



Medical and patient organisations launch first IBD Service Standards to improve care for patients with Colitis and Crohn's disease

Quality Care for Colitis and Crohn's

10th February 2009. London, UK. The IBD Standards Group representing the patient organisation, the National Association for Colitis and Crohn's disease (NACC) in collaboration with six healthcare professional organisations will tomorrow launch the first Service Standards aimed at improving the healthcare of patients who have inflammatory bowel disease (IBD).

Ulcerative colitis and Crohn's disease have a profound impact on the lives of about 240,000 patients and their families in the UK. Many are diagnosed with these life-long conditions in their teens or early twenties. The distressing symptoms of urgency, diarrhoea, pain, profound fatigue and anaemia often follow unpredictable patterns of disease 'flares'. However, with appropriate healthcare provision most patients can sustain economically productive and family support roles.

The new IBD Service Standards reflect the findings of the 2006 National Audit of adult IBD Services and Care, to which 75% of hospitals in the UK submitted data. The voluntary audit demonstrated a widespread professional commitment to evaluation of IBD care and identified many aspects of good organisation and practice. However, the Audit also highlighted unacceptable variations both in service provision and organisation of important aspects of clinical care. These variations reflected the lack of any plans or standards for IBD and led directly to the commitment to develop the Service Standards for IBD that will be launched tomorrow.

Key 2006 Audit findings included:

- One third of hospitals had no dedicated gastroenterology ward.
- Forty four per cent had no specialist IBD nurses - with IBD symptoms often making travelling and hospital visits virtually impossible, nurse-run help lines offer immediate, highly qualified advice to ensure that patients are either prioritised for an out-patient appointment or admitted to hospital.
- On average, dietitian sessions dedicated to gastroenterology were just two per week.
- Less than half of hospitals provided joint or parallel gastroenterology/surgical clinics – since 50-70% of patients with Crohn's disease will require surgery within 5 years of diagnosis, there must be defined

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- Forty six per cent of outpatients with Crohn's Disease received continuous systematic corticosteroid therapy for longer than three months, increasing their risks for osteoporosis and steroid dependency.

Speaking before the launch, Chairman of the Working Group and CEO of NACC, Richard Driscoll, explains, "The new IBD Service Standards will focus more attention by local health services onto the quality of their IBD care. For example, we need to ensure that when patients are diagnosed they receive the information and support they need to understand and manage their illness better, hopefully enabling them to get back to a near normal family and working life.

"We want more patients to receive specialist care and best-practice treatment consistently and without delay. All patients should benefit from the support that can be given by IBD nurses and have greater access to dietitians. With improved access to specialist advice, care for disease flares and effective treatment can begin sooner. A major study has shown that this improves patients' lives and reduces NHS outpatient appointments and admissions¹.

"For those whose illness is more severe and not responding well to treatment, they will benefit from the specialist knowledge of a multi-disciplinary team and be better able to participate in the important decisions about treatment choices such as surgery. Overall, we recommend that IBD Services should be meeting these new standards by September 2010."

The Service Standards will be made widely available to NHS Managers and Commissioning Organisations throughout the UK. The official launches start at The House of Lords tomorrow and will be rolled out to the Scottish Parliament, Welsh and Northern Ireland Assemblies in February and March. A dedicated website www.ibdstandards.org.uk has been created to help NHS managers, healthcare professionals and patients better understand the new Standards.

Professor Chris Hawkey, in-coming President of the British Society of Gastroenterology, one of the medical bodies involved with the development of the Standards, explains, "The BSG believes strongly in minimum standards of care for patients with ulcerative colitis and Crohn's disease, and that they should focus on practical matters that are of importance to patients.

"These proposals will not only help to improve a patient's experience while in hospital, but they will not be expensive to implement. Much of what is proposed can be achieved simply by high professional standards and proper organisation and deployment." **ENDS**

Editors Notes:

The members of the IBD Standards Group are:

- *Association of Coloproctology of Great Britain and Ireland (ACPGBI)*
- *British Dietetic Association (Gastroenterology Group) (BDA)*
- *British Society of Gastroenterology (BSG)*
- *British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN)*
- *National Association for Colitis and Crohn's Disease (NACC)*
- *Primary Care Society of Gastroenterology (PCSG)*
- *Royal College of Nursing (Crohn's and Colitis Special Interest Group) RCN.*

Reference:

1. Robinson A, Thompson DG, Wilkin D, Roberts C. Guided self-management and practice-directed follow-up of ulcerative colitis: a randomized trial. *Lancet* 2001; 358:976-81.

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