



IBD Registry and Pharmacosmos launch iron deficiency anaemia collaboration

A 12-month project aiming to improve treatment outcomes for inflammatory bowel disease (IBD) patients with iron deficiency anaemia (IDA) has been launched using the IBD Registry. A Joint Working project between Pharmacosmos and the British Society of Gastroenterology (BSG) has developed and launched an IDA evaluation, using the IBD Registry web tool to collect the data. This initiative will establish numbers of IBD outpatients with IDA, and observe the type of treatment they receive. The aim is to improve patient outcomes by highlighting the need for improved recognition and treatment of IDA in IBD patients.

Chronic fatigue is a common symptom in IBD, with IDA being one of the primary causes. IDA can have a significant impact on a patient's quality of life, as it reduces the ability to perform many normal activities. The 2014 National IBD Audit showed that not only is the condition very common, but it is also undertreated. In patients admitted to hospital with ulcerative colitis (UC) – one of the conditions of IBD – 49% of the women and 47% of the men had anaemia. Where the anaemia was attributed to iron deficiency, 56% of people received no treatment. The new project aims to find out more about the extent to which people are undertreated, and raise awareness of the need to address IDA in clinical practice.

The audit will measure the prevalence of iron deficiency, total iron deficit, and treatment in five outpatient centres, with each centre collecting data on 10 patients with UC and 10 patients with Crohn's disease. As there is no standard definition of IDA, reporting will also map the data against the various available definitions.

Although there is evidence from secondary care that hospitalised IBD patients do not have their IDA adequately recognised or treated, this audit will be the first to determine whether IBD outpatients are adequately assessed, and whether their treatment is optimal. There are currently no clearly defined audit standards for the treatment of IDA in patients with IBD, so this project will help to define current service standards and identify areas for improvement.

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APPROVED QUOTES:

"The Anaemia Audit represents an important proof of concept for the IBD Registry. It's the first example of the value of the Registry as a tool to easily support collaborative projects with industry that benefit people with IBD."

Stuart Bloom, Chair of the IBD Registry Board

"The BSG promotes high quality patient care by defining best practice and, through the success

and innovation of the IBD Registry, we will be able to improve our understanding of long term outcomes, better define the pattern of ulcerative colitis and Crohn's disease and inform clinical practice, commissioning and service design in order to benefit patients."

Ian Forgacs, President of the British Society of Gastroenterology

"What's exciting is that by adding a small number of fields to the existing Registry dataset, we're able to customise the web tool. This makes the IBD Registry a very nimble solution for capturing real-world data that will quickly have an impact on improving patient care. "

Fraser Cummings, Clinical Lead, IBD Registry

"Pharmacosmos is committed to improving the lives of patients with iron deficiency anaemia. We're incredibly proud to be working with the BSG and the IBD Registry to develop a better understanding of the real-life incidence of iron deficiency anaemia in IBD. We hope that the results will lead to real benefit to patients with iron deficiency anaemia."

Andreas Sidelmann Christensen, Managing Director, Pharmacosmos UK & Ireland

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FOR MORE INFORMATION, CONTACT CLAIRE MUNRO ON 07976 856208

BACKGROUND INFORMATION

INFLAMMATORY BOWEL DISEASE:

It is estimated that inflammatory bowel disease (IBD) affects one in 250 people in the UK. IBD is the term used to describe two diseases: ulcerative colitis (UC) and Crohn's disease (CD) - both are chronic diseases that involve inflammation of the gastrointestinal tract. UC only affects the large intestine (colon), while CD can affect the entire digestive system.

There are other, more rare, types of IBD, known as collagenous colitis and lymphocytic colitis, which are both types of microscopic colitis.

The main symptoms of both UC and CD are similar. They include:

- abdominal pain (more common in CD than in UC)
- recurring or bloody diarrhoea
- weight loss
- extreme tiredness

Symptoms of IBD can come and go over long periods, and sufferers may experience flare-ups or go through periods of no symptoms at all.

There is currently no cure for UC or CD. Treatment aims to relieve symptoms and prevent them from returning. In severe cases, surgery to repair damage, or surgical removal of the inflamed section of the digestive system, may be required.

IRON DEFICIENCY ANAEMIA:

Iron is required to create haemoglobin. In iron deficiency anaemia (IDA) there is a reduction in the haemoglobin produced in the red blood cells, lowering the amount of oxygen they can carry to the tissues and organs. Patients can experience symptoms such as shortness of breath, extreme tiredness and lethargy as a result.

If IDA is left untreated, it can lead to a compromised immune system, which will make a patient more susceptible to illness and infection. Severe IDA may also increase the risk of developing complications that affect the heart or lungs.

THE UK IBD REGISTRY:

The IBD Registry provides the first ever UK-wide repository of anonymised IBD adult and paediatric patient data for prospective audit and research purposes. Bringing this data together for the first time will:

- drive continuous improvement in patient care and access to care across the UK
- inform commissioning and service design
- improve understanding of long term outcomes
- provide local, regional & 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 Registry Patient Management System (PMS) or from existing databases.

The IBD Registry:

- allows services to measure their local performance against national results
- makes it easier to monitor and improve quality
- facilitates benchmarking against the national performance which will inform local pathway development.
- links with IBD Audit
- is an excellent resource for research

The essential principle adopted by the Registry Board is that users get immediate local benefits for themselves and their patients with minimal time spent entering data. The Registry PMS has been designed to make it easy to collect data at the point of consultation, and upload it automatically into the Registry. 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, MDT system etc. Service reports and clinical audit can be generated automatically.

BRITISH SOCIETY OF GASTROENTEROLOGY:

Founded in 1937, the British Society of Gastroenterology (BSG) has over three thousand members, drawn from the ranks of physicians, surgeons, pathologists, radiologists, scientists, nurses, and dietitians. Its mission is to maintain and promote high standards of patient care in gastroenterology and to enhance the capacity of its members and associate members to discover, disseminate and apply new knowledge to the benefit of patients with digestive disorders.

The BSG is intimately involved in all aspects of training of British gastroenterology and committed to original research in the field. The Society's scientific journal, '*Gut*', is Europe's highest ranked journal, by citation-related impact factor. The BSG regularly produces guidelines on aspects of contemporary practice.

PHARMACOSMOS:

Headquartered in Denmark, Pharmacosmos is a family-owned healthcare company with more than 20 years of innovation and leadership in iron deficiency anaemia care. A research-based company, its ongoing R&D programme focuses on improving the lives of patients with iron deficiency anaemia. Pharmacosmos markets its products in more than 50 countries across Europe, the Americas and Asia. Its facilities are approved by both the Danish Medicines Agency and the US Food & Drug Administration. For more information, visit pharmacosmos.co.uk.

JOINT WORKING:

Joint working describes situations where, for the benefit of patients, NHS healthcare professionals and industry organisations pool skills, experience and/or resources for the joint development and implementation of patient centred projects and share a commitment to successful delivery.