are discussed. However, only 40% (70/173) of services reach the IBD Standards' requirement for the MDT to meet at least fortnightly and to be regularly attended by medical, nursing and surgical staff, to be minuted and to have an attendance register.
- 4 There has been a reduction in the number of services reporting that they see all IBD **patients who experience a relapse** within 7 days. 74% (128/173) of services participating in the current round reported that they could meet the 7-day target, compared with 88% (176/201) in round 3. Previous rounds had shown a consistent improvement in the provision of rapid access for patients and the reversal of this trend is concerning.
- 5 Dedicated clinics and support for young patients undergoing **transition from paediatric to adult services** are now offered by 53% (92/173) of services.
- 6 Access to **toilet facilities** for inpatients with IBD has shown little progress over the four rounds of audit. 27% (47/173) of services achieve the standard of one toilet per three beds in the current round, compared with round 1, where 25% (30/118) of services with a dedicated gastroenterology ward met the standard.
- 7 48% (83/173) of services report that they provide regular **education opportunities** for patients and their families.
- 8 The percentage of services with access to a **searchable database or register** for their IBD patients remains low at 36% (62/173), compared with 34% (62/180), 39% (79/205) and 55% (110/201) in rounds 1, 2 and 3, respectively.
- 9 The audit data show that relatively low numbers of **specialist surgical procedures**, such as ileoanal anastomotic pouch surgery, are being conducted at some sites. In the current audit round, 76% (132/173) of participating services indicated that they undertake pouch surgery, but 61% (80/132) of these services carried out fewer than five operations during 2013. Given the low numbers involved, it is essential that surgeons monitor their outcomes closely and it is therefore encouraging that 66% (86/130) of sites reported participation in the national pouch registry.
- 10 Access to **psychological support** for IBD patients remains low; 12% (21/173) of services reported having access to clinical psychology via a defined referral pathway.

## Recommendations

- 1 There are demonstrable improvements in many aspects of care. However, for a number of important, patient-focused quality indicators, progress has been slower, and there will need to be a national plan of action to ensure that IBD services continue to improve in these areas; this applies equally to adult and paediatric services.
- 2 Provision of specialist IBD nurse support remains a priority. Although some progress has been made, further appointments are needed to enable services to meet the standards and to be able to offer patients access to a robust and reliable IBD nurse service.
- 3 Nutritional assessment and dietetic support for IBD patients is an essential aspect of IBD care. Services must implement appropriate protocols to ensure that all IBD patients are reliably screened for nutritional risk factors on hospital admission and have access to dietetic support when required.
- 4 IBD multidisciplinary team meetings have established their pivotal role in the management of complex IBD cases, but now require a formal footing to ensure that they occur regularly and with appropriate structure and resource.
- 5 The apparent decline in access for relapsing patients to be seen quickly (within 7 days) is a concern and we recommend that services implement local systems to monitor waiting times for newly diagnosed and relapsing IBD patients. This will enable local action planning to address any issues identified.
- 6 The fact that over 50% of services offer specialist support for young IBD patients undergoing transition from paediatric to adult services is encouraging, but work needs to be done to share examples of best practice to help roll out services to those sites yet to establish their own transition processes.
- 7 The lack of progress with toilet provision for inpatients with IBD is disappointing and should be made a priority whenever inpatient facilities undergo improvement, or when new healthcare facilities are constructed.
- 8 Patient education is of fundamental importance, given the nature of IBD, and needs to be an integral part of IBD care. Services should be encouraged to develop innovative approaches to deliver patient and family education.
- 9 Despite a strong desire from the IBD community, the slow uptake of IBD databases is holding back innovation and flexibility in IBD care. Work needs to be done at a national level to overcome the barriers to the uptake of the IBD Registry and similar databases. Local clinical champions will also be required to develop business cases for funding and implementation.
- 10 Given the specialist nature and low volumes of pouch surgery performed, it is essential that all pouch surgery outcomes are captured within the national pouch registry. The UK IBD audit must continue to work alongside the pouch registry to monitor this important area of IBD care.
- 11 Provision of psychological support needs greater priority at a local level. This could be helped by sharing examples of successful business cases and local best practice by the small number of sites that have managed to establish a dedicated service.

Further details on how to meet these recommendations can be found in the action plan that follows.

### Implementing change: action plan

This action plan provides a template to support IBD teams in improving the services that they provide for patients. It maps the report's recommendations alongside the required standards and suggests actions for improvement. The organisational audit web tool ([www.ibdqip.co.uk](http://www.ibdqip.co.uk)) hosts a repository of resources in a wide range of topics to support service improvement, including guidelines, business cases and examples of best practice that IBD services have shared. You can download a copy of this action plan from [www.rcplondon.ac.uk/ibd](http://www.rcplondon.ac.uk/ibd).

National recommendation	Related standard and action required	Staff responsible	Progress at your site (Include date of review, name of individual responsible for action)
<p>1 There are demonstrable improvements in many aspects of care. However, for a number of important, patient-focused quality indicators, progress has been slower, and there will need to be a national plan of action to ensure that IBD services continue to improve in these areas; this applies equally to adult and paediatric services.</p>	<p>a) Representatives of all related specialist societies and groups must meet to agree a national strategy</p>	<p>Department of Health British Society of Gastroenterology British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BPSGHAN) Royal College of Nursing – Crohn's and colitis specialist interest group Crohn's and Colitis UK</p>	
<p>2 Provision of specialist IBD nurse support remains a priority. Although some progress has been made, further appointments are needed to enable services to meet the standards and to be able to offer patients access to a robust and reliable IBD nurse service.</p>	<p>IBD services should be staffed in line with <b>IBD Standard A1</b> (1.5 whole-time equivalent IBD nurse per 250,000 population)</p> <p>b) Where sites do not meet this requirement, the lead IBD clinician should develop a business case to secure further IBD nurse support for patients</p>	<p>NHS managers IBD nurses Consultant gastroenterologists</p>	
<p>3 Nutritional assessment and dietetic support for IBD patients is an essential aspect of IBD care. Services must implement appropriate protocols to ensure that all IBD patients are reliably screened for nutritional risk factors on hospital admission and have access to dietetic support when required.</p>	<p>IBD services should be staffed in line with <b>IBD Standard A1</b> (at least 0.5 whole-time equivalent dietitian allocated to gastroenterology)</p> <p>c) 100% of IBD inpatients should have their nutritional status assessed using a recognised, validated tool, eg MUST</p> <p>d) A business case should be put forward to seek dietetic support for IBD patients</p>	<p>Nursing staff Healthcare assistants NHS managers Dietetic staff Consultant gastroenterologists</p>	

National recommendation	Action required	Staff responsible	Progress at your site (Include date of review, name of individual responsible for action)
<p>4 IBD multidisciplinary team meetings have established their pivotal role in the management of complex IBD cases, but now require a formal footing to ensure that they occur regularly and with appropriate structure and resource.</p>	<p>Multidisciplinary working should take place as outlined in <b>IBD Standard A3</b></p> <p>e) Regular, timetabled meetings should take place, preferably weekly</p> <p>f) Meetings should include all members of the IBD team, as listed in the standard</p>	<p>NHS managers All members of the IBD team</p>	
<p>5 The apparent decline in access for relapsing patients to be seen quickly (within 7 days) is a concern and we recommend that services implement local systems to monitor waiting times for newly diagnosed and relapsing IBD patients. This will enable local action planning to address any issues identified.</p>	<p>Patients should have access to IBD specialists as outlined in <b>IBD Standard A11</b></p> <p>g) All patients experiencing a relapse of their IBD should have access to specialist review within a maximum of 5 working days</p> <p>h) A local audit of IBD clinic waiting times should be undertaken, an action plan should be implemented and tracked to monitor change</p>	<p>Consultant gastroenterologists Clinical audit staff</p>	
<p>6 The fact that over 50% of services offer specialist support for young IBD patients undergoing transition from paediatric to adult services is encouraging, but work needs to be done to share examples of best practice to help roll out services to those sites yet to establish their own transition processes.</p>	<p>Arrangements should be made for age-appropriate care as outlined in <b>IBD Standard A12</b></p> <p>i) A policy and protocol for transitional care should be written by the IBD clinical lead</p> <p>j) A named coordinator should be responsible for the preparation and oversight of transition</p> <p>k) Those without an established process for transition should make use of the examples freely provided in the <b>IBQIP resources</b> store</p>	<p>NHS managers Consultant gastroenterologists IBD nurses</p>	
<p>7 The lack of progress with toilet provision for inpatients with IBD is disappointing and should be made a priority whenever inpatient facilities undergo improvement, or when new healthcare facilities are constructed.</p>	<p>Toilet facilities should be provided as outlined in <b>IBD Standard A12</b></p> <p>l) Ward toilets should have floor-to-ceiling partitions, full-height doors and good ventilation</p> <p>m) There should be a minimum of one toilet per three beds; this should be made a priority whenever inpatient facilities undergo improvement</p>	<p>NHS managers Consultant gastroenterologists Ward staff Hospital facilities staff</p>	

National recommendation	Action required	Staff responsible	Progress at your site (Include date of review, name of individual responsible for action)
<p>8 Patient education is of fundamental importance, given the nature of IBD, and needs to be an integral part of IBD care. Services should be encouraged to develop innovative approaches to deliver patient and family education.</p>	<p>As stated in <b>IBD standard D2</b>, IBD services should be providing educational opportunities for patients and their families</p> <p>n) Educational opportunities should cover disease education, treatment options and self-management strategies</p> <p>o) The IBD team should identify an appropriate team member to facilitate this</p>	<p>Consultant gastroenterologists IBD nurses Dietetic staff Hospital Patient Advice and Liaison Services (PALS)</p>	
<p>9 Despite a strong desire from the IBD community, the slow uptake of IBD databases is holding back innovation and flexibility in IBD care. Work needs to be done at a national level to overcome the barriers to the uptake of the IBD Registry and similar databases. Local clinical champions will also be required to develop business cases for funding and implementation.</p>	<p>p) Every IBD service should maintain a local register of all patients diagnosed with IBD – <b>IBD Standard E1</b></p> <p>q) IBD services should encourage and facilitate involvement in multidisciplinary research through national or international IBD research projects and registries – <b>IBD Standard F2</b></p>	<p>NHS managers Consultant gastroenterologists Hospital information technology departments IBD nurses</p>	
<p>10 Given the specialist nature and low volumes of pouch surgery performed, it is essential that all pouch surgery outcomes are captured within the national pouch registry. The UK IBD audit must continue to work alongside the pouch registry to monitor this important area of IBD care.</p>	<p>r) The outcomes of all emergency colectomy, ileoanal pouch (the ACPGBI Ileal Pouch Registry) and abdominal operations for Crohn's disease should be submitted to national audit and data collection as outlined in <b>IBD Standard E3</b></p>	<p>Consultant colorectal surgeons Consultant gastroenterologists</p>	
<p>11 Provision of psychological support needs greater priority at a local level. This could be helped by sharing examples of successful business cases and local best practice by the small number of sites that have managed to establish a dedicated service.</p>	<p>s) The IBD service should have defined access to a psychologist and/or counsellor with an interest in IBD – <b>IBD Standard A2</b></p>	<p>NHS managers Consultant gastroenterologists IBD nurses</p>	
<p>12 ENTER THE LOCAL ACTIONS YOU HAVE IDENTIFIED HERE</p>			

## References

- 1 Molodecky NA, Soon IS, Rabi DM *et al*. Increasing incidence and prevalence of the inflammatory bowel diseases with time, based on systematic review. *Gastroenterology* 2012;142:46-54.
- 2 Lucas C, Bodger K. *Economic burden of inflammatory bowel disease: a UK perspective*. Expert Review of Pharmacoeconomics & Outcomes Research, 2006;6(4):471-82.
- 3 Cummings J F R, Keshav S, Travis SPL. The management of Crohn's disease. *BMJ* 2008;336:1062-6.
- 4 IBD Standards Group. *Standards for the healthcare of people who have inflammatory bowel disease* (IBD Standards), 2013 update. [www.ibdstandards.org.uk](http://www.ibdstandards.org.uk) [Accessed 4 September 2014].

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