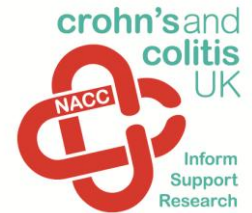


14th February 2014



Mr David Rees AM
Health and Social Care Committee Chair
National Assembly for Wales
Cardiff Bay
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Dear Mr Rees,

Short Inquiry into implementation of national guidance on Inflammatory Bowel Diseases (IBD)

I am writing on behalf of Crohn's and Colitis UK to ask that you and the Health and Social Care Committee consider our proposal for a short inquiry into the implementation of national guidance for Inflammatory Bowel Disease. This replaces the draft, proposed scope for a 'short inquiry into the implementation of national guidance for luminal G.I conditions' that the Committee recently received.

Having had further discussions with colleagues in other patient organisations covered by the original draft proposed scope, we feel that it would be beneficial to narrow the inquiry's proposed scope a little, so that it focuses on IBD exclusively.

We feel that the best case for this inquiry can be made by focusing on IBD specifically, as the issues around inconsistent provision of care are well supported by the three existing rounds of the UK IBD Audit data, with a fourth which will be published in the coming months. However, this same level of data is not readily available for Coeliac Disease nor Irritable Bowel Syndrome.

Crohn's Disease and Ulcerative Colitis (two common gastroenterological conditions, known collectively as Inflammatory Bowel Disease - IBD) impact around 15,500 people in Wales. The symptoms include frequent diarrhoea (sometimes with blood and mucus in cases of IBD), acute abdominal pain, weight loss, and profound fatigue.

IBD can cause blockages in the intestine or ruptures in the lining of the intestinal wall, which require emergency surgical intervention if the condition goes untreated, or in cases of severe disease. Between 50% and 70% of patients with Crohn's Disease will undergo surgery within a lifetime. In Ulcerative Colitis lifetime surgery rates are about 20-30%. There is also an established link between IBD, particularly extensive Ulcerative Colitis, and an increased risk of developing colorectal cancer.

Standards of treatment and care for people with IBD in Wales have improved in recent years. However, they still fall behind the average for the rest of the UK. National guidance was issued in 2009 in the form of the UK IBD Standards – a collaboration between professional organisations and patient groups that sought to define good quality IBD care. In subsequent years, the Standards have been supplemented with NICE Clinical Guidelines for both Crohn's and Colitis.



David Barker, Chief Executive Keith Stewart, Chairman
Crohn's and Colitis UK is the working name for
The National Association for Colitis and Crohn's Disease
Charity registered in England No 1117148 and in Scotland No. SC038632
A company limited by guarantee in England: Company number: 5973370



Despite this, three rounds of independent UK IBD Audit data have demonstrated that basic standards of care are not being met by many Welsh hospitals, notwithstanding the former Health Minister's acknowledgement that Health Boards are 'expected to take into account the Standards'.

Given the disparity in standards of IBD care in the four UK countries, despite national guidelines, Crohn's and Colitis UK believes a short inquiry into the implementation of this guidance is now necessary. Such an inquiry could enable better understanding of the barriers to improved care for people with IBD and help address some of these barriers ahead of the publication of NICE's IBD Quality Standards in September 2014.

If you require further information, I am contactable via Policy and Public Affairs Officer Philip Reynolds at 'philip.reynolds@crohnsandcolitis.org.uk'.

Yours sincerely,

A handwritten signature in blue ink, appearing to read 'D. Barker', with a long horizontal flourish underneath.

David Barker,
Chief Executive
Crohn's and Colitis UK

Health and Social Care Committee

Proposed Scope: Inquiry into implementation of national guidance on Inflammatory Bowel Diseases (IBD)

February 2014

Terminology

Gastroenterology – A specialism that examines the whole of the gut, ranging from the oesophagus to the colon and to various other organs, including the liver, pancreas and gall bladder¹.

Inflammatory Bowel Diseases (IBD) – These are chronic, autoimmune conditions in which intestines become swollen, ulcerated and inflamed. The most common variants are Crohn’s Disease and Ulcerative Colitis.

Prevalence and patient numbers

At least 261,000 people in the UK have Ulcerative Colitis or Crohn’s Disease, with more than one in 200 people affected by IBD. Exact prevalence figures in Wales are unavailable, however, it is estimated that just over 15,500 people have the conditions, based on recent Welsh population figures².

Impact on quality of life

IBD symptoms include acute abdominal pain, weight loss, diarrhoea (sometimes with blood and mucus), tenesmus (constant urge to have a bowel movement), and severe fatigue. Symptoms vary in severity from person to person and from time to time and relapses often occur suddenly and unpredictably.

In addition to physical symptoms, the psychological impact of IBD frequently presents a significant barrier to people actively participating in work and social life. Research conducted by Crohn’s and Colitis UK revealed that the fear of experiencing an episode of incontinence is as debilitating as the actual event.

A person with Crohn’s and Colitis UK explains: *“I don’t go through the door because of that ‘fear factor’ – I won’t have an accident outside the house as I don’t go out. I visit my mum’s once a week and my husband drives me, and I shop at night because there are fewer people around.”*

Another explained that *“being faecally incontinent is completely socially unacceptable. It is more acceptable to be sick in public. Therefore the fear of being faecally incontinent has a great impact on your life.”*

¹ Royal College of Physicians, *Gastroenterology* <http://www.rcplondon.ac.uk/specialty/gastroenterology>

² ONS, <http://www.ons.gov.uk/ons/rel/pop-estimate/population-estimates-for-england-and-wales/mid-2012/mid-2012-population-estimates-for-england-and-wales.html>

Treatment options

Medical management of IBD use a hierarchy of drugs to treat acute episodes and maintain patients in remission or with a reduced level of symptoms. These are corticosteroids, aminosalicylates (5ASA), immunosuppressives (azathioprine, 6-mercaptopurine, cyclosporine) and biologics (infliximab/adalimumab).

If left untreated, or in cases of severe disease, IBD can cause blockages in the intestine or ruptures in the lining of the intestinal wall, which require emergency surgical intervention. Surgical options include resections to remove diseased sections of the gut or the total removal of the large bowel and its replacement with a stoma bag. It is also known that between 50% and 70% of patients with Crohn's Disease will undergo surgery within five years of diagnosis. In Ulcerative Colitis, lifetime surgery rates are about 20-30%.

A high proportion of IBD patients will experience one or more associated inflammatory conditions requiring care from a different specialty – osteoarthritis and inflammation of the eyes or skin are the most common additional conditions. There is also an established link between IBD, particularly extensive Ulcerative Colitis, and an increased risk of developing colorectal cancer.

Guidance

Standards for the healthcare of people who have inflammatory bowel disease. 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
Published October 2013.

British Society of Gastroenterology Commissioning evidence-based care for Patients with Gastrointestinal and Liver Disease
Published June 2012

NICE Guidance

Clinical guidelines

NICE Clinical Guideline CG118 Colonoscopic surveillance for prevention of colorectal cancer in people with ulcerative colitis, Crohn's disease or adenomas.
Published March 2011

NICE Clinical Guideline CG152 Crohn's disease
Published October 2012

NICE Clinical Guideline CG166 Ulcerative colitis
Published June 2013

Quality Standards

NICE Quality Standard Inflammatory bowel disease (to cover Ulcerative colitis and Crohn's disease)

Expected publication date September 2014

Clinical Pathways

NICE Clinical Pathway: Colonoscopic surveillance

Current status

According to WAQ60597, 'The IBD standards were issued to the NHS in February 2010 under cover of a Ministerial Letter (EH/ML/009/10). Health Boards are expected to take into account the Standards for improving IBD services and to use them to inform planning, funding and the delivery of services for IBD within their local areas.'

Although standards of treatment and care for people with Crohn's Disease and Ulcerative Colitis in Wales have improved in recent years, they still fall behind the average for the rest of the UK.

After analysing data from the 2010 UK IBD Audit (the most recent round available) it is clear that basic standards of care are not being met by many Welsh hospitals, despite the former Health Minister's acknowledgement that Health boards are 'expected to take into account the Standards'. This presents a clear contrast with other UK countries.

UK IBD Audit organisational data comparison between UK countries –

2010 Key indicator results for England, Northern Ireland, Scotland & Wales					
IBD Standard	UK Average meeting the standard	England (162 hospitals)	Northern Ireland (11 hospitals)	Scotland (13 hospitals)	Wales (15 hospitals)
Does the IBD Service have a named clinical lead?	76%	80% (129)	45% (5)	69% (9)	67% (10)
Sites with guidelines for the management of Acute Severe Colitis	79%	82% (133)	55% (6)	85% (11)	60% (9)
Sites that hold parallel gastroenterology/colorectal surgery clinics (where IBD patients are seen)	56%	47% (76)	18% (2)	62% (8)	33% (5)

A separate inpatient audit examined the experiences of people with IBD who were admitted to hospitals across the UK. Data reveals that hospitals are failing to weigh patients on admission to hospital, not prescribing blood thinning medication and specialists were not meeting regularly to discuss patients.

IBD Standards	Patients across Welsh hospitals entered into Audit receiving this care	UK average
Standard A10 – 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	65% of Ulcerative Colitis patients seen by specialist (108/165 patients entered into inpatient Audit from the 15 hospitals)	88% of Ulcerative Colitis patients were seen by a specialist
	50% of Crohn’s Disease patients were seen by a specialist (94/185 patients entered into inpatient audits from the 15 hospitals)	78% of Crohn’s Disease patients were seen by a specialist
Standard A10 - All IBD patients admitted should be weighed and their nutritional needs assessed	35% of Crohn’s patients were weighed (66 of 185)	72% of Crohn’s Disease patients were weighed during first admission

Suggested Terms of Reference

To examine the awareness and implementation of current national guidance for Inflammatory Bowel Diseases, especially the measures developed to support and monitor the uptake and effectiveness of such guidance.

The Committee will particularly consider the ongoing impact of guidance on improving standards of care for people in Wales to a level equivalent to that of England.

Suggested witnesses

Crohn’s and Colitis UK

Welsh Association for Gastroenterology and Endoscopy

The UK IBD Standards Group

Suggested sources of information

StatsWales

UK IBD Audit third round reports

UK IBD Audit fourth round reports (available summer 2014)