The importance of the IBD audit for patients who have IBD

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We can take two different patient perspectives to the audit: a collective or national patient view and an individual or local view. While the former should be judged a success story so far, the latter view highlights the disappointment of some patients with the current inflammatory bowel disease (IBD) audit and some challenges for the future.

It is worthwhile recalling some of the drivers for NACC (National Association for Colitis and Crohn's Disease) deciding to participate with the Royal College of Physicians, British Society of Gastroenterology and Association of Coloproctology of Great Britain and Ireland in the application to the Health Foundation for funding of an IBD audit. From discussion at NACC meetings, helpline enquiries and individual patient anecdotes, and from the 'Improving Care for IBD' focus groups commissioned by NACC in 2005, we were aware that many hospitals did not have a defined, planned IBD service and that staffing, resources and organisation of care varied enormously between hospitals. The quality of clinical care was also variable. This situation reflected the absence of any National Health Service (NHS) national priorities or plans for gastrointestinal care (with the exception of cancer and endoscopy), and improvements in IBD care were determined entirely by local factors. The wishes of patients to see improvements in their care crystallised into the NACC campaign for more IBD specialist nurses who were seen by patients as the cornerstone of a better service.

The IBD audit project has fundamentally changed the national picture. The IBD patient and professional community had over time fragmented into more specialist groups, resulting in a loss of national leadership for the development of IBD and gastrointestinal services. However, relationships between individual professionals

remained strong and this provided a sound base for the creation of the IBD project as a formal, national collaboration—the first step in moving towards a national strategy for IBD.

The lack of any national standards for the service aspects of IBD had been identified as a deficiency in the 2006 British Society of Gastroenterology guidelines, and the IBD audit team set out to address this. The presumptive standards developed became, in some respects, a pilot for the national working group set up the following year to agree and publish definitive national standards for IBD.

The first round of the national audit benchmarked hospital services and care in 2006, which was a significant milestone nationally and locally. For the first time we could present a national picture of IBD services and care to politicians and NHS managers and argue for greater attention and support for IBD. Locally, individual hospital teams were able to compare their service and quality of care to a national average. For patients, perhaps the most encouraging aspect of the audit was the message conveyed by the high level of voluntary participation—75% in 2006 and then over 90% in 2008 (the audit's second round).

The results of the two audits confirmed the expected picture of variable provision, organisation and quality of clinical care but it is probably true to say that many health professionals were surprised that their results on basic aspects of care—weighing patients, stool tests, prophylactic heparin, etc—were somewhat poorer than they had anticipated. The 2008 audit showed some modest improvements but also illustrated that measuring alone does not create improvement. A programme of service and quality review with formal local action plans and follow-up is needed to make significant and lasting improvements.

One of the most important successes for the first two rounds of audit has been to demonstrate that there is a clinical commitment in IBD to audit and improvement of care which has led to the inclusion of the IBD audit in the national NHS audit programme for 2010–2012. This is a very significant achievement which begins to address patients' concerns that IBD should feature in the national NHS systems for improving and monitoring patients care.

Given this picture of national success and achievement, why would individual patients express some disappointment? Quite simply it is because they do not have access to the audit results for their hospital or for the other hospitals that they could practically be referred to. There is a real sense of inequality and denial of information among some patients who feel strongly that they have a right to know how well or poorly their hospital is performing.

In considering public access to individual hospital results, a whole set of caveats immediately come to mind which might justify not making the information available—data completeness and accuracy, the difficulties of interpreting data without the full context, issues of case mix and the fact that much of the audit data concern process rather than outcome measures. The caveats are familiar and have some validity but this issue of disclosure must be tackled if future audit is to be seen by patients as having real value.

The IBD standards could provide a basis for a first step in this direction, publication of a selection of individual hospital data from the next audit—for example, staffing and facilities resources and key aspects of the organisation of care. Patients should be able to know whether the service is properly resourced and in this respect consumer pressure for hospitals to meet the IBD standards can only be helpful. Indeed, if the information is in the public domain it removes completely the difficulty that health professionals sometimes express of being thought to be stirring up patient activism.

The clinical care data would need more thought. The data currently collected are largely governed by what is readily available from the hospital notes. Better quality measures that have been suggested, such as proportion of patients receiving steroids for longer than 3 months, are difficult to gather in a retrospective audit of

notes and need good electronic records systems, currently only available in 39% of IBD services. Other possible outcome measures that patients might instinctively see as helpful in comparing services—remission maintained, ability to work, fewer hospital visits, minimum drugs, surgery avoided—all have questions about validity and meaning (eg, less frequent surgery may appear as a good result to a patient and may indeed be a good result, but it might also reflect lack of surgical resource or a policy of not giving patients the option of surgery early enough).

An easier area to develop would be to have publicly available the results of a systematic patient experience audit conducted at the local level. Many of the concerns expressed in the NACC focus groups were about qualitative aspects of care—the approach and attitudes of health professionals, the organisation of investigations, appointments and inpatient stays or the coordination of care. The development of nationally accepted feedback arrangements for IBD patients' experience could provide valuable information for local improvement of services as well as comparable data between hospitals to supplement the IBD standards service data.

The key message from patients is: the IBD audit is important and valuable but it is the action to make improvements and deliver a service that meets the IBD standards that matters most. It is simply not acceptable when we hear an IBD nurse say that in her hospital she monitors the immunosuppression therapy of patients from two consultants but cannot do so for the third; or a gastrointestinal dietitian who explains that consultant A refers all new patients for a discussion about good nutrition and IBD but consultant B does not refer because he does not believe diet has anything to do with IBD. It is the action for improvement that counts and patients are ready to work with their health professionals to support this.

Competing interests None.

Provenance and peer review Commissioned; not externally peer reviewed.

Useful links

IBD Standards website <http://www.ibdstandards.org.uk>

National Association for Colitis and Crohn's Disease (NACC) website <http://www.nacc.org.uk>

UK IBD Audit website <http://www.rcplondon.ac.uk/clinical-standards/ceeu/Current-work/IBD/Pages/Overview.aspx>