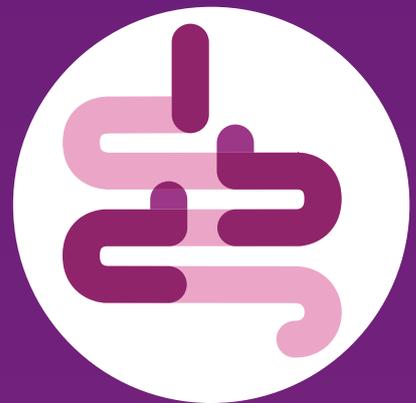


Standards for the Healthcare of People who have Inflammatory Bowel Disease (IBD)

IBD Standards

2013 Update



The IBD Standards Group

Association of Coloproctology of Great Britain and Ireland • British Dietetic Association • British Society of Gastroenterology • British Society of Paediatric Gastroenterology, Hepatology and Nutrition • Crohn's and Colitis UK • Primary Care Society for Gastroenterology • Royal College of Nursing • UK Clinical Pharmacy Association • Royal College of Physicians • Royal Pharmaceutical Society

Foreword

Since the original *Quality Care: Service Standards for the Healthcare of People who have Inflammatory Bowel Disease (IBD)* was produced in February 2009, there have been marked improvements in the delivery of IBD services, as shown by the findings of the UK-wide IBD Audit.

The first national audit of IBD services and care, which took place in 2006, found substantial local variation in the provision, organisation and clinical quality of IBD services and significant aspects of care that did not meet existing clinical guidelines. As a result, organisations representing patients and professionals collaborated to define for the first time what was required in terms of staffing, support services, organisation, patient education and audit to provide integrated, safe, effective, patient-centred, high quality IBD services. The third round of the IBD Audit directly monitored IBD services against the Standards.

The value of the IBD Standards and the IBD Audit has been demonstrated by significant improvements in IBD services over the years they have been in place, but there is still much to do to ensure all IBD services meet the Standards. In updating these, we believe they have a unique and fundamental role in driving specific improvements in the quality and management of IBD services across the UK, with continued support and commitment from Government and the NHS at national, regional and local levels.

This is critical for the hundreds of thousands of patients and their families for whom Ulcerative Colitis and Crohn's Disease have a profound impact on their lives. 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 lifelong support from the NHS to enable them to achieve the best quality of life possible within the constraints of their illness. With appropriate healthcare provision, most people with IBD can sustain economically productive and positive family support roles, with all the benefits that follow both for society and for the self-esteem and wellbeing of the patient and their family.



David Barker
Chair, IBD Standards Group

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Members of the Original IBD Standards Group:

Dr Ian Arnott	Dr Stuart Bloom
Dr Nick Croft	Mr Richard Driscoll
Dr Cathryn Edwards	Professor Chris Hawkey
Dr Keith Leiper	Dr Miranda Lomer
Ms Isobel Mason	Dr Sally Mitton
Professor John Nicholls	Ms Alison Nightingale
Professor John Northover	Professor Greg Rubin
Dr Ian Shaw	Professor Andrew Shorthouse
Dr Simon Travis	Ms Lisa Younge



Primary Care Society
for Gastroenterology



BRITISH SOCIETY OF
GASTROENTEROLOGY



Association of
Coloproctology of Great
Britain and Ireland



British Society of Paediatric Gastroenterology Hepatology and Nutrition



Endorsed by



Standards for the Healthcare of People who have Inflammatory Bowel Disease (IBD)

Produced By

The IBD Standards Group

Organisations Represented

*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
Crohn's and Colitis UK
Primary Care Society for Gastroenterology
Royal College of Nursing Gastrointestinal Nursing Forum
Royal Pharmaceutical Society
Royal College of Physicians
UK Clinical Pharmacy Association Gastroenterology
Interest Group*

Supporting Organisations

*British Association for Parenteral and Enteral Nutrition
British Society of Gastrointestinal and Abdominal
Radiology
CICRA – Crohn's in Childhood Research Association
IA – The ileostomy and internal pouch Support Group
Royal College of GPs
Royal College of Pathologists*

Members of the IBD Standards Group

Dr Ian Arnott Consultant Gastroenterologist,
Western General Hospital, Edinburgh; Clinical
Lead, UK IBD Audit

Mr David Barker Chief Executive, Crohn's and
Colitis UK; Chair, IBD Standards Group; Chair,
UK IBD Strategy Group

Dr Stuart Bloom Consultant Gastroenterologist,
University College London; Chair, IBD Registry;
National Speciality Lead for Gastroenterology,
National Institute for Health Research
Comprehensive Clinical Research Network
(NIHR-CCRN)

Dr Fraser Cummings Consultant Gastroenterologist,
Southampton General Hospital; Clinical Lead,
IBD Registry

Dr James Dalrymple GP Partner, Drayton and
St Faiths Medical Practice; Chair, Primary Care
Society for Gastroenterology

Dr Jayne Eaden Consultant Gastroenterologist and
Clinical Lead for Gastroenterology, University Hospitals
Coventry and Warwickshire; IBD Section Secretary
and IBD Section Representative, British Society
of Gastroenterology

Dr Cathryn Edwards Consultant Gastroenterologist
and IBD Clinical Lead, Torbay Hospital, South Devon;
Senior Secretary, British Society of Gastroenterology

Mr Omar Faiz Consultant Surgeon, St Mark's Hospital,
London; Chair, IBD Sub-Committee, Association of
Coloproctology of Great Britain and Ireland; Chair,
IBD Sub-Committee, National Ileal Pouch Registry;
Vice-Chair, Gastroenterology Surgery Group, Global
Comparators Partnership

Sr Victoria Garrick Paediatric IBD Nurse Specialist,
Royal Hospital for Sick Children, Glasgow; Royal
College of Nursing Gastrointestinal Nursing Forum

Dr Martin Gay National Vice-Chair, Crohn's and
Colitis UK

Ms Jackie Glatter Health Service Development
Adviser, Crohn's and Colitis UK

Dr Robert Heuschkel Consultant Paediatric Consultant,
Addenbrookes Hospital; Chair, IBD Working Group,
British Society of Paediatric Gastroenterology,
Hepatology and Nutrition

Dr Miranda Lomer Consultant Dietitian, Guy's and
St Thomas' NHS Foundation Trust and King's College
London; former Chair, Gastroenterology Specialist
Group, British Dietetic Association

Ms Anja St.Clair Jones Lead Pharmacist, Surgery
and Digestive Diseases, Royal Sussex County Hospital;
Chair, Gastroenterology Specialist Group, UK Clinical
Pharmacy Association

CN Mark Sephton IBD Specialist Nurse, University
Hospital of South Manchester; Royal College of Nursing
Gastrointestinal Nursing Forum

Dr Ian Shaw Consultant Gastroenterologist,
Gloucestershire Hospitals NHS Trust; Clinical Lead,
IBD Quality Improvement Programme

Dr Tom Smith Chief Executive, British Society
of Gastroenterology

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Key Facts

- Recent data suggests that up to 620,000 people in the UK may have IBD
- These are lifelong conditions and commonly 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
- There is no cure. Cause is likely to be multifactorial, a combination of genetic predisposition and environmental triggers
- More than 50% of patients with Crohn's Disease will undergo surgery within 10 years of diagnosis. In Ulcerative Colitis lifetime surgery rates are about 20-30%
- Patients with extensive disease may develop complications that are potentially life-threatening, such as complete blockage or perforation of the bowel
- There is an established link between IBD and an increased risk of developing colorectal cancer
- The lifetime medical costs associated with the care of a person with IBD can be comparable to those with major chronic diseases such as diabetes mellitus or cancer.

Executive Summary

The aim of the IBD Standards is to ensure that patients with IBD 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 meet specific minimum standards.

Aim of the IBD Standards and Progress to Date

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). The prevalence of IBD has risen rapidly in recent years. Current data suggests that up to 620,000 people in the UK may have IBD. It is important not to confuse *Inflammatory Bowel Disease* (IBD) with the different condition *Irritable Bowel Syndrome* (IBS).
2. Following the first UK-wide audit of services and care in 2006, which revealed unacceptable variation in services and aspects of clinical care, a working group of the key professional organisations and Crohn's and Colitis UK, the IBD patient organisation, was formed to recommend national standards for IBD care.
3. In the four years since the IBD Standards were produced, there have been two rounds of the IBD Audit, with interventions to support quality improvement, the establishment of the IBD Quality Improvement Programme and the launch of the UK IBD Registry. The IBD Audit has demonstrated significant improvements in IBD care and service delivery over this time. However, there is still considerable variation in the level and quality of care provided, with many services some way off meeting the IBD Standards and particular deficits in certain aspects of provision across the board.

About Inflammatory Bowel Disease (IBD)

4. Ulcerative Colitis and Crohn's Disease are lifelong conditions, most commonly presenting in young adults, adolescents and children. They affect men and women equally.
5. The causes of both Crohn's Disease and Ulcerative Colitis remain unknown. There is a genetic predisposition which may determine the pattern and severity of the disease in any individual patient. Research has indicated that environmental triggers are also important.

6. 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 urgent and frequent diarrhoea, often with rectal bleeding, pain, profound fatigue and anaemia. In some patients, there is associated inflammation of the joints, skin, or eyes. Malnutrition and weight loss are common, especially in Crohn's Disease. Both conditions follow an unpredictable relapsing and remitting course, with significant variation in the pattern and complexity of symptoms.
7. Education, working, social and family life may all be 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.
8. Patients with extensive disease may develop complications which are potentially life-threatening, such as complete blockage or perforation of the bowel. They also have a long-term increased risk of colorectal cancer.
9. There is currently no cure for IBD. Drugs to suppress the immune system and to induce and maintain remission are the mainstay of medical management, although nutritional therapy as primary treatment is also important in Crohn's Disease. However, 30% of patients fail to respond to these drugs and will then be considered for biological therapies or surgery. More than half of patients with Crohn's Disease and about 20-30% of patients with Ulcerative Colitis will require surgery at some point.

The Cost and Impact of IBD

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

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 focusing services towards prompt detection and optimal outpatient management of disease flare-ups and effective maintenance of remission.
12. The emergence of new biological treatments offers hope to more severely affected individuals and short-term audit data suggests that the high acquisition costs for these drugs may be offset by reductions in costs for other services.
13. IBD also 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. However, with effective management, many of these patients are able to lead rewarding and productive lives within the constraints imposed by their condition.

National Action to Support Local Implementation

14. Since the first publication of the IBD Standards, a considerable amount has been achieved in terms of significant quality improvements in IBD services and care. Four years on, it is critical that this work continues and develops in the context of changing health service provision and priorities.
15. Collaboration between the relevant professional and patient organisations has been fundamental to the progress that has been made. An IBD Strategy Group has recently been formed to continue to bring all key stakeholders together and set down objectives for the future of IBD care and services. This will lead and coordinate developments within the IBD community to support the achievement of consistently high quality IBD services throughout the UK.
16. An important role is identified for Government Health Departments and NHS Managers and Commissioners in each of the four UK countries to continue to support the implementation of the IBD Standards, the continuation of the UK IBD Audit and the successful future development of IBD services.

Further Information

17. Some sources of further information for NHS Managers and commissioning organisations are identified and additional useful links and resources will be available through www.ibdstandards.org.uk

The IBD Standards

Standard A – High Quality Clinical Care

High quality, safe and integrated clinical care for IBD patients based on multidisciplinary 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

Patient-centred care should be responsive to individual needs and offer a choice of care strategies where possible and appropriate.

Standard D – Patient Education and Support

IBD care should empower patients to understand their condition and its management. This will allow them to achieve the best quality of life possible within the constraints of their Inflammatory Bowel Disease.

Standard E – Data, Information Technology and Audit

An IBD service that uses data, IT and audit to support patient care effectively and to optimise clinical management.

Standard F – Evidence-Based Practice and Research

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

For each of the six IBD Standards, the Rationale is given and a set of Implementation Standards is outlined.

Introduction

The aim of the IBD Standards is to ensure that patients with IBD throughout the UK receive consistent high quality care. To achieve this, IBD services need to be knowledge-based, involve local and national networking and modern IT and meet specific minimum standards, as measured by the UK IBD Audit.¹

This document is to inform NHS Managers and commissioning organisations as part of a UK-wide strategy to continue to improve services for patients who have Ulcerative Colitis or Crohn's Disease, the two most common forms of Inflammatory Bowel Disease (IBD).

Since the first publication of the IBD Standards in 2009², further data on the prevalence of IBD in Europe has been published, with this now acknowledged to be between 0.5% and 1% of the population. This would mean that, together, these long-term conditions are estimated to affect as many as 620,000 people in the UK.³

Implementation of the IBD Standards will ensure that IBD services meet key requirements of the strategies and performance measures set out in:

<i>Equity and Excellence: Liberating the NHS, NHS Outcomes Framework and CCG Outcome Indicator Set⁴</i>	England
<i>The Healthcare Quality Strategy for NHS Scotland and HEAT Targets⁵</i>	Scotland
<i>Together for Health⁶</i>	Wales
<i>Quality 2020: A 10-Year Strategy to Protect and Improve Quality in Health and Social Care⁷</i>	Northern Ireland

The starting point for the IBD Standards was the first national audit of adult IBD services and care in 2006⁸, to which 75% of hospitals in the UK voluntarily submitted data. This revealed unacceptable variation, both in service provision and organisation of important aspects of clinical care.

Two further UK-wide IBD audits⁹ have since been carried out, with the third round directly measuring service and care against the IBD Standards and enabling benchmarking to take place. The fourth round will report in 2014. An analysis across the three rounds to date shows a marked improvement in a number of key areas.

1. Further details in Current Initiatives in IBD on p.24 and in Appendix B. www.rcplondon.ac.uk/ibd
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5. The Scottish Government. *The Healthcare Quality Strategy for NHS Scotland*, May 2010, www.scotland.gov.uk/Resource/0039/00398674.pdf. *HEAT Targets*, www.scotland.gov.uk/About/Performance/scotPerforms/partnerstories/NHSScotlandperformance

Change in IBD Service Provision 2006-2010 Data From UK IBD Audit		
IBD Service Provision	2006 (%)	2010 (%)
Provision of dedicated gastrointestinal wards	67	90
Provision of IBD Nurses	56	78
Patients seen by an IBD Nurse Specialist during admission	24	45
Patients with Crohn's Disease being weighed	52	75
Provision of joint or parallel clinics	47	56
Availability of laparoscopic surgery for elective patients	10	44
Availability of laparoscopic surgery for non-elective patients	5	34
Services with guidelines for the management of acute severe Ulcerative Colitis	48	85
Patient involvement in service development	8	21
Services with databases of IBD patients	38	53
Services providing written information to patients with IBD with contacts in the event of a relapse	70	83
Specialist review of those experiencing a relapse within 7 days	69	89
Telephone access to an IBD specialist	78	96
Mortality during admission (Ulcerative Colitis)	1.7	0.8
Mortality during admission (Crohn's Disease)	1.3	0.8
Readmission (Ulcerative Colitis)	51	34

Challenges Ahead

While the table to the left shows significant improvements in key areas of IBD services and care, it is clear that there is still a long way to go. For example, the provision of IBD Specialist Nurses has increased substantially. However, for most services the levels still fall below the recommended minimum of 1.5 whole time equivalent IBD Nurses per 250,000 population set out in the IBD Standards. Patient involvement in service planning is still very low, at only 21%, and almost half of services do not have a database of their IBD patients.

Additional Areas for Improvement Identified by the IBD Audit	
Dietetic Support	60% of non-elective adult patients with Crohn's Disease were not seen by a dietitian during their admission
Psychological Support and Counselling	The provision of psychological support or counselling remains at very low levels - only 24% of adult services have defined access to a Psychologist with an interest in IBD
Age-Appropriate Facilities	Relatively few patients aged 16 or under are cared for in adult hospitals but it is clear that services for these individuals are suboptimal. There is a lack of age-appropriate facilities for endoscopy, personnel who have paediatric experience and/or training and inadequate recording of pubertal status and growth
Clinical Trials	In the first round of audit, fewer than 0.5% of all IBD inpatients were enrolled onto a clinical trial. By the third round, this had only increased to 4% of patients admitted with Ulcerative Colitis and was just 0.5% for Crohn's Disease
Shared Care	Only one third of services have a protocol in place with GPs for the shared outpatient management of IBD patients. Of these services, only 66% share this with the patient, most often verbally (62%)
Rapid Access to Specialist Advice	Many GPs reported being unable to get their patients seen in secondary care within 7 days in the event of a relapse (59%)

This document describes the standards to which local services should adhere and the obligations to national activities of information, audit, training and research which should form the basis of assessment for any 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 Crohn's and Colitis UK, the national organisation for IBD patients of all ages. The specific recommendations were developed by a working group with representation from all these organisations, chaired by Crohn's and Colitis UK. The recommendations were widely circulated for comment by patients, health professionals and industry and have been endorsed by other professional and patient organisations.

In reissuing the IBD Standards four years after their original publication, the IBD Standards Group has drawn on the original work of Crohn's and Colitis UK in identifying patients' needs and wishes, and on current evidence-based service statements and guidelines for the management of IBD produced by the various professional groups and issued by NICE (full details in Appendix A).¹⁰ This work has also been informed by the reports of the first three rounds of the UK IBD Audit¹¹ and the report of the first round of the national Royal College of Nursing Inflammatory Bowel Disease Nursing Audit.¹²

6. Welsh Government. *Together for Health: A five year vision for the NHS in Wales*, 2011 www.wales.gov.uk/topics/health/publications/health/reports/together/?lang=en
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8. UK IBD Audit Steering Group. *UK IBD Audit 2006: National results for the organisation and process of IBD Care in the UK*, February 2007, www.rcplondon.ac.uk/projects/ibdauditround1
9. UK IBD Audit Steering Group. *UK IBD Audit 2nd Round (2008) Report: National Results for the Organisation and Process of Adult IBD Care in the UK*, March 2009 www.rcplondon.ac.uk/projects/ibdauditround2. *National Audits of the Organisation of Adult and Paediatric IBD Services in the UK*, 2011 www.rcplondon.ac.uk/projects/ibdauditround3
10. Appendix A: Evidence-Based Statements and Clinical Guidelines Relating to IBD, p.26
11. Summaries and full reports of the first three rounds of the IBD Audit can be found at www.rcplondon.ac.uk/ibd. Further information in Appendix B, p.28
12. Royal College of Nursing. *Inflammatory Bowel Disease Nursing: Results of an audit exploring the role, responsibilities and activity of nurses with specialist/advanced roles*, 2012 www.rcn.org.uk/__data/assets/pdf_file/0008/433736/004197.pdf. Overview on p.25 of this document.

About 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 equally affected.

It is important to note that IBD means *Inflammatory Bowel Disease* and 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 people with IBD may also have IBS symptoms.

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 someone with IBD and which may determine the pattern and severity of the conditions in any individual patient.¹³ 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 triggers for IBD vary between individuals.¹⁴

Clinical Effects

The key effects of IBD are inflammation and ulceration in the colon and rectum (Ulcerative Colitis) or anywhere in the gastrointestinal tract (Crohn's Disease).

Both conditions can produce symptoms of urgent and frequent diarrhoea, rectal bleeding, pain, profound fatigue, malaise and anaemia. In some patients, there is an associated inflammation of the joints, skin, liver or eyes. Malnutrition and weight loss are common, particularly in Crohn's Disease.¹⁵ When diagnosed in

childhood (about 25% of all cases) the disease is often more severe than if presenting in adulthood, with major consequences for lifelong morbidity.¹⁶ 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 life.¹⁷

Psychosocial Effects

Education, employment, personal relationships and social and family life may all be disrupted by the unpredictable occurrence of IBD 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 people with IBD may normalise an unnecessarily limited pattern of life, as a result of inadequate control of symptoms from poor medical management or anxiety about loss of bowel control if they venture too far from familiar environments.^{18,19}

Complications of IBD

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 caused by 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 fistulas (abnormal channels between the bowel and other parts of the body).

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 life.

There is an established link between IBD and an increased risk of developing cancer, primarily in the colon. The risk of colorectal cancer increases with the extent of disease, severity of inflammation, the age of onset and duration of the disease, concomitant Primary Sclerosing Cholangitis and a family history of bowel cancer.^{20,21}

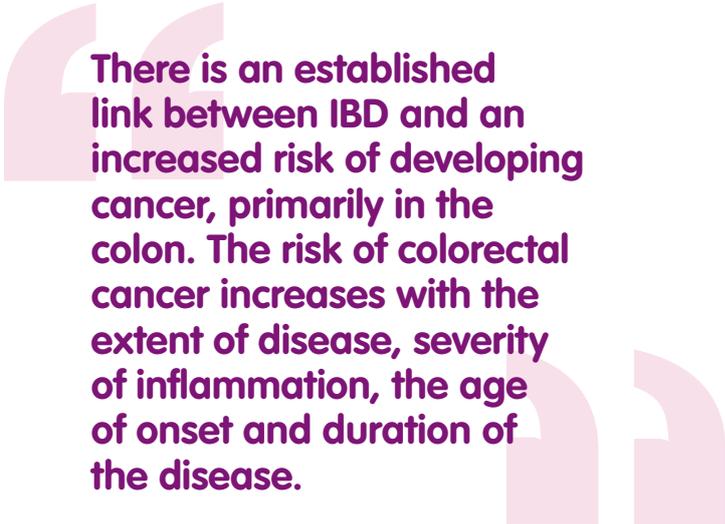
The risk of colorectal cancer at 20, 30 and 40 years after the onset of disease may be as much 3, 8 and 11% respectively.²² The risk to patients who have extensive Crohn's Colitis is similar to that of someone who has extensive Ulcerative Colitis for a similar length of time.²¹ There is also an increased risk of small bowel cancer in some people with Crohn's Disease.²³

Treatment

There is currently no cure for IBD. Aminosalicylates (5ASAs), corticosteroids, exclusive enteral nutrition and immunomodulating 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.²⁴ About 30% of patients will fail to respond to these drugs or are intolerant of them and these patients may then be considered for biological therapies or surgery.

At least 50% of patients with Crohn's Disease will undergo surgery within 10 years of diagnosis, and over 70% may require surgery during their lifetime.²⁵ In Ulcerative Colitis, total lifetime surgery rates are about 20-30%. Of the patients who have chronic relapsing Ulcerative Colitis, about 50% need a colectomy, though rates vary between countries and regions.^{26,27}

The most common form of surgery for Crohn's Disease is removal of the diseased part of the bowel, with or without formation of a stoma, which may be permanent. Surgery for people who have Ulcerative Colitis usually involves removal of the whole colon. This will most often require a stoma, at least, in the short term. Some patients may have restoration of intestinal continuity with the formation of an ileoanal pouch.²⁸



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The Cost and Impact of IBD

Lifetime medical costs of IBD can be comparable to other major diseases, such as diabetes or cancer.

The incidence of IBD has risen rapidly in recent years. Current data on rates of IBD in Europe has been published with the prevalence of IBD acknowledged to be between 0.5% and 1% of the population. In the UK, this would mean that IBD is estimated to affect as many as 620,000 people.²⁹

There is a south-north gradient to the incidence of IBD in the UK, with rates being highest in Scotland.^{30,31,32} Comparing IBD in ethnic communities to the non-Jewish Caucasian population, IBD occurs more frequently in Ashkenazi Jews, at higher levels in second-generation Indian and Pakistani families, and at about the same levels in families originating in Africa or the Caribbean.

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. Despite this, obtaining accurate figures for the cost of treating IBD in the UK is difficult, with studies varying considerably in their estimates. The most recent study published found the cost, based on 2008 prices, to be in the range of £631 - £762 per patient per year.³³ Using current prevalence data²⁹, this suggests an overall annual cost to the NHS of up to £470 million. However, earlier research estimated the annual average cost per patient to be as high as £3,000.^{34,35}

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 two-to-three fold increment in costs compared to stable patients.³⁶ Hence, there are strong arguments, both clinically and economically, for focusing 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

expenditure in the future. These new agents offer hope to more severely afflicted individuals and short-term audit data suggests that the high acquisition costs for these drugs may be offset by reductions in costs for other services.^{37,38}

Ulcerative Colitis and Crohn's Disease have a substantial impact on the physical health, social functioning and quality of life of patients. Both Ulcerative Colitis and Crohn's Disease are chronic relapsing and remitting conditions. It is estimated that 15-20% of patients with Crohn's Disease will have some degree of disability from their disease within five years of diagnosis and around 50% of patients experience at least one relapse per year, of which around 20% will be severe and require hospitalisation. Acute severe colitis remains a serious medical condition which, despite improvements in care, still carries a 1-2% mortality and a 29% chance of requiring colectomy (emergency surgery to remove the inflamed bowel).³⁹

IBD also 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.⁴⁰ However, with effective management, many patients will be able to lead a rewarding and productive life within the constraints imposed by the condition.

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The IBD Standards

The Aim of the IBD 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 multidisciplinary 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

Patient-centred care should be responsive to individual needs and offer a choice of care strategies where possible and appropriate.

Standard D

Patient Education and Support

IBD care should empower patients to understand their condition and its management. This will allow them to achieve the best quality of life possible within the constraints of their Inflammatory Bowel Disease.

Standard E

Data, Information Technology and Audit

An IBD service that uses data, IT and audit to support patient care effectively and to optimise clinical management.

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; standards relating specifically to children who have IBD are documented in the section entitled *Arrangements for the Care of Children and Young People who have IBD* (Standard A12).

The population base for the Standards is 250,000. IBD services with smaller catchment populations may still offer an effective and safe 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 multidisciplinary team working and collaboration across NHS organisational structures and boundaries.

Rationale

The Specialist Team

The significant variation in the pattern and complexity of 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.⁴¹ Faecal biomarkers such as faecal calprotectin, in association with clinical assessment, may be useful in primary care.⁴²

Nutritional Support

A significant number of patients who have IBD suffer from malnutrition.⁴³ Therefore nutritional intake and dietary advice are important when patients are admitted, when they relapse and during periods of remission.^{44,45}

A proportion of patients, especially inpatients, have nutritional needs that go beyond simple dietary advice. Some will require enteral nutrition as primary or adjunctive therapy to induce remission in active Crohn's Disease and it is often the treatment of choice in children.⁴⁶ Others will need specific dietary advice to alleviate symptoms, for example in stricturing disease or for patients who have functional gastrointestinal symptoms. Furthermore, some patients may benefit from tailored dietary advice to meet micronutrient requirements, while supplementation may be more appropriate for others.

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 wellbeing 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 Immodulator and Biological Therapies

Evidence is growing for the benefit of using more powerful and, in the case of biological therapies, more expensive drugs to control the symptoms of IBD. These treatments should be initiated and managed by IBD specialists with experience of their use, though ongoing safety monitoring can be part of a shared-care arrangement agreed with patients and their GPs. The involvement of the Specialist Pharmacist in the management of these complex and emerging therapies is of high clinical and pharmacoeconomic worth. The value of these therapies should be reviewed regularly either in a conventional or virtual clinic.

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.⁴⁷

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.⁴⁸

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 a special interest and competency in IBD
- 1.5 WTE* Clinical Nurse Specialist with a special interest and competency in stoma therapy and ileo-anal pouch surgery
- 0.5 WTE* Dietitian allocated to gastroenterology**
- 0.5 WTE* Administrative support for 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**

* WTE - whole time equivalent

** 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 gastrointestinal interest or a combination of Consultant Paediatrician plus an adult gastrointestinal physician interested in adolescent IBD. Both should be working within a paediatric gastroenterology clinical network with appropriate adult and paediatric nursing support
- 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 gastrointestinal/surgical meeting, but the outcome of the discussions should be formally recorded in the hospital notes. The team should also agree who will discuss the decision with the patient.

These patients 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 unable to achieve sustained steroid-free remission and patients identified to start biological therapy. Specific 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.

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42. NICE Diagnostics Guidance 12: Faecal calprotectin diagnostic test for inflammatory diseases of the bowel, October 2013, www.guidance.nice.org.uk/DT/12
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45. Lomer MCE. Dietary and nutritional considerations for Inflammatory Bowel Disease. *Proc Nutr Soc*, 2011; 70: 329-335
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47. Kaplan GG. Impact of hospital volume on postoperative morbidity and mortality following a colectomy for Ulcerative Colitis. *Gastroenterology*, March 2008;134(3):680-687
48. British Society of Paediatric Gastroenterology, Hepatology and Nutrition. *Guide for purchasers of Paediatric Gastroenterology, Hepatology and Nutrition Services*, 2003 www.bspghan.org.uk/document/GuidelinesforPurchasersSeptember2003.pdf

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 to periodically review their diagnosis in patients with unresponsive, atypical or troublesome abdominal symptoms.
- Faecal biomarkers such as faecal calprotectin may be useful in primary care, in association with clinical assessment.
- 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 two weeks of referral and seen within four 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.
- All new diagnoses of IBD should adhere to current clinical guidelines and should be reviewed by the IBD multidisciplinary team.

Standard A5 - Access to Nutritional Support and Therapy

- Access to a Dietitian should be available to all IBD patients.
- All forms of nutritional therapy should be available to IBD patients, including exclusive liquid diet as therapy for Crohn's Disease.
- All patients with Crohn's Disease should have the choice of receiving appropriately supported 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 the use of Immunomodulator 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.
- Participation in the National Biologics Audit should be mandatory for all units prescribing biologics.
- 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.

- The nature of surgeries performed, along with simple metrics on immediate and delayed complications and referral for medical follow up, should be formally recorded and audited.
- 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 one easily-accessible toilet per three beds. To provide privacy for patients, ward toilets should have floor to ceiling partitions, full height doors and good ventilation to minimise embarrassment. The toilets should be clean and segregated, with separate facilities for men and women. Facilities should be available for the change and disposal of stoma appliances.
- 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 four weeks, maximum, or in more urgent situations, within 24 hours.
- Histological processing should be rapid (minimum standard five working days to report, but with arrangements to report urgent biopsy samples in two days when needed).

Standard A10 - Inpatient Care

- Defined arrangements should exist for admitting existing IBD patients directly to the specialist gastroenterology ward or area.
- Patients admitted with known or suspected IBD should be discussed with and normally 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 Specialist Nurses.
- All IBD patients admitted should be weighed and their nutritional needs assessed.
- All IBD patients should have access to a Specialist Pharmacist for advice on their current and future medical treatment.

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 carried out in a hospital or community clinic, or by telephone follow-up, and should be undertaken 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 five working days.
- IBD patients should be able to choose from a range of options 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 and Young People who have IBD

- Children and young people with IBD should have the choice of being managed in an age-appropriate environment. In most cases, this will occur within a managed clinical network and involve a Paediatric Gastroenterologist, a local Paediatrician with expertise in gastroenterology, an adult Gastroenterologist and an adult and Paediatric Nurse Specialist.
- All children, at least up to their 16th birthday, should be referred to a paediatric gastroenterology service for initial investigation and treatment. Follow up should be provided within a paediatric gastroenterology clinical network.
- Patients over 16 years who are physically mature, have completed their growth, are emotionally mature and without psychological or educational problems, may have investigations undertaken locally.
- Patients, who are over 16 years, but who do not yet meet these criteria, should be discussed with appropriate paediatric services. Local care should then be provided by an Adult Gastroenterologist and Nurse Specialist experienced in the management of adolescents with IBD, and only if the care is shared with a local Paediatrician with an interest in gastroenterology. Standards of care must still meet the National Service Framework (NSF) for Children and Young People.⁴⁹
- 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 apply to services looking after children up to their 19th birthday. The average number of children with IBD for a specialist paediatric gastroenterology unit is around 180.⁵⁰

- » Age-appropriate inpatient facilities; children's nurses for all inpatient, outpatient and day case episodes
- » Endoscopy procedures in a child-friendly unit with accredited Paediatric Anaesthetists or clinicians trained in, and maintaining competency in, sedating children and young people for endoscopies⁵¹
- » Access to appropriate radiological investigations (including MRI) in a setting suitable for children, by staff trained in performing and reporting in children
- » Surgeons with expertise in operating on children and young people with IBD
- » A minimum of 0.5 WTE Paediatric Dietitian experienced in the use of exclusive enteral nutrition as treatment
- » A minimum of 1 WTE Paediatric IBD Nurse Specialist with an identified role and competence in paediatric and adolescent IBD
- » A named Specialist Paediatric Pharmacist with an interest in IBD
- » Defined access (or a pathway for referral) to a Paediatric Psychologist
- » Defined access (or a pathway for referral) to a Paediatric Endocrinologist
- Multidisciplinary team working is an intrinsic part of an IBD service. There should be regular meetings where complex patients are discussed. These meetings should have multidisciplinary attendance, including medical, surgical, nursing, dietetic, radiological and pathology representation.
- Endoscopy should be performed by endoscopists with training and/or extensive experience in endoscopy and ileo-colonoscopy in children and adolescents.
- Appropriate written information and support should be available for a child/young person with IBD and their family.
- There should be a written policy and protocol for transitional care. A named coordinator should be responsible for the preparation and oversight of transition (for example, an IBD Nurse Specialist).^{52,53}
- All staff involved in the care of patients up to the age of 18 years should have up-to-date child protection training to an appropriate level.

49. Department of Health. *National Service Framework for Children, Young People and Maternity Services*, 2004. www.gov.uk/government/publications/national-service-framework-children-young-people-and-maternity-services

50. UK IBD Audit Steering Group. *UK Inflammatory Bowel Disease Audit 3rd Round: Report of the results for the national organisational audit of paediatric Inflammatory Bowel Disease services in the UK*, May 2011 www.rcplondon.ac.uk/projects/ibdauditround3

51. NICE Clinical Guideline 112. *Sedation in children and young people*. www.nice.org.uk/cg112, December 2010

52. Department of Health. *Transition: Getting it right for young people. Improving the transition of young people with long term conditions from children's to adult health services*, National Service Framework for Children, Young People and Maternity Services, 2006

53. NACC, CICRA. *Transition to Adult Healthcare: Guidance for Health Professionals*, 2008 www.ibdtransition.org.uk/downloads/IBD_Transition_Guide_Health_Professionals.pdf

Standard B

Local Delivery of Care

Care for IBD patients 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 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.

Many GPs participate in protocol-based shared care, relating to the prescription of ongoing medication, monitoring of immunosuppressive drugs and monitoring of bone density or other parameters. This could extend to the annual review in appropriate circumstances.

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.⁵⁴

A protocol for shared care needs to be discussed and agreed with interested parties, which includes representatives from primary and secondary care and patient support organisations.⁵⁵

54. London South Bank University. *A Systematic Review of the Effectiveness of Inflammatory Bowel Disease Specialist Nurses*, 2006 www.lsbu.ac.uk/hsc/downloads/reviewboweldisease.pdf

55. The IBD Quality Improvement Programme supports an online resource bank, which includes examples of shared care protocols. www.ibdqip.co.uk/KMS/Default.aspx

Implementation Standards

Standard B1 - Arrangements for Shared Care

- The arrangements and scope for shared care, and the circumstances in which the patient 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, using clear, straightforward and appropriate language.
- 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 immunomodulator 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

Patient-centred care should be responsive to individual needs and offer a choice of care strategies where possible and appropriate.

Rationale

Patient-Centred Care

IBD varies significantly in its pattern and severity between individuals. It can also vary in the same individual due to its unpredictable and relapsing nature. Therefore, patient-centred care needs to offer different approaches at different times within the lifelong 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 severity and complexity of their disease. This will be dependent on local facilities and personal preference. Arrangements should acknowledge that, whilst many patients will wish to be actively engaged in decisions and management, some may prefer a more passive patient role.

Each model of care will require an administrative and clinical infrastructure to support the process. Self-managed care must be properly organised and supported to be safe and effective. It should not be seen as a 'cheap option'.⁵⁶

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 relevant member of the IBD team 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

Patients should be offered choice between their

treatments, after receiving the necessary support and information. For example, this might include choice between drug treatments and dietary therapy for Crohn's Disease or between rescue medical therapy and surgery during a severe relapse of Ulcerative Colitis.

Standard C4 – Supporting Patients to Exercise Choice between Different Care Models

Patients should be supported in their choice of follow up care. This may be continuing hospital management, shared care with their GP or supported self-management. They should be able to choose a different option at different stages of their illness. The appropriate administrative and clinical infrastructure must be in place to support these different strategies.⁵⁷

Patients should have written information explaining clearly what arrangements have been agreed with them for their care.⁵⁸

Standard C5 – Involvement of Patients in Service Improvement

Patients should have a voice and direct involvement 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.

Possible mechanisms include:

- » Patient experience surveys/comment cards
- » Regular meetings with patients who use the IBD service to discuss service improvement such as the model of IBD Patient Panels promoted by Crohn's and Colitis UK⁵⁹
- » IBD departmental open days with discussion/open forum to allow for feedback
- » Involving patients in project planning/service development groups
- » Involving patient representatives in IBD Quality Improvement Programme peer review visits
- » Patient Opinion Website⁶⁰

56. Robinson A, Thompson D G, Wilkin D, Roberts C. Guided self-management and practice-directed follow-up of Ulcerative Colitis: a randomised trial. *Lancet*, 2003; 358:976-81.

57. British Society for Gastroenterology. *Care of Patients with Gastrointestinal Disorders in the UK: A Strategy for the Future*, March 2006 www.bsg.org.uk/pdf_word_docs/strategy06_final.pdf

58. Royal College of GPs. Clinical Innovation & Research Centre. *Care Planning: Improving the Lives of People with Long Term Conditions*, 2011.

59. www.crohnsandcolitis.org.uk/get-involved/Patient+Panels

60. www.patientopinion.org.uk

Standard D

Patient Education and Support

IBD care should empower patients to understand their condition and its management. This will allow them to achieve the best quality of life possible within the constraints of their Inflammatory Bowel Disease.

Rationale

Patient Education

Patients who are well-informed about their condition and how it can be treated will have a greater chance of achieving a better quality of life within the constraints of their IBD. They should have a clear understanding of the service being offered to them and how to access support from the IBD team. This will allow them to adapt to the social and psychological impact of IBD.^{61,62}

Implementation Standards

Standard D1 – Provision of Information

- All patients should be offered appropriate information about their care and treatment options at all stages of their illness. This should be delivered by an identified member of the IBD team.
- Information should be appropriate to the age, understanding and communication needs of the patient and carers.
- Clear, written information about IBD should be provided in outpatient clinics, wards, endoscopy and day care areas.
- Information should be available in languages other than English where the catchment population requires this. It should also be available in a variety of formats including written, DVD and web-based, where appropriate.
- Informed consent should be obtained by a member of the IBD team and written in clear, simple language. A member of the IBD team should ensure patient understanding before signing.
- Patients being considered for surgery, especially pouch surgery or ileostomy, should be offered written, audio-visual or web-based information. Where possible, the opportunity to talk with patients who have had pouch surgery or a permanent ileostomy should be provided. They should also be provided with information about their post-operative care before discharge.
- Information should be provided to all inpatients about their follow up care prior to discharge from the ward.

D2 – Education for Patients

The IBD service should provide educational opportunities for patients and their families. This should include:

- Disease education
- Treatment options
- Self-management strategies

The IBD team should identify an appropriate team member to facilitate this.

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 clearly defined links between the IBD team and the relevant patient organisation, including:

- Crohn's and Colitis UK
- CICRA - Crohn's in Childhood Research Association
- IA - The ileostomy and internal pouch Support Group

Local group meetings should be supported by an identified member of the IBD team, where possible.

61. Coulter A, Ellins J. Effectiveness of strategies for informing, educating, and involving patients, *British Medical Journal*, 2007;335:24

62. Adams RJ. Improving health outcomes with better patient understanding and education. *Risk Manag Healthc Policy*, 2010; 3:61-72.

Standard E

Data, Information Technology and Audit

An IBD service that uses data, IT and audit to support patient care effectively and to optimise clinical management.

Rationale

Data, IT and Audit

Developing a service which provides high quality, benchmarked care to patients is facilitated by the systematic, structured collection of data, ideally at the point of patient contact. This data can then be used by a number of stakeholders, as described below.

1. Patients

By having instant access to patients' disease history, medication and other relevant details, IBD teams will provide a more responsive, safer service to patients. Teams will be able to support patients at home by telephone, email or via patient portals, offer alternative care pathways and support the rigorous monitoring and outcomes of treatments. This should reduce outpatient appointments and admissions. In the future, patients may have access to their own personal data (presented in an appropriate form) to allow greater understanding of their condition and to support self-management, for example via patient portals.

2. IBD Teams

Using robust IT systems to support care of IBD patients will enable the delivery of efficient, cost-effective, high quality patient-centred care.

3. Commissioners

The ability to demonstrate patient outcomes, the quality of services and the appropriate use of high cost drugs will inform commissioning.

Audit

The collection of data at the point of patient contact will facilitate continuous, high quality prospective audit of all aspects of clinical care focused on patient outcomes. Participation in audit will allow the benchmarking of the quality of care against UK-wide data as well as devolved nation or regional data.

Research

Development of cohorts of well characterised patients will become a significant local, national and international research resource.

The UK IBD Audit, IBD Quality Improvement Programme and IBD Registry enable services to benchmark their quality of care, develop action plans for driving improvement and inform local and national planning and research.

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.

Local data should be fed into the UK IBD Registry⁶³ to provide a central, anonymised dataset of IBD patients.

Standard E2 – Using an IBD Electronic Clinical Management System

IBD services should implement an electronic clinical management system which records patients' disease histories and treatments.

Standard E3 - Participation in Audit

Every IBD service should take part in regular audit, including:

- Participation in the UK IBD Audit⁶⁴
- 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 the UK IBD Biologics Audit⁶⁵
- The outcomes of all emergency colectomy, ileoanal pouch (the ACPGBI Ileal Pouch Registry)⁶⁶ and abdominal operations for Crohn's Disease should be submitted to national audit and data collection.

63. UK IBD Registry www.ibdregistry.org.uk

64. UK IBD Audit www.rcplondon.ac.uk/ibd

65. UK IBD Biologics Audit www.rcplondon.ac.uk/projects/biologics

66. ACPGBI Ileal Pouch Registry www.ipdb.org.uk.

Standard F

Evidence-Based Practice and Research

An IBD 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-centred 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 to which units will be expected to contribute and support. Commissioners and Managers should include time and resources to enable IBD teams to contribute to this process.

IBD services should be committed to the objectives of the National Institute for Health Research (NIHR)⁶⁷ and the UK Collaboration for Clinical Research (UKCRC)⁶⁸ and support the portfolio of research relating to IBD.

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, particularly when practising as Independent Prescribers.
- Specialist Pharmacists involved in drug monitoring and other medical therapy clinics should have access to medical support as well as pharmacy supervision, particularly when practising as Independent Prescribers.
- 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 multidisciplinary 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.

67. www.nihr.ac.uk

68. www.ukcrc.org

National Action to Support Local Implementation

The IBD Community

Since the first publication of the IBD Standards, a considerable amount has been achieved in terms of quality improvements in IBD services and care. Four years on, it is critical that this work continues and develops in the context of changing health service policies, priorities and provision.

Collaboration between the relevant professional and patient organisations has been fundamental to the progress that has been made. An IBD Strategy Group will continue to bring all key stakeholders together and set down objectives for the future of IBD care and services.

These will include:

- Providing leadership within the IBD community to achieve consistently high quality IBD services throughout the UK.
- Liaising with NHS Managers, Commissioners and Government Health Departments on the future development of IBD services.
- Continuing the UK IBD Audit and IBD Quality Improvement Programme.
- Supporting the further development, promotion and management of a UK Registry of IBD patients for service planning, audit and research purposes
- Encouraging IBD services to implement electronic clinical management systems for IBD.
- Developing agreed clinical and patient-reported outcome measures that will support ongoing monitoring of the quality, safety and cost-effectiveness of IBD services.
- Identifying potential opportunities for clinically safe and cost-effective integrated care for people who have IBD.

Government Health Departments and the NHS

There is an important role for Government Health Departments and NHS Commissioners and Managers in each of the four UK countries to continue to support the 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 biennial UK-wide IBD Audit and ongoing IBD Registry.
- Assistance in establishing the real 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 IBD services.
- Ensuring that effective arrangements are in place for transition between paediatric and adult care.
- 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 Initiatives in IBD

IBD Strategy Group

An overarching IBD Strategy Group has been formed to plan and coordinate activities and to identify and drive future improvements in IBD services and care.

IBD Audit (2006 – 2014)

www.rcplondon.ac.uk/ibd

At the time of updating this document, three rounds of IBD Audit have taken place and the fourth is in progress and due to report summer 2014. A summary of rounds to date is in Appendix B of this document.

The second IBD Audit was extended to include paediatric IBD services and key elements of the data collected were used by the Healthcare Commission in England (since disbanded) as part of the screening process to validate clinical quality in the Annual Healthcheck of Hospital Trusts for 2008/9.

The third IBD Audit was further extended to include inpatient and primary care questionnaires and directly measured performance against the IBD Standards.

The third and fourth rounds of the UK IBD Audit were commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). The UK IBD Audit is reported in the 2011/2012 and 2012/2013 Quality Accounts and NHS Quality Improvement Scotland has also given its support and financial backing to the audit.

Round four of the UK IBD Audit will involve:

- » Assessing the processes and outcomes of up to 50 consecutive prospectively identified admissions for Ulcerative Colitis. This will represent all Ulcerative Colitis cases for many sites.
- » Questionnaires will be sent by participating hospitals to the 50 patients admitted for Ulcerative Colitis to re-audit IBD inpatient experience.
- » The continued entry of data into the audit of the use of biological therapies for IBD, as recommended by NICE.
- » Entering data on the organisation and structure of IBD services. For the first time, sites will be able to re-audit their IBD service provision against the IBD Standards.

IBD Quality Improvement Programme

www.ibdqip.co.uk

The IBD Quality Improvement Programme was established in 2010 to help IBD services improve the care they offer patients and to achieve the quality of care set out in the IBD Standards. It is managed by the Royal College of Physicians.

Services meet as a multidisciplinary team to complete a web-based self assessment that benchmarks their care in four main domains: patient experience; clinical quality; organisation and choice of care; research, education and audit. Results are graded and services are then guided to complete action plans, supported by a wide range of interventions.

To date, two rounds of data collection have been carried out and the results have shown significant improvements in the quality of care provision.

To support IBD teams in achieving and sustaining their service improvement, the project also coordinates a peer support visits scheme. A pilot project was initiated in July 2012 whereby local services are matched and carry out reciprocal visits. They review their IBDQIP results and exchange ideas on implementing improvements. By the end of the meeting, an action plan has been prioritised.

IBD Registry

www.ibdregistry.org.uk

The IBD Registry, launched in June 2013, is intended to provide the first UK-wide repository of anonymised IBD adult and paediatric patient data for prospective audit and research purposes. The aim in bringing this data together is to:

- Drive continuous improvement in patient care and access to care across the UK
- Inform commissioning and service design
- Improve our understanding of long-term outcomes
- Provide local, regional and national data in order to better define the pattern of Ulcerative Colitis and Crohn's Disease
- Support IBD research

Data can be entered via a web portal, a new IBD Patient Management System or from existing databases. It is anticipated that the IBD Registry will become the vehicle for collecting IBD audit data in future.

For those participating, it offers the following:

- Allows services to measure their local performance against national results
- Easier to monitor and improve quality
- Facilitates benchmarking against national performance which will inform local pathway development
- Links with IBD Audit
- An excellent resource for research.

The essential principle is that users get immediate local benefits for themselves and their patients with minimal time spent entering data. Features include a clinical summary showing the characteristics of the patient's

disease at a glance, GP letters and patient summaries, biologics management system, virtual clinics and multidisciplinary team systems. It will be possible to generate service reports and clinical audit at the click of a mouse button.

Royal College of Nursing Inflammatory Bowel Disease Nursing Audit (2012)

Audit exploring the roles, responsibilities and activity of nurses with specialist/advanced roles.

The first IBD Nursing Audit took place in 2011. Successive national audits of general IBD care across all acute NHS trusts within the UK have shown a significant increase in the number of IBD Nurse Specialists providing IBD nursing care in the UK. However, despite the increase in numbers, 79% (150/202) of sites failed to meet the standard of 1.5 whole time equivalent (WTE) IBD Nurse Specialists per 250,000 population. These audits have not looked at the IBD nursing role in any greater depth.

Aims of the IBD Nursing Audit:

- To evaluate IBD nursing services and identify areas for improvement
- To provide national evidence of IBD Nurse numbers, activity and effectiveness
- To provide direct feedback to individual nurses and their managers to show local impacts of the IBD nursing service.

Key Findings:

- Considerable activity and influence over the patient pathway (estimated 29,000 patient episodes per year by IBD Nurses)
- Secondary care-based role
- Central to complex drug management
- Disappointing levels of formal qualifications
- Services suspended in nurse's absence
- Little administrative support
- Limited audit/publication.

A second wave of the audit is planned.

Patient-Reported Outcome Measures (PROMs)

Increasing emphasis is being placed on patient-reported outcome measures (PROMs) and there are a number of projects currently being undertaken to establish validated measures. Outlined below are two examples.

IBD-Control® is a patient-reported outcome measure (PROM) developed specifically to serve as a tool for rapid and routine capture of outcome data in a busy clinical setting, either to inform traditional face-to-face consultation or to support other models of IBD follow-up (e.g. telephone or 'virtual' clinics). The questionnaire

assesses disease control from the patient perspective over the last two weeks using a short set of generic questions to capture physical, emotional and social impact of IBD and treatment concerns. A simple summary score (IBD-Control-8) is generated from eight questions. The development and validation of the questionnaire is published in the journal *Gut*⁶⁹ and is available to download free as an open access paper (funded by AbbVie). To encourage the use of IBD-Control in practice, a website will be launched for potential users to obtain supporting information (www.ibdcontrol.org).

The Crohn's Life Impact Questionnaire (CLIQ) is the first PROM specific to Crohn's Disease. It has been produced using a scientifically rigorous methodology that will ensure accurate and valid measurement of the Impact of Crohn's Disease from the patient's perspective. It consists of two unidimensional scales with good scaling and psychometric properties: quality of life (27 items) and activity limitations (9 items). The CLIQ is well accepted by patients, easy-to-use and should prove valuable for assessing Crohn's-related activity limitations and quality of life in clinical practice, audit and trials. Its development has been supported by Crohn's and Colitis UK.⁷⁰

Establishing Key Performance Indicators for the Surgical Management of IBD

A research study which aims to achieve international expert consensus on key performance indicators (KPIs) that should be used to measure quality of service provision in IBD surgery is being undertaken and is due to report in 2014.⁷¹

Defining the Aims, Optimal Design and Function of an IBD Multidisciplinary Team Meeting

A research study which aims to use expert consensus to define the aims, optimal design, format and function of an IBD multidisciplinary team meeting is being undertaken and is due to report in 2014.⁷¹

69. Bodger K, Ormerod C, Shackcloth D *et al.* Development and validation of a rapid, generic measure of disease control from the patient perspective: the IBD-Control questionnaire. *Gut*, 2013; [In Press]

70. Wilburn J, McKenna SP, Twiss J, Ben L'amri M, Kemp K, Campbell S. Development and Validation of the Crohn's Life Impact Questionnaire (CLIQ), Presented June 2013, British Society of Gastroenterology Conference, Glasgow. It is intended to publish two manuscripts relating to the CLIQ, one describing how the content for the measure was derived and a second paper on the development and validation of the CLIQ

71. Faiz O, Sevdalis N, Edwards C, Morar P, Read J. Funding for both research studies from Crohn's and Colitis UK and the Jean Brown Memorial Fund.

Appendix A:

Evidence-Based Statements and Clinical Guidelines Relating to IBD

Association of Coloproctology of Great Britain and Ireland (ACPGBI)

- » The management of acute severe colitis: ACPGBI Position Statement. Brown S, Haboubi N, Hampton J *et al. Colorectal Dis*, 2008; 10 Suppl 3:8-29
- » Guidelines for colorectal cancer screening and surveillance in moderate and high risk groups (update from 2002). Cairns S *et al. Gut*, 2010; 59:666–690. Developed on behalf of the ACPGBI and the British Society for Gastroenterology.

British Dietetic Association (BDA) Gastroenterology Specialist Group

- » Evidence-based practice guidelines for the dietetic management of Crohn's Disease in adults. Lee J *et al*, November 2011.

British Society of Gastroenterology (BSG)

- » Guidelines for the management of Inflammatory Bowel Disease in adults. Mowat C *et al. Gut*, May 2011; 60(5):571-607
- » Care of Patients with Gastrointestinal Disorders in the UK: A Strategy for the Future, March 2006. www.bsg.org.uk/pdf_word_docs/strategy06_final.pdf

British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN)

- » Guidelines on the Management of Inflammatory Bowel Disease (IBD) in Children in the UK, October 2008. www.bspghan.org.uk/Word%20docs%20and%20PDFs/IBDGuidelines_000.pdf

Crohn's and Colitis UK

- » Improving Standards of Care for Colitis and Crohn's Disease. Gray J, 2005. www.crohnsandcolitis.org.uk/research

European Crohn's and Colitis Organisation (ECCO)

- » The second European evidence-based consensus on the diagnosis and management of Crohn's Disease: Part 1: Definitions and diagnosis. Van Assche G, Dignass A, Panes J *et al. Journal of Crohn's and Colitis*, 2010; 4:7–27
- » The second European evidence-based consensus on the diagnosis and management of Crohn's Disease: Part 2: Current management. Dignass A, van Assche G, Lindsay J O *et al. Journal of Crohn's and Colitis*, 2010; 4:28–62
- » The second European evidence-based consensus on the diagnosis and management of Crohn's Disease: Part 3: Special situations. Van Assche G, Dignass A, Reinisch W *et al. Journal of Crohn's and Colitis*, 2010; 4:63–101.
- » The second European evidence-based Consensus on the diagnosis and management of Ulcerative Colitis: Part 1: Definitions and diagnosis. Dignass A, Eliakim R, Magro F *et al. Journal of Crohn's and Colitis*, December 2012; 6(10):965-990
- » The second European evidence-based consensus on the diagnosis and management of Ulcerative Colitis: Part 2: Current management. Dignass A, Lindsay J O, Sturm A *et al. Journal of Crohn's and Colitis*, December 2012; 6(10):991-1030
- » The second European evidence-based consensus on the diagnosis and management of Ulcerative Colitis: Part 3: Special situations. Van Assche G, Dignass A, Bokemeyer B *et al. Journal of Crohn's and Colitis*, February 2013; 7(1):1-33
- » N-ECCO Consensus statements on the European nursing roles in caring for patients with Crohn's Disease or Ulcerative Colitis. O'Connor M, Bager P, Duncan J *et al. Journal of Crohn's and Colitis*, 2013 (in press).
- » **All the above available from:** www.ecco-ibd.eu/publications/ecco-guidelines-science/published-ecco-guidelines.html

Primary Care Society for Gastroenterology (PCSG)

- » The Care of Gastrointestinal Disorders Outside Hospital, 2006.

Royal College of Nursing (RCN)

- » Role Descriptives for Inflammatory Bowel Disease Nurse Specialists. RCN Guidance, 2007.
www.rcn.org.uk/_data/assets/pdf_file/0007/107746/003194.pdf

National Institute for Health and Care Excellence (NICE)

- » NICE Clinical Guideline 166: Ulcerative Colitis – Management in adults, children and young people, June 2013. www.nice.org.uk/cg166
- » NICE Clinical Guideline 118: Colonoscopic surveillance for prevention of colorectal cancer in people with Ulcerative Colitis, Crohn’s Disease or adenomas, March 2011. www.guidance.nice.org.uk/cg118
- » NICE Clinical Guideline 152: Crohn’s Disease – Management in adults, children and young people, October 2012. www.nice.org.uk/cg152
- » NICE Technology Appraisal 187: Crohn’s Disease – infliximab (review) and adalimumab (review of TA40), May 2010. www.guidance.nice.org.uk/TA187
- » NICE Technology Appraisal 163: Infliximab for the treatment of acute exacerbations of Ulcerative Colitis, December 2008. www.guidance.nice.org.uk/TA163
- » NICE Technology Appraisal 140: Infliximab for subacute manifestations of Ulcerative Colitis, April 2008. www.guidance.nice.org.uk/TA140
- » NICE Diagnostics Guidance 12: Faecal calprotectin diagnostic test for inflammatory diseases of the bowel, October 2013. www.guidance.nice.org.uk/DT/12

Appendix B: UK IBD Audit

Key Findings over Three Rounds of National Audit (2006-2012)

Background

The development of the IBD Audit over time:

Round of Audit and Date	Round 1 2006-2008	Round 2 2008-2010	Round 3 2010-2012	Round 4 2012-2014
Elements of the UK IBD Audit				
Inpatient Care Audit Quality of treatment for admitted patients	Adult only CD & UC	Adult & Paediatric CD & UC	Adult & Paediatric CD & UC	Adult & Paediatric UC only
Organisational Audit Structure of service provision	Adult only	Adult & Paediatric	Adult & Paediatric	Adult & Paediatric
Inpatient Experience Questionnaires Patient reported experience of admission	-	-	Adult & Paediatric CD & UC	Adult & Paediatric UC only
Biological Therapies Audit Management of patients on biological therapies and patient reported outcomes	-	-	Adult & Paediatric CD & UC & IBDU	Adult & Paediatric CD & UC & IBDU
Providing IBD Treatment Treatment prior to hospital admission and GP experiences of providing IBD treatment	-	-	Adult & Paediatric CD & UC	-

» **KEY:** **CD** = Crohn's Disease / **UC** = Ulcerative Colitis / **IBDU** = Inflammatory Bowel Disease, type unspecified / **Biological Therapies** = Infliximab and Adalimumab

The IBD Audit has achieved more than 90% participation at applicable trusts and health boards throughout the UK. In the three completed rounds of audit, the inpatient care audit alone has captured data from 17,987 IBD admissions.

Over the three rounds of audit, the UK IBD Audit has demonstrated significant improvements in the quality of care for patients with IBD throughout the UK.

A selection of key findings across the completed rounds to date:

- » Mortality in adult patients with Ulcerative Colitis has halved (1.7% in 2006 to 0.8% in 2010), with a reduction also seen for patients with Crohn's Disease
- » The number of sites reporting at least some provision of IBD Nurse time has increased although most still have less than recommended in the IBD Standards (56% in 2006 to 78% in 2010 in adult sites. 61% in 2008 to 83% in 2010 in paediatric sites)
- » Percentage of patients seen by an IBD Nurse has doubled
- » Readmission rates have lowered
- » Collection of stool samples to test for infection has improved
- » Use of prophylactic heparin has continued to increase in adult patients
- » Number of operations has dropped over time, while the percentage undertaken laparoscopically is increasing
- » Rapid expansion in the provision of dedicated gastrointestinal wards
- » 99% of sites state that they provide written information on IBD to patients.

Areas where improvement is still needed:

- » More patients with Crohn's Disease should be being seen by a dietitian during admission (40% in 2010 – adult data)
- » All patients admitted with diarrhoea should have a stool sample collected to exclude infection
- » Recording of pubertal status and growth should be mandatory in all paediatric patients with Crohn's Disease
- » Number of beds per toilet on hospital wards remains below acceptable levels (24% are mixed sex)
- » Provision of psychological support or counselling also remains below acceptable levels
- » Age-specific services for patients aged under 16 that are cared for in adult hospitals are suboptimal
- » When compared with general inpatients (pooled scores from the National Inpatient Survey 2009), IBD patients appeared to give a relatively poorer rating for consistency and coordination of care and nursing care
- » Many GPs reported being unable to get their patients seen in secondary care within 7 days in the event of a relapse (59%).

More information about the previous and current work, including copies of all national reports of the UK IBD Audit, can be found here: www.rcplondon.ac.uk/ibd

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 documents and links will be added as they become available - www.ibdstandards.org.uk

Other Useful Websites

IBD Audit Reports

National reports for all rounds of the UK IBD Audit, along with one page summaries of findings, audit tools, model action plans, presentation templates and other helpful documentation relating to all elements of the IBD Audit.
www.rcplondon.ac.uk/ibd

IBD Quality Improvement Programme

www.ibdqip.co.uk

The IBD Quality Improvement Programme supports an online resource bank.

www.ibdqip.co.uk/KMS/Default.aspx

IBD Registry

www.ibdregistry.org.uk

ACPGBI Ileal Pouch Database

www.ipdb.org.uk

IBD Patient Surveys and Reports from Crohn's and Colitis UK

Crohn's and Colitis UK has conducted various research, surveys and focus groups. The reports from these are available from the Crohn's and Colitis UK website, together with details of Crohn's and Colitis UK services and the support the charity can provide to individuals and to healthcare professionals.

www.crohnsandcolitis.org.uk

Other IBD Patient Organisations:

- CICRA – Crohn's in Childhood Research Association
www.cicra.org
- IA – The ileostomy and internal pouch Support Group
www.iasupport.org
- 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 Association for Parenteral and Enteral Nutrition www.bapen.org.uk
- British Dietetic Association www.bda.uk.com
- British Society of Gastroenterology www.bsg.org.uk
- British Society of Gastrointestinal and Abdominal Radiology www.bsgar.org
- British Society of Paediatric Gastroenterology, Hepatology and Nutrition www.bspghan.org.uk
- European Crohn's and Colitis Organisation www.ecco-ibd.eu
- Primary Care Society for Gastroenterology www.pcsg.org.uk
- Royal College of General Practitioners www.rcgp.org.uk
- Royal College of Nursing www.rcn.org.uk
- Royal College of Pathologists www.rcpath.org
- Royal College of Physicians www.rcplondon.ac.uk
- Royal Pharmaceutical Society www.rpharms.com
- UK Clinical Pharmacy Association www.ukcpa.net

The IBD Standards Group



Association of Coloproctology of Great Britain and Ireland



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