



Quality Care

Service standards for the healthcare of people who have Inflammatory Bowel Disease (IBD)



THE IBD STANDARDS GROUP

Association of Coloproctology of Great Britain and Ireland • British Dietetic Association (Gastroenterology Group) • British Society of Gastroenterology • British Society of Paediatric Gastroenterology, Hepatology and Nutrition • National Association for Colitis and Crohn's Disease • Primary Care Society for Gastroenterology • Royal College of Nursing (Crohn's and Colitis Special Interest Group)

Quality Care: Service Standards for the healthcare of people who have Inflammatory Bowel Disease (IBD)

Produced by

The IBD Standards Group

Representing

*Association of Coloproctology of Great Britain and Ireland
British Dietetic Association (Gastroenterology Specialist Group)
British Society of Gastroenterology
British Society of Paediatric Gastroenterology, Hepatology and Nutrition
National Association for Colitis and Crohn's Disease
Primary Care Society for Gastroenterology
Royal College of Nursing (Crohn's and Colitis Special Interest Group)*

And supported by

*Royal College of Pathologists
British Association for Parenteral and Enteral Nutrition
British Society of Gastrointestinal and Abdominal Radiology
Royal College of General Practitioners
UK Clinical Pharmacy Association
UK Digestive Federation
CICRA – Crohn's in Childhood Research Association
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Foreword

The aim of these Service Standards is to ensure that patients who have inflammatory bowel disease receive healthcare that is safe, effective and of consistently high quality. Our organisations, representing patients and professionals, have collaborated in the IBD Standards Group to define for the first time what is required in terms of staffing, support services, organisation, patients' education and audit to provide integrated, high-quality IBD Services.

The starting point for this initiative was a UK-wide Audit in 2006 which confirmed that there was substantial local variation in the provision, organisation and clinical quality of IBD Services and that there were significant aspects of care that did not meet current clinical guidelines.

We believe that this situation reflects the fact that there is no NHS national strategy and no standards for this long-term condition and indeed for gastroenterology as a whole. Our approach has been to define a set of standards for IBD that will deliver safe, high-quality, patient-centred care as part of an effective gastroenterology service.

The active support of government and the NHS at national, regional and local level will be needed to implement these standards effectively. We are committed to promoting them and to collaborating to achieve this through the IBD Standards Group.

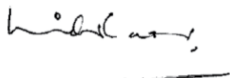
Ulcerative Colitis and Crohn's Disease have a profound impact on the lives of about 240,000 patients and their families in the United Kingdom. Many are diagnosed in their teenage years or early twenties, just at the time when they are undertaking their education, finding their first job and establishing their adult lives. No cure has yet been found and patients need life-long support from the NHS to enable them to achieve the best quality of life they can within the constraints of their illness. With appropriate healthcare provision, most patients can sustain economically-productive and family support roles, with all the benefits that follow both for society and for the self-esteem and well-being of the patient and their family.



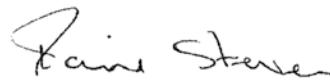
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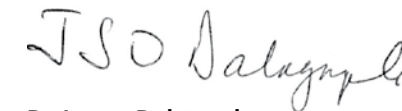
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Contents

05	Introduction
06	Executive Summary
08	What is Inflammatory Bowel Disease (IBD)?
09	Complications, cost and impact of IBD
10	Standards for IBD Services
11	Standard A. High quality clinical care
14	Standard B. Local delivery of care
15	Standard C. Maintaining a patient-centred service
16	Standard D. Patient education and support
17	Standard E. Information technology and audit
18	Standard F. Evidence-based practice and research
19	National action required to support local implementation
20	Sources of further information
21	Appendix A - Data from IBD Audit to be used for Annual Health Check
22	References

Introduction

This document is to inform NHS Managers and Commissioning Organisations as part of a UK-wide strategy to improve services for people who have Ulcerative Colitis or Crohn's Disease, which are the two most common forms of Inflammatory Bowel Disease (IBD). Together these long-term conditions are estimated to affect about 240,000 people in the UK, approximately 400 patients per 100,000 population.¹

Implementation of these standards will ensure that IBD Services meet key requirements of the strategies set out by the Department of Health for England ('High Quality Care for All – NHS Next Stage Review Report' and 'NHS Next Stage Review – Our vision for primary and community care'), NHS Scotland ('Better Health, Better Care Action Plan'), the Welsh Assembly Government ('Designed for Life: creating world class health and social care for Wales') and the 'Developing Better Services' Initiative in Northern Ireland.²⁻⁵

A National Audit of adult IBD Services and Care in 2006, to which 75% of hospitals in the UK voluntarily submitted data, revealed unacceptable variation both in service provision and organisation of important aspects of clinical care.⁶

Key findings included:

- One third of hospitals did not have a dedicated gastroenterology ward.
- 44% had no specialist IBD nurse sessions.
- The median number of dietitian sessions dedicated to gastroenterology was two per week.
- Less than half of hospitals provided joint or parallel gastroenterology/surgical clinics.
- Among patients admitted for Ulcerative Colitis, stool cultures were done in only 52%, Clostridium Difficile Test (CDT) in 47%.
- Only 52% of patients admitted with Crohn's Disease were weighed and 37% seen by a dietitian.
- 46% of outpatients with Crohn's Disease received continuous systematic corticosteroid therapy for longer than three months.
- Less than 0.5% of patients were in a clinical trial.

Our objective is to ensure that IBD patients receive consistent, high-quality care and that IBD Services throughout the UK are knowledge-based, engaged in local and national networking, based on modern IT and that they meet specific minimum standards. The document describes the standards that should be applied to local services and the obligations to national activities of information, audit, training and research that should be accounted for in the commissioning process.

The overall strategy for improving IBD Services and care requires action at local, regional and national levels and has been developed through the collaboration of the key professional groups and NACC, the national organisation for IBD patients of all ages. The specific recommendations were developed by a Working Group with representation from all these organisations and chaired by the IBD patients' organisation NACC. The recommendations were widely circulated for comment by patients, health professionals and industry and are supported by other professional and patient organisations.

In developing the standards the Working Group has drawn on NACC's work identifying patients' needs and wishes, on existing evidence-based guidelines for the clinical management of IBD, the strategic report *Care of Patients with GI Disorders* published by the BSG in 2006 and evidence-based service statements produced by the various professional groups.⁷⁻¹⁹

The results of the 2008 IBD Audit will be reported in March 2009 and will enable services to benchmark themselves against many elements of these standards.

It is recommended that IBD Services should be expected to meet the standards by September 2010.

Key facts

- About 240,000 people in the UK have IBD, approximately 400 patients per 100,000 population.
- The cost of IBD to the NHS has been estimated at about £720 million per annum, based on the prevalence and an average cost of £3,000 per year per patient.
- There is no cure. Cause is likely to be multifactorial, a combination of genetic predisposition and environmental triggers.
- These are lifelong conditions and most commonly first present in the teens and twenties (25% present in adolescence; median age at diagnosis is 29.5 years).
- Men and women are diagnosed in equal numbers.
- Between 50% and 70% of patients with Crohn's Disease will undergo surgery within 5 years of diagnosis. In Ulcerative Colitis lifetime surgery rates are about 20-30%.
- Patients with extensive disease may develop complications which are potentially life-threatening.
- There is an established link between IBD and an increased risk of developing colorectal cancer.
- The lifetime medical costs associated with the care of IBD can be comparable to major chronic diseases such as diabetes mellitus or cancer.

Executive summary

The aim of the standards is to ensure that IBD patients receive consistent, high-quality care and that IBD Services throughout the UK are knowledge-based, engaged in local and national networking, based on modern IT and that they meet specific minimum standards.

Aim of the Standards

1. This document is to inform NHS Managers and Commissioning Organisations as part of a UK-wide strategy to improve services and care for patients who have Ulcerative Colitis or Crohn's Disease. These conditions are the two most common forms of Inflammatory Bowel Disease (IBD) and together affect about 240,000 people in the UK. It is important not to confuse *Inflammatory Bowel Disease* (IBD) with the different condition *Irritable Bowel Syndrome* (IBS).
2. Following a UK-wide Audit of IBD Services and Care which revealed unacceptable variation in services and aspects of clinical care, a Working Group of the key professional organisations and NACC, the IBD patient organisation, was formed to recommend national standards for IBD care. The aim of the standards is to ensure that IBD patients receive consistent, high-quality care and that IBD Services throughout the UK are knowledge-based, engaged in local and national networking, based on modern IT and that they meet specific minimum standards. It is recommended that IBD Services should meet these standards by September 2010.

About Inflammatory Bowel Disease

3. Ulcerative Colitis and Crohn's Disease are lifelong conditions, most commonly presenting in young adults, adolescents and children and affecting men and women about equally. The diseases cause inflammation and ulceration in the colon and rectum (Ulcerative Colitis) or anywhere in the gastrointestinal tract (Crohn's Disease). The main symptoms are very urgent and frequent diarrhoea, pain, profound fatigue and anaemia, with, for some patients, associated inflammation of the joints, skin, or eyes. Malnutrition and weight loss are common. The diseases follow an unpredictable relapsing and remitting course with significant variation in the pattern and complexity of symptoms that may affect each patient.
4. Drugs to suppress the immune system and to induce and maintain remission are the mainstay of medical management, though nutritional therapy as primary treatment is also important in Crohn's Disease and often used in children. Drug treatments aim to suppress the symptomatic effects, but the extent to which they alter the natural course of the disease remains unclear. 30% of patients fail to respond to these drugs and will then be considered for anti-TNF α biological therapies or surgery. Over half of patients with Crohn's Disease and about 20-30% of patients with Ulcerative Colitis will undergo surgery.
5. Education, working, social and family life are all disrupted by the unpredictable occurrence of flare-ups. The symptoms of IBD can severely affect self-esteem and social functioning, particularly among the young and newly-diagnosed. A proportion of patients normalise an unnecessarily limited pattern of life.

6. The causes of both Crohn's Disease and Ulcerative Colitis remain unknown. There is a genetic predisposition in some families and this probably determines the pattern and severity of the disease in any individual patient. Research is also focused on environmental triggers for the disease, but these probably vary between individuals.
7. Patients with extensive disease may develop complications which are potentially life-threatening. They also have a long-term increased risk of colorectal cancer.

Cost and impact of Inflammatory Bowel Disease

8. There is a south-north gradient to the incidence of IBD and the incidence is therefore higher in Scotland. Compared to the non-Jewish Caucasian population, IBD occurs more frequently in Ashkenazi Jews and at about the same level in families originating in Africa or the Caribbean. For second-generation Indian and Pakistani families, the incidence of Crohn's Disease is about the same, but for Ulcerative Colitis is higher.
9. A UK-wide Registry of IBD patients identifying the IBD population accurately would significantly improve the ability of health authorities to ensure IBD Services are planned and managed effectively.
10. The cost of IBD to the NHS has been estimated at about £720 million, based on the prevalence and an average cost of £3,000 per year per patient. Drug costs have accounted for about a quarter of total direct health service costs for IBD in Europe. New biological treatments may increase this, but the high acquisition costs for these drugs may be offset by reductions in costs for other services.
11. Half of all annual direct healthcare costs from IBD relate to the inpatient management of a minority of patients who need intensive medical or surgical intervention. There are strong arguments both clinically and economically for focussing services towards prompt detection and optimal outpatient management of disease flare-ups and effective maintenance of remission.
12. There is a significant morbidity and mortality in economically active young people requiring elective or emergency surgery for Ulcerative Colitis and Crohn's Disease, with a major adverse impact on the potential economic contribution of the many young people affected. However, with effective management many of these patients are able to lead rewarding and productive lives within the constraints imposed by their condition.

The IBD Standards

13. The six standards agreed by the Working Group are:

Standard A – High quality clinical care

High quality, safe and integrated clinical care for IBD patients based on multi-disciplinary team working and effective collaboration across NHS organisational structures and boundaries.

Standard B – Local delivery of care

Care for IBD patients that is delivered as locally as possible, but with rapid access to more specialised services when needed.

Standard C – Maintaining a patient-centred service

Care for IBD patients that is patient-centred, responsive to individual needs and offers choice of clinical care and management where possible and appropriate.

Standard D – Patient education and support

Care for IBD patients that assists patients and their families in understanding Inflammatory Bowel Disease and how it is managed, and that supports them in shared decision-making and achieving the best quality of life possible within the constraints of the illness.

Standard E – Information technology and audit

An IBD Service that uses IT effectively to support patient care and to optimise clinical management through data collection and audit.

Standard F – Evidence-based practice and research

A service that is knowledge-based and actively supports service improvement and clinical research.

14. For each of the six standards, the Working Group has set out the Rationale and a set of Implementation Standards (Pages 10-18)

National action required

15. National action is required to support the successful local implementation of the IBD Standards and the Working Group has identified key actions for the IBD professional and patient community and for UK Government Health Departments and NHS Management.
16. The IBD community should continue to support an IBD steering group with representation from all professional and patient groups to establish and implement a UK-wide strategy for the further development of IBD Services. The essential purpose of such a group would be to lead and co-ordinate developments within the IBD community to support the achievement of consistently high-quality IBD Services throughout the UK.
17. The specific objectives proposed for the Group include liaison with NHS Management and Government Health Departments, continuation of the UK-wide IBD Audit, establishment of a UK-wide Registry of IBD patients, encouragement of IBD Services to implement electronic record systems for IBD, establishing a Quality Improvement Programme for IBD and encouraging the development of agreed clinical and patient-reported outcome measures for monitoring the quality of IBD Services.
18. An important role is identified for Government Health Departments and NHS Management in each of the four UK countries to support the introduction and implementation of

the IBD Standards and the successful future development of IBD Services. Several supportive actions are proposed including explicit support in promoting the IBD Standards to local health organisations to encourage implementation, funding for the continuation of the biennial UK-wide IBD Audit, support for the full implementation of Managed Clinical Networks in Paediatric IBD Services and support for piloting new models of the organisation of care for adult IBD patients.

IBD Audit and IMAGE Project

19. Two important current activities in IBD are described – the UK-wide Audit of IBD Services and Care which will report the results of the second round of the Audit in March 2009 – the results of which will be used by the Healthcare Commission as part of their screening for the Annual Health Check in England - and the IMAGE Project which is exploring how the management of four gastrointestinal diseases, including IBD, can be improved by building on the approaches introduced within the Quality Outcomes Framework (QOF).

Further information

20. Some sources of further information for NHS Managers and Commissioning Organisations are identified and where possible these have been gathered together on a new website for ease of access – www.ibdstandards.org.uk

A UK-wide Registry of IBD patients identifying the IBD population accurately would significantly improve the ability of health authorities to ensure IBD Services are planned and managed effectively.

What is Inflammatory Bowel Disease (IBD)?

Ulcerative Colitis and Crohn's Disease are the main conditions described as IBD. They are lifelong conditions and most commonly first present in the teens and twenties (25% present in adolescence; median age at diagnosis is 29.5 years). Men and women are diagnosed in more or less equal numbers. The overall prevalence of IBD in the UK is estimated to be 240,000, approximately 400 patients per 100,000 population.¹

It is important to note that IBD means *Inflammatory Bowel Disease*, this is not the same as IBS; which means *Irritable Bowel Syndrome*. The latter is a functional disorder of the digestive system and is treated in a completely different way. Some IBD patients may also have IBS.

Clinical effects

The key effects of the disease are inflammation and ulceration in the colon and rectum (Ulcerative Colitis) or anywhere in the gastrointestinal tract (Crohn's Disease). Crohn's Disease can follow either of two patterns – stricturing disease (narrowing of the intestine causing obstruction) or fistulising disease (where the disease creates holes in the bowel wall that allow the faecal contents to leak out).

Both conditions can produce symptoms of urgency, diarrhoea, pain, profound fatigue and anaemia, with, for some patients, associated inflammation of the joints, skin, liver or eyes. Malnutrition and weight loss are common with patients often altering their eating habits to alleviate symptoms. When diagnosed in childhood (about 25% of all cases) the disease is often more severe than if presenting in adulthood with major consequences on life-long morbidity.²⁰

IBD follows an unpredictable relapsing and remitting course with significant variation in the pattern and complexity of the symptoms both between patients and in the individual patient at different times in his or her illness.^{9,10,12,13}

Treatment

Aminosalicylates (5ASA), corticosteroids and immunosuppressive drugs are the mainstay of medical management for inducing and maintaining remission. They suppress the symptomatic effects, but the extent to which they alter the natural course of the disease remains unclear.²¹ 30% of patients will fail to respond to these drugs or be intolerant

of them and these patients may then be considered for anti-TNF α biological therapies or surgery.

Between 50% and 70% of patients with Crohn's Disease will undergo surgery within 5 years of diagnosis. In Ulcerative Colitis lifetime surgery rates are about 20-30% for total Ulcerative Colitis. Of the patients who have chronic relapsing Ulcerative Colitis, about 50% need a colectomy though rates vary between countries and regions.^{22,23,8}

The most common forms of surgery are removal of the diseased part of the small bowel, with or without part of the colon; partial or total removal of the colon and/or rectum (proctocolectomy) with formation of a stoma, which may be permanent. For people who have Ulcerative Colitis, restorative proctocolectomy is the most common operation. This involves removal of the colon and rectum, combined with the fashioning of an ileal pouch. This is made from the terminal ileum and joined to the anus to form a reservoir which replaces the rectum, thus avoiding a permanent ileostomy.^{9,10,12,13,24}

Psycho-social effects

Education, employment, personal relationships, social and family life are all disrupted by the unpredictable occurrence of flare-ups. The frequent and urgent need for the toilet, together with loss of sleep and the invisible symptoms of pain and continual or profound fatigue, can severely affect self-esteem and social functioning, particularly among the young and newly-diagnosed. For understandable reasons, a proportion of patients normalise an unnecessarily limited pattern of life either due to inadequate control of symptoms from poor medical management or because of the loss of self-esteem and deep anxiety about losing bowel control if they venture too far from familiar environments.^{25,26}

Causation

The causes of both Crohn's Disease and Ulcerative Colitis remain unknown. There is a genetic predisposition which increases the risk of IBD about tenfold in first degree relatives of an IBD patient and which probably determines the pattern and severity of the disease in any individual patient. Much research is focused on understanding the role of bacteria in the gut and the many different parts of the immune system's response to external triggers. It seems quite likely that the trigger for the disease varies between individuals.^{9,12,27}

IBD can produce symptoms of urgency, diarrhoea, pain, profound fatigue and anaemia, with, for some patients, associated inflammation of the joints, skin, liver or eyes. Malnutrition and weight loss are common with patients often altering their eating habits to alleviate symptoms.

Complications, cost and impact of IBD

Severe cases may lead to life-threatening complications such as complete blockage or perforation of the bowel.

Complications

In cases where diarrhoea is prolonged, or bloody and severe, water and salt loss and poor absorption of nutrients may occur, leading to anaemia, dehydration and severe weight loss.

The inflammation in Crohn's Disease may lead to strictures (narrowing) of the bowel resulting in abdominal pain due to partial blockage. Severe cases may lead to life-threatening complications such as complete blockage or perforation of the bowel. Crohn's Disease is often associated with anal problems such as fissure, tags, abscess and fistula formation.

There is an established link between IBD and an increased risk of developing cancer, primarily in the colon. The risk of colorectal cancer in Ulcerative Colitis increases with the extent and severity of the disease, the age of onset and duration of the disease. Systematic reviews have shown the risk of colorectal cancer at 10, 20 and 30 years after the onset of the disease to be 2, 8 and 18% (respectively). The risk in patients who have colonic Crohn's Disease may be slightly less.^{28,29,30}

Cost and impact

The overall prevalence of IBD in the UK is estimated to be 240,000 and in 2006 the cost to the NHS was estimated at about £720 million, based on the prevalence and an average cost of £3,000 per patient per year.^{31,32}

Given the availability of new therapeutic advances, this cost is likely to rise, although new biological therapy for Crohn's Disease in the UK has been shown to reduce the need for hospital inpatient-care.³³

There is a south-north gradient to the incidence of IBD, with rates in the UK being highest in Scotland. Compared to the non-Jewish Caucasian population, IBD occurs more frequently in Ashkenazi Jews and at about the same level in families originating in Africa or the Caribbean. For second-generation Indian and Pakistani families, the incidence of Crohn's Disease is about the same, but for Ulcerative Colitis is higher.³⁴

A UK-wide Registry of IBD patients identifying the IBD population accurately would significantly improve the ability of health authorities to ensure IBD Services are planned and managed effectively.

Inflammatory Bowel Diseases are chronic, relapsing conditions which may begin in early life and require individuals to seek healthcare repeatedly over many decades of disease. As a result, the lifetime medical costs associated with the care of IBD can be comparable to major chronic diseases such as diabetes mellitus or cancer.

Half of all annual direct healthcare costs associated with IBD relate to the inpatient management of a minority of patients who need intensive medical or surgical intervention. In a UK study, six-month direct medical costs for patients who had required a period of hospitalisation were 20-fold higher than for IBD outpatients who remained in remission. Disease flares responding to outpatient management were associated with a 2-to-3 fold increment in costs compared to stable patients.³⁵ Hence, there are strong arguments both clinically and economically for focussing services towards prompt detection and optimal outpatient management of disease flare-ups and effective maintenance of remission.

Traditionally, drug costs have accounted for about a quarter of total direct health service costs for IBD in Europe. However, the emergence of new biological treatments is likely to alter the traditional profile of expenditures in future. These new agents offer hope to more severely afflicted individuals and short-term audit data suggest that the high acquisition costs for the drug may be offset by reductions in costs for other services.³³

Ulcerative Colitis and Crohn's Disease have a substantial impact on the physical health, social functioning and quality of life of patients, but with effective management many patients will be able to lead a rewarding and productive life within the constraints imposed by the condition.

However, there is a significant morbidity and mortality in active people requiring elective or emergency surgery for Ulcerative Colitis and Crohn's Disease. IBD has a major adverse impact on the potential economic contribution of the many young people affected through the loss of productive work and an additional impact on their families' lives.³⁶



Standards for Inflammatory Bowel Disease Services

The aim of the standards

The aim of the IBD Standards is to ensure that NHS services throughout the UK are designed and supported to deliver:

Standard A

High quality clinical care

High quality, safe and integrated clinical care for IBD patients based on multi-disciplinary team working and effective collaboration across NHS organisational structures and boundaries.

Standard B

Local delivery of care

Care for IBD patients that is delivered as locally as possible, but with rapid access to more specialised services when needed.

Standard C

Maintaining a patient-centred service

Care for IBD patients that is patient-centred, responsive to individual needs and offers choice of clinical care and management where possible and appropriate.

Standard D

Patient education and support

Care for IBD patients that assists patients and their families in understanding Inflammatory Bowel Disease and how it is managed, and that supports them in shared decision-making and achieving the best quality of life possible within the constraints of the illness.

Standard E

Information technology and audit

An IBD Service that uses IT effectively to support patient care and to optimise clinical management through data collection and audit.

Standard F

Evidence-based practice and research

A service that is knowledge-based and actively supports service improvement and clinical research.

The standards apply to the care of patients with IBD of all ages, except for those relating specifically to children who have IBD, which are documented in the section entitled 'Care of Children and Young People who have IBD'.

The population base for these standards is 250,000. Hospitals with smaller catchment populations may still offer an effective and safe IBD Service close to the patient's home, provided satisfactory networking arrangements are demonstrated to be in place to meet the defined standards of specialist activity and supporting services.

Standard A

High quality clinical care

High quality, safe and integrated clinical care for IBD patients based on multi-disciplinary team working and collaboration across NHS organisational structures and boundaries.

Rationale

The specialist team

The significant variation in the pattern and complexity of the symptoms between patients, and over time in the same patient, requires experienced and individualised clinical management with continuing collaboration between the patient and the professional team.

The professionals involved in providing IBD care must have specialist knowledge about IBD and its impact on patients and their families and have adequate time for training and education. A multidisciplinary approach is essential to achieving the best care for patients.

The IBD Team described is considered to be the minimum viable team for a full IBD Service to be provided for a population of 250,000. Hospitals with smaller catchment populations may still offer an effective and safe IBD Service provided satisfactory networking arrangements are in place to enable the service to meet the defined standards of specialist activity and supporting services.

Referral pathways

Many patients report that their IBD diagnosis was only made after long periods of coping with difficult and distressing symptoms. Protocols and pathways need to be agreed locally to ensure prompt referral and investigation.³⁷

Nutritional support

A significant number of patients who have IBD suffer from malnutrition. Therefore nutritional intake and dietary advice are important when patients are admitted, when they relapse and during periods of remission. In Crohn's Disease enteral nutrition can be used to induce remission of disease and is often the treatment of choice in children. A proportion of patients, especially inpatients, have nutritional needs that go beyond simple dietary advice and consideration of enteral diets as a primary therapy. A multidisciplinary nutrition support team needs to be available for advice on those patients who may require more complex enteral and/or parenteral nutritional support.

Rapid access to specialist care

Flare-ups of the disease need active management instituted quickly to minimise the impact of the relapse on the patient's well-being and life. The unpredictable nature of relapses requires a responsive service with prompt access to doctors and nurses who are knowledgeable about IBD and can decide with patients which course of action is required. This may be an immediate change of treatment undertaken by the patient at home, an early outpatient appointment or immediate admission.

Use of immunomodulator and biologic therapies

Evidence is growing for the benefit of using more powerful and, in the case of biologic therapies, more expensive drugs to control the symptoms of IBD. These treatments should be initiated and managed by IBD specialists, though ongoing safety monitoring can be part of a shared-care arrangement agreed with patients and their GPs.

Access to specialist surgical care

Patients requiring pouch or salvage pouch surgery, or more complex Crohn's Disease procedures, should have these operations carried out by specialists with training and experience and with appropriate nursing, dietetic and ancillary support. This may involve a patient being transferred to another IBD Centre identified by the IBD Team that is caring for them locally.^{10,13,38,39}

Paediatric and adolescent care

Paediatric and adolescent care is most appropriately undertaken by Paediatric Gastroenterologists with specialist nursing and dietetic support. These teams should operate in a Managed Clinical Network covering a wide area, which can facilitate local shared-care arrangements with adult gastroenterology colleagues and paediatricians who have an interest in gastroenterology, particularly IBD, and ensure a planned transition to adult care.^{15,40}

Implementation Standards

Standard A1 - The IBD Team

Patients with IBD should be cared for by a defined IBD Team with named personnel. Members of the IBD Team must establish a collaborative approach to the provision of care for IBD patients and may cross-cover for each other provided the person covering has the necessary competencies. Some of the sessions may be provided within a broader gastrointestinal role.

One member of the IBD Team should be the named Clinical Lead for the IBD Service.

Based on the need for cross-cover and the defined population of 250,000, the IBD Team should have a minimum of:

- 2 WTE Consultant Gastroenterologists
- 2 WTE Consultant Colorectal Surgeons
- 1.5 WTE Clinical Nurse Specialists with an identified role and competency in IBD
- 1.5 WTE Clinical Nurse Specialists with an identified role and competency in stoma therapy and ileo-anal pouch surgery
- 0.5 WTE Dietitian allocated to gastroenterology
- 0.5 WTE administrative support for the IBD meetings, IBD database recording and audit
- 1 named Histopathologist with a special interest in gastroenterology*
- 1 named Radiologist with a special interest in gastroenterology*
- 1 named Pharmacist with a special interest in gastroenterology*

*with arrangements for cover in the event of his or her absence

Standard A2 - Essential Supporting Services

The IBD Service should have defined access to the following named personnel who should have an IBD interest:

- Psychologist and/or Counsellor
- Rheumatologist
- Ophthalmologist
- Dermatologist
- Obstetrician
- Nutrition Support Team
- Consultant Paediatrician with a special interest in gastroenterology **or** a combination of Consultant Paediatrician plus a Gastroenterologist with an interest in adolescent IBD. Both should be working within a Paediatric Gastroenterology Clinical Network
- An established link with a GP to provide a liaison and educational role with local GPs

Standard A3 - Multidisciplinary Working

A3.1 - IBD Team Meetings

The IBD Team should have regular timetabled meetings preferably weekly, to discuss IBD patients with complex needs. These might be part of an established meeting such as a GI/surgical meeting, but the outcome of the discussions should be formally recorded in the hospital notes. The Team should agree who will discuss the decision with each patient.

The patients to be discussed will be identified by the team. They are likely to include patients with complex needs, patients with perianal Crohn's Disease, patients with aggressive Crohn's Disease at high risk of needing a further resection, new fistula patients and

patients unable to achieve sustained steroid-free remission, but criteria for inclusion can be agreed locally.

- The IBD Team Meetings should include the above complex cases, service issues and development, and a review of all IBD deaths.
- IBD Team Meetings should involve all members of the IBD Team.
- Attendance at IBD Team Meetings should be recorded and minutes kept.
- All decisions at the IBD Team Meetings should be recorded and relevant audit data noted.

A3.2 - Medical/Surgical Interaction

- Patients should have access to a parallel or joint surgical-medical clinic in a unit that meets the standards set out in this document, that is held at least monthly, with a recognised Colorectal Surgeon (adult or paediatric as appropriate) interacting with the Gastroenterologist.
- There must be a defined arrangement for joint discussion with patients whose clinical condition would not permit waiting until the next available clinic where specialist care and follow-up would be available.

Standard A4 - Referral of Suspected IBD Patients

- Guidance should be developed for the identification and referral of symptomatic patients in whom IBD is suspected. GPs should be prepared periodically to review their diagnosis in patients with unresponsive, atypical or troublesome abdominal symptoms.
- A communication pathway must be agreed for referral of possible IBD patients to the IBD Service for rapid consultation and assessment. Such patients should be contacted within 2 weeks of referral and seen within 4 weeks, or more rapidly if clinically necessary.
- Newly-diagnosed IBD patients for whom surgery is not an immediate consideration and who have initially been referred to a surgeon should normally be transferred to the care of the medical gastroenterology team.

Standard A5 - Access to nutritional support and therapy

- Access to a dietitian should be available to all IBD patients.
- Nutritional support should be available to IBD patients.
- Patients with Crohn's Disease, particularly children and patients of all ages with primary small intestinal disease, should have access to appropriate liquid enteral nutritional therapy as primary treatment.
- Patients with complex nutritional needs, which may include enteral and parenteral feeding, must be able to access a full multidisciplinary nutrition support team for comprehensive assessment, management and advice to the IBD Team.

Standard A6 - Arrangements for use of immunosuppressive and biological therapies

- There must be defined clinical responsibility and protocols for the prescribing, administration and monitoring of these therapies in an appropriate clinical setting or in the home, and with consideration for the patient's needs.
- Outcomes of biological therapy and the patients receiving biological therapy should be reviewed regularly.
- Local practice of both immunomodulator and biological therapy should be audited.

Standard A7 – Surgery for IBD

- IBD surgery should be undertaken by recognised colorectal surgeons who are core members of the IBD Team, or their supervised trainees, in a unit where the operations are done regularly.
- Pouch failure and salvage should be managed in a high-volume specialist unit.
- Expert pathological assessment before surgery is important. This may involve referral of cases to a nationally recognised expert in the diagnosis, and differential diagnosis, of chronic inflammatory bowel disease.

Standard A8 - Inpatient Facilities

- Inpatients with IBD should, whenever possible, be cared for on a designated specialist ward area - gastroenterology, surgery, or joint gastroenterology-surgery.
- Gastroenterology and colorectal surgical facilities should preferably be in close proximity.
- Wards for IBD patients should have a minimum of 1 easily-accessible toilet per 3 beds. To provide privacy for patients, ward toilets should have floor to ceiling partitions, full height doors and good ventilation to minimise embarrassment for patients. The toilets should be clean and segregated, ideally with separate facilities for men and women. Facilities should be available for change of stoma appliances and disposal.
- There must be 24 hour access to Intensive Care facilities on site.

Standard A9 - Access to Diagnostic Services

- Patients requiring endoscopic assessment because of relapse of Ulcerative Colitis should have access to investigation within 72 hours.
- There should be access to ultrasound/MRI/CT/contrast studies and endoscopic assessment within 4 weeks maximum, or, in more urgent situations, within 24 hours.
- Histological processing should be rapid (minimum standard 5 working days to report, but with arrangements to report urgent biopsy samples in 2 days when needed).

Standard A10 - Inpatient Care

- Defined arrangements should exist for admitting existing IBD patients direct to the specialist gastroenterology ward or area.
- Patients admitted with known or suspected IBD should be discussed with and normally be transferred to the care of a Consultant Gastroenterologist and/or Colorectal Surgeon within 24 hours of admission.
- All IBD patients admitted should be notified to the IBD medical or surgical specialist nurses.
- All IBD patients admitted should be weighed and their nutritional needs assessed.

Standard A11 - Outpatient Care

- All patients with confirmed IBD should have their details maintained on the Register of IBD patients even when they are no longer regularly attending outpatient clinics.
- All IBD patients who are not under immediate or ongoing care, including those in remission, should have an annual review and basic information recorded. This may be undertaken in a hospital or community clinic or by telephone follow-up, and should be done by a healthcare professional with recognised competence in IBD.
- The criteria for annual review should be agreed by the IBD Team, but would normally include assessment of the need for colorectal cancer surveillance, renal function and bone densitometry.

- All IBD patients who have a concern or questions about their IBD should have access to a dedicated telephone service (IBD Helpline) that is either answered or has an answerphone facility providing a response by the end of the next working day.
- Patients experiencing a possible relapse of their IBD should have access to specialist review within a maximum of 5 working days.
- IBD patients should be able to choose from a range of arrangements for their outpatient care. These should include attending hospital as an outpatient, guided self-management with access to support when required, and care in a primary or intermediate care setting with defined links to the IBD Team.

Standard A12 - Arrangements for the Care of Children & Young People who have IBD

- For initial investigation and treatment children and adolescents should be referred to a Paediatric Gastroenterology Service which is part of a Paediatric Gastroenterology Clinical Network. Follow up should be shared with the referring district hospital and Paediatrician with an interest in gastroenterology as part of this clinical network.
- For the physically mature patient, who has completed their growth, is emotionally mature and without psychological or educational problems, investigations may be undertaken locally. This would have to be with an adult service Gastroenterologist experienced in the management of adolescents with IBD, provided the care is shared with a local Paediatrician with an interest in gastroenterology and standards meet the National Service Framework (NSF) for Children and Young People.⁴¹
- The following standards for staffing and facilities are based on the requirements of the National Service Framework for Children and Young People in England and further guidance is available from the BSPGHAN website.^{40,41} BSPGHAN estimate the catchment population for a Specialist Paediatric Gastroenterology unit to be 2 million people.⁴⁰
 - Children's wards and children's nurses for all inpatient, outpatient and day case stays.
 - Endoscopy procedures in a fully child friendly unit with appropriate anaesthetic sessions and facilities.
 - Accredited Paediatric Anaesthetists.
 - Radiological investigations in a setting suitable for children, by staff trained in performing and reporting them in children.
 - Surgeons with an expertise in paediatric IBD.
 - A minimum of 0.5 WTE Paediatric Dietitian experienced in the use of exclusive enteral feeds as a treatment.
 - A minimum of 0.5 WTE Paediatric Nurse Specialist with an identified role and competence in paediatric and adolescent IBD (this may be combined with other specialist paediatric GI nursing roles).
 - Paediatric Psychologist.
 - Paediatric Endocrinologist.
- Endoscopy should be performed by endoscopists with training and/or extensive experience in endoscopy and ileo-colonoscopy in children.
- Information and support must be available to the parents and siblings of a child who has IBD.
- There must be a defined policy and protocol for transitional care with a named coordinator responsible for the preparation and oversight of transition.(e.g. IBD Nurse Specialist).^{42,43}

Standard B

Local delivery of care

Care for IBD patients that is delivered as locally as possible, but with rapid access to more specialised services when needed.

Rationale

Primary/secondary care interface

At present the great majority of IBD care is provided by healthcare professionals based in secondary care. Some aspects of the management of adults with IBD can be provided outside of secondary care where this will help to take services closer to the patient or offer choice, subject to demonstration that the standards of IBD care provision will be met.

The majority of GPs could participate in a degree of protocol-based shared care – prescription of ongoing medication, monitoring of immunosuppressive drugs and sometimes monitoring of bone density or other parameters.

Some specialist IBD nurses outreach into primary care to help bring expert care closer to the patient and this is an area for potential development.⁴⁴

Implementation Standards

Standard B1 - Arrangements for Shared Care

- The arrangements and scope for shared care and the circumstances in which the patients should be referred back to hospital care must be clearly defined between the hospital staff and the GP. They must be explained verbally to the patient and written information on this provided to the patient, ideally as a care plan.
- A system for sharing of information about test results or treatment changes should be in place through the use of IT, written communication between the GP and hospital or a patient-held record.
- Treatment with immunosuppressive or biological therapies should only be initiated by clinicians with expertise in their use for IBD. Shared care protocols should be developed to support the ongoing prescribing and monitoring of these drugs in general practice.
- Arrangements should always be made in discussion with the patient.

Standard C

Maintaining a patient-centred service

Care for IBD patients that is patient-centred, responsive to individual needs and offers choice of clinical care and management where possible and appropriate.

Rationale

Patient-centred care

Since IBD varies significantly in its pattern and severity between individuals and over time in the same individual, patient-centred care needs to offer different approaches at different times within the life-long disease. No single model is appropriate for all patients all the time, and choice between three approaches is appropriate: hospital care, shared-care with primary care and supported self-managed care.

Offering personalised and responsive healthcare means that any patient can migrate between models of care according to the activity and complexity of disease, local facilities and personal preference. They can also make different choices at different times in their illness. Arrangements should acknowledge that whilst many patients will wish to have active engagement in decisions and management, some may prefer a more passive patient role.

Each model of care needs an administrative and clinical infrastructure to support the process. Self-managed care must be properly organised and supported to be safe and effective and should not be seen as a 'cheap option'.⁴⁵

Implementation Standards

Standard C1 – Information on the IBD Service

All IBD patients should have information describing the IBD Service and how it can be accessed. This should include information on how patients who have concerns about their condition or their care can request discussion of their case at the IBD Team meeting or request a second opinion. It should also explain how patients can give feedback on the care they receive or participate actively in service development.

Standard C2 – Rapid access to specialist advice

There should be a clear process for patients to obtain access to specialist advice and support from a named specialist nurse/stomatherapist by the end of the next working day. Ideally there should be a choice of telephone and email contact.

Standard C3 – Supporting patients to exercise choice between treatments

Where there are alternative treatment options then information and support should be offered to patients to enable them to participate in decisions about which treatment to select. This might include choice between drug and dietary therapy for Crohn's Disease, between steroids or aminosalicylates (5ASA) for inducing remission in Ulcerative Colitis, between rescue medical therapy and surgery during a severe, acute relapse.

Standard C4 – Supporting patients to exercise choice between care strategies for outpatient management

Patients may prefer continuing hospital management, shared care with their GP or supported self-management and they may wish to choose a different option at different stages in their illness. The appropriate administrative and clinical infrastructure must be in place to support these different strategies¹⁸ and patients should have written information, preferably a care plan, explaining clearly what arrangements have been agreed with them for their care.⁴⁶

Standard C5 – Involvement of patients in service improvement

Patients should have a voice in the development of the IBD Service. The service must be able to demonstrate that mechanisms are in place to obtain and respond to patient feedback about their IBD Service and to provide opportunities for more direct involvement. Possible mechanisms include:

- Patient satisfaction questionnaires or user surveys
- Regular meetings or open forum sessions with patients about the service (e.g. NACC Patient Panels).⁴⁷

Standard D

Patient education and support

Care for IBD patients that assists patients and their families in understanding Inflammatory Bowel Disease and how it is managed, and that supports them in shared decision-making and achieving the best quality of life possible within the constraints of the illness.

Rationale

Patient education

Patients who are well-informed about their illness and how it can be treated, who have a clear understanding of the service being offered to them and who receive support from the IBD Team in adapting to the social and psychological impact of IBD, will be able to manage their illness more effectively and have a greater chance of achieving a better quality of life within the constraints of their illness.⁴⁶

Implementation Standards

Standard D1 – Provision of information

- All patients must be offered appropriate information about their care, treatment options and condition at all stages of their illness. Information should be appropriate to the age, understanding and communication needs of the patient and carers.
- Written information about IBD in straightforward English should be provided in outpatient clinics, ward, and endoscopy areas.
- Information should be available in languages other than English where the catchment population requires this.
- Communications relating to informed consent should be written in clear, straightforward language and staff should ensure they are understood by the patient before signing.
- Patients being considered for surgery, especially pouch surgery or ileostomy, should be offered written and/or audio-visual information, and where possible the option to talk with patients who have had pouch surgery or a permanent ileostomy. They should also be provided with information about their post-operative care, including histology.
- Information should be provided to all inpatients about their care following discharge and the arrangements for follow up.

D2 – Education for patients

The IBD Service should provide education opportunities for patients and their families, as individuals or in groups, to enable them to understand their illness and the options for treatment and to support them in managing their own care.

D3 – Information about patient organisations

All patients should be provided with contact information for the relevant patient organisations.

D4 – Support for patient organisations

There should be regular contact and support from the IBD Team for educational activities for patients e.g. NACC Group meetings, NACC or CICRA paediatric events, IA (The Ileostomy and Internal Pouch Support Group) meetings, local pouch support groups.

Standard E

Information Technology and audit

An IBD Service that uses IT effectively to support patient care and to optimise clinical management through data collection and audit.

Rationale

IT and audit

Providing effective specialist support to patients at home by telephone or email enables them to manage their concerns and relapses more quickly and effectively and reduces outpatient appointments and admissions.⁴⁵ Having patients' records available electronically is essential to the effective provision of an IBD Helpline, enabling immediate assessment of the patient's current concern with full knowledge of their past symptoms and treatment.

Collecting the clinical data prospectively not only enables the care of the individual patient to be optimised and made safer through electronic monitoring and reminders, but it also enables monitoring and assessment of the management and outcomes of all the IBD patients. The quality of care provided can then be audited routinely, with the emphasis being on clinical indicators of quality rather than process measures. Key aspects such as the outcomes of immunosuppressive, biological and surgical care can be assessed and indicators such as the proportion of patients on steroids for greater than three months can be monitored routinely and discussed in IBD Team meetings.

Provision of data for national audit becomes much easier and again this can begin to focus on quality of clinical care. (In England this will be one factor in the 2010 requirement for assessment and reporting of quality of care.)⁴⁸

Implementation Standards

Standard E1 - Register of patients under the care of the IBD Service

Every IBD Service should maintain a local Register of **all** diagnosed IBD patients in the catchment area (including those who have been diagnosed but are not currently being managed in secondary care) recorded on a searchable database and with adequate clerical support to maintain this.

Standard E2 – Developing an IBD database

IBD Services should develop towards keeping electronic records of patients' disease histories and treatments.

Standard E3 - Participation in Audit

Every IBD Service should take part in regular audit, including

- Participation in national audit and data-collection.^{6,49}
- All IBD deaths must be fully discussed at the IBD Team meeting and the outcome of the discussion recorded and submitted to national data collection.
- The outcomes for patients receiving biological therapies should be submitted to national data collection.
- The outcomes of all emergency colectomy, ileo-anal pouch and abdominal operations for Crohn's Disease should be submitted to national audit and data-collection.

Standard F

Evidence-based practice and research

A service that is knowledge-based and actively supports service improvement and clinical research.

Rationale

Training and education

The IBD unit should offer high level training in Inflammatory Bowel Disease to all healthcare professionals involved in IBD care in both primary and secondary care to enable them to provide skilled, specialist and patient-orientated care to high standards. Practitioners wishing to provide IBD Services, whether in primary or secondary care, should declare a specialist interest and should be named members of the IBD Team.

Research

The principle of a knowledge-based service requires that necessary research should be identified and prioritised. Nationally the objective is to develop a balanced portfolio of research funded from a variety of sources that units will be expected to support and contribute to. Commissioners and managers should include time and resources to enable IBD Teams to contribute to this process. The IBD Services should be committed to the objectives of the National Institute for Health Research (NIHR) and the UK Collaboration Clinical Research (UKCRC) and support the portfolio of research relating to IBD.⁵⁰⁻⁵¹

Implementation Standards

Standard F1 - Training and Education

- All members of the IBD Team should be expected and enabled to participate in local and national professional education to maintain their competence and knowledge in a fast-developing subspecialty.
- Advanced nursing practitioners within the IBD Team should have access to medical support as well as nursing supervision.
- The IBD Team should provide IBD awareness and education opportunities for GPs. These should focus on the initial presentation of IBD, as well as its treatment. A lead GP should be identified to assist in this.

Standard F2 - Research

- IBD Services should encourage and facilitate involvement in multi-disciplinary research through national or international IBD Research projects and registries.
- IBD Services should contribute patients to UKCRN clinical trials and be supported to meet any targets for research activity that UKCRN might set.
- All patients should be given the opportunity to participate in clinical trials and to provide samples for ethically approved projects.

Standard F3 - Service Development

- IBD Teams should participate in local and national activities intended to improve the quality of IBD care and services.
- IBD Teams should take an active part in clinical network arrangements and events with neighbouring IBD Services.
- IBD Teams should be encouraged to hold an Annual Review Day to reflect on their service and where appropriate to consult with relevant stakeholders.

National action to support local implementation

The IBD community

The IBD Standards Working Group and the IBD Audit Steering Committee are recommending that the IBD patient and professional organisations should continue to support a collaborative steering group which would develop a UK-wide strategy for the further development of IBD Services. The aims of this collaborative group should include:

- Providing leadership within the IBD community to achieve consistently high-quality IBD Services throughout the UK.
- Liaison with NHS Management and Government Health Departments on the future development of IBD Services.
- Continuation of the UK-wide IBD Audit.
- Establishment of a UK-wide Registry of IBD patients for service planning, audit and research purposes.
- Encouragement of IBD Services to implement electronic record systems for IBD.
- Establishing a Quality Improvement Programme for IBD with funding for key clinical and allied professional staff and patient representatives to give their time and leadership to the programme.
- Ensuring the development of agreed clinical and patient-reported outcome measures that will support ongoing monitoring of the quality, safety and cost-effectiveness of IBD services.
- Encouraging the development of discussions between primary and secondary care institutions on clinically safe and cost-effective ways to promote integrated care for IBD.

Government Health Departments and NHS

There is an important role for Government Health Departments and NHS Management in each of the four UK countries to support the introduction and implementation of these IBD Standards and the successful future development of IBD Services. Key supportive actions would be:

- Explicit support in promoting the IBD Standards to local health organisations.
- Support for the development and implementation of a UK-wide strategy for the development of IBD Services.

- Funding for the continuation of a UK-wide IBD Audit and ongoing IBD Registry.
- Assistance in establishing the costs of providing safe and effective healthcare for IBD patients to inform commissioning and funding.
- Support for the full implementation of Managed Clinical Networks in Paediatric Gastroenterology Services.
- Ensuring that effective arrangements are in place for transition between paediatric and adult care.
- Support for the piloting of Managed Clinical Networks for adult IBD Services.
- Support for piloting one or more models of community-based provision of outpatient adult IBD Services to explore whether these can provide a safe and effective service closer-to-home and reach those patients who have IBD but are not being actively managed in either primary or secondary care.

Current national IBD activities

The IBD Audit (2006 – 2009)

The second round of the IBD Audit took place in the autumn of 2008 and will be reported in March 2009 at the British Society of Gastroenterology Annual Meeting. The audit covers organisation and structure of services, inpatient care for both Ulcerative Colitis and Crohn's Disease and outpatient care for Crohn's Disease. The 2008 Audit included paediatric IBD services for the first time. The Audit is a project funded by the Health Foundation until September 2009.⁶

Key elements of the data collected will be used by the Healthcare Commission in England as part of the screening process to validate clinical quality in the Annual Health Check of Hospital Trusts for 2008/9. The service and clinical criteria that will be used from the IBD Audit data are listed in Appendix A.

The IMAGE Project (2007 – 2010)

This three year project is exploring how management of four gastrointestinal diseases in primary care can be improved. One of these conditions is IBD. Patient focus groups identified patient priorities for improvement and these were considered alongside professional guidelines and evidence to set the aims for improved GP management.⁵² The project has adopted some of the IT-based approaches introduced within the Quality and Outcomes Framework (QOF) for other conditions. This project will report in 2010 and is also funded by the Health Foundation.

Sources of further information

As many of the resources and references as possible have been brought together on a supporting website to assist commissioning and provider organisations in planning IBD Services. Further information and links will be added as they become available - www.ibdstandards.org.uk

Useful websites

IBD Audit 2006 Report and IBD Audit Toolkit

The toolkit contains examples of protocols, job descriptions and good practice from IBD Teams around the UK. All of the documents have been provided on the basis that they can be adapted and used by other IBD Teams.

www.rcplondon.ac.uk/college/ceeu/ceeu_uk_ibd_audit.htm

IBD Patient Surveys and Reports from NACC

NACC has conducted various research, surveys and focus groups. The reports from these are available from the NACC website together with details of NACC services and the support the charity can provide to hospitals.

www.nacc.org.uk/content/research/articles.asp

IBD patient organisations:

- **NACC** The National Association for Colitis and Crohn's Disease
www.nacc.org.uk
- **CICRA** Crohn's in Childhood Research Association
www.cicra.org
- **IA** The Ileostomy and Internal Pouch Support Group
www.the-ia.org.uk
- **EFCCA** The European Federation of Ulcerative Colitis and Crohn's Associations
www.efcca.org

Professional organisations

- **Association of Coloproctology of Great Britain and Ireland** www.acpgbi.org.uk
- **British Dietetic Association** www.bda.uk.com
- **British Society of Gastroenterology** www.bsg.org.uk
- **British Society of Gastroenterology, Hepatology and Nutrition**
www.bspghan.org.uk
- **Primary Care Society for Gastroenterology**
www.pcs.org.uk
- **Royal College of Nursing**
www.rcn.org.uk and www.ibdnurses.com

Other useful websites:

- **IMAGE Project**
Management of GI Diseases in Primary Care
www.kcl.ac.uk/gp/image
- **ACPGBI Ileal Pouch Database**
www.ipdb.org.uk
- Do once and share "Requirements for an Electronic Care Record for IBD patients"
<http://www.gloshospitals.org.uk/pdf/requirements.pdf>

Appendix 1.

The UK IBD Audit 2nd Round and the Healthcare Commission 2008/9 Annual Health Check/Core Standards

Key elements of the data collected will be used by the Healthcare Commission in England as part of their screening process to cross check Hospital Trusts' declarations against Core Standards to identify risk as part of the Annual Health Check. The following are the service and clinical criteria that the UK IBD Audit Steering Group recommended and were accepted by the Healthcare Commission.

To be asked in the Audit Section:

- Did your hospital participate in the UK IBD Audit 2008?

Questions for screening data:

Organisation of services

- Do timetabled IBD Team meetings take place and who attends?
- Is there an IBD Clinical Nurse Specialist on site?
- Is there a dedicated gastroenterology ward and do they have a maximum of three beds per toilet in the ward?
- Is there a searchable database of IBD patients on site?
- Is there a hospital nutrition team?
- Is there written information for patients with IBD about who to contact in the event of a relapse?
- In general, how soon could a relapsed patient expect to be seen in clinic?
- Do patients have access to an IBD specialist by means of a drop-in-clinic, telephone or e-mail?
- Are there any joint or parallel clinics run between Gastroenterologists and Colorectal Surgeons?
- Are patients provided with written information about IBD?

- Is there a paediatric to adult handover clinic for young patients with IBD?
- Is a registered counsellor available to patients as part of your IBD Service?
- Are there any Psychologists attached to the Gastroenterology Service?
- Do pathways exist for direct access to psychological support?
- Is there an acute pain management team on site?
- Does the hospital offer open forums or meetings for patients with IBD?
- Are any of the following activities or systems in place to involve patients in giving their views on the development of IBD Services: regular patient surveys, individual patient representatives, patient panel meetings?

Ulcerative Colitis Inpatients:

- Taking of Stool Samples for Standard Stool Cultures and CDT.
- Prophylactic heparin given.

Crohn's Disease Inpatients:

- Patient is weighed on admission and the weight recorded in the notes.
- Prophylactic heparin given.
- Taking of Stool Samples for Standard Stool Cultures and CDT.

Crohn's Disease Outpatient care:

- Established immunosuppressive therapy was monitored by full blood count at least 3 monthly.
- No patients receiving systemic corticosteroid therapy for more than 3 months.

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