

# *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.

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This Report has been prepared by PricewaterhouseCoopers Australia (PwC) for the purposes of providing advice to Crohn's & Colitis Australia (CCA) on seeking funding to improve the current care programs and resources for IBD patients. It is not to be used for any other purpose.

The information, statements, statistics and commentary (together the 'Information') contained in this report have been prepared by PwC from publicly available material, consultation with stakeholders, input from CCA, and other available PwC data. PwC have not sought any independent confirmation of the reliability, accuracy or completeness of this information. It should not be construed that PwC has carried out any form of audit of the information which has been relied upon. Accordingly, while the statements made in this report are given in good faith, PwC accepts no responsibility for any errors in the information contained herein, nor the effect of such errors on our analysis, recommendations or report.

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# 1 Introduction

## Inflammatory Bowel Disease

Inflammatory Bowel Disease (IBD) refers to a group of gastrointestinal disorders made up predominantly of two conditions, Crohn's Disease and Ulcerative Colitis. They are lifelong conditions that commonly present themselves in children, adolescents and adulthood. During a disease flare, inflammation in the colon, rectum and gastrointestinal tract can become so severe that sufferers need to be hospitalised and require surgery. IBD can be largely unpredictable with significant variation in the degree and pattern of symptoms affecting each patient.

The relapsing and chronic nature of IBD has broader impacts on a person's emotional, physical and social wellbeing. Patients may also develop complications that are potentially life threatening, with links between IBD and increased risks of colorectal cancer as well as the adverse side effects of treatment.

The prevalence of IBD has markedly increased, the severity of the disease has worsened and people are being diagnosed at an earlier age. As at June 2012, the estimated prevalence of IBD in Australia was between 68,058 and 83,666. This estimate, although conservative, is largely consistent with incidence rates for developed countries.

### 1.1 An introduction to the report

PwC have been commissioned by Crohn's & Colitis Australia (CCA) with assistance from the PwC Foundation<sup>1</sup> to support CCA build a case for improving IBD service models across Australia through dedicated resources. The work involved consultation with a stakeholder group involving gastroenterologists and nurses as well as a desktop review of current literature, best practice and analysis of place-based studies.

The report is structured to include:

- 1 An overview of IBD, its impacts and complications, and updated prevalence statistics in Australia
- 2 Investigation into the key problems associated with IBD care models and resources
- 3 An outline of the potential benefits of addressing these problems for patients, the healthcare system and broader society
- 4 Assessment of a range of possible interventions in responding to current IBD care problems
- 5 Recommendations to facilitate a coordinated approach to creating evidence-based and consistent care programs and resources for IBD.

### 1.2 What is Inflammatory Bowel Disease?

IBD refers to a group of inflammatory gastrointestinal disorders characterised by their chronic and relapsing nature, most frequently diagnosed between the ages of 15-40 years. With this onset early in adulthood, IBD sufferers must confront a life of chronic illness, largely concealed from the outside world, along with a fear of substantial side effects and associated risks of treatment.

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<sup>1</sup> The PwC Foundation's aim is to make a positive and sustainable impact on the communities in which we live and work. This approach requires deep relationships with our 19 charity partners, so that we can understand and support them in achieving their goals. The Foundation works to leverage PwC's skills and position in the business community to impact on social change.

The two most prominent diseases in the IBD category, Crohn's Disease and Ulcerative Colitis, are idiopathic with no apparent or known cause. Crohn's Disease can affect any part of the digestive tract, is incurable and normally results in repeated surgical resection and intensive medical therapy. Ulcerative Colitis on the other hand is restricted to the large intestine and rectum. Although it can be 'cured' by surgical removal of the large intestine, this is an extreme option to be avoided if possible, with reduced quality of life<sup>2</sup>.

Crohn's Disease is **incurable** and is associated with a 47% increase in the mortality risk.

Ulcerative Colitis is only 'curable' through **radical surgery**, and if untreated, severe disease may also lead to death.

*Access Economics, 2007*

Chronic inflammation in IBD sufferers results in recurrent incidences of abdominal pain, diarrhoea, vomiting, fever, weight loss and rectal bleeding. When experiencing a flare, an IBD patient requires near-continuous care to address their clinical needs<sup>3</sup> and surgical treatment is often required to control IBD or manage the associated complications. The severity of the symptoms coupled with the morbidity associated with IBD and the impacts of its therapies have a profound impact on a person's physical, social, professional and emotional wellbeing.

IBD has a number of associated complications, including increased risks of colonic carcinoma<sup>4</sup>, colorectal cancer<sup>5</sup>, lymphoma<sup>6</sup> and osteoporosis<sup>7</sup>. In addition, many of the drugs used to treat IBD, particularly immunosuppressive agents, have a number of well recognised adverse effects. Potential drug interactions require long-term monitoring and strict patient compliance<sup>8</sup>. The need for management of IBD medication is vital to ensure IBD flares are controlled whilst also containing the side effects of the drugs.

### 1.3 Prevalence in Australia

IBD has been referred to as 'an emerging global disease'<sup>9</sup> and, for reasons not yet clearly understood, is largely a disease of the developed world. Although the cause remains unknown, there has been broad agreement on three key points:

- **prevalence** of IBD has **markedly increased** in recent decades
- **severity** of the condition has **worsened**
- **onset** is most prevalent in the **earlier** ages of adulthood.<sup>10</sup>

Although detailed Australia-wide prevalence data for IBD is currently unavailable, a breadth of studies has recorded the prevalence in specific jurisdictions across the country.

According to a 2010 study, the estimated incidence of IBD in Australia is high *even compared to other countries with high incidences of IBD*<sup>11</sup>. A study investigating Crohn's Disease in Victorian children

2 Access Economics, 'The Economic Costs of Crohn's Disease and Ulcerative Colitis', 2007, pg. 4.

3 Francesc Casella, M.D., Josefa Lopez-Vivancos, M.D., Xavier Badia, M.D., Jaime Vilaseca, M.D., Juan-Ramon Malagelada, M.D., 'Impact of Surgery for Crohn's Disease on Health-Related Quality of Life', *The American Journal of Gastroenterology*, Vol. 95, No. 1, 2000, pg. 177. This may itself add secondary morbidity associated with the intestinal or colonic resection.

4 Jones, 2004, in, Business Case Proposal for Sponsorship of IBD Nurse Position, Logan Hospital Queensland, 2012.

5 Charles N. Bernstein, James F. Blanchard, Erich Kliwer, Andre Wajda, 'Cancer risk in patients with inflammatory bowel disease: A population-based study', *American Cancer Society*, Vol. 91, Issue 4, 2001.

6 Corey A Siegel, 'Risk of lymphoma in inflammatory bowel disease', *Gastroenterol Hepatol*, Vol. 5, No. 11, 2009.

7 H Andreassen, J Rungby, JF Dahlerup, L Mosekilde, 'Inflammatory bowel disease and osteoporosis', *Scand J Gastroenterol*, Vol. 32, No. 12, 1997.

8 Business Case Proposal for Sponsorship of IBD Nurse Position.

9 Tony James, 'IBD "an emerging global disease"', *Gastroenterological Society of Australia*, 2011.

10 Peter R. Gibson, 'Overview of inflammatory bowel disease in Australia in the last 50 years', *Journal of Gastroenterology and Hepatology*, 2009, g. S63.

11 Based on a sample population taken from the Geelong region. Jarrad Wilson et al. 'High incidence of inflammatory bowel disease in Australia: A prospective population-based Australian incidence study', *Inflammatory Bowel Diseases*, Vol. 16, Issue 9, 2010

found a significant increase in the incidence of newly diagnosed sufferers over the last three decades, consistent with a worldwide increase in the incidence of this disease in both children and adults<sup>12</sup>. Based on the sample population of the Geelong region (which was taken to be representative of the national population composition), the reported IBD incidence rate was 29.2 per 100,000 - compared to 25.2 in New Zealand, 23.1 in Denmark and 22.2 in the UK<sup>13</sup>.

As at June 2012, the estimated prevalence of IBD in Australia has been calculated between 68,058 and 83,666, with a mean of 74,955 (prevalence rate of approximately 0.33 per cent). This number was based on a triangulation method across three recent Australian studies (Refer to Appendix A for approach to calculation of prevalence, assumptions and data sources utilised).

There has not yet been a nationwide study on prevalence to date. As a result, prevalence breakdown between states in Australia is based on ABS population distribution.

**Figure 1: Estimated prevalence of IBD in Australia by state territory (June 2012)**

	<i>Total</i>	<i>NSW</i>	<i>VIC</i>	<i>QLD</i>	<i>SA</i>	<i>WA</i>	<i>Tas</i>	<i>NT</i>	<i>ACT</i>
<b>Lower</b>	<b>68,058</b>	21,988	16,875	13,642	4,995	7,172	1,559	705	1,121
<b>Upper</b>	<b>83,666</b>	27,031	20,745	16,770	6,141	8,817	1,916	867	1,378
<i>Mean</i>	74,955								
<i>Median</i>	75,265								

The table below outlines projected prevalence of IBD over the next ten years. These projections may be conservative as they utilise a straight line ratio of new cases rather than accounting for an increase in the rate of incidence of IBD. As seen below, there may be up to 100,000 IBD sufferers across Australia by 2022.<sup>14</sup>

**Figure 2: Projected prevalence of IBD (2013-2022)**

	<i>2013</i>	<i>2014</i>	<i>2015</i>	<i>2016</i>	<i>2017</i>	<i>2018</i>	<i>2019</i>	<i>2020</i>	<i>2021</i>	<i>2022</i>
<b>Lower</b>	69,215	70,392	71,588	72,805	74,043	75,302	76,582	77,884	79,208	80,475
<b>Upper</b>	85,088	86,535	88,006	89,502	91,024	92,571	94,145	95,745	97,373	99,028

Comparing prevalence statistics, although problematic due to different mortality levels of diseases, presents an interesting picture of the extent of the problem in Australia relative to other more 'well known' conditions. For example:

- the prevalence of Multiple Sclerosis in Australia is of the order of 18,000 to 20,000 people<sup>15</sup>
- approximately 24,000 people in Australia are living with HIV<sup>16</sup>
- prevalence of epilepsy is reported to be in the band between 88,000 and 220,000<sup>17</sup>.

<sup>12</sup> AIHW, 'Young Australians: their health and wellbeing 2007', Australian Government, 2007.

<sup>13</sup> Jarrad Wilson et al. 'High incidence of inflammatory bowel disease in Australia: A prospective population-based Australian incidence study'.

<sup>14</sup> Refer to Appendix B for projected prevalence by state/territory.

<sup>15</sup> Multiple Sclerosis Research Australia 'Overview of multiple sclerosis', *MS Research Australia*, 2008.

<sup>16</sup> Australian Federation of AIDS Organisations, 'HIV statistics in Australia', AFAO, 2012.

<sup>17</sup> Australian Chapter of the International Bureau for Epilepsy, 'Inquiry into the impact of epilepsy in Australia today', *Joint Epilepsy Council of Australia*, 2008.

In spite of IBD affecting a younger and often larger cohort than the above, IBD remains a closeted disease that is relatively unknown<sup>18</sup>. CCA, who has offered education, support and advocacy for the growing IBD community for over 27 years, receives no government funding.

In less than ten years there may be up to **100,000 IBD sufferers** nationally.

*PwC, 2013*

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<sup>18</sup> The burden of Inflammatory Bowel Disease in Canada, *Crohn's and Colitis Foundation of Canada*, 2008.

## 2 The problem

### Summary of the problem

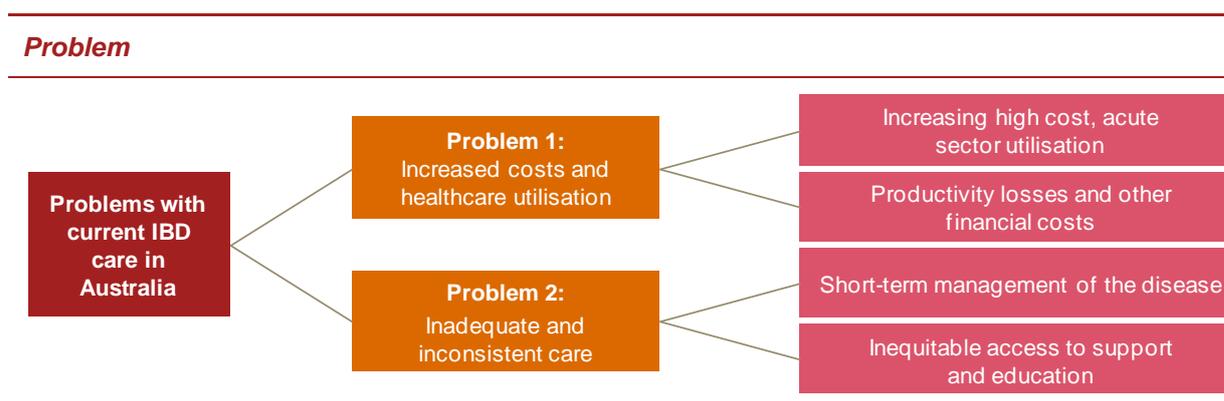
The primary problems focused on in this report in the approach to IBD care currently are:

- 1 **Increased costs and healthcare utilisation** due to increasing separations, productivity losses and other financial costs.
- 2 **Inadequate and inconsistent care** as a result of short-term management of the disease and inequitable access to support and education

Although there have been steps made across individual sites in Australia to improve the quality of care for IBD patients, access to appropriate and cost effective treatment for the disease remains uncoordinated and inequitable. The overarching current model of care and support is inconsistent, leading to inefficiencies and a lack of effectiveness and does not lead to improvements for the patient, their families and the healthcare system.

IBD's onset when young, coupled with the morbidity and severity of relapse, have an effect on an individual's quality of life. Exacerbating these issues, and the focus of this report, is the inconsistency in the current model of care for IBD patients across Australia. The two problems examined in this report are outlined below.

Figure 3: The key problems



### 2.1 Problem 1: Increased costs and healthcare utilisation

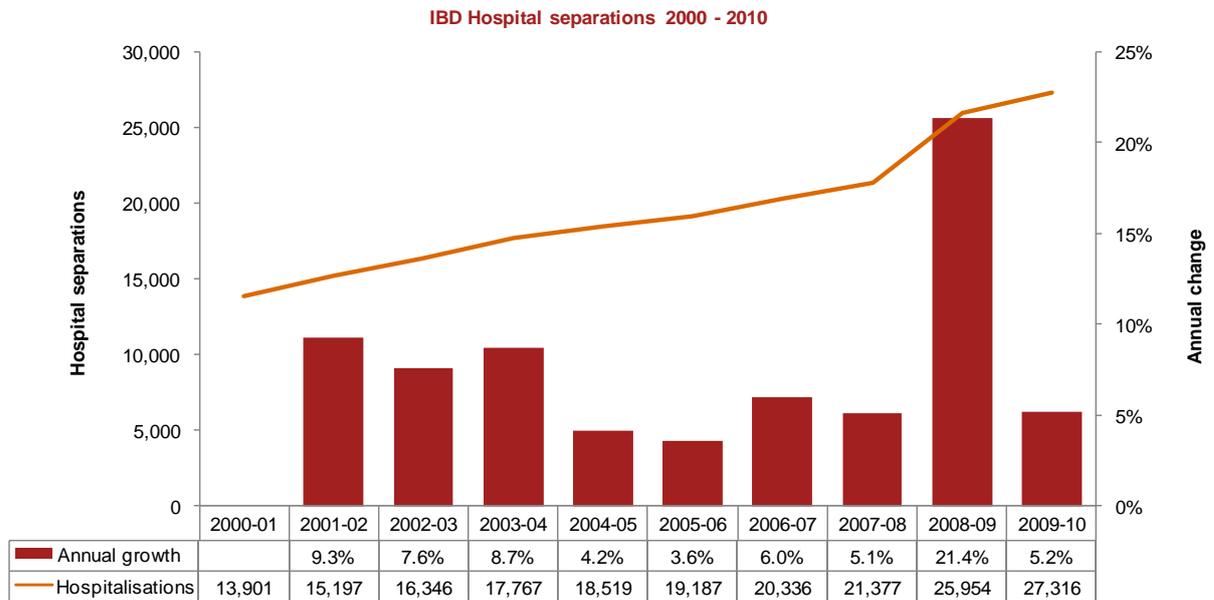
#### Increasing high cost, acute sector utilisation of IBD conditions

The periods of controlled management disrupted by symptomatic flares that characterise IBD place a significant burden on the health system.

As shown in Figure 4, hospitalisations for IBD have increased significantly over the last ten years, by 49 per cent from 2001/01 to 2009/10 and on average by more than 6% per year<sup>19</sup>. Increasing hospital separations and longer patient stays have led to an increased consumption of resources and driven up spending.

<sup>19</sup> AIHW National Morbidity Database, Includes hospitalisations where the principal diagnosis was K50 and K5. Significant increases in 2008-09 have been unable to be identified at the time of reporting, however may be due to increases in same day separations.

**Figure 4: Hospitalisations for IBD<sup>20</sup>**



A comprehensive analysis of total costs for IBD cases is difficult due to limited publicly available data and as sufferers of IBD also access hospital services for illnesses potentially unrelated to their chronic condition.

To provide some base assessment on the direct costs of IBD conditions in the hospital sector, analysis was conducted against Round 13 of the National Hospital Cost Data Collection (NHCCD) with the Diagnosis Related Group (DRG) 'Inflammatory Bowel Disease' (G64Z) considered the most relevant. National costs associated with this DRG total \$25.8m<sup>21</sup>.

Notwithstanding the need for additional service utilisation and costing research, a detailed state dataset was examined<sup>22</sup> and found that:

- in 2008-09 there were nearly 5,000 total separations for patients with a principal or secondary diagnosis of K50 Crohn's Disease (regional enteritis) or K51 Ulcerative Colitis.
- the total cost of IBD patients, with a diversity of DRGs, was significantly higher than the national costs for just G64Z (ie one state's costs for all IBD patient admissions was more than the national total for G64Z of \$25.8m).
- approximately 9.7 per cent of costs were attributable to non-IBD events (such as obstetric services).

By extrapolating this analysis using the national prevalence share, **PwC estimates that national total hospital costs for IBD is in the order of \$100m per annum.** In addition to these estimated costs, an audit from a major tertiary hospital demonstrated that approximately 50 per cent of patients who underwent surgery over an 18 month period had had potentially avoidable operations.<sup>23</sup>

<sup>20</sup> AIHW National Morbidity Database.

<sup>21</sup> Round 13, NHCCD results. Total costs for G64Z

<sup>22</sup> PwC were provided a confidential report of state admitted data on IBD sufferers. No audit or assessment of source data was conducted and the analysis is provided as an estimate only. Further research is recommended on actual patient costs and detailed admission analysis.

<sup>23</sup> Gapasin, J., Van Langenberg DR, Holtmann, G., Hetzel, DJ, Andrews, JM, 'Potentially avoidable surgery in inflammatory bowel disease: what proportion of patients come to resection without optimal preoperative therapy?' Intern Med J, Vol. 42, No. 5, May 2012. The audit at the RAH over an 18 month period showed that 11 of the 22 patients (ie 50%) who underwent surgery had potentially avoidable operations.

### Effects of high cost, acute sector utilisation

- 3 The annual cost for managing IBD patients is substantial. Direct costs for IBD as a result of hospitalisation have been increasing over time, with a significant cost burden related to health care utilisation.
- 4 Avoided operations can reflect outcomes of suboptimal medical therapy. The downstream consequences of this failure are magnified as patients who require surgical intervention are at much higher risk of further surgery.<sup>24</sup>

## Productivity losses and other costs

The chronic nature of IBD has been associated with short and long-term productivity losses for sufferers and the broader economy.

IBD can affect productivity in a number of ways including:

- **Education:** IBD has an early age of onset and can disrupt the primary, secondary and post-secondary education of sufferers. Education may be affected by temporary absences from school due to hospital admission or while recovering at home, the inability to study or sit exams, poor concentration, fatigue, pain and frequent toileting, unawareness or discrimination by teachers and lecturers<sup>25</sup>.
- **Absenteeism:** Analysis has found that 43 per cent of IBD sufferers in employment on average have 7.2 lost days of work<sup>26</sup> per annum. The reported number for Crohn's Disease sufferers has been as high as an average of 30 days.<sup>27</sup>
- **Employment impacts:** The severity of symptoms, as well as associated higher levels of depression, anxiety and other mental health issues<sup>28</sup>, may result in an individual not being able to study or participate in the workforce at full capacity.<sup>29</sup> In addition, hospitalisation is more common in people of working age (15-54). Four randomised clinical trials incorporating presenteeism reported a mean reduction of work productivity due to IBD ranging from 34 to 48 per cent<sup>30</sup>.
- **Premature death:** There is increased risk of premature death for those with Crohn's Disease. There has been a reported 47 per cent<sup>31</sup> increased risk of death associated with Crohn's Disease as well as an increased risk of colorectal cancer<sup>32</sup> in both Crohn's Disease and Ulcerative Colitis.

In 2012, productivity losses attributable to IBD amounted to over \$360 million. Refer to Appendix A for detailed costings and assumptions.

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<sup>24</sup> R.C.Sack, et al., 'A chronic care model significantly decreases costs and healthcare utilisation in patients with inflammatory bowel disease',

<sup>25</sup> Ibid, pg. 41.

<sup>26</sup> Ibid, pg. 44.

<sup>27</sup> Van der Valk, 'Productivity losses in inflammatory bowel disease: a systematic review', *European Crohn's and Colitis Organisation*, 2011

<sup>28</sup> Access Economics, 'The Economic Costs of Crohn's Disease and Ulcerative Colitis', pg. 40.

<sup>29</sup> Australian Institute of Health and Welfare, 'Australia's health 2012', *Australian Government*, 2012.

<sup>30</sup> Ibid.

<sup>31</sup> The burden of Inflammatory Bowel Disease in Canada, *Crohn's and Colitis Foundation of Canada*, 2008.

<sup>32</sup> Colorectal cancer is the second most commonly diagnosed cancer in Australia (after prostate cancer) as well as being the second most common cause of death (after lung cancer). Around 80 Australians die each week from the disease. Australian Government, 'National Bowel Cancer Screening Program', *Department of Health and Ageing*, January 2013.

**Figure 5: Productivity losses due to IBD**

<i>Productivity</i>	<i>2012 (\$)</i>
Loss earnings	234,561,613
Absenteeism	115,221,025
Premature death	11,716,594
<b>Total Productivity loss</b>	<b>361,499,232</b>

There are a number of other financial and economic costs associated with the management of IBD, including taxation revenue impacts, carer costs, out-of-pocket expenses, funeral costs and deadweight losses from transfers<sup>33</sup>. In 2012, these costs were estimated at **over \$2.7 billion**.

**Figure 6: Other financial and economic costs**

<i>Other financial and economic costs</i>	<i>Detail</i>	<i>2012 (\$)</i>
Deadweight losses	Cost of raising taxation revenue, loss of consumer and producer surplus	104,875,001
Informal care	Replacement value of family and other informal care	38,232,382
Funeral Costs	Associated with premature death due to Crohn's Disease	650,764
Out of pocket expenditure	Aids and modification, expenditure on day to day tasks, travel/accommodation costs, communication costs and complementary therapies	58,243,374
Welfare payments	Welfare and income support available to IBD patients	24,403,648
Burden of disease	Estimated gross cost of lost wellbeing	2,527,108,469
<b>Total other financial and economic costs</b>		<b>2,753,513,638</b>

**Effects of productivity losses and other costs**

- 1 Disruptions throughout school, tertiary and vocational education can have flow on effects throughout the individual's life and may contribute to significant employment and earnings detriment.
- 2 IBD can affect the long-term productive capacity of the labour force through long-term absence from work, reduction in hours worked, long-term reduction in productivity per hour worked, premature retirement and premature mortality<sup>34</sup>.

In 2012, productivity losses attributable to IBD amounted to **over \$380 million**.

An additional **\$2.7 billion of** financial and economic costs have been associated with the management of IBD.

*PwC, 2013*

<sup>33</sup> PwC's scope for this review excluded new economic analysis, however utilised other financial and economic costings provided in the following study-Access Economics, 'The Economic Costs of Crohn's Disease and Ulcerative Colitis', 2007. Verification of the methodology involved in the calculation of these costs was not performed as part of this report. For limitations and assumptions of the costing refer to Appendix A.

<sup>34</sup> Access Economics, 'The Economic Costs of Crohn's Disease and Ulcerative Colitis', pg. 47.

## 2.2 Problem 2: Inadequate and inconsistent care

### Short-term management of the disease

As a lifelong and chronic disease IBD relies on long-term and targeted management to improve the outcomes of sufferers and the healthcare system. The current model of care for IBD however is largely untimely and unspecialised. The traditional reactive model characterised by utilisation of acute services when the condition flares and an absence of contact when the patient is well<sup>35</sup> is not appropriate for the chronic nature of IBD.

When long-term disease management is absent there is increased risk of ad hoc and unspecialised treatment. Research undertaken by the University of Adelaide and the Royal Adelaide Hospital reported that GPs are often the first point of contact for initial symptoms as well as disease flares. This is problematic as evidence has shown that many GPs are not comfortable managing patients with IBD:

- 37 per cent of the 409 GPs surveyed responded they were 'uncomfortable' with IBD management
- 71 per cent and 91 per cent were uncomfortable with the use of immunomodulators and biologics respectively<sup>36</sup>
- GPs' comfort with managing IBD did not correlate with their IBD specific knowledge.

In day-to-day clinical care it is a challenge to provide IBD patients with the level of **continuous care required** to address their clinical needs.

C.Sack et. al, 2011.

The reactive model is exacerbated by a limited availability of IBD specialist services in hospitals. At the Royal Adelaide Hospital in 2008, before the creation of the IBD service, 30 per cent of patients with IBD received their hospital based IBD care from non-Gastroenterologists including GPs, surgeons and emergency room physicians.<sup>37</sup> This is problematic as even amongst gastroenterologists, there have been concerns raised about the knowledge across the system of IBD, with one gastroenterologist commenting that '*caring for and treating IBD patients may represent the most challenging aspect of a gastroenterologist's clinical practice*'<sup>38</sup>.

There is also misalignment between the required long-term surveillance necessary for those risks associated with IBD and its treatments, including increased risks of cancer. A Victorian gastroenterologist<sup>39</sup> noted the monitoring of drugs with specific toxicities is vital as some medications can lead to bone marrow suppression, lymphoma, skin cancer, opportunistic infections, osteoporosis, excessive radiation exposure from poorly coordinate care, liver complications, potential increased risk of developing tuberculosis and other avoidable complications. There are no consistent guidelines upon discharge for the coordination of support outside the hospital. Referral processes are often undefined, and patients commonly visit a number of practitioners at different locations without effective communication or coordination.<sup>40</sup> This means the patient is expected to navigate, often unsuccessfully, around multiple sites and access points for medical imaging, blood tests, pathology testing, prescriptions and proformas of medication dosages.

The breadth of care received by IBD sufferers is also problematic. When acutely unwell, patients with IBD are usually attended to in a hospital, where a holistic and coordinated care model is largely absent in the care of sufferers. The severity of the situation can result in inadequate concentration on the emotional and social issues of the patient. This is problematic as research has found that psychological

35 C.Sack, V.A. PHan, R. Grafton, G.Holtmann, D.R. van Langenberg, K.Brett, M.Clark, J.M. Andrews, 'A chronic care model significantly decreases costs and healthcare utilisation in patients with inflammatory bowel disease', *Journal of Crohn's and Colitis*, Vol. 6, 2012, p. 303.

36 M. Tan, R.H. Holloway, K. Lange, J.M. Andrews, 'General practitioners' knowledge of and attitudes to inflammatory bowel disease', *Internal Medicine Journal*, 2011, pg. 3.

37 C.Sack et. al 'A chronic care model significantly decreases costs and healthcare utilisation in patients with inflammatory bowel disease', p. 303.

38 Christian D. Stone, 'The economic burden of inflammatory bowel disease: clear problem, unclear solution', *Dig Dis Sci*, Vol 57, 2012.

39 Refer to Appendix 5 for a list of stakeholder consulted in preparation of this report.

40 Antonia A. Mickocka-Walus, Deborah Turnbull, Gerald Holtmann, Jane M. Andrews, 'An Integrated Model of Care for Inflammatory Bowel Disease Sufferers in Australia: Development and the Effects of its Implementation', *Inflammatory Bowel Disease*, Vol. 18, No. 8, 2012, pg. 1579.

disorders are highly prevalent in patients with IBD, with some researchers proposing that anxiety and depression may influence the clinical course of the disease.<sup>41</sup> Peter Gibson, of Monash University, stated that for those clinicians that manage patients with IBD, the most troublesome issues are not the choice of application of therapies but those that arise from physiological, nutritional, and other life issues that arise in association with chronic illness and IBD.<sup>42</sup> Andrews et al have termed these 'unpromoted issues'.<sup>43</sup>

### **Effects of short-term management of IBD**

- 1 The approach of providing subsequent treatment when required means that the patient has become so unwell that they require near-continuous<sup>44</sup> care to address their flare.
- 2 Flare ups rarely coincide with scheduled appointments as relapses are unpredictable. Failure to treat active disease when needed can result in prolonged exposure to medications, adverse side effects, and potentially invasive surgery and death<sup>45</sup>
- 3 If a patient fails to attend a routine appointment, there is no formal process for follow-up, meaning some patients may 'fall out' of the system.
- 4 The absence of long-term surveillance of increased risks of cancer and the surveillance of treatments can increase the burden of the disease in the long-term for the sufferer and the health system.
- 5 There is an increased likelihood that other issues, including psychological and nutritional issues, are not treated.

### ***Inequitable access to support and education***

Access to support for IBD sufferers and their carers is vital to cope initially with diagnosis as well as to manage the disease over the course of the patient's life. However, problems with access to care and education do not enable equitable or effective management of the disease, its treatments or complications.

The process of writing this report revealed an absence of national information available on IBD resources to provide clarity on the disparate resources, roles and funding sources. Access to a specialist support model is constrained outside dedicated clinics, often leading to patients delaying presentation to services until they reach a crisis point, which usually results in an ED presentation. An IBD nurse coordinator stated '*Accessibility is the key. If they can't get into a specialist, they wait until they are too sick and need to be hospitalised*'.

The figure below outlines the current understanding of the distribution of IBD nurse positions nationally.<sup>46</sup>

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41 Antonina A. Mikocka-Walus, Deborah A. Turnbull, Nicole T. Moulding, Ian G. Wilson, Jane M. Andrews Gerald J. Holtmann, 'Controversies surrounding the comorbidity of depression and anxiety in inflammatory bowel disease patients: a literature review', *Inflammatory Bowel Diseases*, Vol. 13, Issue 2, 2007.

42 Peter R. Gibson, 'Overview of inflammatory bowel disease in Australia in the last 50 years', *Journal of Gastroenterology and Hepatology*, 2009, pg. S65.

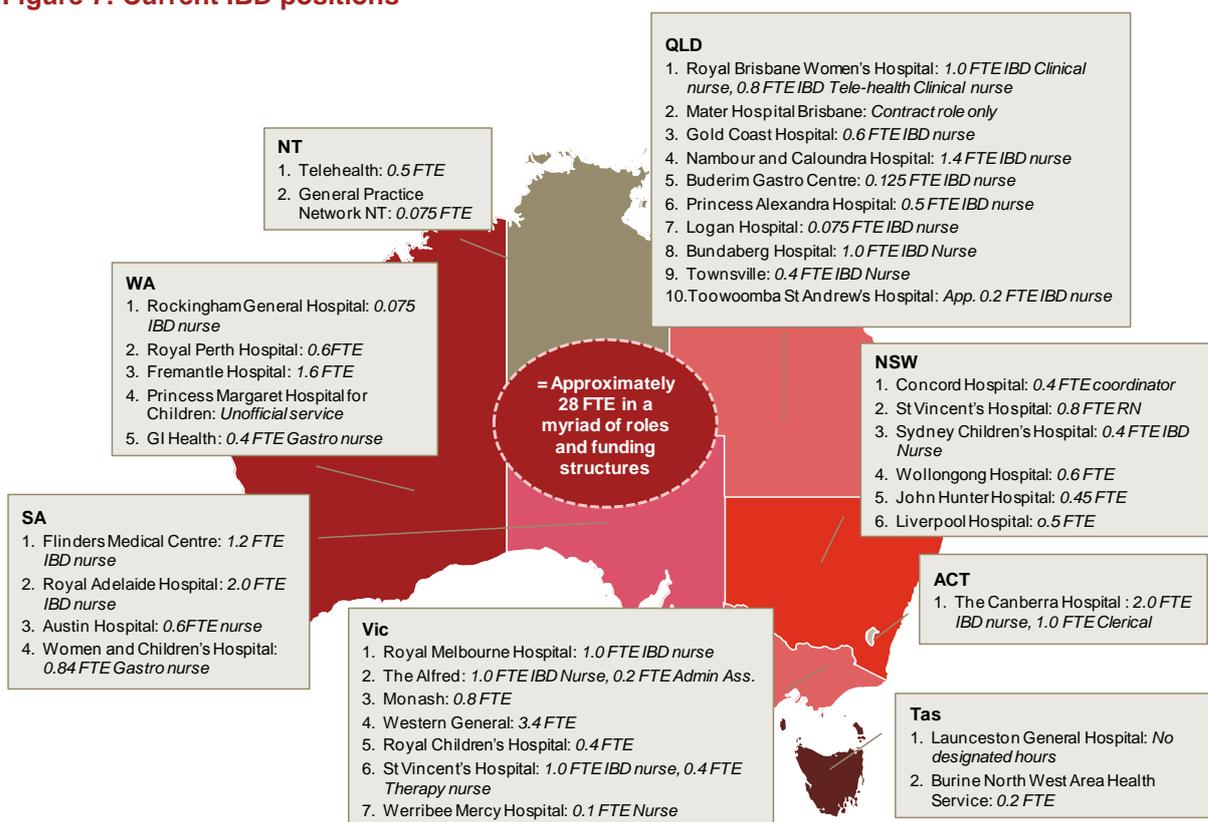
43 JM Andrews, RE Mountfield, DT Van Langenberg al, 'Unpromoted issues in inflammatory bowel disease: opportunities to optimise care', *Med. J. Int.* (in press), in Peter R. Gibson, 'Overview of inflammatory bowel disease in Australia in the last 50 years', *Journal of Gastroenterology and Hepatology*, 2009, pg. S65.

44 Ibid, p. 303.

45 NSW Health, 'Inflammatory bowel disease: Building alliances to help clients manage chronic disease', 2007 NSW Health Awards Entry, 2007.

46 It is noted that these are positions known to CCA at time of writing the report and it is not a definitive or accurate list as a full audit of current roles is not available).

Figure 7: Current IBD positions<sup>47</sup>



The hospitals and clinics that have proactively designed and implemented an integrated, formal IBD care model are hampered by disparate and insecure funding, while sufferers in remote areas and those without dedicated ID resources cannot access such levels of care.

Key reflections on current funding arrangements for IBD services are problematic:

- *At present I have a five month contract for 0.6 FTE which will not be renewed. All contract positions in QLD health are being terminated.*
- *I tried to get the IBD role recognised for three years with no success. I work alone in this role so leave is a problem as I can't find anyone to relieve me for long periods.*
- *We are very backward in the IBD department basically because of funding. We have no helpline and no hours designated solely for IBD. Would love to extend further but it would mean more funding.*
- *The IBD role is not funded by Queensland Health. This is the reason the role has little room to grow. Our hands are tied. Because of the nature of the funding my contract is only offered on a yearly basis.*
- *We have been preparing a business plan to management for a full time IBD position but have been told there are no funds at present.<sup>48</sup>*

There is also inconsistency in the provision of IBD education for patients, carers and GPs. An experienced gastroenterologist stated that the generic education provided to GPs is neither effective nor efficient. Although a number of GPs are proactive, care provided in this model is dependent on the

<sup>47</sup> This information was obtained from a survey sent to known IBD positions throughout Australia. The results were collated by CCA.

<sup>48</sup> Ibid.

individual GP and as each FTE GP may only care for between two and ten patients with IBD on average, becoming experts on IBD may not be the most efficient use of their time.

### **Effects of inequitable access to support and education**

- 1 The inconsistency of IBD care is problematic as the existing highly trained gastroenterologist specialist support model is difficult to access, particularly for patient cohorts that are socioeconomically disadvantaged or live in areas outside of major population centres.
- 2 Whilst there are places in Australia providing excellent care for IBD patients, this is disparate, with funding and role discrepancies leading to inequitable access to services for sufferers.
- 3 The specialist driven model of care has meant that patients often do not know who to ask questions to, or don't want to 'bother' doctors with questions. This potentially results in serious consequences including a patient stopping their medication, dropping out of care, or simply not knowing how to access the system, leading to a crisis point with effective management of the disease.
- 4 Issues concerning the education of sufferers are problematic as the efficacy, side effects and burden of administration associated with prescribed therapies are often difficult to understand and deal with.
- 5 Not comprehending the severity of their situation is incredibly worrying, stated one gastroenterologist and IBD specialist, as without a sufficient understanding and education, patients tend to spend time coping, then spiralling into crisis of chronic pain and further social drift.

Poor understanding and fear of side effects leads people to stop taking their medications, which in turn **contributes to flare ups and the deterioration of their condition.**

*Crohn's & Colitis Australia, 2012*

## **2.3 Why address this problem now?**

IBD is a sensitive and largely hidden disease affecting approximately 1 in 250 people aged 5-49 in Australia. It is a disease that presents a constant and veiled struggle across a sufferer's personal, social and work life.

Although Australia has one of the highest rates of prevalence and incidence in the world, international examples and literature have made evident that other parts of the world have moved ahead of Australia in the expectation of care for IBD in regards to consistency and accessibility of support.

Across individual sites in Australia there has been a paradigm shift in IBD treatment, which is correlated with improved outcomes. There are several examples of key centres that demonstrate improvements in IBD support and treatment and the difference they make to sufferers. However, the inconsistent nature of this care as well as the fragmented and insecure nature of available resources leads to suboptimal outcomes for Australian patients, their families and the healthcare system.

Improving the quality and consistency care of IBD as a chronic disease is aligned with federal and state policy objectives<sup>49</sup>, as well with priorities on risks associated with IBD. It is now the time for a formalised and nationally consistent approach to IBD care programs and service resources.

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<sup>49</sup> Refer to Appendix D for an analysis of the alignment between Commonwealth and State policy objectives and improved and consistent national IBD care.

# 3 Benefits of addressing the problem

## Summary of the benefits

Addressing the problems associated with current care approaches for IBD have been shown to result in:

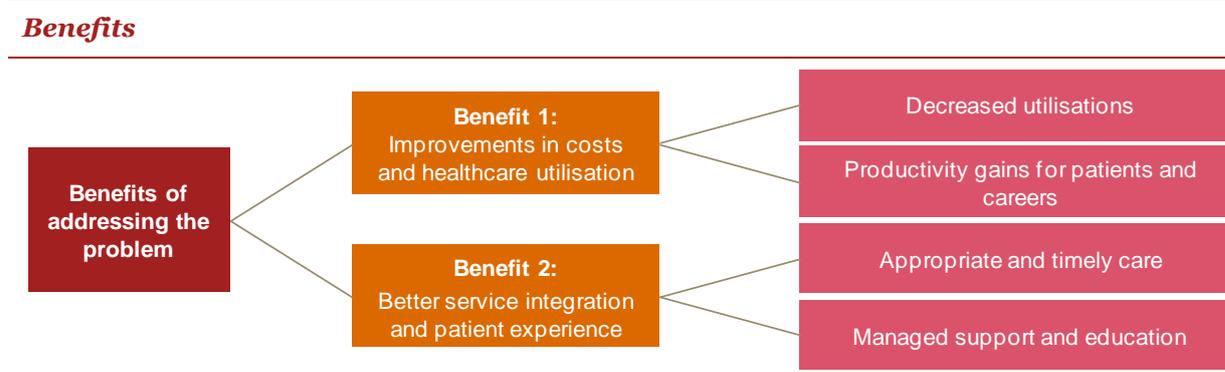
- 1 Improvements in costs and healthcare utilisation through:
  - A reduction in avoidable admissions and saved bed days
  - Productivity gains for patients and carers
- 2 Better service integration and patient experience through:
  - Coordination of appropriate and timely care
  - Access to education and support

Due to an absence of comparable and consistent data on services and resources, improvements in costs and healthcare utilisation cannot be quantified at a national level. However, there is evidence that these benefits lead to improved quality of life for IBD sufferers as well as a more efficient and effective system of care more broadly.

There is a notable absence of nationally consistent roles and resources for IBD programs, however available evidence indicates that targeted services have shown improved patient care and lead to decreased morbidity, decreased surgical referral and optimal outcomes<sup>50</sup>.

The key benefits of addressing problems in the current care model are outlined below:

Figure 8: Benefits of addressing the problem



50 Business Case Proposal for Sponsorship of IBD Nurse Position, 2012.

## 3.1 Benefit 1: Improvements in costs and healthcare utilisation

### Decreased hospital utilisation

In clinical practice, a formalised program has been shown to reduce the proportion of IBD patients admitted and also the length of stay (LoS) of those admitted through a combination of:

- timely treatment
- reduced bed days as a result of education of treatment and management
- decreased number of admissions requiring surgery.

A dedicated IBD service quantitatively and qualitatively **improves outcomes** in less than 18 months.

*Andrews et al., 2012*

In specific locations and incidences, multidisciplinary IBD care has shown to *reduce health system costs due to a reduction in admissions and bed days*. A study<sup>51</sup> performed in South Australia (SA) compared the inpatient health care utilisation of IBD patients with the (inpatient) health care utilisation of non-IBD patients. The audit found the mean number of admissions saved per patient was as high as 40 per cent, with admissions resulting from the ED dropping by 10 per cent in the study timeframe.

A formal follow-up procedure may also enable earlier discharge of IBD patients. Patients who require inpatient management for an exacerbation of IBD often remain in hospital whilst they are converted from intravenous to oral therapy. This has been avoided by follow up with early discharge and next day phone/email contact.<sup>52</sup> The mean cumulative total length of stay for the SA cohort studied in the period prior to and before the change in the care model dropped from 15.37 days to 5.38 days<sup>53</sup>, providing evidence of the degree of earlier discharge possible.<sup>54</sup>

#### Note: National benefits of a formal IBD program

It is difficult to extrapolate and quantify these nationally due to variable causal factors including:

##### 1 Incomparable data sets

The data utilised in calculating the \$100 m (Chapter 2) hospitalisation costs of IBD in Chapter 2 recorded separations principal or secondary diagnosis of K50 Crohn's Disease (regional enteritis) or K51 Ulcerative Colitis in one state.

The SA study that calculated the benefits through studying patient case notes from one hospital recorded materially different cost drivers (ie ALOS). The ALoS benefits found in the SA cannot be nationalised due to the differences in this data to the ALoS recorded in the state based data. The state-based data indicated lower LoS, which is likely to include hospital models that do not have dedicated IBD resources, thus making the extrapolation of benefits from the SA study difficult.

##### 2 Inconsistency of service models

The SA study was based on a formalised IBD service consisting of, but not limited to, a dedicated weekly IBD clinic, a joint medical-surgical clinic for IBD patients and a specialty IBD nurse. It is difficult to assign benefits amongst these roles and extrapolate nationally without an in depth appraisal of the value added by the individual processes and resources.

Although it is difficult to report benefits of a dedicated IBD service nationally at this stage, it is noted that the model in SA has been formally acknowledged as being able to deliver better outcomes at low cost as it was awarded the **2012 SA Health Award for 'Enhancing Hospital Care'**.

51 Sack et al, 'A chronic care model significantly decreases costs and healthcare utilisation in patients with inflammatory bowel disease', p. 302.

52 South Adelaide Local Health Network, 'Business Change Form-Inflammatory Bowel Disease Nurse', 2011.

53 Sack et al, 'A chronic care model significantly decreases costs and healthcare utilisation in patients with inflammatory bowel disease', p. 302

54 Ibid.

## Productivity gains

Reported benefits of a formalised and multidisciplinary approach to IBD care include a range of other financial benefits, including productivity losses, carer costs, out-of-pocket expenses and deadweight losses. The main opportunity for broader savings comes from the provision of consistent high quality care to limit unnecessary progression and frequency of relapses of IBD. If active disease periods can be reduced and the length of time between relapse be extended, there is less need for clinical intervention, admissions and surgery.

The flow on effects to reduced absenteeism and higher productivity due to a formalised approach have not been quantified in Australia, however patient statements make evident the difference made to various aspects of their lives, including hospital stay, number of surgeries, and increased productivity and quality of life.

### Case study: IBD Sufferer<sup>55</sup>

I have had Crohn's Disease for most of my adult life and have experienced many acute episodes over the years that have required surgical intervention and long stay hospital admissions, including bowel resections and a temporary ileostomy.

Most of my life living with Crohn's Disease has been spent in what I call a Boom or Bust Cycle, where I have gradually experienced an increase in symptoms to the point that I would then be extremely unwell and require medical and surgical intervention only to have a small window of well time before symptoms then again began to appear. In my experience this cycle was perpetuated by the long waiting lists to see specialists and the slow response times to my emerging symptoms.

For a few years now I have been part of an IBD Clinic and have had an IBD nurse as my 'go to person' whenever I have experienced a hurdle or challenge in my health. I can proudly say that as a direct response to this care, in the past six years I have not had one hospital admission for Crohn's Disease. Prior to my involvement with the IBD Nurse I would have at least one admission every year.

On a personal note, my access to a Nurse Co-ordinator has meant that I have fast, accessible advice as soon as I have any illness that may affect my Crohn's Disease or any symptoms. This has also provided me with quick access to my treaters, which has prevented my decline to acute symptoms. The resulting 'wellness' I have experienced has allowed me to work full time – something I could never sustain before in my life. It has also allowed me to complete a degree in Occupational Therapy and provide support and care for my family.

### Effects of decreased utilisations and productivity gains

Formal IBD services adopted in Australia have provided evidence that an integrated and proactive approach to IBD care can improve patient and healthcare outcomes as a result of the following:

- 1 Reduced proportion of IBD patients admitted
- 2 Decreased ALoS
- 3 Decreased the number of admissions requiring surgery
- 4 Ability to attend school and work more regularly
- 5 Reduced carer days.

Obtaining data at a national level across the different IBD service mixes will help us to better understand how the different models of care improve patient outcomes. This will enable us to understand which roles and resources are *deriving the greatest benefits*.

PwC, 2013

<sup>55</sup> All patient and carer case studies supplied by CCA.

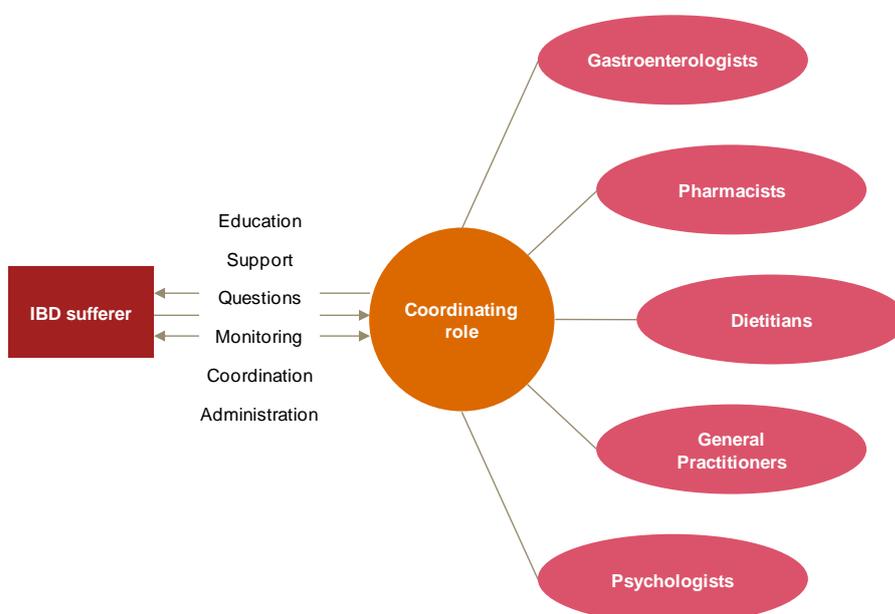
## 3.2 Benefit 2: Better service integration and patient experience

### Appropriate and timely care

Experts and health policy advocates have suggested that instituting quality care measures in the care of patients with chronic illness can improve patient outcomes.<sup>56</sup> Although care models across Australia have not been prospectively or comprehensively evaluated, evidence has shown that the provision of coordinated and timely care can generate key benefits for IBD sufferers and the broader healthcare system. Coordination of roles draws together a number of specialities, providing a first point of contact for an IBD sufferer to initiate the appropriate urgent outpatient review in patients with worsening IBD. One patient recounted:

*'(my nurse) is invaluable to me...she is a brilliant link between me and my specialist and helps me organise my blood tests and access the information I need. Instead of dealing with lots of people I have one familiar face who knows how to navigate the system. That helps take a lot of fear and confusion out of managing such a complex, and sometimes scary disease.'*<sup>57</sup>

Figure 9: IBD coordinating role



Improving the quality of life of sufferers and their families through coordinated care cannot be undervalued, as displayed in the following case study.

<sup>56</sup> Corey A Siegel et al, 'Improving quality of care in IBD: A STEEEP Challenge', *Inflammatory Bowel Disease*, Vol. 16, Issue 1, 2010.

<sup>57</sup> Sean Wessex-Brown in, Francesca Manglaviti, 'Support for South Australia funding', *Crohn's & Colitis Australia*, November 2010.

### **Case study: Husband of IBD sufferer**

As Sandra's\* husband, I have observed first-hand the pain and suffering this terribly debilitating disease can cause. I have been with her on every occasion that she has had to visit the ER at that hospital and I have seen the uncertainty and anxiety of junior doctors in trying to deal with a disease that apparently receives little attention during medical training.

Prior to the introduction of the Crohn's Co-ordinator, there were delays of several hours before the extent of the problem was fully understood and appropriate treatment commenced. In the meantime, Sandra had to endure excessive pain that was simply treated with paracetamol that was inadequate to the task and to repeatedly explain the nature of the disease and past successful treatments; only to have this ignored until a specialist was brought into the case and the treatment Sandra had advocated was implemented.

The Crohn's Co-ordinator is able to talk to the medical staff from a position of knowledge and strength and as an equal. The Co-ordinator can cut through much of the red tape that attends hospital admissions and, because the Co-ordinator frequently has a detailed knowledge of the patient's history and works with the patient's attending specialist, is able to advise on appropriate treatment. This means that the patient's condition is diagnosed more quickly and admission to the general hospital can be arranged without undue delay. The early commencement of appropriate treatment means that the patient is less distressed and will therefore be released from the hospital more quickly than would otherwise be the case.

Ultimately the hospital benefits because an emergency room bed is made available at an earlier time; the ED medical staff are released to attend to other patients and the time the patient stay in the hospital is lessened thereby reducing costs to the hospital and freeing a bed for another patient.

Quite apart from the benefits of this position to the patients, there is also the unsung value to the family. There have been many occasions when I have had concerns about Sandra's condition and a telephone call to the IBD nurse has provided me with understanding and advice to deal with the situation. The intervention by the IBD Nurse provides additional reassurance to Sandra that she will not have to endure the usual debilitating processes of ED and this reduces the stress on myself other members of the family.

*\* All names have been changed to support client confidentiality*

Providing appropriate care programs for IBD patients can heighten the focus on 'unpromoted issues'. A move to holistic management of the disease promotes the relationship between biological, psychological and social factors in the cause and experience of IBD. These 'unpromoted issues' include:

- the psychosocial burden of chronic disease
- quality of life and specific psychological comorbidities
- comorbidity with functional gastrointestinal disorders
- maintenance therapy
- monitoring and compliance
- smoking
- sexuality, fertility, family planning and pregnancy
- iron deficiency and anaemia.<sup>58</sup>

Long-term holistic management of IBD through increased focused on 'unpromoted issues' and the surveillance of associated risks has also shown to have key benefits for patients, carers and the healthcare system.

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<sup>58</sup> JM Andrews et al, 'Unpromoted issues in inflammatory bowel disease: opportunities to optimise care'.

### Effects of appropriate and timely care

- 1 Joining up of services to improve the effectiveness and efficiency of the patient journey
- 2 Avoidance of either direct presentation or referral to ED
- 3 Reduced fear and confusion of sufferers
- 4 Surveillance of long-term associated risks with IBD for early detection and proactive management.

### Managed support and education

Making sense of the complexities of the disease and its medication is vital for improved quality of life and reduced time spent in formal care. Personalised education and empowerment has a role to play in this.

The role of the IBD Nurse in managing and preventing disease activity **cannot be overstated.**

Communication with our members tells us that the key attributes that the IBD Specialist Nurse brings to the care and treatment of an IBD patient are **time, support and expertise** – in that order.

*Francesca Manglaviti CEO CCA, 2010*

Encouraging and monitoring adherence and compliance to medication is vital in the management of IBD. Although some medications have unpleasant side effects, some patients do not know that these are only predominant in the early phases and subsequently pull themselves off the medication.

An experienced gastroenterologist who has performed research on linkages between smoking and IBD flares noted there is a clear and important role for a nurse to aid in counselling around smoking. This value is greatly enhanced when the support provides a 'constant presence' in the patient's disease encouraging greater identification and management of these aspects of care.<sup>59</sup>

There has been evidence to suggest that the provision of educational material alone does not have the same impact of nurse-supported educational packages. Research has shown that for unselected IBD patients, provision of educational reading material alone does not alter quality of life<sup>60</sup>, but a nurse-supported educational package can increase adherence to prescribed treatment.<sup>61</sup> A subsequent study in Europe found that the provision of information was the greatest contributing factor to improved quality of care.<sup>62</sup>

### Effects of managed education and support

- 1 Personalised education and empowerment has been shown to have a major effect on both early discharge and readmission rates, reflecting the fact that compliance and representation with poorly controlled disease are major factors in these potentially avoidable hospital admissions.
- 2 Understanding the disease through education has been linked with improvements in compliance and anxiety levels, which have reduced presentations at emergency departments.

59 JM Andrews et al, 'Unpromoted issues in inflammatory bowel disease: opportunities to optimise care'.

60 Borgaonkar M, Moody G, Donnelly M, Srinivasan T, Irvine EJ. 'Patient education does not improve health-related quality of life in inflammatory bowel disease'. *Gastroenterology*, 1999

61 Schreiber S, Hamling J, Wedel S, Nikolaus SN, Buhr HJ, Raedler A. 'Efficacy of patient education in chronic inflammatory bowel disease in a prospective controlled multicentre trial. *Gastroenterology*, 1999.

62 Ingrid van der Eijk et al., 'The role of quality of care in health-related quality of life in patients with IBD', *Inflammatory Bowel Disease*, Vol. 10, No., 4, 2004.

# 4 Addressing the problem

## Strategic response to the problem

A number of strategic responses have been identified in addressing the problems associated with the variation and quality of IBD care across Australia. They are:

- **Option 1:** specialist helpline
- **Option 2:** national partnership to conduct a large scale audit of IBD patient care and service resources
- **Option 3:** appointment of clerical worker
- **Option 4:** appointment of specialist nurse.

These interventions were assessed against a number of high-level key criteria agreed with a stakeholder group. Options 2 and 4 were recommended for further investigation.

This chapter outlines the strategic interventions identified in response to the problems and benefits addressed. The strategic options are informed by academic literature, international examples, stakeholder consultation, identified information and data gaps existing at a national level, and successful initiatives witnessed in particular locations throughout Australia.

The strategic options have been assessed against a range of criteria in order to establish preferred responses. The assessment is done at a strategic and high level to inform a more detailed investigation into a shorter list of options in Chapter 5.

## 4.1 Strategic interventions considered

There is an emerging understanding internationally of what needs to be done to achieve better service integration and improved patient experience:

*The care of patients with IBD is becoming more complex as we develop new diagnostic tools, new treatment algorithms, and the promise of an array of new biologic agents to choose from. Guidelines, like textbooks, are often outdated before they are published, and levels of evidence change with each society meeting. We must develop a systematic program of assessing and treating patients to ensure safe, timely, effective, efficient, equitable, and patient-centred care that will be flexible as new data emerge.<sup>63</sup>*

In order to deliver the benefits outlined above, a number of initiatives were considered at a strategic level. These interventions were considered an appropriate and broad mix of responses to the problems identified.

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63 Corey A Siegel et al, 'Improving quality of care in IBD: A STEEEP Challenge', *Inflammatory Bowel Disease*, Vol. 16, Issue 1, 2010.

**Figure 10: Strategic interventions**

<i>Intervention</i>	<i>Description</i>
<b>Option 1</b> Develop specialist helpline	<ul style="list-style-type: none"> <li>• telephone led direct access to facilitate fast and easy access for patients</li> <li>• provides counselling and education for patients</li> <li>• allow for prompt assessment of disease symptoms, telephone triage and access into clinics as appropriate to disease activity and severity of symptoms.</li> </ul>
<b>Option 2</b> National partnership to conduct a large scale audit of IBD care programs service resources	<ul style="list-style-type: none"> <li>• assess current structure and provision of IBD patient care</li> <li>• assess processes and outcomes of care in selected settings</li> <li>• evaluate the roles, responsibilities and activity of nurses with specialist/advanced roles</li> <li>• identify resource and organisational factors that may account for variations</li> <li>• formation of Working Group to recommend national standards for care and subsequent resource requirements (such as dedicated nurse roles).</li> </ul>
<b>Option 3</b> Appointment of clerical worker	<ul style="list-style-type: none"> <li>• manage IBD database</li> <li>• perform administrative tasks.</li> </ul>
<b>Option 4</b> Appointment of specialist nurse	<ul style="list-style-type: none"> <li>• points as per Option 1</li> <li>• work collaboratively with gastroenterologists</li> <li>• meet and support role to newly diagnosed sufferers</li> <li>• review and management of case database</li> <li>• management of clinic appointments according to clinical need</li> <li>• surveillance and monitoring of cancer, infections, vaccinations, immunology</li> <li>• coordination of treatment clinical pathway and application process for biologics.</li> </ul>

The following interventions were considered throughout the intervention identification process, however, have not been considered further for the reasons stated below:

- *Do nothing*  
This response was not considered further as it retains the status quo of no consistent approach to the management of IBD nationwide. As outlined above, there are key problems in the current model of care that have shown improvements with formalised IBD care and thus maintaining the status quo is not considered an appropriate strategic response.
- *Appointment of medical practitioner*  
The creation of a new position to provide targeted and specialist care for IBD patients is not considered as a viable option. There are already workforce supply shortages and this option is more likely to be of relatively high cost. In addition chronic and complex conditions such as IBD require management in a community setting, with specialist oversight rather than a specialist model of care.

## 4.2 Method and criteria

The interventions were assessed on their ability to meet a number of criteria, including:

- **Benefits sought:** enhanced patient experience and outcomes and improvements in costs and healthcare utilisation (as outlined in Chapter 3)
- **Ability to execute:** readiness, capability and capacity to enact change
- **Key principles:** a number of key principles were developed and agreed in order to provide guidance in evaluating options (see Figure 11). The principles were developed using input from the current mission of CCA and through a workshop with CCA.

**Figure 11: Key principles**

<b>Achievement</b>	<ul style="list-style-type: none"> <li>• Achieve an environment where people living with IBD can fully participate in everyday social and economic activities that others take for granted.</li> </ul>
<b>Innovation</b>	<ul style="list-style-type: none"> <li>• Continually finding new and innovative ways to maximise the efficiency and value of our service to the IBD and broader Australian community, by funding new research and developing meaningful programs that create change for the betterment of people living with IBD.</li> </ul>
<b>Sustainability</b>	<ul style="list-style-type: none"> <li>• Building a strong organisation for future generations, providing leadership within the industry, and developing capabilities .</li> </ul>

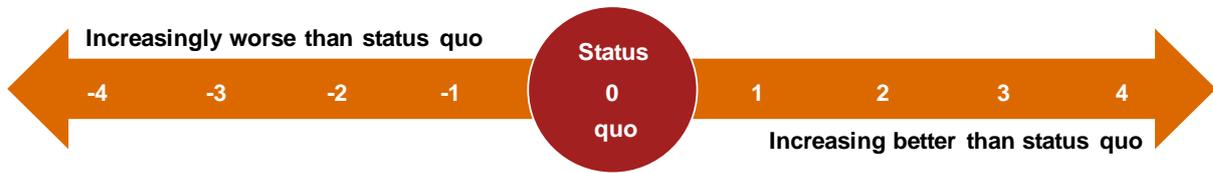
An evaluation framework for assessing the strategic responses using a scoring system was developed and used in order to rank the options that best meet the overall set and intent of the benefit, principles and ability to execute. The weighting of each of these were tested and agreed with CCA.

**Figure 12: Criteria and weighting**

#	Criteria	Weighting
<b>1</b>	<b>Ability to deliver benefits</b> <ul style="list-style-type: none"> <li>• enhanced patient experience and outcomes</li> <li>• improvements in costs and healthcare utilisation.</li> </ul>	1/3
<b>2</b>	<b>Alignment with principles</b> <ul style="list-style-type: none"> <li>• achievement</li> <li>• innovation</li> <li>• sustainability.</li> </ul>	1/3
<b>3</b>	<b>Ability to execute</b> <ul style="list-style-type: none"> <li>• readiness, capability and capacity to enact change</li> </ul>	1/3
		<b>100%</b>

The options have been evaluated in the criteria above using the rating scale detailed below.

**Figure 13: Rating Scale**



A qualitative comparative evaluation of the strategic options has been conducted against the above criteria to derive the preferred strategic response. The scorings are based on a rating scale from -3 to +3 based on the relative situation as compared to status quo. The scorings were based on a qualitative, high-level assessment of the options and were tested and agreed with CCA.

**Figure 14: Assessment of strategic interventions**

<i>Intervention</i>	<i>Scoring</i>			<i>Result</i>	
	<i>Ability to deliver benefits</i>	<i>Alignment with principles</i>	<i>Ability to execute</i>	<i>Weighted score</i>	<i>Rank</i>
<b>1</b> Develop specialist helpline	3	3	3	9	3
<b>2</b> National partnership to conduct a large scale audit of IBD care programs and service resources	3	3	4	10	=1
<b>3</b> Appointment of clerical worker	3	2	2	7	4
<b>4</b> Appointment of specialist nurse	4	4	2	10	=1

The recommended options to be investigated are:

- Option 2: National partnership to conduct a large scale audit of IBD care programs and service resources
- Option 4: Appointment of specialist nurse.

These options will be detailed and assessed in the following chapter.

# 5 Recommendations

## Recommendations

CCA should seek funding to organise and formalise a national partnership that will work to conduct a national audit of IBD care programs and service resources (Option 2). A high level costing of the selected options indicates that Option 2 will cost approximately \$955k over two years.

The work performed has made evident that although key benefits are linked to the provision of IBD services, there are significant gaps in existing data and consistency of knowledge that need to be filled to properly evaluate the impact that IBD care programs could have in Australia. The available research indicates that a formal IBD nurse program and dedicated resources can lead to a variety of benefits, however given substantial variation in practice across the country, there is further work required to understand the extent to which these benefits could be delivered consistently across Australia.

## 5.1 Preferred options

Two key initiatives were identified as appropriate responses to the problems relating to current IBD care. Further detail and a high level costing of each of these options have been performed.

### ***Option 2: National partnership to conduct a large scale audit of IBD care programs and service resources***

Consultation, best practice literature, evidence from the United Kingdom, Canada and the United States has informed a number of key activities required to inform a more appropriate model of care and to understand where value can be best delivered to the health system. These activities include:

- assess current structure and provision of IBD patient care
- assess processes and outcomes of care in selected settings
- evaluate the roles, responsibilities and activity of nurses with specialist/advanced roles
- identify resource and organisational factors that may account for variations
- formation of Working Group(s) to recommend national standards for care and subsequent resource requirements (such as dedicated nurse roles).

For the purposes of this report, we have assumed that the Working Group will be a nationwide partnership of varied skills and the appropriate breadth and depth of expertise associated with IBD. Parties involved may include:

- Crohn's & Colitis Australia
- Australian Inflammatory Bowel Disease Association (part of the Gastroenterological Society of Australia)
- Colorectal Surgical Society of Australia and New Zealand
- The Royal Australian College of General Practitioners
- Gastroenterological Nurses College of Australia
- Dietitians Association of Australia
- IBD patients.

The activities in Option 2 are based on audits performed in the United Kingdom and research elsewhere (outlined in the table below). Utilising parts of these evidence bases that are applicable to the gaps found in the Australian context, Option 2 has been scoped on the basis that further work is

necessary to measure the quality of IBD care on a larger scale and to develop a consistent approach to implementing improvements nationally. Although this is not a definitive list of audit requirements and may be further refined by the specialist Working Group, it shows the types of information and rigour needed to support additional resource requirements.

**Figure 15: Basis of Option 2**

<i><b>Audit</b></i>	<i><b>Objectives</b></i>	<i><b>Outcomes</b></i>
<b>UK Inflammatory Bowel Disease Audit First Round 2006</b>	<ol style="list-style-type: none"> <li>1 Assess the current structure and organisation of care for those patients with IBD</li> <li>2 Assess the processes and outcomes of care delivery (inpatient and outpatient) in IBD</li> <li>3 Enable Trusts to compare their performance and quality of care against national standards</li> <li>4 Identify resource and organisational factors that may account for variations in care</li> <li>5 Facilitate, develop and institute an intervention strategy to improve quality of patient care</li> <li>6 Repeat the audit</li> <li>7 Establish measures that healthcare services can use beyond the study to compare quality of IBD services</li> <li>8 Develop a sustainability programme to maintain quality of patient care.</li> </ol>	<p>281 acute hospitals participants were invited to take part and the audit achieved a 75 per cent participation rate. Data was collected for over 5,600 IBD patients.</p> <p>The audit revealed unacceptable variation in services and aspects of client care.</p> <p>Following these results, a Working Group of the key professional organizations was formed to recommend national standards for care. A timeline was set for IBD services to meet these standards.</p> <p>The standards included implementation arrangement for high quality clinical care, providing minimum numbers for IBD teams viable for a full IBD service.</p> <p>Service improvements in many aspects of IBD care over a 2 year period (number of dedicated gastroenterology wards and increase in both number of IBD clinical nurse specialists at the time dedicated to IBD care)</p>
<b>National Association for Crohn's and Colitis Disease (UK)</b>	<ol style="list-style-type: none"> <li>1 Define the scope of specialist nursing roles</li> <li>2 Examining the evidence relating to their perceived value, benefits and effectiveness.</li> </ol>	<p>The literature showed variation in the extent and scope of specialist nursing roles in gastroenterology.</p> <p>Recommendations for further research led to the Royal College of Nursing audit (below).</p>
<b>Royal College of Nursing (UK) audit of IBD nurses</b>	<ol style="list-style-type: none"> <li>1 To identify a common set of skills, knowledge and competencies required of IBD nurse specialists</li> <li>2 To identify the educational preparation necessary for IBD nurse specialists and their ongoing training and development needs</li> <li>3 To carry out a scoping exercise to identify the number of IBD nurse specialists currently in post, their scope and model of practice, and the contexts in which they operate</li> <li>4 For prospective, rigorously designed studies, exploring the clinical and cost effectiveness of the IBD nursing role.</li> </ol>	<p>Published role descriptors and FTE minimums</p> <p>Outlined next steps:</p> <ul style="list-style-type: none"> <li>• to evaluate IBD nursing services and identify areas for improvement</li> <li>• to provide national evidence of IBD nurse numbers, activity and effectiveness</li> </ul> <p>to provide direct feedback to individual nurses and their managers to show local impacts of the IBD nursing service.</p>

The work performed above provides a starting point for the types of information that could be included in the audit. It is noted that these audits are still preliminary and there would be further work required to quantify the variations in care and assign benefits to different care models witnessed in Australia.

An example of the steps involved in improving quality of care is outlined below.

#### **Case study: Changing care for Cystic Fibrosis<sup>64</sup>**

Cystic Fibrosis (CF) is the most common, genetically acquired, life-shortening chronic illness affecting young Australians today.

Cystic Fibrosis Australia is focussed on national sponsorship, advocacy and awareness raising and on the promotion and funding of research. All State and Territory CF organisations together with CF Australia work together collaboratively in a loosely coupled network to ensure better standards of care and quality of life for all Australians living with Cystic Fibrosis.

Currently, CF clinics have variable healthcare provision standards and inconsistent resources for providing Cystic Fibrosis care. This is primarily due to limited clinic resources that are available. There is no independent monitoring of these clinics. The Quality of Care is a campaign to ensure the Standards of Care guidelines for CF care are followed by clinics across Australia.

The Standards of Care project scope included assessment of need for CF guideline development, particularly focussing on the requirements of facilities, staffing and services to provide CF care with specific reference to health care delivery and systems, population demographics and climate in Australia.

A multidisciplinary Steering Committee which included representatives from clinical care teams, lay organisations and adults with CF from Australia was established to oversee the overall development of the project, including review of published guidelines for CF. The scope of the project included:

- 1 Assessment of areas of need for CF guideline development:
  - what constitutes a CF centre and clinic
  - assessment of the requirements for facilities, staffing and services to provide CF care
  - assessment of the requirements for outpatient care
  - assessment of the requirements for the delivery of inpatient care
  - assessment of the requirements for assessment and education of newly diagnosed patients with CF.
- 2 Guidelines were to be written with specific reference to health care delivery and systems, population demographics and climate in Australia.

The Quality of Care program will perform an evaluation on all major specialist Cystic Fibrosis clinics in Australia against the comprehensive standards. Many of the clinics without adequate resources will then be able to approach funding bodies with these independent reports, and to lobby for increased funding resources to bring their clinics up to the standard. The objective is that these reviews will result in beneficial changes to the clinics leading to high quality healthcare delivery as standard at all major CF clinics in Australia.

#### **Option 4: IBD specialist nurses**

Option 4 involves a formal and consistent approach to funding IBD nurses throughout gastroenterology clinics in Australia. Through evidence of best practice, consultation with IBD nurses and gastroenterologists, the long-list of roles of the IBD nurse to perform are outlined below. It is noted that there is not yet consensus around the best scope of the role and where the greatest value is derived.

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<sup>64</sup> Cystic Fibrosis National Office, 'CF Clinic Peer Review', 2012, Accessed online at <http://www.cysticfibrosis.org.au/cfa/clinic-peer-review>

**Figure 16: Roles for IBD nurse**

<i>Option</i>	<i>Detail</i>
<b>Appointment of IBD nurse</b>	<ul style="list-style-type: none"> <li>• telephone led direct access to facilitate fast and easy access for patients</li> <li>• provides counselling and education for patients</li> <li>• allow for prompt assessment of disease symptoms, telephone triage and access into clinics as appropriate to disease activity and severity of symptoms</li> <li>• work collaboratively with gastroenterologists</li> <li>• meet and support role to newly diagnosed sufferers on the ward</li> <li>• review and management of case database</li> <li>• management of clinic appointments according to clinical need</li> <li>• surveillance and monitoring of cancer, infections, vaccinations, immunology</li> <li>• coordination of treatment clinical pathway and application process for biologics.</li> </ul>

Consultation uncovered that there is a need for approximately 31 FTE registered nurses across the country. This was based on consultation with CCA and the approximate number of current IBD clinics with an existing specialist nurse role across the country.<sup>65</sup> It is an estimate only and no broader consultation into need based on prevalence was performed as part of the scope of this project.

**Figure 17: Proposed IBD nurse numbers**

<i>State</i>	<i>IBD Clinics</i>	<i>Proposed # of FTE IBD Nurses</i>
NSW	5	7
Vic	7	9
Qld	3	5
SA	2	4
WA	1 – 2	2
Tas	0	1
ACT	1	2
NT	0	1
<b>Total number of IBD nurses</b>		<b>31</b>

<sup>65</sup> There is not enough information to specify exact locations of IBD nurses in proportion to the number of patients across the country.

The work involved in outlining this option uncovered the lack of consensus across the industry as to the implementation requirements of this option, including, but not limited to:

- the number of IBD specialist nurses currently in post, their scope and model of practice, and the contexts in which they operate
- identification of a common set of skills, knowledge and competencies required of IBD specialist nurses
- identification of the educational preparation requirements for IBD specialist nurses and their ongoing training and development needs
- exploration of the clinical and cost effectiveness of IBD specialist nursing roles.

## 5.2 Costing of the options

The methodology, including key assumptions utilised in the determination of the costs for each of the options are detailed in Appendix B. Due to the variation in current nurse roles seen throughout Australia and Europe, the constraints of this report, and limited industry agreement on training and implementation protocols for IBD nurses, a number of assumptions were made in the deriving the cost of this option.

The table below details the implementation and annual recurrent costs over two years (anticipated 2013/14 and 2014/15).

**Figure 18: Summary costs (2013/14 – 2014/15)**

<i>Options</i>	<i>Option 2: National partnership audit</i>	<i>Option 4: IBD specialist nurses</i>
Salaries and wages	\$783,206	\$4,575,115
Oncosts	\$156,641	\$915,023
Recruitment	\$15,000	\$77,500
Training	-	\$46,500
Administration	(inc. in salaries and wages)	\$79,667
<b>Total</b>	<b>\$954,847</b>	<b>\$5,693,805</b>

### Recommended option

Available evidence demonstrates that benefits can be achieved through a formal IBD system, however there are a number of areas where further research is required to understand the variations in care currently available and determined the most effective and efficient response.

It is recommended that CCA seek funding for Option 2 to form a national partnership to conduct an audit of IBD care programs and service resources. Investigating the current service model in detail will more definitively uncover where and why variations in practice exist so that refinements to existing resources for IBD can be targeted, practical and consistent.

## 5.3 Implementation of the option

An indicative audit framework and associated timelines is outlined below to guide the Working Group to formalise the scope and nature of the audit during the planning stages.

**Figure 19: Proposed audit framework**

<i>Audit category</i>	<i>Proposed data sources</i>	<i>Proposed sites</i>
Activity	<ul style="list-style-type: none"> <li>• Patient numbers</li> <li>• Admissions</li> <li>• DRGs</li> <li>• Demographics: age, sex, geography</li> <li>• Length of Stay</li> <li>• Surgery or medication</li> </ul>	A selection of hospitals (approximately 100) wherein the audit team will speak to and obtain data and insight from those teams in charge of service delivery as well as operations.
Role delineation	<ul style="list-style-type: none"> <li>• Staff profile</li> <li>• Delineation of services (e.g. tertiary referral, specialist, metropolitan, regional etc.)</li> </ul>	
Resource availability	<ul style="list-style-type: none"> <li>• IBD staffing</li> <li>• Number of beds</li> <li>• Geography</li> </ul>	
Patient experience/outcomes	<ul style="list-style-type: none"> <li>• Patient pathway</li> </ul>	
Financial effectiveness	<ul style="list-style-type: none"> <li>• Funding</li> </ul>	

**Figure 20: Proposed timing**

<i>Activities</i>	<i>13/14</i>				<i>14/15</i>			
	<i>July</i>	<i>Oct</i>	<i>Jan</i>	<i>Apr</i>	<i>July</i>	<i>Oct</i>	<i>Jan</i>	<i>Apr</i>
<i>Qtr beginning</i> Formalise the partnership <ul style="list-style-type: none"> <li>• Memorandum of Understanding</li> <li>• Workshop</li> </ul>	█							
Formalise the audit framework and planning <ul style="list-style-type: none"> <li>• Breadth and depth of audit</li> <li>• Data requirements</li> <li>• Contact and coordination of hospitals</li> </ul>	█							
Conducting the audit <ul style="list-style-type: none"> <li>• Project Management Office</li> <li>• Formalise audit implementation</li> <li>• Formalise audit publication and communications</li> </ul>	█							
Formalise audit recommendations	█							

This audit framework was established with the outcome of providing an evidence base that will:

- uncover how variable current care programs and resources are
- to show where the variation stems from

- provide recommendations for the optimal patient pathway
- national capability framework for IBD care programs and corresponding resource requirements.

# *Appendices*

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# Appendix A Methodology and assumptions

## Updating prevalence

To update prevalence numbers, PwC used a triangulation method based on three studies. The studies draw upon their own research and analysis.

Figure 21: Approach to updating prevalence

Study	Finding	Date	Approach to update	Updated prevalence	
Access Economics, 'The Economic Costs of Crohn's Disease and Ulcerative Colitis', 2007.	61,000 prevalence	2006	<ul style="list-style-type: none"> <li>using new cases per year 1,622 (Access)</li> <li>scale by population growth factor (ABS).</li> </ul>	Low	68,075
				High	72,354
Corrie Studd et al, 'High incidence and prevalence of inflammatory bowel disease in Victoria; a prospective, observational, population-based Australian epidemiology study', St Vincent's Hospital, Melbourne, VIC, Australia.	344.6 per 100,000 prevalence	2011	<ul style="list-style-type: none"> <li>population 2011 Census (ABS)</li> <li>scale by population growth factor (ABS).</li> </ul>	Low	78,176
				High	83,666
Jarrad Wilson et al. 'High incidence of inflammatory bowel disease in Australia: A prospective population-based Australian incidence study', Inflammatory Bowel Diseases, Vol. 16, Issue 9, 2010	29.6 incidence rate	2008	<ul style="list-style-type: none"> <li>compared with other jurisdictions with similar incidence rates to approximate prevalence</li> <li>scale by population growth factor (ABS).</li> </ul>	Low	68,058
				High	79,401
				Mean	74,955
				Median	75,265

Limitations of this approach:

- We have not conducted source level review of the research conducted in the three studies
- Prevalence results from the studies were assumed to be at financial year end unless otherwise stated
- State prevalence projections: based on 2012 percentage of population extrapolated out to 2022. The projection considered proportionate population growth in each state
- Any extrapolation of overall prevalence from this study is complicated and needs to be viewed with some caution. Prevalence is a function of historical incidence rates, duration of disease, and migration into or out of the population. Any errors in calculation of incidence will be magnified with an estimation of prevalence.<sup>66</sup>

## ***Costs of IBD***

### ***Financial costs***

A comprehensive analysis of total costs for IBD cases is difficult due to limited publicly available data and the fact that sufferers of IBD also access hospital services for illnesses potentially unrelated to their chronic condition. To provide some base assessment on the direct costs of IBD conditions in the hospital sector, analysis was conducted against Round 13 of the National Hospital Cost Data Collection (NHCDC) with the Diagnosis Related Group (DRG) 'Inflammatory Bowel Disease' (G64Z) considered the most relevant.

A detailed state dataset was examined<sup>67</sup> and results were extrapolating this analysis using the national prevalence share.

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<sup>66</sup> Jarrad Wilson et al. 'High incidence of inflammatory bowel disease in Australia: A prospective population-based Australian incidence study'.

<sup>67</sup> PwC were provided a confidential report of state admitted data on IBD sufferers. No audit or assessment of source data was conducted and the analysis is provided as an estimate only. Further research is recommended on actual patient costs and detailed admission analysis.

## Non financial and economic costs

This report drew upon results from the following report:

- Access Economics, ‘The Economic Costs of Crohn’s Disease and Ulcerative Colitis’, 2007

We have not conducted source level review of the methodology and assumptions used as part of this study.

Refer below for approach to updating costing.

**Figure 22: Approach to updating other financial and economic costs**

### Assumptions

CPI – 2 %-ABS growth rate 2011-2012

Health CPI-7.2%-ABS growth rate 2011-2012

Average weekly earnings-\$1,495 – ABS May 2012

<b>Other financial and economic Costs</b>	<b>Assumption for updating cost</b>	<b>2005 (\$m)</b>	<b>2006</b>	<b>2007</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>	
<b>Productivity</b>										
Loss earnings	CPI	204.2	208.284	212.44968	216.6986736	221.0326471	225.4533	229.962366	234,561,613.3	
Absenteeism	(7.2 days/year on average)	Average weekly earnings May 2012	52.3						115,221,025	
Premature death	(lost income stream)	CPI	10.2	10.404	10.61208	10.8243216	11.04080803	11.26162419	11.48685668	11,716,593.81
<b>Total Productivity</b>									<b>361,499,232</b>	

### Other Financial and economic costs

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**Other Financial and economic costs**

Disability support	Health CPI	12.1	12.9712	13.9051264	14.9062955	15.97954878	17.13007629	18.36344178	19,685,609.59
NewStart allowance	Health CPI	2.6	2.7872	2.9878784	3.203005645	3.433622051	3.680842839	3.945863523	4,229,965.70
Sickness Allowance	Health CPI	0.3	0.3216	0.3447552	0.369577574	0.39618716	0.424712635	0.455291945	488,072.97

**Total Welfare payments**

**24,403,648.25**

Deadweight losses	Associated with transfers such as welfare payments and taxation revenue foregone	CPI	91.3	93.126	94.98852	96.8882904	98.82605621	100.8025773	102.8186289	104,875,001
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Informal care	Informal care for people with IBD in the community from families and others	Health CPI	23.5	25.192	27.005824	28.95024333	31.03466085	33.26915643	35.66453569	38,232,382
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Funeral Costs	Funeral costs associated with premature death	Health CPI	0.4	0.4288	0.4596736	0.492770099	0.528249546	0.566283514	0.607055927	650,764
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Out of pocket expenditure	Aids and modifications, formal care (housekeeping, childcare etc), travel and accommodation costs, communication costs, complementary therapies	Health CPI	35.8	38.3776	41.1407872	44.10292388	47.2783344	50.68237447	54.33150544	58,243,374
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**Total Other Costs**

**202,001,521**

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**Other Financial and economic costs**

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Burden of disease	Suffering and premature death experienced by people with IBD	Health CPI	2,200	2,244	2,289	2,335	2,381	2,429	2,478	2,527,108,469
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**Total other economic and financial costs** **2,753,513,638.00**

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**Benefits of IBD nurses**

Calculating the overall benefit of an IBD nurse problem used results from the following study:

- C.Sack, V.A. Phan, R. Grafton, G.Holtmann, D.R. van Langenberg, K.Brett, M.Clark, J.M. Andrews, 'A chronic care model significantly decreases costs and healthcare utilisation in patients with inflammatory bowel disease', Journal of Crohn's and Colitis, Vol. 6, 2012, p. 303.

The cost savings from the place-based study were applied to the overall costs of IBD outlined in Chapter 2.

# Appendix B Financial assumptions and costing

Figure 23: Assumptions for costing

Option	Activity	Assumptions for costing
National Partnership Audit	Formalise the partnership	
	<ul style="list-style-type: none"> <li>• Memorandum of Understanding</li> <li>• Workshop</li> </ul>	<ul style="list-style-type: none"> <li>• 6 FTE (2013/14) – 1 week + travel and workshop expenses</li> </ul>
	Formalise the audit framework and planning	
	<ul style="list-style-type: none"> <li>• Breadth and depth of audit</li> <li>• Data requirements</li> <li>• Contact and coordination of hospitals</li> </ul>	
	Conducting the audit	
	<ul style="list-style-type: none"> <li>• Project Management Office</li> <li>• Formalise audit implementation</li> <li>• Formalise audit publication and communications</li> <li>• Formalise audit recommendations</li> </ul>	<ul style="list-style-type: none"> <li>• 2 FTE (18 months)</li> <li>• 3 FTE (2013/14) – 18 months</li> </ul>
Oncosts	<ul style="list-style-type: none"> <li>• 20% Program Costs</li> </ul>	
Recruitment	<ul style="list-style-type: none"> <li>• \$2,500 per FTE</li> </ul>	

- Fair work ombudsman Senior specialist Pay points Per annum Pay point 3 87,705 Medical Practitioners Award

<i>Option</i>	<i>Detail</i>	<i>Assumptions for costing</i>	
<i>Appointment of IBD nurse</i>	<ul style="list-style-type: none"> <li>• telephone led direct access to facilitate fast and easy access for patients</li> <li>• provides counselling and education for patients</li> <li>• allow for prompt assessment of disease symptoms, telephone triage and access into clinics as appropriate to disease activity and severity of symptoms</li> <li>• work collaboratively with gastroenterologists</li> <li>• meet and support role to newly diagnosed sufferers on the ward</li> <li>• review and management of case database</li> <li>• management of clinic appointments according to clinical need</li> <li>• surveillance and monitoring of cancer, infections, vaccinations, immunology.</li> </ul>	31 FTE (Ongoing)	<ul style="list-style-type: none"> <li>• Consultation with CCA</li> <li>• NSW award rates</li> </ul>
		• 2013 – 2017	
		• Registered Nurse 5th year (\$66,444 (NSW rate))	
		• On-costs (20%)	
		• Training (\$1,500 per FTE)	
		• Administration and set-up (2% of cost in first year, 1% ongoing).	

**Figure 24: Costing tables Option 2**

<i>Line item</i>	<i>2013</i>	<i>2014</i>	<i>Total cost</i>
Salaries and wages	\$548,156	\$235,049	\$783,206
On-costs	\$109,631	\$47,010	\$156,641
Recruitment	\$15,000		\$15,000
Training	-	-	-
Administration and set-up	-	-	-
	<b>\$672,788</b>	<b>\$282,059</b>	<b>\$954,847</b>

**Figure 25: Costing tables Option 4**

<i>Line item</i>	<i>2013</i>	<i>2014</i>	<i>Total cost</i>
Salaries and wages	\$2,208,067	\$2,367,048	\$4,575,115
On-costs	\$441,613	\$473,410	\$915,023
Recruitment	\$77,500	--	\$77,500
Training	\$46,500	-	\$46,500
Administration and set-up	\$44,161	\$35,506	\$79,667
	<b>\$2,817,842</b>	<b>\$2,875,963</b>	<b>\$5,693,805</b>

## Appendix C Prevalence tables

Figure 26: Prevalence by state

State/Territory	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022
NSW	24,217	24,628	25,047	25,473	25,906	26,346	26,794	27,250	27,713	28,184	28,663
VIC	18,585	18,901	19,223	19,549	19,882	20,220	20,564	20,913	21,269	21,630	21,998
QLD	15,024	15,280	15,540	15,804	16,072	16,346	16,624	16,906	17,194	17,486	17,783
SA	5,501	5,595	5,690	5,787	5,885	5,985	6,087	6,190	6,296	6,403	6,511
WA	7,899	8,033	8,170	8,309	8,450	8,594	8,740	8,888	9,039	9,193	9,349
Tas	1,717	1,746	1,775	1,806	1,836	1,868	1,899	1,932	1,964	1,998	2,032
NT	777	790	803	817	831	845	860	874	889	904	919
ACT	1,235	1,256	1,277	1,299	1,321	1,344	1,366	1,390	1,413	1,437	1,462
	74,955	76,229	77,525	78,843	80,184	81,547	82,933	84,343	85,777	87,235	88,718

Figure 27 provides a state and remoteness category breakdown of prevalence. The remoteness structure is based on ABS remoteness areas. As characteristics of remoteness are determined in the context of Australia as a whole, not all remoteness areas are represented in each state or territory.<sup>68</sup> This analysis indicates that over one in ten of IBD sufferers live in outer regional and remote/very remote locations. These demographics cause a range of problems in the current model of care for IBD and are discussed in Part 2 of this report.

**Figure 27: Estimated prevalence of IBD in Australia by remoteness category (June 2012)<sup>69</sup>**

	<i>Total</i>	<i>NSW</i>	<i>VIC</i>	<i>QLD</i>	<i>SA</i>	<i>WA</i>	<i>Tas</i>	<i>NT</i>	<i>ACT</i>
Major City	<b>51,279</b>	17,783	13,490	9,120	4,024	5,629	-	-	1,233
Inner Regional	<b>13,821</b>	4,825	3,497	3,218	677	1,044	562	-	0
Outer Regional	<b>6,493</b>	1,486	792	2,221	597	672	288	437	-
Remote/Very Remote	<b>3,359</b>	123	807	466	203	554	867	340	-

<sup>68</sup> Within a state or territory, each remoteness area represents an aggregation of non-contiguous geographical areas which share common characteristics of remoteness. As characteristics of remoteness are determined in the context of Australia as a whole, not all remoteness areas are represented in each state or territory. The delimitation criteria for remoteness areas are based on the Accessibility/Remoteness Index of Australia (ARIA+), which measures the remoteness of a point based on the physical road distance to the nearest Urban Centre in each of the five size classes, Australian Bureau of Statistics, Regional Population Growth, 31 July 2012/

<sup>69</sup> The mean is used when estimating prevalence by remoteness category. The mean is useful for predicting future results when there are no extreme values in the data set. Refer to Appendix A for a full list of assumptions and methodology.

**Figure 28: Prevalence by remoteness area**

<i>Remoteness area</i>	<i>NSW</i>	<i>VIC</i>	<i>QLD</i>	<i>SA</i>	<i>WA</i>	<i>Tas</i>	<i>NT</i>	<i>ACT</i>	<i>Total</i>
Major City	17,783	13,490	9,120	4,024	5,629	-	-	1,233	51,279
Inner Regional	4,825	3,497	3,218	677	1,044	562	-	0	13,821
Outer Regional	1,486	792	2,221	597	672	288	437	-	6,493
Remote/Very Remote	123	807	466	203	554	867	340	-	3,359
									<b>74,953</b>

# Appendix D Alignment with policy objectives

Figure 29: Alignment with policy objectives

<i>Strategy</i>	<i>Alignment</i>	<i>Alignment of problem with policy objectives</i>
<i>Commonwealth government</i>		
National Healthcare Agreement (2011)	<i>High</i>	<p>Identifies long-term objectives of Commonwealth, State and Territory governments.</p> <ul style="list-style-type: none"> <li>• high quality and affordable primary and community health services, hospital and hospital-related care, and aged care services</li> <li>• positive health and aged care experiences.</li> <li>• social inclusion and reduction of disadvantage.</li> </ul>
Strategic Review of Health and Medical Research (2011)	<i>High</i>	<p>New awareness of the changing landscape of health and medical research. The first change of the landscape is acknowledged as:</p> <ul style="list-style-type: none"> <li>• the burden of disease in Australia has altered.</li> <li>• Chronic diseases, including those associated with ageing, and mental illness, are now the leading causes of morbidity and mortality.</li> </ul>
Primary Health Care Research, Evaluation and Development (PHCRED) Strategy Phase Three 2010-14 (2010)	<i>High</i>	<p>Underpinning primary health care policy, the Australian Government will maintain its commitment to primary health care research both through funding for research capacity and through the use of research-based evidence to inform policy and practice.</p>
A National Health and Hospitals Network For Australia's Future (2010)	<i>High</i>	<p>These reforms focus on improving public hospital and primary health care services. The reforms acknowledge that chronic disease is a large and increasing burden on our health system:</p> <ul style="list-style-type: none"> <li>• As well as training more health professionals, need to be more effective at making the most of the skills and dedication of our existing health workforce.</li> <li>• Too many patients are either falling through the gaps or receiving uncoordinated care. Changes that streamline the delivery of care and remove fragmentation in services are long overdue, particularly for people living with chronic disease.</li> <li>• In addition, not all Australians get the services they need. People living in rural and regional areas, for example, sometimes struggle to access primary health care. Many people are unable to access out of hours GP services.</li> </ul>

<b>Strategy</b>	<b>Alignment</b>	<b>Alignment of problem with policy objectives</b>
<b>State government</b>		
<b>Victorian Government Department of Health</b>		
Strategic Directions	<i>High</i>	<ul style="list-style-type: none"> <li>• improve health service performance</li> <li>• strengthen prevention and health promotion develop our health service system and organisation</li> <li>• reduce health inequalities.</li> </ul>
<b>NSW Ministry of Health</b>		
NSW 2021 Performance Report 2012-13 (2012)	<i>High</i>	<ul style="list-style-type: none"> <li>• return quality service</li> <li>• keep people healthy and out of hospital</li> <li>• provide world class clinical services with timely access and effective infrastructure</li> <li>• invest in the workforce by employing approximately 500 more nursing staff at hospitals throughout the State.</li> </ul>
Chronic Care Program	<i>High</i>	<ul style="list-style-type: none"> <li>• underpinned by several key principals that involve coordinating care through a comprehensive health assessment, the use of multidisciplinary shared care plans, the application of evidence-based treatment protocols and the promotion of person centred care with active self management support where possible.</li> </ul>
<b>Government of South Australia SA Health</b>		
South Australia Health Care Plan 2007 – 2016	<i>High</i>	<ul style="list-style-type: none"> <li>• better coordinated hospital services</li> <li>• a responsive health workforce for the future</li> <li>• improved management of chronic diseases.</li> <li>• workforce : create new roles to free up the time of highly skilled professionals to care for those most in need. New roles will include physician assistants and an increased number of nurse practitioners.</li> </ul>
<b>Queensland Health</b>		
Queensland Health Strategic Plan 2012-2016 (2012)	<i>High</i>	<ul style="list-style-type: none"> <li>• health services emphasise keeping people well, and avoiding unnecessary hospitalisations</li> <li>• contribute to improving the quality and use of the evidence base for individual and community health promotion and reducing rates of chronic disease.</li> </ul>
Queensland Statewide Health Services Plan 2007-2012	<i>High</i>	<ul style="list-style-type: none"> <li>• build the capacity in the community to provide comprehensive health care</li> <li>• establish comprehensive community-based chronic disease management programs focusing on the reduction of morbidity and the incidence of avoidable hospital admissions.</li> </ul>

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<i>Strategy</i>	<i>Alignment</i>	<i>Alignment of problem with policy objectives</i>
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**Western Australia Department of Health**

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WA Chronic Health Conditions Framework 2011-2016	<i>High</i>	Effective prevention and management of chronic health conditions rely on integrating and coordinating services for consumers across the continuum of care <ul style="list-style-type: none"><li>• Four key principles:</li><li>• integration and service coordination</li><li>• interdisciplinary care planning and case management</li><li>• evidence-based and consumer-centred care</li><li>• health literacy and self-management for chronic health conditions.</li></ul>
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**Tasmanian Department of Health and Human Services**

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Connecting Care: Chronic Disease Action Framework for Tasmania 2009-2013	<i>High</i>	Coordinated and strategic approach towards better prevention, detection and management of chronic disease. Action areas: <ul style="list-style-type: none"><li>• healthy lifestyles and environments for all individuals and all communities</li><li>• appropriate management and clinical care for people with chronic disease</li><li>• people with or at risk of chronic disease supported to actively self-manage their health</li><li>• integration and coordination of prevention and care</li><li>• skilled and supported Workforce</li><li>• effective surveillance, monitoring evaluation and research.</li></ul>
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# Appendix E Stakeholder list

- 1 Francesca Manglaviti  
*Chief Executive Officer, CCA*
- 2 Dr Greg Moore  
*IBD specialist gastroenterologist, founder of the IBD Unit at Monash Medical Centre, CCA Board Member and member of Australian Inflammatory Bowel Disease Association*
- 3 Professor Michael A Kamm  
*Professor of Gastroenterology: St Vincent's Hospital, Melbourne; University of Melbourne; Imperial College, London.*
- 4 Dr Jane Andrews  
*IBD specialist gastroenterologist, Head of IBD Services at Royal Adelaide Hospital and member of Australian Inflammatory Bowel Disease Association*
- 5 Dr Peter de Cruz  
*Gastroenterologist and IBD Research fellow*
- 6 Stephanie Buckton  
*IBD Nurse Practitioner*
- 7 Peta Leach  
*IBD Nurse Co-ordinator*
- 8 Crohn's & Colitis Australia Board

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