

## The Findings of a Nationwide Audit – The Future of NHS Inflammatory Bowel Disease Services

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### ABSTRACT

Cases of inflammatory bowel disease across the United Kingdom continue to rise. This article examines the opportunities that exist in different care settings to improve inflammatory bowel disease services, given the financial constraints currently faced by NHS.

**Key Words:** inflammatory bowel disease; audit; Crohns disease; Ulcerative colitis

### Introduction

The proportion of the United Kingdom suffering from inflammatory bowel disease (IBD) [encompassing both Crohn's disease and ulcerative colitis (UC)] is currently at 1 in 200 (Table 1). This is a significant section of the population and accounts for an estimated cost to the National Health Service of £720 million each year<sup>1</sup>.

**Table 1: Comparison of Crohn's Disease and Ulcerative Colitis<sup>2</sup>**

	Crohn's Disease	Ulcerative Colitis
<b>Average age of patient at onset</b>	<ul style="list-style-type: none"><li>• 10 - 40</li></ul>	<ul style="list-style-type: none"><li>• 10 - 40</li></ul>
<b>Signs and symptoms</b>	<ul style="list-style-type: none"><li>• Reduction in appetite</li><li>• Weight loss</li><li>• Diarrhoea</li><li>• Abdominal pain</li><li>• Perianal abscesses</li></ul>	<ul style="list-style-type: none"><li>• Bloody diarrhoea with mucus</li><li>• Pain in the lower abdomen</li><li>• Weight loss</li></ul>
<b>Extra intestinal manifestations</b>	<ul style="list-style-type: none"><li>• Inflammation of joints</li><li>• Inflammation of eyes</li><li>• Inflammation of skin</li><li>• Inflammation of liver</li></ul>	<ul style="list-style-type: none"><li>• Inflammation of joints</li><li>• Inflammation of eyes</li><li>• Inflammation of skin</li><li>• Inflammation of liver</li></ul>
<b>Common medications</b>	<ul style="list-style-type: none"><li>• Oral or i.v. glucocorticosteroids</li><li>• Azathioprine or 6 mercaptopurine</li><li>• Infliximab (Remicade)</li><li>• Adalimumab (Humira)</li><li>• Surgery is not curative</li></ul>	<ul style="list-style-type: none"><li>• Oral or i.v. glucocorticosteroids</li><li>• 5-aminosalicylic acid (e.g. mesalazine)</li><li>• Sulfasalazine</li><li>• Surgery (colectomy) can be curative</li></ul>

The characteristics of IBD, such as chronic inflammation of the colon in UC, or any aspect of the gastrointestinal tract in Crohn's, alongside (bloody) diarrhoea and abdominal pain, mean that the contact that this group of patients have with healthcare professionals and associated costs are considerable. These are relapsing and remitting conditions and consequently, although the requirement for care may fluctuate in its intensity, it must constantly be available. To assess the availability and quality of such care, between September and December of 2006 a nationwide audit of IBD services and care was carried out<sup>3</sup> (with a total of 212 hospitals submitting data out of 281 invited), which noted wide variations in care between centres. Subsequently, a working group was set up which established the IBD standards for patient care<sup>4</sup> to try and standardise the healthcare that patients with IBD receive. The working group, comprising organisations such as the British Society of Gastroenterology and Crohn's and Colitis UK, set the following standards:

- High quality clinical care
- Local delivery of care
- The maintenance of a patient centred service
- Patient education and support
- Information technology and audit
- Evidence based practice and research

Since 2006 subsequent audits have been carried out every two years to monitor progress. This has primarily been done through the use of questionnaires, which does have limitations as a means to obtain clinical data - with such a method there is a standardisation of questioning which leaves questions open to possible misinterpretation and the often retrospective nature of questioning allows for error. However these disadvantages have to be balanced against the large amounts of data from a variety of sources that can be gathered through this means to improve patient care. The finite resources available to the NHS make the standardisation of care a challenge; however there are opportunities within the reports that could lead to improvement in care provision without placing an additional burden upon the NHS.

### Primary Care

Often, when a patient first experiences IBD symptoms advice is sought from their general practitioner (GP). GPs must recognise symptoms of IBD promptly and refer patients to specialists to receive appropriate care. The same also applies when an existing IBD patient experiences an exacerbation of symptoms and requires access to secondary care services through their GP. The severity of symptoms can accelerate quickly, underpinning the need for swift action to be taken.

The report on the results of the UK wide primary care questionnaire<sup>5</sup> (to which there were 1675 respondents) carried out as part of the 2010 third round of the IBD audit, found a correlation between the level of confidence felt by GPs in recognising IBD symptoms and the ease with which secondary care was accessed. The report noted that, over 30% of GPs [from the 1675 respondents] who felt they were somewhat or very confident in recognising IBD symptoms reported no problems in accessing secondary care services, compared to just over 20% of GPs who expressed less confidence. While both of these figures are undoubtedly lower than is desirable, an increase in confidence in the handling of these conditions is proven as having a positive effect on the ability to access secondary care. This demonstrates the importance of establishing good communication between local GP practices and hospitals - knowing the correct person in the hospital to contact locally helps raise the confidence amongst GPs in appropriately dealing with their patients. Not being aware of an

appropriate referral pathway could lead to a patient experiencing a delay to any specialist input, causing a further exacerbation of symptoms and necessitating a hospital admission which otherwise may have been avoided.

Another significant finding was that only 47% of GPs agreed with their respective hospitals that it would be possible to receive a referral within seven days for a patient experiencing an exacerbation of symptoms. Overall 59% of GPs believed that it would not be possible to receive a referral within seven days, in contrast to the 88% of their respective 184 hospitals surveyed who stated that this would be possible for adult patients. It may also be argued that an inconsistency between what is 'thought' by GPs and hospitals is inconsequential as long as the hospitals have achieved targets for 7-day referral lists. However it is indicative of the existence of a lack of communication between care providers that could negatively impact other aspects of IBD patient management. Lastly, there was disparity between the results relating to the management of patients receiving immunosuppressive therapies, which require regular review due to their potent side-effect profile. In 78% of cases where GPs stated that the monitoring of these patients was either the responsibility of primary care or was shared between primary and secondary care, the monitoring was stated by the local hospital as being their responsibility alone.

The results of this questionnaire highlight that work focused at improving communication between healthcare professionals in primary and secondary care and making clear clinical care pathways are required to help optimise clinical care that patients receive. Low levels of confidence amongst GPs in being able to effectively handle IBD patients have to be addressed. This may occur through increased availability of education as part of continued professional development (for example, such as those offered by the BMJ learning<sup>6</sup>) and through increased interaction with secondary care so that neither exist in isolation from each other.

#### **Key Recommendations for Developing Primary Care Management of IBD**

- + Improve confidence levels amongst GPs in treating patients with IBD
- + Increase educational opportunities available to GPs about IBD
- + Improve communication between primary and secondary care

#### **Secondary care**

The duty of care for IBD patients falls primarily to secondary care clinicians so this naturally is the area where most of the focus has been on in terms of improving and developing services. Whilst, in some cases, improvements in care can only result through significant cost being incurred by the NHS (such as the increased provision of toilets on dedicated gastroenterology wards or increasing the number of clinics provided), they can also be made through restructuring of current facilities and making them more clinically efficient. The third round of the IBD audit<sup>7</sup> identified the importance of a named clinical lead amongst an IBD team. Three quarters of the 202 centres that took part in the audit stated that a clinical lead had been appointed; this still leaves 25% of centres without an individual occupying this position. A clinical lead can play an important role in promoting high quality care and the improving of services, in helping to develop a management plan for patients experiencing a range of symptoms, and also in building relationships with other health care workers. While it is to a centre's, and therefore to a patient's, advantage for someone from an existing team to occupy this position, a costly investment in training would have to occur and demand to justify such an appointment would have to be proven.

Patients who suffer from IBD may be treated with a wide variety of complex drugs; this may include corticosteroids, immunosuppressants and biologicals. Each drug has the potential to cause significant side effects to a patient (Table 2).

**Table 2: IBD drug classes and possible side effects<sup>2</sup>**

Drug class	Side effects
Corticosteroids (e.g. prednisolone)	<ul style="list-style-type: none"> <li>• Immunosuppression</li> <li>• Cushing's Syndrome or Cushing-like symptoms</li> <li>• Increase in blood sugar</li> <li>• Decrease in bone mineral density</li> </ul>
Immunosuppressants (e.g. azathioprine)	<ul style="list-style-type: none"> <li>• Increased risk of opportunistic infections</li> <li>• Nausea</li> <li>• Hair loss</li> <li>• Small increased risk of lymphoma</li> </ul>
Biologicals (e.g. infliximab)	<ul style="list-style-type: none"> <li>• Immunosuppression, leading to increased risk of opportunistic infections</li> <li>• Infusion related reaction such as shortness of breath</li> <li>• Small increased risk of lymphoma</li> </ul>

Hospital pharmacists can play a key role in advising IBD specialists and the patients about the benefits and potential risks of these drugs before a course of treatment is started. The third round of the audit<sup>8</sup> revealed that less than 50% of hospital sites had a pharmacist with a special interest in IBD as part of the IBD team, and only 9% of IBD meetings had regular pharmacy input. The majority of drugs used in IBD are widely used for other autoimmune conditions (such as rheumatoid arthritis, psoriasis and systematic lupus erythematosus), so it is probable (in large general hospitals at least) that pharmacists with knowledge of these drugs would be on site and could offer valuable input to IBD meetings. It has been proven that pharmacists may be able to provide advice that can improve drug regimens for patients with chronic illnesses thus reducing potential side effects that are suffered<sup>9</sup>.

Rapid access to specialist care was mentioned in the context of GP referral. However, in some centres access to specialists is given directly to the patients, whether this may be via telephone, email or drop in clinics. 90% of centres offered a telephone helpline<sup>10</sup>. Giving patients the ability to directly contact specialists places them at the centre of their own care whilst ensuring that lengthy delays in treatment are not incurred. It should, however, be made clear to patients that such a service must only be used when new IBD symptoms are experienced, as it could prove costly both in terms of finances and in terms of the specialist's time if unnecessary contact is frequently made. Patients must be sufficiently educated to have an understanding of their conditions, enabling them to recognise any break through symptoms. A similar system of rapid access to secondary care services is present in other conditions such as cancer, where patients have access to oncology telephone advice twenty four hours a day to ensure that care is readily available when needed<sup>11</sup>.

**Key Recommendations for Developing Secondary Care Management of IBD**

- + Appointment of a clinical lead
- + Consultation with hospital pharmacists
- + Rapid access to specialists

## Self-care

A diagnosis of IBD can have a dramatic impact on a person's life. The diagnosis is frequently made in young people, and it is vital then that they feel able to handle their condition (managing symptoms, stoma care, nutrition, knowing side-effects of medications). Specialists must work in partnership with patients and ensure that their concerns are fully and appropriately addressed. Each patient presents with a unique combination of symptoms and responses to drug therapies, consequently care must be tailored to the individual if positive health outcomes are to result. A report<sup>12</sup> on the results of an inpatient questionnaire conducted as part of the third round of the IBD audit found that 51% of 2028 patients that responded stated that they felt all their doctors during their hospital stay knew enough about their condition. This appears to be an area where some improvement is required to raise confidence levels amongst patients in the medical staff treating them. However, such figures may be misleading as they may have resulted from IBD patients coming in contact with a number of doctors at different levels of training during an average stay in hospital. Patient education is also central to the promotion of self-care. 99% of hospital sites provided patients with contact information for patient organisations (primarily Crohn's and Colitis UK)<sup>13</sup>. These organisations help to educate patients about their conditions, while also bringing them in contact with other sufferers. This reduces feelings of isolation amongst patients (and their families) and provides comfort in knowing that others are also experiencing similar, often embarrassing, symptoms. The NHS recognises the value that education can add to patients with chronic diseases and (in England) an 'Expert Patients Programme' exists that all patients with chronic health conditions can access<sup>14</sup>. This emulates the 'Chronic Disease Self-Management Program' that has been present in the United States since the 1970s and has been proven to have a positive impact on quality of life<sup>15</sup>. Care plans are often used for people with long-term health conditions and can play an important role in IBD management. A written care plan for patients was only available in 33% of sites in a recent review<sup>16</sup>. A care plan may cover areas like diet, exercise, medicines and emergency contact numbers. The development of such plans helps to ensure that patients who are less likely to ask questions about the management of their conditions receive the same high levels of information as patients who readily make enquiries. This is especially relevant in newly diagnosed patients and those receiving immunosuppressant and biological therapies.

### Key Recommendations for Developing Self Care Management of IBD

- + Providing patients with contact details of patient organisations
- + Patient education
- + Development of care plans

## Conclusion

Cases of inflammatory bowel diseases continue to rise and it is essential that the NHS be able to meet the requirements of this group of patients. As has been demonstrated through consideration of most recently published IBD audit results there are key areas where improvements can be made at little or no cost to the NHS. These improvements involve health care professionals reflecting on their own practice - good communication skills and respect between colleagues cannot be overstressed as central to this. Primary and the patient is able to achieve the highest quality of life possible for them.

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