National clinical audit of inpatient care for adults with ulcerative colitis

UK inflammatory bowel disease (IBD) audit

Executive summary report
June 2014

Prepared by the Clinical Effectiveness and Evaluation unit at the Royal College of Physicians on behalf of the IBD programme steering group
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The Clinical Effectiveness and Evaluation Unit (CEEU) of the Royal College of Physicians runs projects that aim to improve healthcare in line with the best evidence for clinical practice: national comparative clinical audit, the measurement of clinical and patient outcomes, clinical change management and guideline development. All of our work is carried out in collaboration with relevant specialist societies, patient groups and NHS bodies. The unit is self-funding, securing commissions and grants from various organisations including the Department of Health and charities such as the Health Foundation.

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Foreword
The first round of UK IBD audit took place in 2006 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 change. 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, published in 2006, examined inpatient care of 40 people with inflammatory bowel disease (IBD) at each site and the organisation and structure of IBD services. Paediatric services were included in round 2 and biological therapies and inpatient experience were added in round 3. Round 4 has seen substantial changes to methodology, with the prospective collection of data for up to 50 patients per site with ulcerative colitis and the adoption of the IBDQIP tool for the assessment of organisation of services and to drive quality improvement. We have assessed patient outcomes more thoroughly in terms of disease activity, quality of life, patient-reported outcome measures and patient experience.

The data presented in this audit report demonstrate multifaceted, sustained improvement in patient care. This has encompassed basic aspects of care such as the collection of stool cultures and the prescription of prophylactic heparin. Even just the rise of prophylactic heparin prescription, from 54% in round 1 to over 90% in round 4, is worthy of reflection. There have also been substantial improvements in aspects of care that have needed additional resource, for example the provision of some nurse support, availability of specialist wards and a formalised IBD team. Improvement has also been seen in mortality, therapeutics, drug monitoring, multidisciplinary team (MDT) working, information provision and to some extent patient involvement. The progress seen in round 4 is particularly encouraging, as many aspects of care that could be considered the ‘easy wins’ will have already improved prior to this round of audit.

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 serves to complement more recent service standards published by 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 dietitians 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 change. The challenge for the 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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Clinical director, UK IBD audit

Dr Michael Glynn
National clinical director, GI and liver diseases,
NHS England

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Executive summary

Background
Ulcerative colitis (UC) is the most common type of inflammatory bowel disease (IBD); it is a lifelong, chronic, relapsing–remitting condition. The main symptoms include abdominal pain, bloody diarrhoea, fatigue, weight loss and rectal bleeding, 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.

The incidence of UC continues to rise and is reported to be as high as 24.3 per 100,000 per year in Europe. Reported prevalence is as high as 505 per 100,000 and this corresponds to 320,000 people in the UK with a diagnosis of UC. The cause of UC is unknown and, although it can develop at any age, the peak incidence is between the ages of 15 and 25 years, resulting in profound effects on education, work, social and family life.\(^1,2\) The 3-month, per-patient cost for UC was calculated at £1211 in 2010, with the majority of this cost attributed to inpatient stays.\(^3\)

This report examines the inpatient care provided to people admitted to hospitals in the UK for treatment of UC between 1 January 2013 and 31 December 2013. For the first time, a small number of questions also address the outpatient care provided to each patient prior to their admission to hospital.

The UK IBD audit provides the widest view of current practice of treatment for people with UC in the UK. Through the collection of these data, the audit seeks to improve all aspects of care for people with IBD. Reports due to be published in September 2014 will address organisational aspects of care and biological therapies.

Key message
This work was widely supported by the healthcare community, with 95% (154/162) of UK trusts/health boards participating.

The data presented in this report inspire optimism: they demonstrate continued steady improvements in many aspects of IBD care. This is particularly encouraging because many of the easy gains will have already been realised. The observed improvements are attributable to the hard work, dedication and persistence of the clinical teams across the country.

Of particular note, the observed mortality has continued to fall despite the significantly larger number of patients included in this round of IBD audit than previously. Other basic aspects of care have also improved, with the increasing collection of stool samples and prescription of prophylactic heparin. Although the rates of readmission within 2 years appear to be falling, one in five patients are readmitted within 30 days and it is possible that therapeutic opportunities are missed, with a significant minority of patients on no treatment when they are admitted and almost half who did not have treatment started or escalated in outpatient clinics.

It is also clear that other important aspects of care remain below desirable levels. Previous rounds of UK IBD audit have demonstrated substantial improvements in specialist nurse provision, but these levels remain well below those outlined in the IBD standards.\(^4\) A nutritional assessment is mandatory for all people with IBD who are admitted to hospital, but numbers seeing a dietitian remain low. In addition, all patients who are steroid dependent should be offered steroid-sparing therapies.

Further UK IBD audit and quality improvement in IBD will continue to drive change and improve standards in deficient aspects of care. It is therefore vital that policymakers, service commissioners, NHS managers and healthcare professionals continue to support this work.
Key findings
1. Mortality remains substantially low and is below 1% (round 2: 1.54%, round 4: 0.75%). (Section 2, Table 2)
2. The percentage of patients seen by an IBD nurse during admission increased significantly from round 2, from 27% to 48% in round 4. (Section 2, Table 2)
3. 27% (1078/3987) of patients had also been admitted to hospital for UC in the 2 years prior to the audited admission. 12% (134/1078) of these patients were readmitted within 30 days. (Full national data Q2.2.2)
4. Over 90% of admitted patients in round 4 were prescribed prophylactic heparin, a significant increase from 73% in round 2. (Section 2, Table 2). A thrombotic episode was reported in 1% (46/4359) of patients. (Section 2, Table 6)
5. There was a significant increase from round 3 in the prescription of bone protection for patients discharged home on steroids (74% in round 4). (Section 2, Table 2)
6. Nutritional risk assessment was undertaken in 82%, and the patient did not see a dietitian in 60%, of applicable admissions. (Section 2, Table 3)
7. In 11% (352/3065) of admissions for active UC, the patient was on no medication for their disease at the time of admission to hospital (excludes new diagnoses). (Section 2, Table 3)
8. Anti-TNFα was the most common second-line medical therapy used following non-response to corticosteroids (ciclosporin 22% / anti-TNFα 43%) in round 4. (Section 2, Table 2). Previously (in round 2), ciclosporin was more commonly used (ciclosporin 27% / anti-TNFα 12%).
9. Where active disease was recorded at the last outpatient appointment and the patient was not admitted to hospital at that time, standard treatments were not started or escalated in 42% of cases. (Section 2, Table 3)
10. Of the 684 admissions where the patient had been prescribed steroids for longer than 3 months, no steroid-sparing therapies had been tried in 22% (151/684). (Full national data Q6.2.2)
11. The patient was anaemic in 48% (2052/4288) of admissions (using WHO definition). (Section 2, Table 6)
12. Where anaemia was attributed to iron deficiency, no treatment was received in 56% (783/1406) of admissions. (Full national data Q6.3.3)

Recommendations
1. All outpatients with UC should have their disease activity accurately assessed (eg using symptoms and faecal calprotectin), and treatment should be initiated or escalated in those with active disease. Early intervention may prevent admission.
2. All patients with a new diagnosis of UC, those for whom the use of anti-TNFα is considered and those requiring additional information should be seen by an IBD nurse during admission.
3. IBD services should ensure that inpatient IBD care provided by the IBD nurse is appropriately resourced in line with IBD Standard A1 (1.5 whole-time equivalent nurse per 250,000 population).
4. All IBD patients admitted to hospital should be weighed and their nutritional needs assessed, in line with IBD Standard A10.
5. Bone protection should be prescribed to all patients with UC who receive corticosteroids.
6. Heparin should be given to all patients for whom it is not contraindicated, to reduce the risk of thromboembolism.
7. All patients on steroids for longer than 3 months should be considered for steroid-sparing agents such as azathioprine.
8. Anaemia should be actively investigated, and the cause should be identified and treated appropriately.
9. Further national audit in IBD should be commissioned.
Implementing change: action plan

This action plan will enable you to take forward the recommendations of this national audit and allows for adaptation through the addition of further actions as you feel appropriate for your own service. We would recommend the ‘resource’ section of the organisational audit web tool (www.ibdqi.co.uk) as being particularly useful when considering the actions required below; here you can freely access guidelines, business cases and examples of best practice from around the UK. You can download a copy of this action plan from www.rcplondon.ac.uk/ibd.

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<tr>
<th>National recommendation</th>
<th>Action required</th>
<th>Staff responsible</th>
<th>Progress at your site (Include date of review, name of individual responsible for action)</th>
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<tr>
<td>1 All outpatients with UC should have their disease activity accurately assessed (eg using symptoms and faecal calprotectin), and treatment should be initiated or escalated in those with active disease. Early intervention may prevent admission.</td>
<td>a) Use of accurate symptom assessment or disease activity score at all points of clinical interaction &lt;br&gt;b) Adoption of faecal calprotectin or other biomarker to aid assessment of disease activity &lt;br&gt;c) Implementation of a treatment pathway that is readily available to aid timely treatment decision making</td>
<td>All healthcare professionals responsible for treating people with IBD in outpatient settings</td>
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<td>2 All patients with a new diagnosis of UC, those for whom the use of anti-TNFα is considered and those requiring additional information should be seen by an IBD nurse during admission.</td>
<td>d) Business cases should be put forward to promote the need for further IBD nurse support for inpatients &lt;br&gt;e) Existing IBD nurse job plans should be reviewed to ensure that they allow sufficient time for inpatient care</td>
<td>NHS managers IBD nurses Consultant gastroenterologists</td>
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<td>4 All IBD patients admitted to hospital should be weighed and their nutritional needs assessed, in line with IBD Standard A10.</td>
<td>g) 100% of IBD inpatients should have their nutritional status assessed using a recognised, validated tool eg MUST &lt;br&gt;h) A business case should be put forward to seek dietetic support for IBD inpatients</td>
<td>Nursing staff Healthcare assistants Consultant gastroenterologists</td>
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<td>5 Bone protection should be prescribed to all patients with UC who receive corticosteroids.</td>
<td>i) Local protocol should be updated to indicate that bone protection agents are prescribed to all IBD patients started on steroid treatment</td>
<td>Consultant gastroenterologists Hospital policy managers IBD nurses</td>
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<td>6 Heparin should be given to all patients for whom it is not contraindicated, to reduce the risk of thromboembolism.</td>
<td>j) 100% of patients should be given heparin, unless contraindicated</td>
<td>Consultant gastroenterologists IBD nurses</td>
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<td>7 All patients on steroids for longer than 3 months should be considered for steroid-sparing agents such as azathioprine.</td>
<td>k) Any patient on long-term steroids (&gt;3 months) should be under regular review</td>
<td>Consultant gastroenterologists IBD nurses</td>
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<td>l) 100% of patients on steroids for longer than 3 months should be considered for a steroid-sparing agent</td>
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<td>8 Anaemia should be actively investigated, and the cause should be identified and treated appropriately.</td>
<td>m) Local protocols should include the assessment of haematinsics for all anaemic patients</td>
<td>Consultant gastroenterologists IBD nurses</td>
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<td></td>
<td>n) Treatment of underlying deficiency or disease activity should be attempted in all anaemic patients</td>
<td>GPs</td>
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<td>9 Further national audit in IBD should be commissioned.</td>
<td>o) Review of current IBD national audit and consideration of the appropriate future format should take place to address deficient areas within 1 year</td>
<td>National policymakers</td>
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References

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