

Lay Summary

Inflammatory bowel disease (IBD) is a chronic illness with often unpredictable symptoms that can have a profound effect on an individual's quality of life. Typically when IBD becomes acutely active, access to specialist healthcare advice is vital to initiate interventions to settle flare-ups. Any delays or barriers to this access may increase stress and worsen disease control.

The condition predominantly affects young people, with patients frequently diagnosed in teenage years or early twenties. This is often at a time when they are establishing their adult lives, either through education or finding their first job. Variations in IBD care were recognized through national auditing. In 2009 the IBD Standards working group produced a comprehensive document with the aim of ensuring IBD patients receive consistent, excellent care. Six standards were agreed after studying evidence with the aims to provide high quality care and deliver this locally. Maintain a patient-centred service, provide education and support, deliver evidence-based treatment, support research and use IT effectively, to optimise clinical management.

This innovative proposal aims to enhance IBD care through these guiding principles, with the development and testing of an IBD-specific electronic patient record - 'IBD Patient View'.

IBD Patient View consists of: -

1. A personal IBD record, which is accessed through the Internet by a secure login process. This will provide access to clinic letters, blood results, medications, endoscopy reports, radiology reports and current management plans, anywhere in the world.
2. A number of interactive tools to enable the patient to self assess their symptoms, including disease activity measuring tools where abnormal scores will be highlighted through a trigger email to the IBD Nurse Specialist. A patient discussion forum will also be incorporated.
3. Access to information, using a format similar to our established patient guidebooks. Patients will also have links to Crohn's and Colitis information leaflets, lectures, current research and 'blog casts' from key members of the IBD community.

This online programme aims to empower patients and promote a team approach to disease management, enabling patients to be better equipped to take a more active role in managing their IBD, whilst greatly improving communication between GPs and hospitals.

The study will be based at Salford Royal Infirmary, an ideal site for the web-portals development; having established patient electronic records for over 10 years and with a cohort of 1500 people with IBD. We aim to build upon previous extensive work around developing patient-orientated care and guided self-management. We envisage 'IBD Patient View' will provide a future model of care for many individuals with IBD. Once fully developed with strong patient-group support, participants will be randomised over a 6-month period, into either receiving access to the 'IBD Patient View' following training or to continue the normal standard of care and follow up.

We hypothesise that the web-portal will be beneficial to a majority of IBD patients and aim to prove its acceptability. Further measures of its impact will be measured, including its effect on quality of life, knowledge, disease activity and adherence to medications.

Following success, the aim would be to roll out the service to other hospitals with the necessary IT infrastructure, in an incremental fashion and to develop the site in conjunction with the developing National IBD registry. The aim is to provide a patient-focused database to help monitor IBD and improve future research recruitment, facilitating a better understanding of this often life-long chronic condition.