

# *Improving Inflammatory Bowel Disease care across Australia*

*Crohn's & Colitis  
Australia*

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## ***Improving Inflammatory Bowel Disease care across Australia: Executive Summary***

*There is a clear imperative for addressing the variation in care received by Inflammatory Bowel Disease (IBD) patients across Australia. Although there have been steps made across individual sites to improve the model of care, access to appropriate and cost effective services remains inconsistent, with hospital costs nationally in excess of \$100 million per year. An integrated national evidence-based approach is necessary.*

### ***What is IBD?***

Crohn's Disease and Ulcerative Colitis, the predominant IBD conditions, are chronic and lifelong diseases that cause inflammation in the colon, rectum and gastrointestinal tract. Diagnosis of IBD commonly occurs in adolescence and young adulthood, with the cause remaining unidentified.

The diseases are characterised by unpredictable relapsing and remitting course, with a range of symptoms including abdominal pain, weight loss, fever, diarrhoea, rectal bleeding and fatigue. In addition, there are numerous effects on development, psychological wellbeing, education and employment productivity, family life and relationships.

### ***IBD is becoming more prevalent, more complex, and more severe...***

IBD is a chronic and largely hidden disease affecting approximately 1 in 250 people aged 5 – 49 nationally.

Australia has one of the highest rates of prevalence and incidence in the world and each year more and more young people are being diagnosed. Over 74,955 Australians are burdened with a constant and often hidden struggle that affects a sufferer's personal, social and work life.

### ***...healthcare utilisation and costs are increasing...***

The annual cost for managing IBD patients is substantial both in human and monetary terms. Direct costs for IBD as a result of hospitalisation have been increasing over time, with a significant cost burden related to health care utilisation.

PwC estimates that national total hospital costs for IBD are in the order of \$100 million per annum.

Productivity losses attributable to IBD in 2012 are estimated at over \$380 million. An additional \$2.7 billion of financial and economic costs have been associated with the management of IBD.

### ***...and care is inconsistent and inadequate.***

IBD is a chronic disease with an onset early in adult life. As a result, optimal management with the avoidance of potentially avoidable morbidity is essential to minimise its impact on patients, the healthcare system and the economy. However, the predominant reactive model of only treating IBD acute flares is at odds with the long-term management required for the chronic condition.

Coordination of long-term surveillance to monitor increased cancer risks, management of medications and the broader needs of an IBD sufferer are largely non-existent.

Access to quality IBD care in Australia is inequitable. Those hospitals and clinics that have proactively implemented an integrated and formal IBD care model have disparate and insecure funding. Sufferers in remote areas and those without dedicated IBD resources cannot easily access such care.

The specialist support model is constrained outside dedicated clinics, often leading to patients delaying presentation to services until they reach an acute point. Patients are often treated by a range of clinicians, who may not have a deep understanding of the complex disease and its treatment options.

### ***The benefits of improving IBD care cannot be ignored...***

In particular clinics and hospitals in Australia formalised and coordinated IBD care approaches have produced significant benefits to patients and cost savings to the healthcare system.

Benefits of addressing problems in the care model are significant, ranging from increased adherence and compliance to medication through to decreased hospitalisations and emergency department presentations, decreased need for surgery, less morbidity, improved quality of life and work productivity.

### ***...but there is more work to be done.***

Notwithstanding these achievements, it is evident that there is a gap in data and consistent knowledge across the country on patient pathways and outcomes, service coordination and resources. In assessing a range of possible interventions, PwC recommend that the best first step would be the formation of a national partnership to conduct an audit of IBD care programs and service resources.

### ***A plan for action***

CCA should seek funding of approximately \$1 million over two years to construct an evidence base from which to develop nationally consistent responses for the improvement of IBD care.

A Working Group, including CCA, the Australian Inflammatory Bowel Disease Association, the Colorectal Surgical Society of Australia and New Zealand, the Royal Australian College of General Practitioners, the Gastroenterological Nurses College of Australia, and the Dietitians Association of Australia, will plan the audit. This may be based on PwC's proposed framework focused on obtaining data into the service delivery and operations of up to 100 Australian hospitals.

The audit will inform recommendations of an optimal patient pathway and a national capability framework for IBD care programs and corresponding service requirements.