9 June 2007

The Economic Costs of Crohn's Disease and Ulcerative Colitis

Proposal by Access Economics Pty Limited for

Australian Crohn's and Colitis Association (ACCA)

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GLOSSARY OF COMMON ABBREVIATIONS

ABS	Australian Bureau of Statistics
ACCA	Australian Crohn's and Colitis Association
AIHW	Australian Institute of Health and Welfare
AWE	Average Weekly Earnings
BEACH	Bettering the Evaluation and Care of Health
BoD	Burden of Disease
CD	Crohn's Disease
DALY	Disability Adjusted Life Year
DCIS	Disease Costs and Impact Study
DWL	Deadweight Loss
GI	gastrointestinal
IBD	Inflammatory bowel disease (in this report IBD refers to the combination of CD and UC)
ICD-10	International Classification of Disease, Tenth Revision
NHMD	National Hospital Morbidity Database (AIHW)
NHS	National Health Survey (ABS)
NPV	Net Present Value
PBS	Pharmaceutical Benefits Scheme
PPP	purchasing power parity
QALY	Quality Adjusted Life Year
RR	Relative Risk
SDAC	Survey of Disability, Ageing and Carers (ABS)
UC	Ulcerative Colitis
VLY	Value of a Life Year
VSL	Value of a Statistical Life
YLD	Years of Healthy Life Lost due to Disability
YLL	Years of Life Lost due to Premature Mortality

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EXECUTIVE SUMMARY

Inflammatory bowel disease (IBD) is the name of a group of disorders that cause the intestines to become inflamed, which can lead to long term chronic disability and premature death. The main forms of IBD are Crohn's disease (CD) and Ulcerative Colitis (UC).

The prevalence, health and wellbeing impacts and other economic costs of IBD in Australia underline the need for greater public and professional awareness to enhance community participation and reduce social stigma, and for timely cost effective interventions that improve quality of life for people living with Crohn's and colitis.

In 2005, **around 61,000 Australians** live with IBD – an estimated 28,000 with CD and 33,000 with UC. IBD is more common than epilepsy or road traffic accidents; its prevalence is comparable with Type 1 diabetes or schizophrenia. There are around 776 new cases of CD and 846 new cases of UC per year.

- By 2020, the number of people with CD is projected to increase by 19.6% to around 33,500, while the number with UC is projected to increase by 25% to over 41,000.

IBD has an **onset in early adulthood and a lifelong impact**. It is most frequently diagnosed in people between the ages of 15-40 years, when many people are studying, establishing careers, starting families or financially committed (eg, buying their first home).

- IBD has long term disabling symptoms with life changing effects; CD is incurable and is associated with a 47% increase in the mortality risk. UC is only 'curable' through radical surgery, and if untreated, severe disease may also lead to death.

The total financial costs of IBD in 2005 were estimated as nearly $500m – $239m for CD and $258m for UC.

Because of the younger onset, IBD can cause disruption to education and employment, leading to **productivity losses**, which cost $266.7m in 2005 (including $128.8m for CD and $137.9m for UC). This was the largest cost component (over half of financial costs) for both conditions.

- **Lost earnings** due to workplace separation and early retirement from IBD cost $204.2m ($94.3m for CD and $109.9m for UC). On average, IBD was associated with a statistically significant 13% (95% CI:11%-15%) reduction in the probability that the person would be employed (relative risk of 0.87).
- **Absenteeism** cost $52.3m in 2005 ($8.2m borne by employees and $44.1m borne by employers), of which $24.3m was for CD and $28.0m was for UC. Each employed person with IBD took 7.2 days off per year, on average, due to their IBD.
- **Premature death** cost $10.2m in lost income streams for people with IBD aged 15-64 years and their families.
- Associated with these productivity losses was a $97.9m **loss of potential taxation revenue**.

Allocated health expenditures on IBD were conservatively estimated as $68.0m ($1,114 per person) each year, comprising $33.9m for CD and $34.1m for UC in 2005.

- The majority (49%) of allocated health expenditure was for inpatient hospital services – $33.4m.

- Second largest were expenditures on pharmaceuticals (mainly prescription drugs), comprising a further 23% or $15.4m. Biological therapies are efficacious in symptom remission and can prevent the need for surgery, but are relatively expensive.
- Out-of hospital medical services (GPs and specialists) were third, at $8.4m (12%).
- Outpatient hospital services and allied health service were each about 7% of the total.
- There was a further $11.1m in unallocated health costs – ie, capital, community and public health, health administration, aids and appliances.
- Health expenditure on IBD was only 0.1% of the total allocated recurrent health expenditure in Australia.

Informal care for people with IBD in the community from families and others was estimated to be worth $23.5m ($10.8m for people with CD and $12.7m for people with UC), based on a replacement valuation at $25.01 per hour for the 939,087 hours of informal care provided to people with IBD (15.39 hours per person per annum).

Out-of-pocket expenses cost an estimated $35.8m ($16.2m for people with CD and $19.6m for people with UC). Funeral costs associated with premature death due to CD cost a further $0.4m.

People with IBD received an estimated $15.0m in **welfare payments** ($6.9m for CD and $8.1m for UC) – $12.1m in Disability Support Pension, $2.6m in Newstart Allowance and $0.3m in Sickness Allowance. Of these, $13.1m were payments additional to what would have been received based on the general population rate of welfare payments.

- Associated with transfers such as welfare payments and taxation revenue foregone is a "**deadweight loss**" which, unlike the transfers themselves, imposes a real economic cost. For IBD in 2005, the DWL was $91.3m ($43.1m for CD and $48.2m for UC).

In addition, the burden of disease – the suffering and premature death experienced by people with IBD – is estimated to cost an additional 7,211 DALYs for CD and 7,392 DALYs for UC (DALYs are a measure of years of healthy life lost), 0.4% of the total Australian burden of disease.

- **IBD causes more disability and loss of life than all chronic back pain, slipped disks, machinery accidents, rheumatic heart disease or mental retardation**.
  - The disability from CD and UC are comparable with a broken rib or sternum, mild arthritis, severe asthma or the amputation of an arm, and disability is more severe than Type 1 diabetes or epilepsy.
- The **net disease burden in 2005 is estimated to cost $2.2 billion, over four times the financial costs – and $1.1 billion for each of CD and UC**.[1]
  - **Altogether the financial and disease burden of IBD is estimated to cost nearly $2.7 billion per annum**.

Challenges exist to reduce the costs of IBD and enhance the quality and options for care. Based on the challenges identified, listed below are recommendations that government and the private sector could jointly pursue in disease management of Crohn's and colitis.

- **1. Community awareness:** It is recommended that programs are developed and implemented to raise awareness and common understanding of CD and UC across Government, media and the general community. In particular such programs should

[1] This estimate is based on the value of a statistical life of $3.7m and a discount rate of 3.3%.

aim for a change in community perceptions and attitudes to IBD and a reduction in stigma.

- **2. Diagnosis:** It is recommended that education programs are developed and implemented to raise awareness and knowledge across the medical and health sector, and particularly for GPs and Emergency Departments to assist with earlier differential diagnosis, reduce misdiagnosis and reduce the long lags between onset of symptoms and diagnosis with treatment.
- **3. Access to pharmaceuticals:** Better access to newer treatments in particular biological therapies can improve the management of some of the most debilitating symptoms of IBD that prevent participation in employment and other forms of community life.
- **4. Health services:** It is recommended that referral practices to IBD specialists are reviewed to ensure timely access to specialist care, and geographical areas of need are identified, together with strategies for enhancing services to meet the specific needs of Australians disadvantaged in terms of geographical location (ie, rural and remote Australians), ethnicity (those who are from culturally and linguistically diverse backgrounds) or in terms of socioeconomic status. There needs to be continuing attention to workforce development in outer metropolitan and rural locations. Access to endoscopy in the public sector should be a particular focus. It is also recommended that community care is better coordinated, in particular across Australian and jurisdictional governments to result in more seamless, flexible and multidisciplinary care with the aim of supporting people in the community; any need for institutional accommodation should be age-appropriate and incorporate specific care for disease related symptoms.
- **5. Employment issues**: It is recommended that programs are developed aimed at retention and adaptation of existing jobs for people with CD and UC and other chronic illnesses. Such programs should involve innovative strategies such as workplace environment adaptation, job restructuring or tailoring, part-time and flexible work-from-home options, and transport assistance, as appropriate. Rehabilitation and workers' compensation models should be considered for integration into job retention policy and programs. Existing employer incentive schemes could be extended to include employers supporting workers with IBD and other disabilities in job retention programs. Education and awareness strategies should be developed to counter workplace misperceptions and discrimination against people with disabilities (including CD and UC) and encourage employers and employees to identify and implement positive long term solutions.
- **6. Support for people with IBD and their carers:** It is recommended that counselling, support, youth and family programs are designed and delivered to assist people with IBD and their family and carers, particularly respite care to assist employed carers. Support and respite services should be flexible, age-appropriate, lifestyle-friendly, timely and available over the long term. Improved case management input would help ensure good planning and packaging of services.
- **7. Research and development:** It is recommended that R&D efforts further investigate the epidemiological observation that the incidence of CD is increasing, with particular emphasis on environmental trigger research as these factors may be modifiable.

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1. INTRODUCTION

Access Economics was commissioned by the Australian Crohn's and Colitis Association (ACCA) to estimate the economic cost of Crohn's Disease (CD) and Ulcerative Colitis (UC). The ACCA's mission is to support the Crohn's and colitis community with a focus on confidential support programs including education, advocacy, counselling, increasing awareness and generating and utilising funds for research and support.

In Australia there is a lack of public and professional awareness of the impacts of Crohn's and colitis. Raising awareness of the economic and health impacts is considered important in achieving early effective interventions and reducing social stigma, which in turn are important in improving quality of life for people with Crohn's and colitis.

1.1 STUDY OBJECTIVES

The aim of the project is to estimate the demographic prevalence, financial cost and disease burden of CD and UC in Australia. Prevalence refers to the number of people with CD or UC in a population at a given point or over a certain period of time (one year prevalence is estimated in this study).

The financial costs of Crohn's and colitis include health system costs as well as productivity losses (due to education and employment impacts, worker absenteeism and premature death), carer costs, out-of-pocket expenses borne by people with Crohn's and colitis, as well as deadweight (efficiency) losses (DWLs) from transfer payments (such as government welfare and income support payments).

The burden of disease (BoD) refers to the years of healthy life lost due to disability and premature mortality caused by Crohn's and colitis, and is measured by Disability Adjusted Life Years (DALYs).

1.2 APPROACH

Access Economics drew upon evidence from a plethora of historical and current Australian and international clinical studies to assemble current age and gender-specific prevalence and incidence data for CD and UC, both nationally as well as by State/Territory. Robustness checks were conducted to ensure that the methodology for incorporating data from these clinical studies did not unduly affect the prevalence and incidence rates used in this study. Future prevalence estimates were then produced using demographic projections from the Australian Bureau of Statistics (ABS). In addition, mortality risks associated with CD and UC were calculated via meta-analysis of findings from disparate international studies.

The costs associated with Crohn's and colitis were estimated in three broad categories.

1. Health system costs

Direct financial costs to the Australian health system comprise the costs of running hospitals and nursing homes (buildings, care, consumables), GP and specialist services reimbursed through Medicare and private funds, the cost of prescribed and over-the-counter pharmaceuticals (Pharmaceutical Benefits Scheme and private), allied health services, research and "other" direct costs (such as health administration).

Estimates for direct health system costs of CD and UC were drawn from statistics collected by the Australian Institute of Health and Welfare (AIHW) for all digestive disorders, based upon an extensive process developed in collaboration with the National Centre for Health Program Evaluation for the Disease Costs and Impact Study (DCIS). The approach measures health services utilisation and expenditure (private and public) for specific diseases and disease groups in Australia (based on ICD-10 categorisation[2]). The DCIS methodology has been gradually refined over the past decade to now estimate a range of direct health costs from hospital morbidity data, case mix data, *Bettering the Evaluation and Care of Health* (BEACH) data, the National Health Survey and other sources.

Health system costs were estimated by age, gender and type of cost (hospital inpatient, hospital outpatient, out-of-hospital medical services, other professional services, pharmaceuticals, and research).

2. Other financial costs

Other financial costs include:

- **Productivity losses** of people with CD and UC comprise those from employment impacts, absenteeism and/or premature mortality.
- **Carer costs** comprise the value of care services provided in the community primarily by informal carers and not captured in health system costs.
- **Other costs** include government and non-government expenditure on aids, equipment and modifications that are required to help cope with illness, transport and accommodation costs associated with receiving treatment, programs such as respite and community palliative care and the bring-forward component of funerals.
- **Transfer costs** comprise the DWL associated with government transfers such as taxation revenue foregone, welfare and disability payments.

Data on other financial costs (including productivity losses, carer costs, out-of-pocket expenses and DWLs from transfers) are drawn from a variety of sources – for example, the literature (focussing on Australian literature but sometimes supplemented by international material), data from the ABS Survey of Disability, Ageing and Carers (SDAC) and Average Weekly Earnings (AWE), and so on.

In order to estimate productivity losses, a frictional approach was used for short term losses and a human capital approach for long term losses. Types of productivity losses include employment impacts, absenteeism and premature mortality costs for replacement workers. Long term costs were estimated in terms of the net present value of the future income streams lost. SDAC data were used to establish the average number of informal carers for people with Crohn's and colitis and average care hours. The value of care provided by these carers in Australia was estimated using a replacement valuation methodology, in the absence of data to enable an opportunity cost valuation. Other costs (such as costs for aids and equipment, formal care, travel and accommodation costs, communication costs and complementary or alternative therapies) were based on international literature, again in the absence of robust Australian data. Finally, DWLs from transfers were estimated. Additional taxation revenues need to be raised where welfare payments or government spending is incurred, leading to DWLs due to the administration of the taxation system and distortionary impacts on production and consumption choices of raising taxation.

[2] International Classification of Disease, tenth revision.

3. Burden of disease

The disability, loss of wellbeing and premature death that result from Crohn's and colitis are more difficult to measure, but have been analysed in terms of the years of healthy life lost, both quantitatively and qualitatively. BoD from Crohn's and colitis in Australia was based on disability weights and methodology from the AIHW extrapolated to 2005. The BoD approach is well-established and involves the calculation of DALYs lost from injuries and disease. The methodology was developed by the World Health Organisation, World Bank and Harvard University in the mid-1990s (Murray and Lopez, 1996) and first applied in Australia by the AIHW (Mathers et al, 1999). A rigorous process of attributing DALY components (the years of healthy life lost to disability and those due to premature mortality) has been developed and applied by Access Economics in conjunction with the estimation of the value of a statistical life year (VLY). The latter aspect, based on meta-analysis of wage-risk trade-off studies (eg, Viscusi and Aldy, 2002) enables the conversion of the wellbeing component into a financial estimate for cost benefit analysis. The loss of wellbeing from Crohn's and colitis in Australia is presented in dollar as well as DALY terms.

1.3 STRUCTURE OF THE REPORT

This report is structured as follows.

- The next chapter provides background information on CD and UC, including disease sub-types, symptoms, possible causes, methods of diagnosis, and treatment options.
- Chapter 3 presents current and projected future prevalence and incidence data for both diseases.
- Chapters 4 and 5 discuss the health system costs and other financial costs associated with the two diseases respectively.
- Chapter 6 presents BoD calculations in terms of DALYs.
- Chapter 7 concludes the report with a strategic focus.

2. BACKGROUND

2.1 INFLAMMATORY BOWEL DISEASE

Inflammatory bowel disease (IBD) is the name of a group of disorders that cause the intestines to become inflamed (red and swollen). The main forms of IBD are CD and UC. Because the symptoms of CD and UC are so similar, it is sometimes difficult to establish the diagnosis definitively. In fact, approximately 10% of colitis cases are unable to be defined as either UC or CD and are called indeterminate colitis. Categorical issues are still evolving (Silverberg et al, 2005).[3]

Both CD and UC have one strong feature in common. They are marked by an abnormal response by the body's immune system. The immune system is composed of various cells and proteins. Normally, these protect the body from infection. In people with IBD, however, the immune system reacts inappropriately. Researchers believe that the immune system mistakes microbes, such as bacteria that is normally found in the intestines, for foreign or invading substances, and launches an attack. In the process, the body sends white blood cells into the lining of the intestines, where they produce chronic inflammation. These cells then generate harmful products that ultimately lead to ulcerations and bowel injury. When this happens, the patient experiences the symptoms of IBD.

Although CD most commonly affects the end of the small intestine (the ileum) and the beginning of the large intestine (the colon), it may involve any part of the GI tract. In UC, on the other hand, the GI involvement is limited to the colon. In CD, all layers of the intestine may be involved; this can result in deep ulcers that go through the wall of the bowel completely. These generally cause abscesses in the abdomen but can lead to the development of connections between the bowel and other organs (fistulas). For example there can be connections between the small bowel and bladder (leading to recurrent urinary tract infections), the rectum and the vagina (leading to the passage of faecal material through the vagina), the bowel and the skin and so on. In the bowel CD is often discontinuous and there can be normal healthy bowel in between patches of diseased bowel. In contrast, UC affects only the superficial layers (the mucosa) of the colon in a more even and continuous distribution, which starts at the level of the anus. In addition, CD and UC present with extra-intestinal manifestations (such as liver problems, arthritis, skin manifestations and eye problems) in different proportions.

Currently there is no cure for CD and the individual's best outcome is managing the disease to maintain remission after an acute episode. In comparison, while a similar regimen is often used for colitis, it can generally be 'cured' by surgical removal of the large intestine (although this is an extreme option which is preferably avoided if possible).

Both CD and UC have significant impacts on the person's quality of life through pain, bleeding, fatigue, vomiting, diarrhoea, itchiness or irritation around the anus, flatulence and bloating. Weight loss and anaemia also pose significant problems, due to the individual preferring to limit the amount they eat to lessen symptoms and the impact of the disease in absorbing vital nutrients. The ongoing quality of life impact combined with potential mental

[3] Other closely related conditions are collagenous colitis, lymphocytic colitis, ischaemic colitis, diversion colitis, Behçet's syndrome and infective colitis. It should be noted that irritable bowel syndrome (IBS) is unrelated, although frequently confused with IBD. IBS is due to increased awareness of normal bowel activity and/or excessive contractility (spasm or cramping) of the bowel, while IBD is due to potentially life-threatening inflammation of the bowel.

health issues and the timing of onset (in many cases when educational and career attainment is of prime importance), together contribute to a greater likelihood that people with CD and UC will be disadvantaged in terms of participation in the workforce and lifetime earnings which, subsequently, may result in higher use of other government services. Table 2-1 summarises some of the major differences between CD and UC.

TABLE 2-1: COMPARISONS OF CHARACTERISTICS OF CD AND UC

	CD	UC
Occurrence	More females than males	Similar for males and females
	All ages, usual onset 15-35 years	All ages, usual onset 15-45 years
Symptoms	Diarrhoea, fever, sores around the anus, abdominal pains and cramps, pain and swelling in the joints, anaemia, fatigue, loss of appetite, weight loss	Bloody diarrhoea, mild fever, inflamed rectum, abdominal pains and cramps, fatigue, loss of appetite, weight loss, pain and swelling in joints
Terminal ileum involvement	Common	Rarely
Colon involvement	Often	Always
Rectum involvement	Often	Usually
Peri-anal disease	Common	Never
Bile duct involvement	Lower rate of primary sclerosing cholangitis	Higher rate of primary sclerosing cholangitis
Distribution of Disease	Patchy areas of inflammation	Continuous area of inflammation
Endoscopy	Deep geographic and serpiginous (snake-like) ulcers	Diffuse ulceration
Depth of inflammation	May be transmural, deep into tissues	Shallow, mucosal
Fistulas, abnormal passageways between organs	Common	Never
Stenosis	Common	Seldom
Granulomas on biopsy	Common	Very uncommon
Surgical 'cure'	Often returns following removal of affected parts	Usually 'cured' by removal of colon[4]
Treatment	Drug treatment (aminosalicylates, corticosteroids, immune modifiers, antibiotics, biologic therapies)	Drug treatment (aminosalicylates, corticosteroids, immune modifiers, antibiotics)
	Diet and nutrition	Surgery (rectum/colon removal)
	Surgery (repair fistulas, remove obstruction, resection and anastomosis)	
Cure	Incurable	Through colectomy only
	Maintenance therapy is used to reduce the chance of relapse	Maintenance therapy is used to reduce the chance of relapse
Cytokine response	Associated with Th1	Vaguely associated with Th2
Complications	Obstruction or blockage of intestine due to welling or formation of scar tissue, sores or ulcers (fistulas), malnutrition	Bleeding from ulcerations, perforation (rupture) of the bowel, abdominal distension
Smoking	Higher risk for smokers	Lower risk for smokers
Mortality risk	Increased risk of lymphoma	Increased risk of colorectal cancer and cholangiocarcinoma

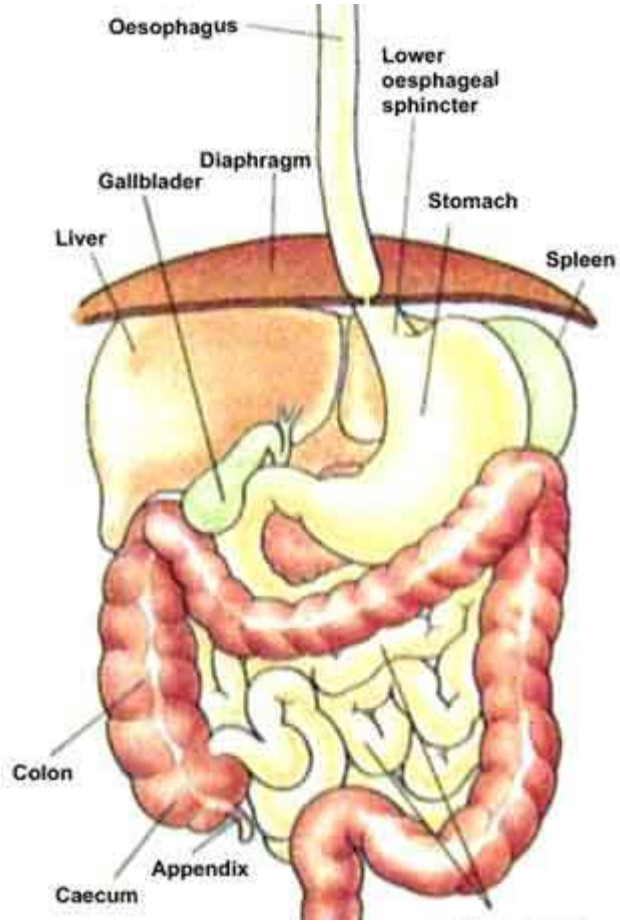
Sources: Wikipedia (2006), Crohn's & Colitis Foundation of America, IBD Club UK, Masala et al (2006).

[4] Colon removal prevents recurrence but an ileostomy may or may not have complications, a pouch may not always work, and there is a risk of decreased fertility or sexual prowess depending on sex.

2.1.1 CAUSES OF IBD

Although considerable progress has been made in IBD research, investigators do not yet know what causes this disease. Studies indicate that the inflammation in IBD involves a complex interaction of factors: the genes the person has inherited, the immune system, and something in the environment. Foreign substances (antigens) in the environment may be the direct cause of the inflammation, or they may stimulate the body's defences to produce an inflammation that continues without control. Researchers believe that once the immune system is "turned on," it does not know how to properly "turn off" at the right time. As a result, inflammation damages the intestine and causes the symptoms of IBD. The main goal of medical therapy is therefore to help patients improve the regulation of their immune system.

FIGURE 2-1: THE LOWER GI TRACT



2.1.2 DIAGNOSIS OF IBD

There is no single test that can establish the diagnosis of IBD with certainty. To determine the diagnosis, physicians evaluate a combination of information from the patient's history and physical exam. They examine the results of laboratory tests, X-rays, and findings on endoscopy and pathology tests, and exclude other known causes of intestinal inflammation. X-ray tests may include barium studies of the upper and lower GI tract.

Endoscopy tests most frequently involve colonoscopy, which allows the physician to examine the colon with a lighted tube that is inserted through the anus. Flexible sigmoidoscopy may also sometimes be used, where the physician passes a flexible instrument into the rectum

and lower colon, allowing visualisation of the extent and degree of inflammation in these areas. A colonoscopy permits examination of the distal small bowel, with ileocolonoscopies most usually performed, whereby a physician can detect inflammation, bleeding, or ulcers on the colon wall, as well as determine the extent of disease. During these procedures, he/she may take samples of the colon lining, called biopsies, and send these to a pathologist for further study. UC can thus be distinguished from other diseases of the colon that cause rectal bleeding – including CD of the colon, diverticular disease, and cancer.

2.2 CROHN'S DISEASE

As noted above, CD is a chronic (ongoing) disorder that causes inflammation of any area of the GI tract from the mouth to the anus, although it most commonly affects the small intestine and/or colon. The disease is named after Dr Burrill B Crohn. In 1932, Dr Crohn and two colleagues, Dr Leon Ginzburg and Dr Gordon D Oppenheimer, published a landmark paper describing the features of what is known today as CD (Crohn et al, 1932).

2.2.1 TYPES OF CD

The symptoms and complications of CD differ, depending on what part of the intestinal tract is inflamed. The following are five types of CD, together with their presenting symptoms.[5]

- **Ileocolitis:** The most common form of Crohn's, affecting the ileum and colon. Symptoms include diarrhoea and cramping or pain in the right lower part or middle of the abdomen. Often accompanied by significant weight loss.
- **Ileitis:** Affects the ileum. Symptoms same as ileocolitis. Complications may include fistulas or inflammatory abscess in right lower quadrant of abdomen.
- **Gastroduodenal CD:** Affects the stomach and duodenum (the first part of the small intestine). Symptoms include loss of appetite, weight loss and nausea. Vomiting may indicate that narrowed segments of the bowel are obstructed.
- **Jejunoileitis:** Produces patchy areas of inflammation in the jejunum (upper half of the small intestine. Symptoms include abdominal pain (ranging from mild to intense) and cramps following meals, as well as diarrhoea. Fistulas may form.
- **Crohn's (granulomatous) colitis:** Affects the colon only. Symptoms include diarrhoea, rectal bleeding, and disease around the anus (abscess, fistulas, ulcers). Skin lesions and joint pains are more common in this form of Crohn's than in others.

2.2.2 SYMPTOMS

Persistent diarrhoea (loose, watery, or frequent bowel movements), crampy abdominal pain, fever, and, at times, rectal bleeding are the hallmark symptoms of CD, but they vary from person to person and may change over time. Loss of appetite and subsequent weight loss may also occur. However, the disease is not always limited to the GI tract; it can also affect the joints, eyes, skin and liver. Fatigue is another common complaint. Children who have CD may suffer delayed growth and sexual development.

Some patients may develop tears (fissures) in the lining of the anus, which may cause pain and bleeding, especially during bowel movements. Inflammation may also cause a fistula to develop. A fistula is a tunnel that leads from one loop of intestine to another, or that connects

[5] These anatomical descriptions are provided for ease of the lay reader, although the clinical community may be more familiar with the Vienna or Montreal classification systems.

the intestine to the bladder, vagina or skin. Fistulas occur most commonly around the anal area. If this complication arises, the patient may notice drainage of mucus, pus, or stool from this opening.

Symptoms may range from mild to severe. Because Crohn's is a chronic disease, patients will go through periods in which the disease flares up, is active, and causes symptoms. These episodes are followed by times of remission – periods in which symptoms disappear or decrease and good health returns. In general, people with CD lead mostly full, active and productive lives.

2.2.3 TREATMENT OPTIONS

As there is no cure for CD, the goal of medical treatment is to suppress the inflammatory response leading to remission – the long term goal is to maintain this remission. This step accomplishes two important goals: it allows the intestinal tissue to heal and it also relieves the symptoms of fever, diarrhoea, and abdominal pain. Once the symptoms are brought under control (this is known as inducing remission), medical therapy is used to decrease the frequency of disease flares (this is known as maintaining remission, or maintenance).

Several groups of drugs are used to treat CD today. They are:

- **Corticosteroids:** Prednisone and methylprednisolone are available orally and rectally. Corticosteroids can also be given intravenously. They non-specifically suppress the immune system and are used to treat moderate to severely active CD. These drugs have significant short- and long-term side effects so are not used as a maintenance medication.
- **Immune modifiers:** Azathioprine (Imuran®), 6-MP (Purinethol®) and methotrexate, sometimes called immunomodulators, are used to help decrease corticosteroid dosage and also to help heal fistulas. In addition, immune modifiers help maintain disease remission.
- **Antibiotics:** metronidazole, ampicillin, ciprofloxacin and others help heal infections.
- **Aminosalicylates (5-ASA):** This class of anti-inflammatory drugs includes sulfasalazine and oral formulations of mesalamine and 5-ASA drugs also may be administered rectally. These medications typically are used to treat mild symptoms.
- **Biological therapies:** Infliximab (Remicade®) is indicated for moderately to severely active Crohn's in patients who have not responded adequately to conventional immune modifier therapy, and may also be used for reducing the number of draining enterocutaneous fistulas. Given by infusion, infliximab is a chimeric (a hybrid consisting of 75% human, 25% mouse protein) monoclonal antibody. The antibody works by blocking the immune system's production of tumour necrosis factor-alpha (TNF-alpha), a cytokine (chemical) that intensifies inflammation. Several other biologic agents for both CD and UC have been shown to be effective in clinical trials and may be submitted for approval by the regulatory authorities in Australia over the next few years.

Surgery

Two-thirds to three-quarters of patients with CD will require surgery at some point during their lives. Surgery becomes necessary in CD when medications can no longer control the symptoms. It may also be performed to repair a fistula or fissure. Another indication for surgery is the presence of an intestinal obstruction or other complication, such as an intestinal abscess. In most cases, the diseased segment of bowel and any associated abscess is removed (resection). The two ends of healthy bowel are then joined together in a procedure called an anastomosis. While resection and anastomosis may allow many

symptom-free years, this surgery is not considered a cure for CD, because the disease frequently recurs at or near the site of anastomosis.

An ileostomy also may be required when surgery is performed for CD of the colon. After the surgeon removes the colon, he brings the small bowel to the skin, so that waste products may be emptied into a pouch attached to the abdomen. This procedure is needed if the rectum is diseased and cannot be used for an anastomosis.

The overall goal of surgery in CD is to conserve bowel where possible and return the individual to the best possible quality of life.

2.2.4 COMPLICATIONS

The most common complication of CD is obstruction or blockage of the intestine due to swelling and the formation of scar tissue. The result is thickening of the bowel wall and a significantly narrowed intestinal passage. Symptoms of intestinal obstruction include crampy pain around the mid-abdomen, frequently associated with vomiting. The abdomen may also become bloated and distended. Medications may relieve the obstruction by reducing the local area of inflammation, but surgery may be required if the obstruction is severe and does not respond to medical treatment. Surgery may also be indicated if the blockage recurs frequently.

Another complication is sores or ulcers within the intestinal tract that sometimes turn into fistulas. These affect about 30% of people with CD and often become infected. If the fistula is small, medical treatment may be sufficient to heal it. Large or multiple fistulas, on the other hand, may signal the need for surgery, particularly if they are accompanied by fairly persistent symptoms, such as fever or abdominal pain. Occasionally a fistula forms an abscess, or collection of pus, near the intestine. This is a pocket of infection that requires drainage either through a catheter inserted by a radiologist or a special drain that is surgically inserted. The areas around the anus and rectum are often involved. In addition to fistulas, cracks or fissures may also develop in the lining of the mucus membrane of the anus.

Another type of complication commonly encountered in people with CD is related to malnutrition or the presence of nutritional deficiencies. These are deficiencies of proteins, calories, and vitamins. They generally do not develop unless the disease is extensive and of long duration, conditions that may contribute to inadequate dietary intake and poor absorption of nutrients. Medical treatment is usually effective in the replacement of nutrients. For example, a deficiency in vitamin B_{12} can be corrected by an injection of this vitamin. Similarly, an iron deficiency can be reversed by taking this mineral in liquid or tablet form, and is also often given as an infusion requiring a day or overnight admission to a hospital high dependency ward. Nutritional supplements, containing both vitamins and minerals, are available in concentrated form.

2.3 ULCERATIVE COLITIS

UC is a chronic (ongoing) disease of the colon. The disease is marked by inflammation and ulceration of the colon mucosa, or innermost lining. Tiny open sores, or ulcers, form on the surface of the lining, where they bleed and produce pus and mucus. Because the inflammation makes the colon empty frequently, symptoms typically include diarrhoea (sometimes bloody) and often crampy abdominal pain.

The symptoms of UC, as well as possible complications, will vary depending on the extent of inflammation in the rectum and the colon.

2.3.1 TYPES OF UC

Inflammation usually begins in the rectum and lower colon, but it may also involve the entire colon. UC always involves the rectum and extends a variable distance proximally. It is usually anatomically defined as *proctitis* (affecting the rectum), *left-sided disease* (affecting up to the splenic flexure ie, left side of the colon) and *pan colitis* (affecting the entire colon).

For a less than 10% of all patients with UC, the illness begins as **ulcerative proctitis**. In this form of the disease, bowel inflammation is limited to the rectum. Because of its limited extent (usually less than the 15cm of the rectum), ulcerative proctitis tends to be a milder form of UC. It is associated with fewer complications and offers a better outlook than more widespread disease.

In addition to ulcerative proctitis, the other types of UC are:

- **Proctosigmoiditis:** Colitis affecting the rectum and the sigmoid colon (the lower segment of colon located right above the rectum). Symptoms include bloody diarrhoea, cramps and tenesmus (straining to have a bowel movement). Moderate pain on the lower left side of the abdomen may occur in active disease.
- **Left-sided colitis:** Continuous inflammation that begins at the rectum and extends as far as the splenic flexure (a bend in the colon, near the spleen). Symptoms include loss of appetite, weight loss, diarrhoea, severe pain on the left side of the abdomen, and bleeding.
- **Pan-ulcerative (total) colitis:** Affects the entire colon. Symptoms include diarrhoea, severe abdominal pain, cramps, and extensive weight loss. Potentially serious complications include massive bleeding and acute dilatation of the colon (toxic megacolon), which may lead to perforation (a life-threatening leak in the bowel wall comparable to a ruptured ulcer). Serious complications may require surgery.

2.3.2 SEVERITY

In addition to the extent of involvement, patients may also be characterised by the severity of their disease.

- **Mild disease** correlates with fewer than four stools daily, with or without blood, no systemic signs of toxicity, and a normal erythrocyte sedimentation rate (ESR). There may be mild abdominal pain or cramping. Patients may believe they are constipated when in fact they are experiencing tenesmus, which is a constant feeling of the need to empty the bowel accompanied by involuntary straining efforts, pain, and cramping with little or no fecal output. Rectal pain is uncommon.
- **Moderate disease** correlates with more than four stools daily, but with minimal signs of toxicity. Patients may display anaemia (not requiring transfusions), moderate abdominal pain, and low grade fever, 38 to 39 ℃ (9 9.5 to 102.2 ℉).
- **Severe disease** correlates with more than six bloody stools a day, and evidence of toxicity as demonstrated by fever, tachycardia, anaemia or an elevated ESR.
- **Fulminant disease** correlates with more than ten bowel movements daily, continuous bleeding, toxicity, abdominal tenderness and distension, blood transfusion requirement and colonic dilatation (expansion). Patients in this category may have inflammation extending beyond just the mucosal layer, causing impaired colonic motility and leading to toxic megacolon. If the serous membrane is involved, colonic perforation may ensue. Unless treated, fulminant disease may lead to death.

Severity is measured not just by stool frequency but also more often by nocturnal stool frequency and number of liquid stools (simple colitis index).

2.3.3 SYMPTOMS

The first symptom of UC is a progressive loosening of the stool. The stool is generally bloody and may be associated with crampy abdominal pain and severe urgency to have a bowel movement. The diarrhoea may begin slowly or quite suddenly. Loss of appetite and subsequent weight loss are common, as is fatigue. In cases of severe bleeding, anaemia may also occur. In addition, there may be skin lesions, joint pain, eye inflammation, and liver disorders. Children with UC may fail to develop or grow properly. Approximately half of all patients with UC have relatively mild symptoms. The symptoms of UC tend to come and go, with fairly long periods in between flare-ups in which patients may experience no distress at all. These periods of remission can span months or even years, although symptoms do eventually return. The unpredictable course of UC may make it difficult for physicians to evaluate whether a particular course of treatment has been effective or not.

2.3.4 TREATMENT OPTIONS

Currently, there is no medical cure for UC. However, effective medical treatment can suppress the inflammatory process. As such, the treatment of UC involves medications that decrease the abnormal inflammation in the colon lining and thereby control the symptoms, with the goal of maintaining this induced remission. Medical options are centred around 5-ASAs and topical (rectal) therapy for which there is evidence (unlike in CD). Otherwise the medication range is the same.

In one-quarter to one-third of patients with UC, medical therapy is not completely successful or complications arise. Under these circumstances, surgery may be considered. This operation involves the removal of the colon (colectomy). Unlike CD, which can recur after surgery, UC is "cured" once the colon is removed.

Depending on a number of factors, including the extent of the disease and the patient's age and overall health, one of two surgical approaches may be recommended. The first involves the removal of the entire colon and rectum, with the creation of an ileostomy or external stoma (an opening on the abdomen through which wastes are emptied into a pouch, which is attached to the skin with adhesive). A more recently developed procedure also calls for removal of the colon, but it avoids an ileostomy. By creating an internal pouch from the small bowel and attaching it to the anal sphincter muscle, the surgeon can preserve bowel integrity and eliminate the need for the patient to wear an external ostomy appliance.

2.3.5 COMPLICATIONS

Local complications of UC include profuse bleeding from deep ulcerations, perforation (rupture) of the bowel, or simply failure to respond appropriately to the usual medical treatments.

Another complication is severe abdominal distension. A mild degree of distention is common in individuals without any intestinal disease and is somewhat more common in people with UC. However, if the distention is severe or of sudden onset, and if it is associated with active colitis, fever, and constipation, a physician may suspect a serious complication of colitis, called toxic megacolon. Fortunately, this is a rare development. It is produced by severe inflammation of the entire thickness of the colon, with weakening and ballooning of its wall. The dilated colon is then at risk of rupturing. Treatment is aimed at controlling the

inflammatory reaction and restoring losses of fluid, salts, and blood. If there is no rapid improvement, surgery may become necessary to avoid rupture of the bowel.

Other important complications are colorectal cancer and cholangiocarcinomas, which are nearly always fatal.

2.4 LIVING WITH CD AND UC

Emotional stress can influence the course of CD or UC – or, for that matter, any other chronic illness. People occasionally experience emotional problems before a flare-up of their disease, although there is no evidence to show that stress, anxiety or tension are responsible for CD or UC. It is much more likely that the emotional distress that patients sometimes feel is a reaction to the symptoms of the disease itself. Factors of most concern include loss of energy, loss of control, body image, isolation and fear, not reaching full potential, feeling dirty, and lack of information from the medical community (Vitetta et al, 2001). Patients with UC require understanding and emotional support from their families and physicians. Although formal psychotherapy is generally not necessary, some patients are helped considerably by speaking with a therapist who is knowledgeable about IBD or about chronic illness in general.

Coping techniques for dealing with CD and UC may take many forms. Attacks of diarrhoea, pain, or gas may make people fearful of being in public places. In such a situation, some practical advance planning may help alleviate this fear, such as finding out where the toilets are in restaurants, shopping areas, theatres, and on public transportation ahead of time. Some patients find it helpful to carry along extra underclothing or toilet paper for particularly long trips.[6]

While CD and UC are serious chronic diseases, they are not usually considered fatal illnesses. Most people with the illness may continue to lead useful and productive lives, even though some may be hospitalised frequently or need to take regular medication to retain remission. In between flare-ups of the disease, many individuals feel well and may be relatively free of symptoms.

[6] ACCA provide people with IBD with “emergency cards” to allow them to expedite access to public toilets.

3. PREVALENCE, MORTALITY AND INCIDENCE

The prevalence of CD and UC varies considerably across time and countries. Prevalence rates appear to be affected by genetics and environmental factors. People belonging to certain ethnic groups or living in certain regions in particular countries appear to be more predisposed to developing these diseases than others.

3.1 IMPORTANCE OF HEREDITY, ETHNICITY, GENDER AND ENVIRONMENT

3.1.1 GENETICS

IBD may cluster in families, although on most occasions patients have no affected relative. Studies have shown that about 20-25% of patients may have a close relative with either CD or UC. If a person has a relative with the disease, his or her risk is about 10 times greater than that of the general population. If that relative happens to be a brother or sister, the risk is 30 times greater.

Researchers have been working actively for some time to find a link to specific genes that control the transmission of this illness. An important breakthrough was achieved with the identification of an abnormal mutation or alteration in a gene known as NOD2/CARD 15 (Ogura et al, 2001; Hugot et al, 2001). This mutation, which limits the ability to recognise bacteria as harmful, occurs twice as frequently in Crohn's patients as in the general population. There is currently no way to predict which, if any, family members will develop CD. The data further suggest that more than one gene may be involved. With new technologies, researchers are closing in on additional genes that may be involved in IBD.

3.1.2 ETHNICITY AND GENDER

IBD also appears to affect certain ethnic groups more than others. For example, American Jews of European descent are four to five times more likely to develop IBD than the general population. In America, IBD has long been thought of as a disease predominantly affecting whites. However, there has been a steady increase in reported cases of both CD and UC among African-Americans. The prevalence rates among Hispanics and Asians are lower than those for whites and African Americans.

There are data that Maori and Pacific Island people are at lower risk for developing IBD from New Zealand (Eason et al, 1982; Wigley et al, 1962; Gearry et al, 2006a), which may be the same for indigenous Australians as well. There may be genetic reasons for this difference as shown in New Zealand Maori (Gearry et al, 2006b).

3.1.3 ENVIRONMENT

For reasons that are not yet clearly understood, IBD is largely a disease of the developed world, and is found principally in the US, Europe and other high income countries. Moreover, the frequency of disease increases when specific groups of people move from developing to developed countries (and vice versa).[7] Similarly, CD and UC are reported to be more common in urban than in rural areas and in colder rather than warmer climates. The

[7] For example, high rates of IBD especially UC have been noted in second generation subcontinental migrants to the UK – stressing the role of environmental factors, presumably in childhood.

incidence of IBD, in particular CD, is increasingly indicating a major role for environmental factors. Many hypotheses have been raised for environmental contributors to the pathogenesis of IBD.

- **Smoking:** UC has a lower prevalence in active smokers and potentially a higher prevalence in recent quitters than in never-smokers (Abraham et al, 2003).
- **Appendectomy**: Previous appendectomy is a protective factor for UC (Andersson et al, 2001).
- **Childhood exposures/infections**. There have been conflicting reports of the protection of breastfeeding in the development of IBD, with one Italian study showing a potential protective effect. There is also conflicting evidence in relation to other factors, although the hygiene hypothesis is gaining some credibility.
- **Diet:** as the colon is exposed to many different dietary substances that may encourage inflammation, dietary factors have been hypothesised to play a role in the pathogenesis of both UC and CD. There have been few robust conclusions, although a number of studies have investigated a potential association between IBD (especially CD) and refined sugar (Gibson and Shepherd, 2005).

In summary, while smoking and appendectomy are well accepted protective factors for UC, other linkages are much less certain.

3.2 LITERATURE

In this report 'prevalence' refers to the number of people with CD or UC in a population at a given point or over a certain period of time (usually one year), while the 'prevalence' rate refers to those people expressed as a proportion of their respective source population.

Detailed Australian prevalence data by age-gender groupings for CD and UC are currently unavailable. Even the estimated overall prevalence rate for the Australian population varies enormously, as do the estimates across countries found in international studies.

3.2.1 PREVALENCE IN AUSTRALIAN STUDIES

The best method of measuring community prevalence is through well-designed clinical studies of populations, preferably longitudinal and prospective. However, so far there is a lack of data on the prevalence of CD and UC in Australia. Prevalence estimates from five sources vary significantly and most do not provide much detail on the individual diseases or age- and gender-specific prevalence rates (Table 3-1).

- ACCA previously estimated that there were 43,000 people with IBD in Australia in 2006 – 30,000 people with CD and 13,000 people with UC.[8] Based on this estimate, the prevalence rate was calculated as 0.21% (0.15% for CD and 0.06% for UC[9]).
- According to the ABS National Health Survey (NHS) 2004-05, which is based on self-reported data, there were 51,900 people (18,600 males and 33,400 females) with CD and UC in Australia in that year, a prevalence rate of 0.26% (see Table 3-2).

[8] **http://www.acca.net.au/module.asp?module=leftmenu&gotoid=What+is+IBD%3F**

[9] The higher ratio of CD to UC in the previous ACCA estimates may reflect referral bias in that those with CD may be more likely to join or contact ACCA.

- Cavanaugh et al (2001) estimate that the Australian prevalence rate of IBD is 0.20%, suggesting 40,673 people with IBD in Australia in 2005. No estimates on prevalence of CD or UC were provided.
- According to Mathers et al (1999), in turn based on overseas studies, in 1996 there were 66,470 people with IBD in Australia. The AIHW updated this estimate in 2003 to 71,894 (Begg et al, 2007). Based on this prevalence rate of 0.36% (0.33% for males and 0.39% for females), the number of people with IBD in Australia in 2005 would be 73,177.

TABLE 3-1: AUSTRALIAN PREVALENCE ESTIMATES OF CD AND UC

Author	Number of IBD (CD + UC) Cases in Australia (2005)	Prevalence of IBD (CD + UC)
ACCA	43,000	0.21%
ABS NHS 2005	51,900	0.26%
Cavanough et al (2001)	40,673	0.20%
Mathers et al (1999)	73,177	0.36%

Even fewer details are available on mortality rates and the incidence of CD and UC in Australia. The only estimate is by the AIHW who calculated that there were 37 deaths (19 males, 18 females) due to IBD in Australia in 1996 (Mathers et al, 1999). The incidence rate was estimated as 0.01% (0.01% for males and 0.01% for females), suggesting that there were 2,034 new cases of IBD in Australia in 2005.

TABLE 3-2: PREVALENCE OF CD AND UC IN AUSTRALIA, ABS DATA

	0-14 years	15-44 years	45-64 years	65+ years	Total
Males	>100	9,900	5,400	3,300	18,600
Males (%)	0.00%	0.23%	0.22%	0.28%	0.18%
Females	1,500	16,200	12,300	3,400	33,400
Females (%)	0.08%	0.37%	0.49%	0.23%	0.33%
Persons	1,600	26,000	17,600	6,700	51,900
Persons (%)	0.04%	0.30%	0.35%	0.25%	0.26%

3.2.2 PREVALENCE IN INTERNATIONAL STUDIES

There are several prevalence estimates in the international literature, but few include details on age- or gender-specific prevalence of CD or UC. Prevalence rates are thus estimated in two steps. First, international estimates for prevalence estimates are applied to 2005 Australian population data. Second, age-gender specific prevalence estimates from New Zealand and Canada – the only two sources found – are applied to 2005 Australian population data to derive the age-gender distribution of the two diseases in Australia.

3.2.2.1 GENERAL PREVALENCE OF CD AND UC

Internationally, prevalence estimates vary considerably. If prevalence rates from international studies were applied to Australia, estimates of prevalence of both conditions could range from 1,975 (0.01%) based on Japanese prevalence rates (Higashi et al, 1988) to 105,973 (0.52%) based on Canadian estimates (CCFC, 2006). However, these Japanese and Canadian estimates and the Mate-Jimenez et al (1994) Spanish estimate of 12,853 (0.06%) appear to be outliers compared to all the other estimates, which otherwise range from 30,708 (0.15%) in Denmark (Binder et al, 1982) to 90,498 (0.45%) also in Denmark (Jacobsen et al, 2006) but using more recent observations (Table 3-3). Probert et al (1993)

also appears to generate an outlier (low) estimate of CD, if those rates (in Leicestershire Asians) were applied to Australians.

The proportions of CD and UC also differ. Of 13 studies, six studies found CD to be the more common disease, while seven studies found UC to be more common.

Moreover, there are differences in time and geography, partly due to differences in methods of data collection, but temporal changes over the last fifty years have been large (Binder et al, 2004). While the incidence of IBD has stabilised in some countries, it continues to rise in others. The wide range of estimates is highlighted in Table 3-3, albeit some of the variation is due to different methodologies used to identify cases.

TABLE 3-3: INTERNATIONAL PREVALENCE ESTIMATES OF CD AND UC

		Number of Cases in Australia (2005) using Intl Prev Rates			Shares		Prevalence		
Author	Location	CD in AUS	UC in AUS	IBD in AUS	% CD/IBD	% UC/IBD	CD	UC	IBD
Binder et al (1982)	Copenhagen (1978)	23,794	6,914	30,708	77%	34%	0.12%	0.03%	0.15%
Higashi et al (1988)	Japan	1,596	378	1,975	81%	19%	0.01%	0.00%	0.01%
Loftus et al (1998/99)	Olmsted County, Minnesota (1991)	27,048	46,571	73,618	37%	63%	0.13%	0.23%	0.36%
Probert et al (1993)	Leicestershire – Europeans	15,415	18,466	33,881	45%	55%	0.08%	0.09%	0.17%
Probert et al (1993)	Leicestershire - Asians	6,752	27,454	34,206	20%	80%	0.03%	0.14%	0.17%
Mate-Jimenez et al (1994)	Spain (1981-88)	8,826	4,027	12,853	69%	31%	0.04%	0.02%	0.06%
Bernstein et al (1999)	Canada (1989-94)	40,368	34,511	74,879	54%	46%	0.20%	0.17%	0.37%
Rubin et al (2000)	North Tees, England	29,488	49,418	78,906	37%	63%	0.15%	0.24%	0.39%
Stone et al (2003)*	Trent region, England	26,438	49,418	80,533	33%	61%	0.13%	0.24%	0.40%
IBD Club UK (2006)	UK	12,710	33,894	46,605	27%	73%	0.06%	0.17%	0.23%
NACC (2006)	UK	20,266	40,532	60,797	33%	67%	0.10%	0.20%	0.30%
CCFC (2006)	Canada	-	-	105,973	-	-	-	-	0.52%
Jacobsen et al (2006)	Denmark (1978-2002)	59,790	30,708	90,498	66%	34%	0.29%	0.15%	0.45%
Gearry et al (2006c)**	NZ (2004)	30,778	28,387	59,165	52%	48%	0.16%	0.15%	0.30%

*Also includes 4,677 cases (6%) of other IBD. The prevalence rate of other IBD is 0.02%.

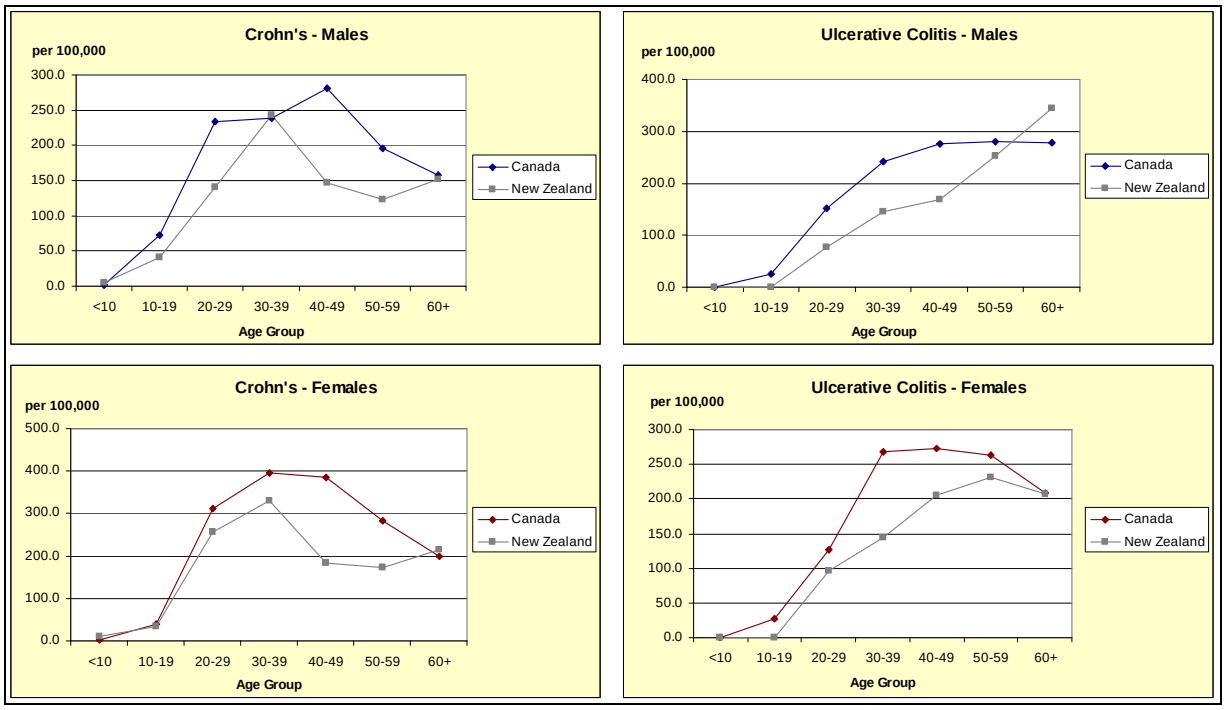
** Includes an estimated 91% of people with IBD in the Canterbury cohort, so potentially underestimated overall.

3.2.2.2 AGE-GENDER SPECIFIC PREVALENCE OF CD AND UC

The only two studies with age- and gender-specific prevalence rates of CD and UC are by Bernstein et al (1999) and Gearry et al (2006c), looking at the Canadian province of Manitoba between 1989 and 1994 and the Canterbury region in New Zealand between 2004 and 2005 respectively. Both studies were based on a large sample population: 2,725 patients in the case of Canada and 1,420 patients in the case of New Zealand.

Interestingly, there are some significant differences in the age and gender-specific prevalence rates between the two countries (Figure 3-1) and overall prevalence is higher in Canada than New Zealand for both CD (0.20% compared with 0.16%) and UC (0.17% compared with 0.15%).[10]

FIGURE 3-1: PREVALENCE RATES OF CD AND UC: CANADA AND NEW ZEALAND



3.3 BEST ESTIMATE OF CURRENT CD AND UC PREVALENCE

3.3.1 METHODOLOGY USED

In order to estimate the 2005 prevalence for CD and UC in Australia, the Australian and international studies discussed previously were used, with estimates based on the maximum number of studies available.

First, the total number of people with IBD or, more precisely, the sum of people with CD and UC, was estimated by using an average of the Australian studies (except for the to-be-updated ACCA figure) and international studies, excluding the outliers (ie, excluding Mate-Jimenez et al 1994, Higashi et al 1988, Probert et al 1993 and CCFC 2006). Overall, it was estimated that a total of 61,180 (rounded to 61,000) Australians suffer from CD or UC.

Next, all studies with details on CD or UC – which were only international studies – were used to calculate the average number of people with CD and the average number of people

[10] Interestingly, there have been international trends for CD incidence to overtake that of UC incidence but only in the New Zealand Canterbury study has prevalence of CD been shown to be higher than that of UC. This is probably due to the fact that incidence has been higher in Canterbury for long enough for this phenomenon to occur. Even the seven year gap between the Canadian Manitoba and Canterbury studies is sufficient for significant differences to occur. Furthermore, it is likely that the "IBD wave" across the world arrived earlier in Canada than NZ (due to undefined environmental factors) confounding direct comparisons. This can also be seen by the younger age of IBD patients in the Canterbury cohort compared to the Manitoba cohort despite not dissimilar age of onset data (Richard Gearry, pers. comm., February 2007).

with UC in order to calculate the relative share of the diseases. This share was found to be 46%:54% with CD being slightly less common than UC.

> Hence, it was estimated that there were around **28,000 Australians with CD** and **33,000 Australians with UC in 2005**.

Finally, the average of the gender distribution and the age-gender prevalence rates from Canada and New Zealand – the only two studies with those details – were applied to the prevalence estimates with the results shown in Table 3-5 and Table 3-6.

3.3.2 ALTERNATIVE METHODOLOGIES

Given that the methodology used is not a very straightforward process and may therefore be controversial, alternative methodologies were considered to test the robustness of the chosen methodology for the year 2005.

1 The average of all studies with details on CD and UC – international studies only – was used in order to estimate the number of people with each condition. Based on this methodology, there were 23,000 people with CD and 29,000 people with UC in Australia (a relative share of 46%:54%), a total of 52,000 Australians with IBD.

2 Excluding outlier values (Higashi et al 1988, results for Asians in Probert et al 1993, Mate-Jimenez et al 1994 and CCFC 2006), the same methodology was repeated with the result that there were 26,000 people with CD and 31,000 people with UC in Australia (a relative share of 45%:55%), an estimated total of 57,000 people with IBD.

3 Finally, New Zealand prevalence estimates were used based on the assumption that the demographic structure of New Zealand is very similar to that of Australia and because of the recent timeframe and detail of the New Zealand study. Based on this, there were 31,000 people with CD and 28,000 people with UC in Australia (a relative share of 52%:48%), an estimated total of 59,000 people with IBD.

Overall, it was found that different methodologies lead to very similar conclusions: there are around 60,000 people with either CD or UC in Australia and the split between the two diseases is fairly even (Table 3-4).

TABLE 3-4: SUMMARY OF POSSIBLE METHODOLOGIES

2005	Persons with CD	Persons with UC	Persons with IBD	% CD/IBD	% UC/IBD
Methodology Used	28,000	33,000	61,000	46%	54%
Alternative Methodology 1	23,000	29,000	52,000	46%	54%
Alternative Methodology 2	26,000	31,000	57,000	45%	55%
Alternative Methodology 3	31,000	28,000	59,000	52%	48%

3.3.3 BEST ESTIMATE

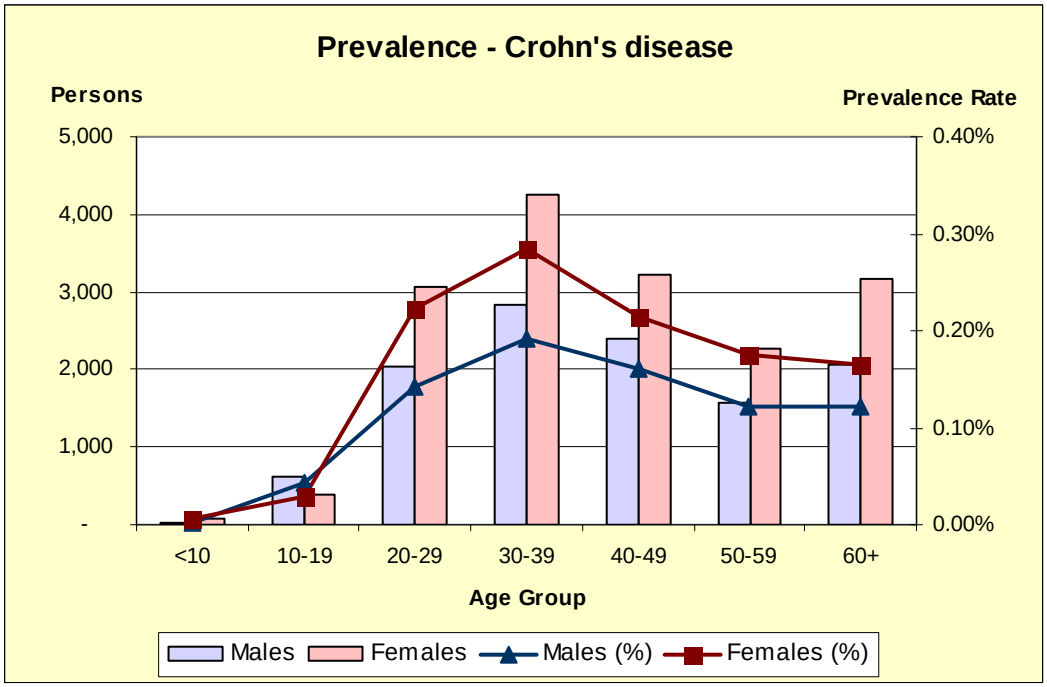
The figure of 28,000 people with CD and 33,000 people with UC was used as the best estimate for the prevalence of IBD in Australia. The average of the age-gender specific prevalence rates from Canada and New Zealand was used to derive age-gender specific prevalence rates for Australia, although those rates were scaled to fit the overall prevalence estimate for Australia.

Of the 28,000 Australians with CD, the majority (around 16,500 or 59%) were females and only around 11,500 (41%) were males. Prevalence was highest in the 30-39 year age group with around 7,100 people (around 2,800 males and 4,300 females) suffering from CD. One quarter of people with CD were in that age group. This is also reflected by the prevalence rate for that group (0.24%) compared with 0.14% for the overall population. Moreover, prevalence is particularly high for females in that age group (0.28%).

TABLE 3-5: PREVALENCE OF CD, 2005

		< 10	10-19	20-29	30-39	40-49	50-59	60+	Total
Persons	Males	36	613	2,032	2,833	2,408	1,575	2,051	11,548
	Females	74	388	3,068	4,257	3,217	2,267	3,180	16,452
	Total	110	1,002	5,099	7,091	5,625	3,842	5,231	28,000
Prevalence Rate	Males	0.00%	0.04%	0.14%	0.19%	0.16%	0.12%	0.12%	0.11%
	Females	0.01%	0.03%	0.22%	0.28%	0.21%	0.18%	0.16%	0.16%
	Total	0.00%	0.04%	0.18%	0.24%	0.19%	0.15%	0.14%	0.14%

FIGURE 3-2: PREVALENCE OF CD, 2005

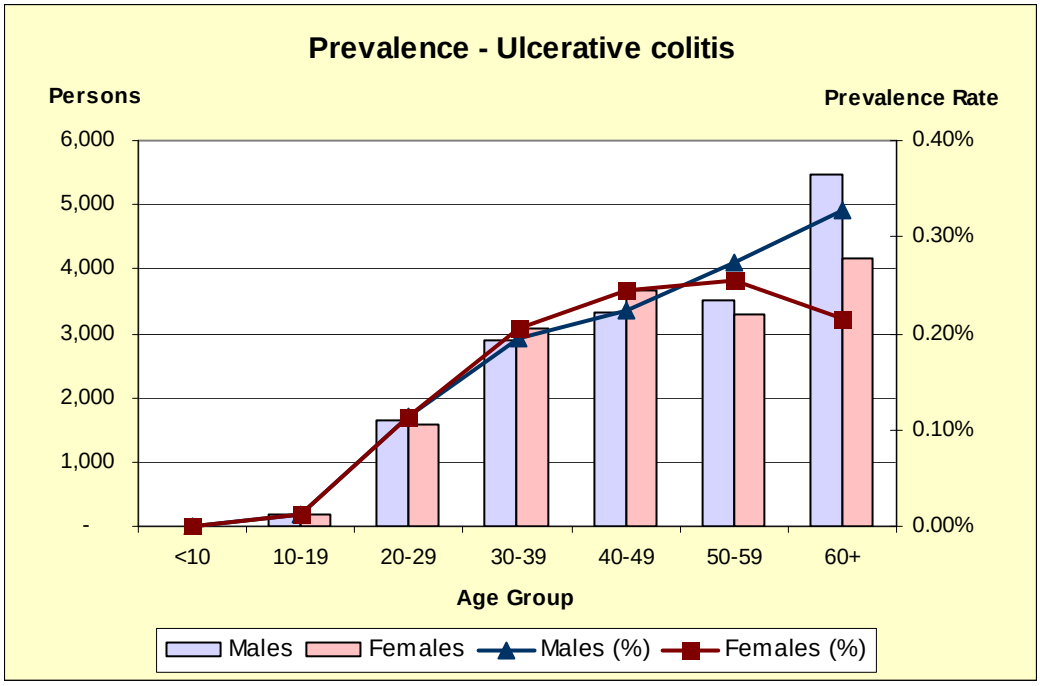


In contrast to CD, the gender distribution of UC was more even: of the 33,000 Australians with UC, around 17,000 (52%) were males and 16,000 (48%) were females. Prevalence was highest in the 60+ age group with around 9,600 people (around 5,500 males and 4,200 females) suffering from UC. Almost 30% of people with UC were in that age group. This is also reflected by the prevalence rate which is 0.27% compared with 0.16% for the overall population. The prevalence rate is particularly high for males in that age group (0.33%). Hence, while prevalence of CD peaks for people aged 30-39 and is lower for older people, prevalence for UC increases with age.

TABLE 3-6: PREVALENCE OF UC, 2005

		< 10	10-19	20-29	30-39	40-49	50-59	60+	Total
Persons	Males	0	176	1,638	2,896	3,342	3,528	5,469	17,048
	Females	0	172	1,575	3,082	3,671	3,286	4,166	15,952
	Total	0	348	3,212	5,978	7,012	6,815	9,635	33,000
Prevalence Rate	Males	0.00%	0.01%	0.11%	0.20%	0.22%	0.27%	0.33%	0.17%
	Females	0.00%	0.01%	0.11%	0.21%	0.24%	0.25%	0.22%	0.16%
	Total	0.00%	0.01%	0.11%	0.20%	0.23%	0.26%	0.27%	0.16%

FIGURE 3-3: PREVALENCE OF UC, 2005



3.4 PREVALENCE BY JURISDICTION

The age-gender prevalence rates that were derived in the previous section were applied to demographic data for each State and Territory from the ABS. While there may be ethnic differences between jurisdictions that may help in part to explain observed differences, this is largely speculative due to lack of data regarding difference in prevalence rates for indigenous and other ethnicities in Australia.

It should be noted that the prevalence projections are valid if the incidence remains stable. In fact, it is likely that this will continue to increase so the projections are conservative.

3.4.1 PREVALENCE OF CD BY JURISDICTION

Table 3-7 compares the population shares of each State and Territory with their shares of total prevalence for CD, while Table 3-8 shows the prevalence estimates by age group and gender for each of the States and Territories. Prevalence estimates by gender and State/Territory are also shown in Figure 3-4.

Overall, prevalence rates of CD were found to be highest in the ACT, Victoria and NSW and lowest in the Northern Territory, Tasmania and Queensland, although differences were only minor. This variation is due to differences in the age structure of the States and Territories.

The share of females in the total prevalence ranges between 58.3% and 59.1% for all States and Territories except the Northern Territory where the number of females with CD is only 55.7%. The Australian average was 58.8%.

TABLE 3-7: POPULATION AND PREVALENCE OF CD BY JURISDICTION, 2005

	Australia	NSW	VIC	QLD	SA	WA	TAS	NT	ACT
Population ('000 people)	20,330	6,779	5,022	3,961	1,540	2,012	486	202	326
Population (% share of Australian total)	100.0%	33.3%	24.7%	19.5%	7.6%	9.9%	2.4%	1.0%	1.6%
Prevalence (% share of Australian total)	100.0%	33.4%	25.0%	19.3%	7.6%	9.8%	2.3%	1.0%	1.6%

*Figures for States/Territories do not add to that for Australia due to exclusion of other regions including Jervis Bay, Christmas Island and Cocos Islands.

FIGURE 3-4: PREVALENCE OF CD BY JURISDICTION AND GENDER, 2005

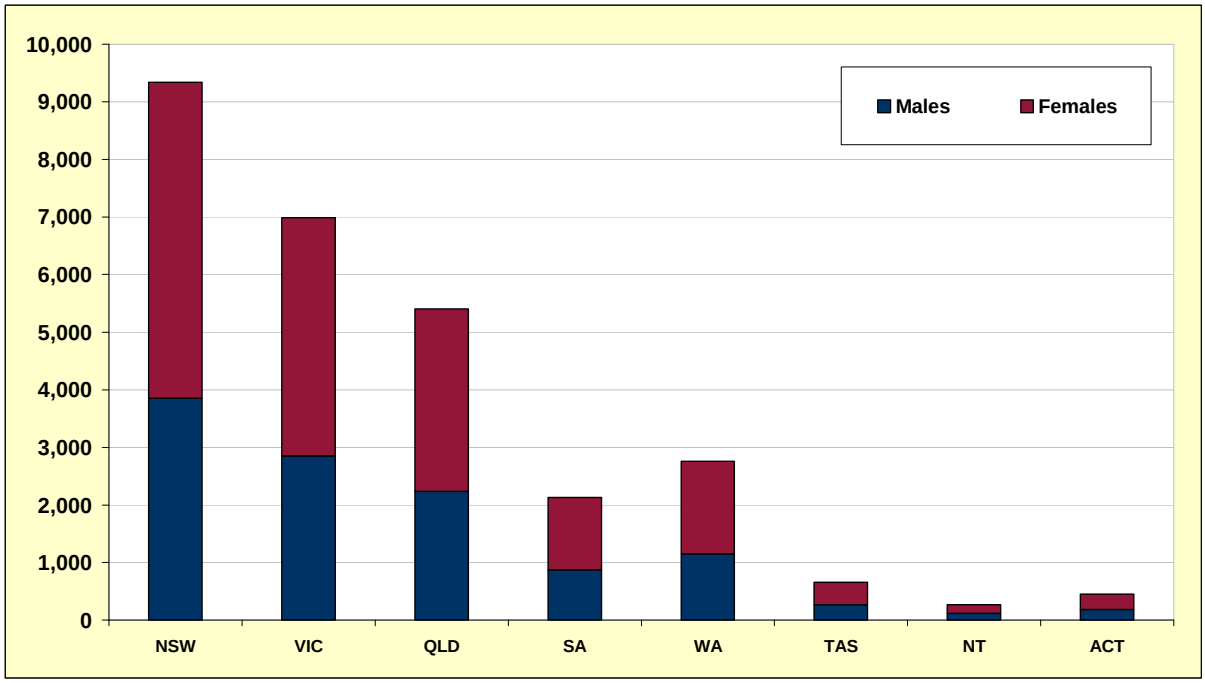


TABLE 3-8: PREVALENCE OF CD BY JURISDICTION, AGE AND GENDER, 2005

	Australia	NSW	VIC	QLD	SA	WA	TAS	NT	ACT
Males									
0-9	36	12	9	7	3	4	1	0	1
10-19	613	201	147	124	45	63	15	7	10
20-29	2,030	669	508	396	146	205	42	25	39
30-39	2,832	948	711	547	204	283	58	35	47
40-49	2,408	804	589	464	184	245	58	26	38
50-59	1,574	521	379	309	124	160	40	15	25
60+	2,051	702	508	389	172	189	55	11	25
Total M	**11,545**	**3,856**	**2,851**	**2,237**	**878**	**1,149**	**269**	**118**	**186**
% of M Population	0.11%	0.11%	0.12%	0.11%	0.12%	0.11%	0.11%	0.11%	0.12%
Females									
0-9	74	25	18	15	5	7	2	1	1
10-19	388	127	94	78	28	40	10	4	6
20-29	3,065	1,012	776	600	213	307	63	35	59
30-39	4,256	1,417	1,088	826	297	416	92	48	71
40-49	3,217	1,063	794	626	246	324	79	31	53
50-59	2,267	745	557	442	182	226	59	18	38
60+	3,180	1,097	808	577	278	285	85	12	40
Total F	**16,447**	**5,485**	**4,134**	**3,164**	**1,251**	**1,606**	**389**	**149**	**268**
% of F Population	0.16%	0.16%	0.16%	0.16%	0.16%	0.16%	0.16%	0.15%	0.16%
F % of Total	58.8%	58.7%	59.2%	58.6%	58.7%	58.3%	59.1%	55.7%	59.1%
Persons									
0-9	110	37	27	22	8	11	3	1	2
10-19	1,001	329	241	202	73	103	25	11	16
20-29	5,095	1,680	1,283	996	359	512	105	60	98
30-39	7,088	2,365	1,799	1,373	500	699	150	83	118
40-49	5,624	1,866	1,383	1,090	430	569	137	56	91
50-59	3,842	1,266	936	751	307	386	99	33	64
60+	5,231	1,799	1,316	966	451	474	139	22	65
Persons	**27,991**	**9,341**	**6,985**	**5,401**	**2,129**	**2,755**	**657**	**267**	**454**
% of Population	0.14%	0.14%	0.14%	0.14%	0.14%	0.14%	0.14%	0.13%	0.14%

Note: Totals may not sum due to rounding.

3.4.2 PREVALENCE OF UC BY JURISDICTION

The same method was applied to derive the state prevalence estimate for UC. Table 3-9 compares the population shares of each State and Territory with their shares of total prevalence for UC, while Table 3-8 shows the prevalence estimates by age group and gender for each of the States and Territories. Prevalence estimates by gender and State/Territory are also shown in Figure 3-5.

Prevalence rates of ulcerative were slightly higher than the average in South Australia, Tasmania, Victoria and NSW and slightly lower than the average in the Northern Territory, the ACT, Queensland and Western Australia due to differences in the age structure of the States and Territories. The share of females in the total prevalence ranges between 45.8% and 49.3% for all States and Territories, with the Australian average being 48.3%.

TABLE 3-9: POPULATION AND PREVALENCE OF UC BY JURISDICTION, 2005

	Australia	NSW	VIC	QLD	SA	WA	TAS	NT	ACT
Population ('000 people)	20,330	6,779	5,022	3,961	1,540	2,012	486	202	326
Population (% share of Australian total)	100.0%	33.3%	24.7%	19.5%	7.6%	9.9%	2.4%	1.0%	1.6%
Prevalence (% share of Australian total)	100.0%	33.5%	24.8%	19.2%	7.8%	9.8%	2.4%	0.9%	1.6%

Note: Totals may not sum due to rounding.

FIGURE 3-5: PREVALENCE OF UC BY JURISDICTION AND GENDER, 2005

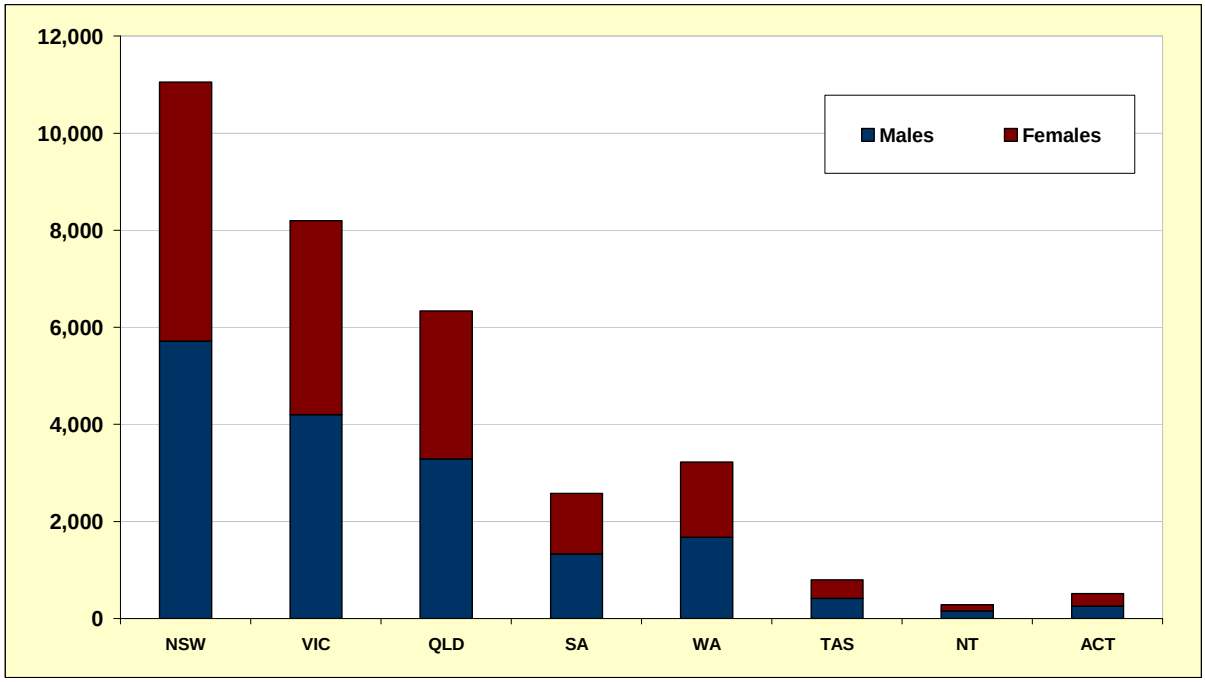


TABLE 3-10: PREVALENCE OF UC BY JURISDICTION, AGE AND GENDER, 2005

	Australia	NSW	VIC	QLD	SA	WA	TAS	NT	ACT
Males									
0-9	0	0	0	0	0	0	0	0	0
10-19	175	58	42	35	13	18	4	2	3
20-29	1,636	539	409	319	118	165	34	20	32
30-39	2,895	969	727	559	208	289	59	35	48
40-49	3,341	1,115	817	644	256	340	80	36	53
50-59	3,528	1,167	849	693	279	359	90	33	57
60+	5,469	1,871	1,355	1,038	460	503	145	28	68
Total M	**17,044**	**5,718**	**4,200**	**3,288**	**1,333**	**1,674**	**413**	**155**	**260**
% of M Population	0.17%	0.17%	0.17%	0.17%	0.17%	0.17%	0.17%	0.15%	0.16%
Females									
0-9	0	0	0	0	0	0	0	0	0
10-19	172	56	42	35	13	18	4	2	3
20-29	1,573	519	398	308	110	158	32	18	30
30-39	3,081	1,026	787	598	215	301	67	35	51
40-49	3,670	1,212	906	715	281	370	90	35	61
50-59	3,286	1,080	807	640	264	327	85	26	55
60+	4,167	1,437	1,058	755	365	373	111	15	52
Total F	**15,949**	**5,331**	**3,999**	**3,051**	**1,247**	**1,547**	**389**	**131**	**252**
% of Population	0.16%	0.16%	0.16%	0.15%	0.16%	0.15%	0.16%	0.14%	0.15%
F % of Total	48.3%	48.2%	48.8%	48.1%	48.3%	48.0%	48.5%	45.8%	49.3%
Persons									
0-9	0	0	0	0	0	0	0	0	0
10-19	348	114	84	70	25	36	9	4	6
20-29	3,209	1,058	807	627	227	323	66	38	62
30-39	5,975	1,994	1,515	1,157	423	590	126	70	99
40-49	7,011	2,328	1,723	1,358	536	710	170	71	114
50-59	6,814	2,246	1,656	1,334	543	686	176	60	112
60+	9,636	3,308	2,413	1,793	824	877	256	44	120
Persons	**32,994**	**11,049**	**8,199**	**6,339**	**2,579**	**3,222**	**802**	**286**	**512**
% of Population	0.16%	0.16%	0.16%	0.16%	0.17%	0.16%	0.17%	0.14%	0.16%

Note: Totals may not sum due to rounding.

3.5 PROJECTIONS OF FUTURE PREVALENCE

3.5.1 PROJECTIONS FOR CD

Table 3-11 and Figure 3-6 report the projected prevalence of CD in the Australian population, on the basis of demographic ageing (fertility, mortality and migration trends) only, not taking

into account potential changes in risk factors or treatment that may influence age-gender prevalence rates. The estimates of future prevalence are thus likely to be conservative.

The number of Australians with CD is projected to increase from 28,000 in 2005 to 33,486 in 2020, an increase of 19.6% over the period.

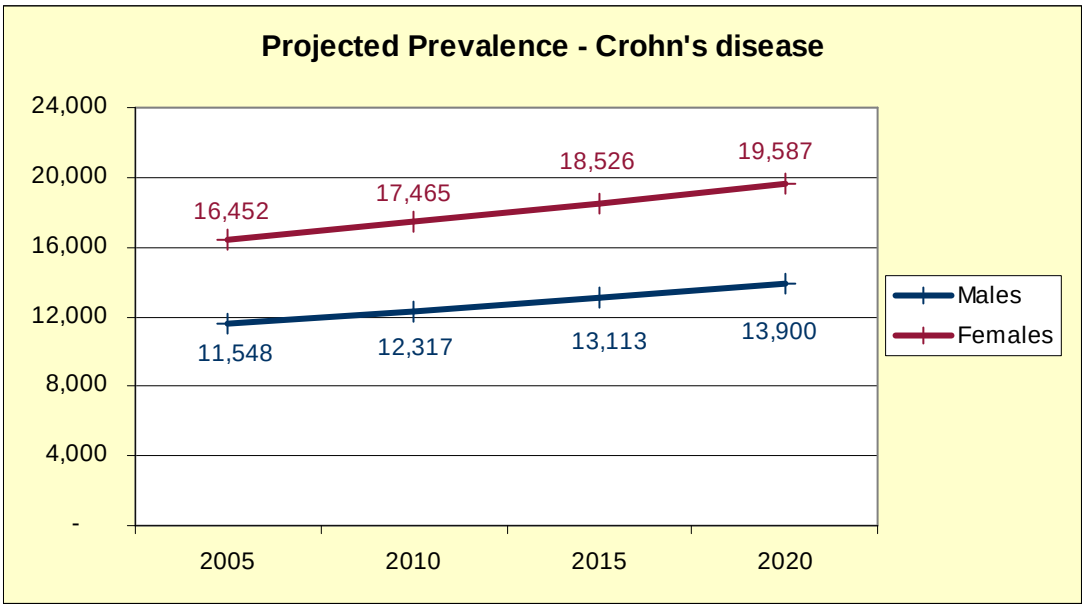
CD is expected to remain more common in women than in men in the coming years, although the relative difference between the genders is projected to decrease slightly.

TABLE 3-11: PROJECTED PREVALENCE TO 2020, CD

		< 10	10-19	20-29	30-39	40-49	50-59	60+	Total	Prev (%)
Males	2005	36	613	2,032	2,833	2,408	1,575	2,051	**11,548**	0.11%
	2010	36	624	2,225	2,848	2,449	1,683	2,453	**12,317**	0.12%
	2015	36	611	2,353	2,956	2,487	1,811	2,860	**13,113**	0.12%
	2020	37	606	2,389	3,216	2,503	1,845	3,303	**13,900**	0.12%
Females	2005	74	388	3,068	4,257	3,217	2,267	3,180	**16,452**	0.16%
	2010	73	394	3,356	4,217	3,261	2,454	3,710	**17,465**	0.16%
	2015	74	386	3,544	4,306	3,305	2,629	4,283	**18,526**	0.16%
	2020	75	382	3,592	4,675	3,277	2,669	4,916	**19,587**	0.16%
Total	2005	110	1,002	5,099	7,091	5,625	3,842	4,231	**28,000**	0.14%
	2010	109	1,018	5,581	7,066	5,710	4,136	6,162	**29,782**	0.14%
	2015	109	997	5,897	7,262	5,792	4,440	7,143	**31,639**	0.14%
	2020	112	988	5,981	7,891	5,780	4,514	8,220	**33,486**	0.14%

Note: Totals may not sum due to rounding.

FIGURE 3-6: PROJECTED GROWTH IN CD BY GENDER, 2005 TO 2020



3.5.2 PROJECTIONS FOR UC

Table 3-12 and Note: Totals may not sum due to rounding.

Figure 3-7 report the projected prevalence of UC in the Australian population based on demographic ageing.

The number of Australians with UC is projected to increase from 33,000 in 2005 to 41,249 in 2020, an increase of 25.0%.

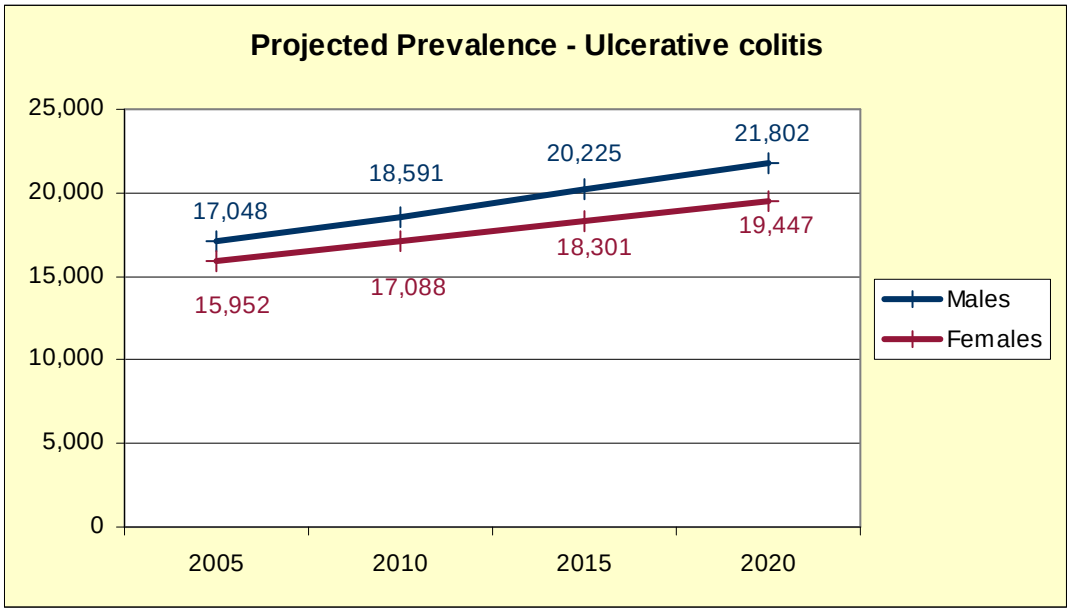
UC is expected to remain more common in men than in women with the relative difference expected to increase.

TABLE 3-12: PROJECTED PREVALENCE TO 2020, UC

		< 10	10-19	20-29	30-39	40-49	50-59	60+	Total	Prev (%)
Males	**2005**	0	176	1,638	2,896	3,342	3,528	5,469	**17,048**	0.17%
	2010	0	179	1,794	2,911	3,398	3,770	6,539	**18,591**	0.17%
	2015	0	175	1,896	3,021	3,451	4,057	7,624	**20,225**	0.18%
	2020	0	173	1,926	3,287	3,473	4,135	8,807	**21,802**	0.18%
Females	**2005**	0	172	1,575	3,082	3,671	3,286	4,166	**15,952**	0.16%
	2010	0	175	1,722	3,053	3,721	3,556	4,861	**17,088**	0.16%
	2015	0	171	1,819	3,117	3,771	3,811	5,612	**18,301**	0.16%
	2020	0	170	1,844	3,384	3,739	3,869	6,442	**19,447**	0.16%
Total	**2005**	0	348	3,212	5,978	7,012	6,815	9,635	**33,000**	0.16%
	2010	0	353	3,516	5,964	7,119	7,327	11,400	**35,679**	0.17%
	2015	0	346	3,715	6,138	7,222	7,868	13,237	**38,526**	0.17%
	2020	0	343	3,769	6,671	7,212	8,004	15,249	**41,249**	0.17%

Note: Totals may not sum due to rounding.

FIGURE 3-7: PROJECTED GROWTH IN UC BY GENDER, 2005 TO 2020



3.6 MORTALITY IN CD AND UC

3.6.1 CD

Determining the mortality risk in CD is a challenging and difficult task, as CD is a relatively uncommon event and misclassification bias can play an important role. Furthermore, large studies with long follow-up times are often required to capture enough deaths to draw any meaningful conclusions.

At least ten population-based studies looking at mortality in CD and estimating a standardised mortality rate have been published to date (Table 3-13). Seven of those studies observed increased mortality (between 1.20 and 1.85), while three studies reported a slightly reduced mortality risk (between 0.72 and 0.97).

The increased risk of mortality in CD may be explained by increased death rates from cancer, cardiovascular disease, pulmonary and GI diseases, malnutrition, volume depletion, anaemia, peritonitis, septicaemia and complications following medical and surgical interventions. In addition, smokers have a higher risk of developing CD than non-smokers, which causes the prevalence of smoking-related diseases in people with CD to be higher than in the average population.

TABLE 3-13: MORTALITY IN CD

Author	Location	Time Period	Patients	Deaths	Average follow-up time (years)	Risk Ratio (95% CI)
Positive Studies						
Ekbom et al, 1992	Uppsala, Sweden	1965-1983	1469	179	10*	SMR = 1.6 (1.4-1.9)
Persson et al, 1996	Stockholm, Sweden	1955-1990	1251	174	15*	SMR = 1.51 (1.29-1.75)
Palli et al, 1998	Florence, Italy	1978-1996	231	23	10.1	SMR = 1.36 (0.9-2.0)
Jess et al, 2002	Copenhagen, Denmark	1962-1997	374	84	17	SMR = 1.3 (1.101-1.56)
Wolters et al, 2005	Europe, Israel	1991-2004	380	37	10	SMR = 1.85 (1.30-2.55)
Masala et al, 2006	Florence, Italy	1978-2001	231	37	15.4	SMR = 1.51 (1.06-2.08)
Jess et al, 2006	Olmsted, MN, USA	1940-2004	314	56	14	SMR = 1.2 (0.9-1.6)
Negative Studies						
Probert et al, 1992	Leicestershire, UK	1972-1989	610	32	9*	SMR = 0.72 (0.49-1.01)
Cottone et al, 1996	Palermo, Italy	1973-1987	325	9	7.8	SMR = 0.97 (0.4-1.8)
Farrokhyar et al, 2001	Midlands, UK	1978-1993	196	23	8.3	SMR = 0.94 (0.59-1.40)

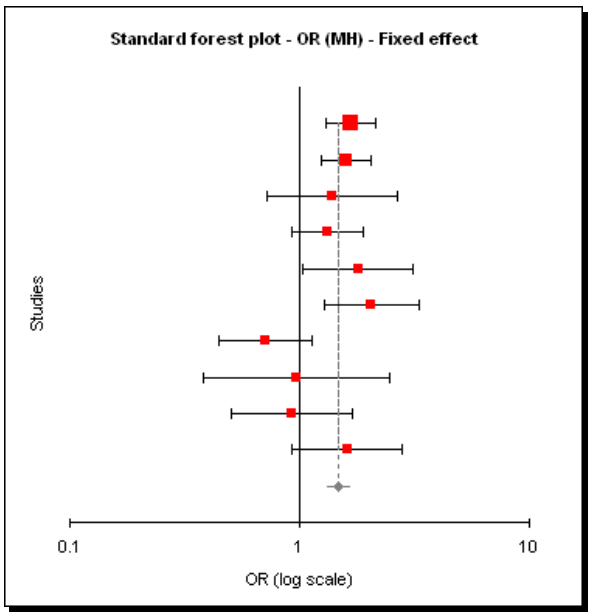
Source: Adapted from Osterman (2006).

Note: CI=Confidence interval. SMR = standardised mortality rate. * Estimated from figures provided in the publication.

A meta-analysis using a fixed effects model was conducted and it was found that, on average, **CD was associated with a 47% increase in the mortality risk. The relative risk of mortality in CD was 1.47 (95% CI: 1.30-1.67)**.

This impact was found to be statistically significant (Figure 3-8).

FIGURE 3-8: FOREST PLOT OF META-ANALYSIS OF MORTALITY IN CD



OR = odds ratio.

TABLE 3-14: META-ANALYSIS OF MORTALITY IN CD

META-ANALYSIS	
Number of studies	10
Number of participants	10762 (10762)
OR (MH) - Fixed effect model	
Meta-analysis outcome	1.4711
95% CI lower limit	1.2966
95% CI upper limit	1.6691
z	5.9916
p-value (two-tailed)	< 0.0001
Heterogeneity	
Q	17.3871
p-value (two-tailed)	0.043
H	1.3899
95% CI lower limit	1
95% CI upper limit	1.9998
I^2	48.24%
95% CI lower limit	0%
95% CI upper limit	75%
t^2	0.0426

Source: MIX software meta-analysis.

What is meta-analysis?

Meta-analysis is a statistical technique for combining the findings from multiple independent studies. It is most often used to assess the clinical effectiveness of healthcare interventions – it does this by combining data from two or more randomised control trials. Meta-analysis of trials provides a precise estimate of treatment effect, giving due weight to the size of the different studies included.

The validity of the meta-analysis depends on the quality of the systematic review on which it is based. The main requirements of a systematic review are a complete, unbiased collection of original, high-quality studies that examine the same therapeutic question. Good meta-analyses aim for complete coverage of all relevant studies, look for the presence of heterogeneity, and explore the robustness of the main findings using sensitivity analysis.

The usual way of displaying data from a meta-analysis is by a pictorial representation that displays the findings from each individual study as a small square (the measured effect), with a horizontal line (usually the 95% confidence interval) around the main finding. The size of the square may vary to reflect the amount of information in that individual study.

3.6.2 UC

As with CD, determining the mortality risk in UC is difficult, particularly as deaths are even less common than with CD. At least eight population-based studies looking at mortality in UC and estimating a standardised mortality rate have been published to date (Table 3-15). Three of those studies observed a slightly increased mortality risk (between 1.03 and 1.37), while five studies reported a reduced mortality risk (between 0.62 and 0.98).

While there was an increased risk of mortality due to some diseases (such as GI diseases, malnutrition, anaemia, volume depletion, peritonitis, septicaemia and colon cancer), people with UC also had a lower risk of mortality due to other diseases (such as cardiovascular deaths and other types of cancer including lung cancer, mainly due to the fact that non-smokers have a higher risk of getting UC than smokers). In effect, the increased risks for some diseases and the reduced risks for others cancelled themselves out in the aggregate.

TABLE 3-15: MORTALITY IN UC

Author	Location	Time Period	Patients	Deaths	Average follow-up time (years)	Risk Ratio (95% CI)
Positive Studies						
Persson et al, 1996	Stockholm, Sweden	1955-1990	1547	255	15*	SMR = 1.37 (1.20-1.54)
Farrokhyar et al, 2001	Midlands, UK	1978-1993	356	41	8.3	SMR = 1.03 (0.79-1.40)
Winther et al, 2003	Copenhagen County, Denmark	1962-1997	1160	261	19	SMR = 1.05 (0.92-1.19)
Negative Studies						
Probert et al, 1993	Leicestershire, UK	1972-1989	1014	92 Europeans 1 Asian	8.5*	Europeans: SMR = 0.93 (0.75-1.14) *Asians: SMR = 0.26 (0.00-1.47)*
Davoli et al, 1997	Rome, Italy	1970-1989	508	27	10.5*	SMR = 0.98
Palli et al, 1998	Florence, Italy	1978-1996	689	47	10.1	SMR = 0.62 (0.4-0.8)
Masala et al, 2006	Florence, Italy	1978-2001	689	81	15.2	SMR = 0.70 (0.56-0.88)
Jess et al, 2006	Olmsted, MN, USA	1940-2004	378	62	14	SMR = 0.8 (0.6-1.0)

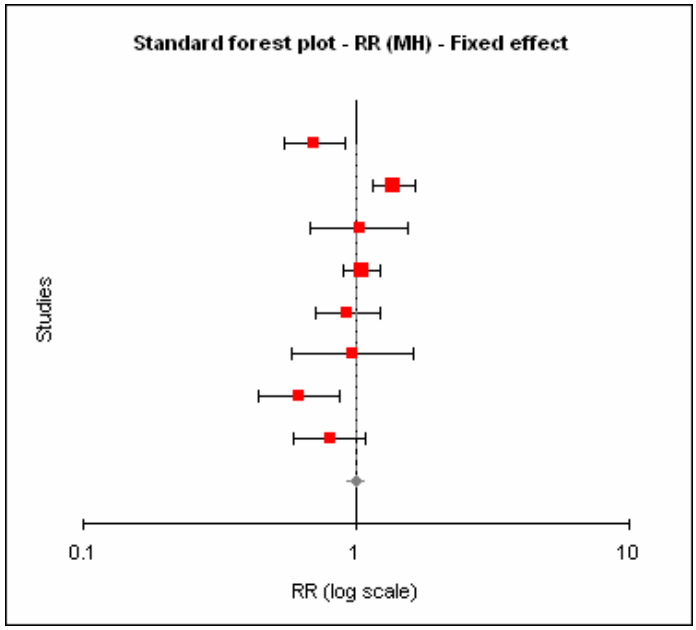
Note: CI=Confidence interval. SMR = standardised mortality rate. * Estimated from figures provided in the publication.

A meta-analysis using a fixed effects model was conducted and it was found that, on average, **UC was associated with a 1% reduction in the mortality risk. The relative risk of mortality in UC was 0.99 (95% CI: 0.91-1.08)**.

This impact was not found to be statistically significant (Figure 3-9 and OR = odds ratio.

Table 3-16), suggesting that the mortality risk is neither significantly reduced nor increased. Hence, it is safest to assume a mortality risk of 1.0 for UC.

FIGURE 3-9: FOREST PLOT OF META-ANALYSIS OF MORTALITY IN UC



OR = odds ratio.

TABLE 3-16: META-ANALYSIS OF MORTALITY IN UC

META-ANALYSIS	
Number of studies	8
Number of participants	12682 (12682)
RR (MH) - Fixed effect model	
Meta-analysis outcome	0.9948
95% CI lower limit	0.9123
95% CI upper limit	1.0848
z	0.1174
p-value (two-tailed)	0.9066
Heterogeneity	
Q	29.3148
p-value (two-tailed)	0.0001
H	2.0464
95% CI lower limit	1.4473
95% CI upper limit	2.8936
I^2	76.12%
95% CI lower limit	52.26%
95% CI upper limit	88.06%
t^2	0.0426

Source: MIX software meta-analysis.

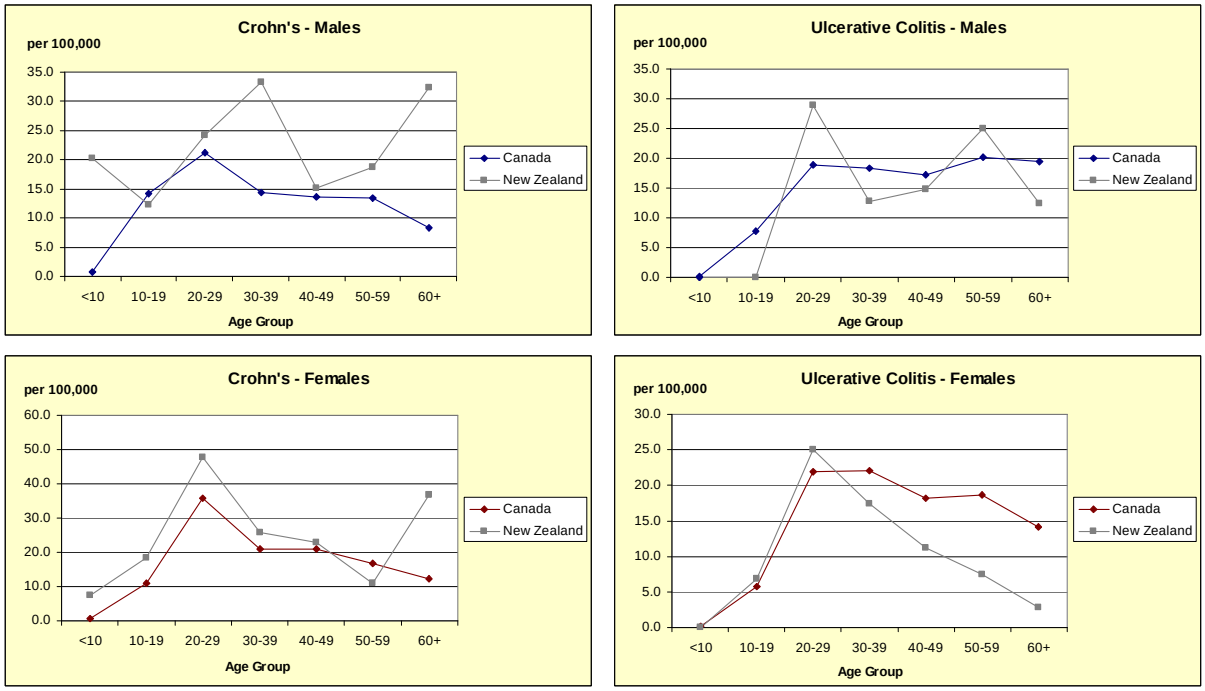
3.7 INCIDENCE OF CD AND UC

3.7.1 INTERNATIONAL INCIDENCE STUDIES

As in the case of prevalence rates, the only two studies with age- and gender-specific incidence rates of CD and UC are by Bernstein et al (1999) and Gearry et al (2006c), looking at the Canadian province of Manitoba between 1989 and 1994 and the Canterbury region in New Zealand between 2004 and 2005 respectively. Applied to Australian population data, incidence numbers of CD in 2005 would be 2,980 using the Canadian rates and 4,875 using the New Zealand rates. The incidence numbers of UC are 3,002 and 2,366 respectively.

There are some significant differences in the age and gender-specific incidence rates between New Zealand and Canada (Figure 3-10) and overall incidence of UC is higher in Canada than New Zealand (24.0 per 100,000 compared with 11.6 per 100,000), while overall incidence of CD is similar in both countries (14.7 per 100,000 compared with 14.8 per 100,000.

FIGURE 3-10: INCIDENCE RATES FOR CD AND UC: CANADA AND NEW ZEALAND



3.7.2 METHODOLOGICAL ISSUES

This report utilises the prevalence (annual costs) approach to estimating the costs of CD and UC, as the data sources generally lend themselves to utilisation of such an approach, and as this avoids the uncertainty surrounding estimates of future treatment costs associated with the alternative incidence (lifetime costs) approach.

3.7.3 AUSTRALIAN INCIDENCE ESTIMATES

The incidence of CD and UC in Australia can be derived using the software program DISMOD-II from the prevalence estimates and mortality rates discussed above for the year 2005. Applying this methodology, it was estimated that 776 Australians (334 males and 442

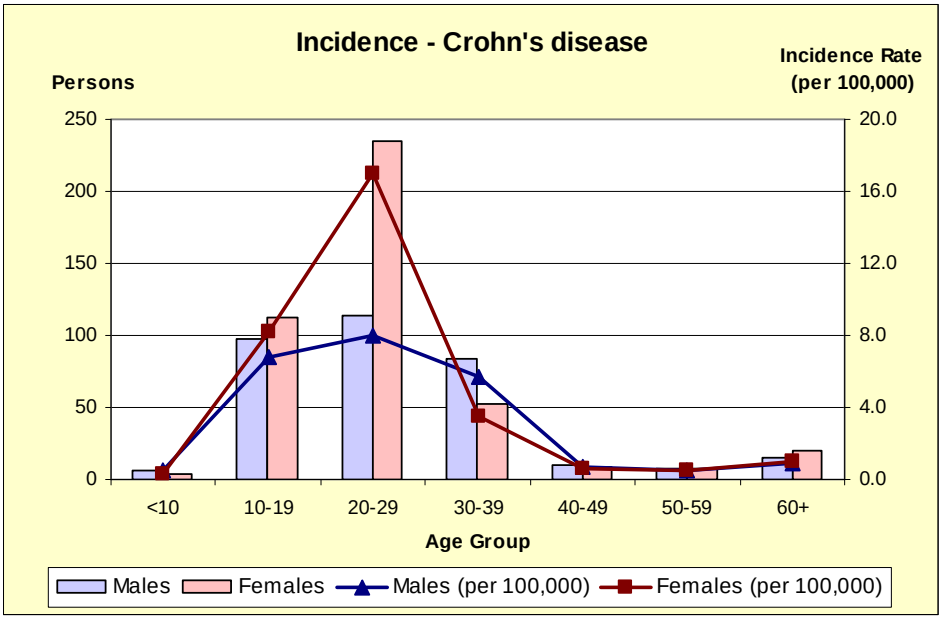
females) were diagnosed with CD in 2005 (Table 3-17), while 846 Australians (469 males and 377 females) were diagnosed with UC. These numbers are significantly below those from the Canadian and New Zealand studies.

Of the 776 Australians diagnosed with CD in 2005, the majority (442 or 57%) were females and 334 (43%) were males. The onset of CD peaks in the teens and twenties: prevalence was highest in the 20-29 year age group with around 349 new cases (114 males, 235 females) of CD. Almost half (45%) of new cases of CD were in that age group. Incidence was particularly high for females in that age group (see Figure 3-11).

TABLE 3-17: INCIDENCE OF CD, 2005

		< 10	10-19	20-29	30-39	40-49	50-59	60+	Total
Persons	Males	6	97	114	84	10	7	15	334
	Females	4	112	235	53	9	7	20	442
	Total	10	209	349	137	19	14	35	776
Incidence Rate (per 100,000)	Males	0.5	6.8	8.0	5.7	0.7	0.5	0.9	3.3
	Females	0.3	8.2	17.0	3.5	0.6	0.5	1.0	4.3
	Total	0.4	7.5	12.4	4.6	0.6	0.5	1.0	3.8

FIGURE 3-11: INCIDENCE OF CD, 2005

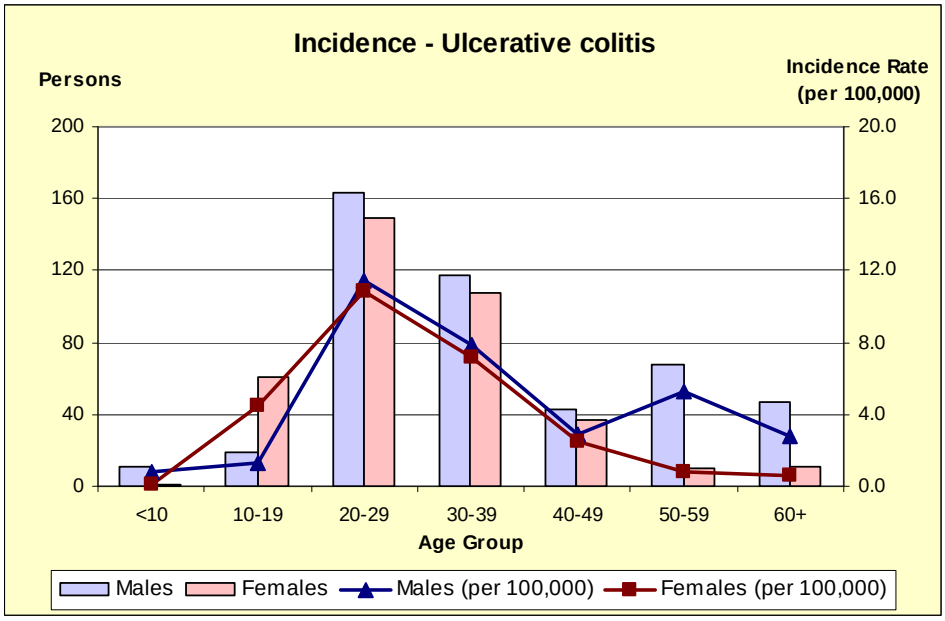


The majority of the 846 Australians diagnosed with UC in 2005 were males (469 or 55%), while 377 (45%) were females (Table 3-18). As in the case of CD, incidence peaked in the younger age groups: incidence was highest in the 20-29 year age group with around 312 new cases (163 males, 149 females) of UC. More than a third (37%) of new cases of UC were in that age group.

TABLE 3-18: INCIDENCE OF UC, 2005

		< 10	10-19	20-29	30-39	40-49	50-59	60+	Total
Persons	Males	11	19	163	117	43	68	47	469
	Females	1	61	149	107	37	10	11	377
	Total	12	80	312	224	80	78	58	846
Incidence Rate (per 100,000)	Males	0.8	1.3	11.4	7.9	2.9	5.3	2.8	4.6
	Females	0.1	4.5	10.8	7.1	2.5	0.8	0.6	3.7
	Total	0.5	2.9	11.1	7.5	2.7	3.0	1.6	4.2

FIGURE 3-12: INCIDENCE OF UC, 2005



4. HEALTH SYSTEM COSTS

4.1 METHODOLOGY

Estimates for direct health system costs are derived in Australia by the Australian Institute of Health and Welfare (AIHW) from an extensive process developed in collaboration with the National Centre for Health Program Evaluation for the Disease costs and Impact Study (DCIS). The approach measures health services utilisation and expenditure (private and public) for specific diseases and disease groups in Australia. The DCIS methodology has been gradually refined over the 1990s to now estimate a range of direct health costs from hospital morbidity data, case mix data, *Bettering the Evaluation and Care of Health* (BEACH) data, the National Health Survey and other sources. AIHW (2005) provides a summary of the main results of estimates of health expenditures by disease and injury for the year 2000-01. The advantage of a top-down methodology is that cost estimate for the various diseases will be consistent, enhancing comparisons and ensuring that the sum of the parts does not exceed the whole (total health expenditure in Australia).

The AIHW include only 87.5% of total recurrent health expenditures in their estimates of expenditure by disease and injury, referred to as 'allocated' health expenditure. The 'unallocated' remainder includes capital expenditures, expenditures on community health (excluding mental health), public health programs (except cancer screening), health administration and health aids and appliances.

Access Economics requested data from the AIHW for costs associated specifically with CD and UC. However, health system cost data were only provided at the aggregate level for all diseases of the digestive system. To provide an approximation of the health system costs for CD and UC, Access Economics has used 2000-01 statistics from the AIHW's National Hospital Morbidity Database (NHMD) to compute the proportion of hospital separations associated with CD and UC relative to hospital separations associated with all digestive disorders. This proportion was then applied to health system costs for all digestive disorders to obtain an approximation of the health system costs associated with CD and UC. As this proportion was small (2.05%), the approximation errors are likely to be large by cost type.

The NHMD is compiled from data supplied by the state and territory health authorities. It is a collection of electronic confidentialised summary records for separations (that is, episodes of care) in public and private hospitals in Australia. Data are held for the years 1993-94 to 2004-05. Diagnoses, procedures and external causes of injury are recorded using the International Classification of Diseases (ICD). Almost all hospitals in Australia are included in the database: public acute and public psychiatric hospitals, private acute and psychiatric hospitals, and private free standing day hospital facilities.

4.2 TYPES OF HEALTH SYSTEM COSTS

The allocated health costs arising from IBD are estimated to be **$68.0 million in 2005** (Table 4-1). This includes $33.9 million for CD and $34.1 million for UC.

The overall figure equates to **$1,114 per person with IBD per annum**, nationally ($1,210 per person with CD and $1,033 per person with UC).

TABLE 4-1: IBD, ALLOCATED HEALTH SYSTEM EXPENDITURE, 2005 ($M)

	In-patients	Out-patients	Total hospital	Aged care homes	Out-of hospital medical services	Pharma-ceuticals	Other health profes-sionals	Research	Total
Males									
0-9	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	**0.0**
10-19	0.4	0.1	0.5	0.0	0.1	0.2	0.1	0.0	**0.9**
20-29	2.0	0.3	2.3	0.0	0.5	0.9	0.3	0.0	**4.1**
30-39	3.1	0.4	3.6	0.1	0.8	1.4	0.4	0.1	**6.4**
40-49	3.1	0.4	3.6	0.1	0.8	1.5	0.4	0.1	**6.4**
50-59	2.8	0.4	3.2	0.1	0.7	1.3	0.4	0.1	**5.7**
60+	4.1	0.6	4.7	0.1	1.0	1.9	0.6	0.1	**8.4**
Total	**15.7**	**2.2**	**17.8**	**0.4**	**3.9**	**7.2**	**2.2**	**0.4**	**31.9**
Females									
0-9	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	**0.1**
10-19	0.3	0.0	0.3	0.0	0.1	0.1	0.0	0.0	**0.6**
20-29	2.5	0.3	2.9	0.1	0.6	1.2	0.4	0.1	**5.2**
30-39	4.0	0.6	4.6	0.1	1.0	1.9	0.6	0.1	**8.2**
40-49	3.8	0.5	4.3	0.1	0.9	1.7	0.5	0.1	**7.7**
50-59	3.0	0.4	3.5	0.1	0.8	1.4	0.4	0.1	**6.2**
60+	4.0	0.6	4.6	0.1	1.0	1.9	0.6	0.1	**8.2**
Total	**17.7**	**2.4**	**20.2**	**0.4**	**4.5**	**8.2**	**2.5**	**0.4**	**36.1**
Persons									
0-9	0.1	0.0	0.1	0.0	0.0	0.0	0.0	0.0	**0.1**
10-19	0.7	0.1	0.8	0.0	0.2	0.3	0.1	0.0	**1.5**
20-29	4.6	0.6	5.2	0.1	1.1	2.1	0.6	0.1	**9.3**
30-39	7.2	1.0	8.1	0.2	1.8	3.3	1.0	0.2	**14.6**
40-49	6.9	1.0	7.9	0.2	1.7	3.2	1.0	0.2	**14.1**
50-59	5.8	0.8	6.6	0.1	1.5	2.7	0.8	0.1	**11.9**
60+	8.1	1.1	9.3	0.2	2.0	3.8	1.1	0.2	**16.6**
Total	**33.4**	**4.6**	**38.0**	**0.8**	**8.4**	**15.4**	**4.6**	**0.7**	**68.0**

Figure 4-1 shows health expenditure by type of cost for people with IBD.

- The majority (49%) of health expenditure is directed to inpatient hospital services – $33.4 million in 2005.
- Expenditures on pharmaceuticals (mainly prescription drugs) are the second largest, comprising a further 23% or $15.4 million in 2005.
- Expenditure on out-of hospital medical services is the third most substantial cost element at $8.4 million (12%).

FIGURE 4-1: IBD, HEALTH EXPENDITURE BY COST TYPE, 2005 (%)

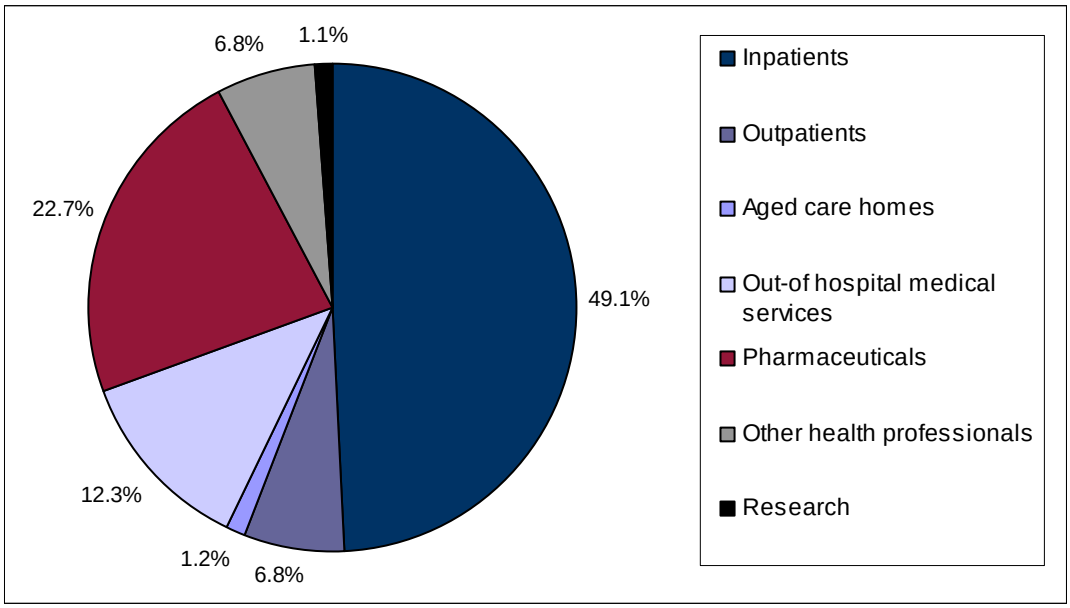
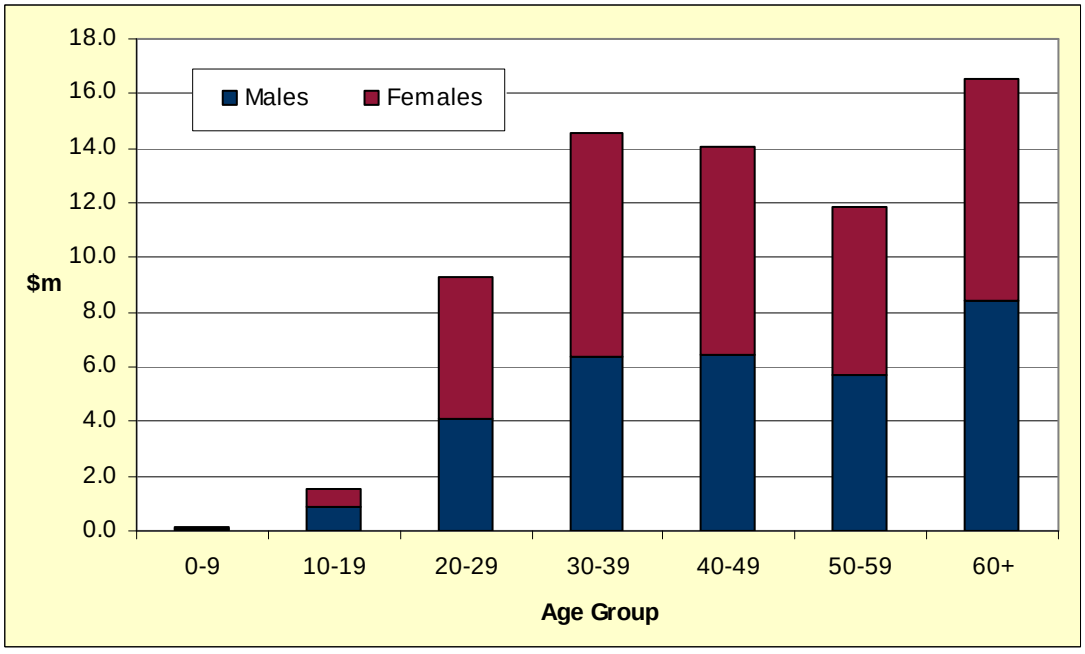


Figure 4-2 shows health expenditure by age and gender.

- 53% of total health spending ($36.1 million) is on females and 47% ($31.9 million) is on males, reflecting prevalence proportions.
- The shares are 59% ($19.9 million) for females and 41% ($14.0 million) for males in the case of CD and 48% ($17.6 million) for females and 52% ($16.5 million) for males in the case of UC.

FIGURE 4-2: IBD, HEALTH EXPENDITURE BY AGE AND GENDER, 2005 ($M)



Adjusting the health expenditure data for expenditures not allocated by AIHW (that is, including $11.1 million in unallocated health costs) brings the **total cost of health expenditure on IBD to $79.0 million in 2005**. This comprises $39.4 million for CD and $39.7 million for UC.

4.3 HEALTH SYSTEM EXPENDITURE BY JURISDICTION

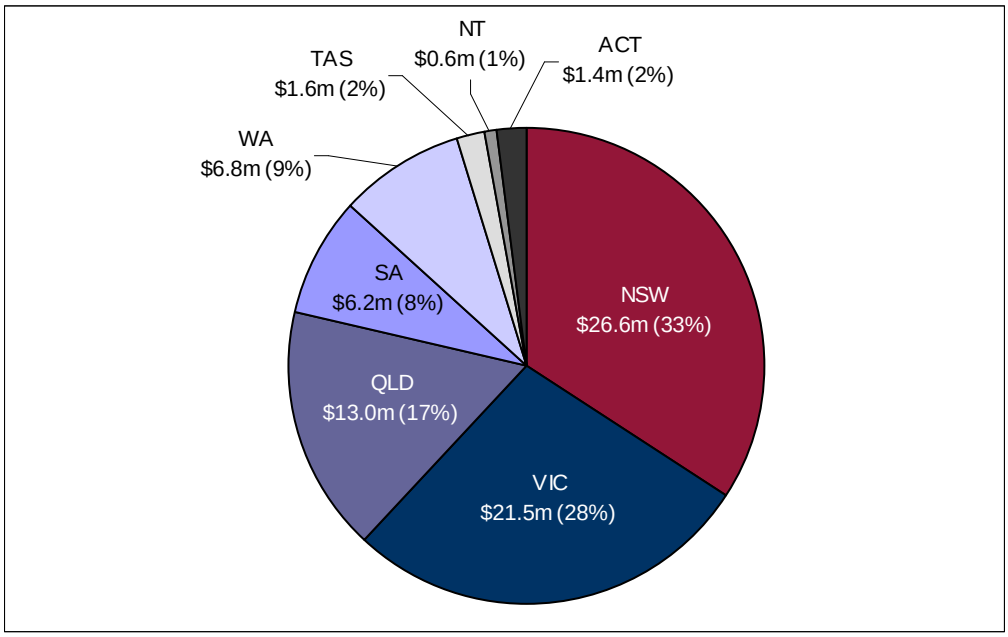
The costs of IBD were then allocated to States and Territories on the basis of hospital inpatient shares. The distribution is summarised in Table 4-2 and Figure 4-3.

TABLE 4-2: IBD HEALTH COSTS BY JURISDICTION, 2005 ($M)

IBD	Australia	NSW	VIC	QLD	SA	WA	TAS	NT	ACT
Health Costs									
Hospitals	38.0	13.0	10.5	6.3	3.0	3.3	0.8	0.3	0.7
Aged care	0.8	0.3	0.2	0.1	0.1	0.1	0.0	0.0	0.0
Other health costs	29.2	10.0	8.1	4.9	2.3	2.6	0.6	0.2	0.5
Allocated health	68.0	23.2	18.8	11.3	5.4	6.0	1.4	0.6	1.2
Unallocated health	11.1	3.8	3.1	1.8	0.9	1.0	0.2	0.1	0.2
Total health costs	**79.0**	**27.0**	**21.9**	**13.2**	**6.3**	**6.9**	**1.6**	**0.7**	**1.5**

Note: Totals may not sum due to rounding.

FIGURE 4-3: IBD, HEALTH EXPENDITURE BY JURISDICTION, 2005



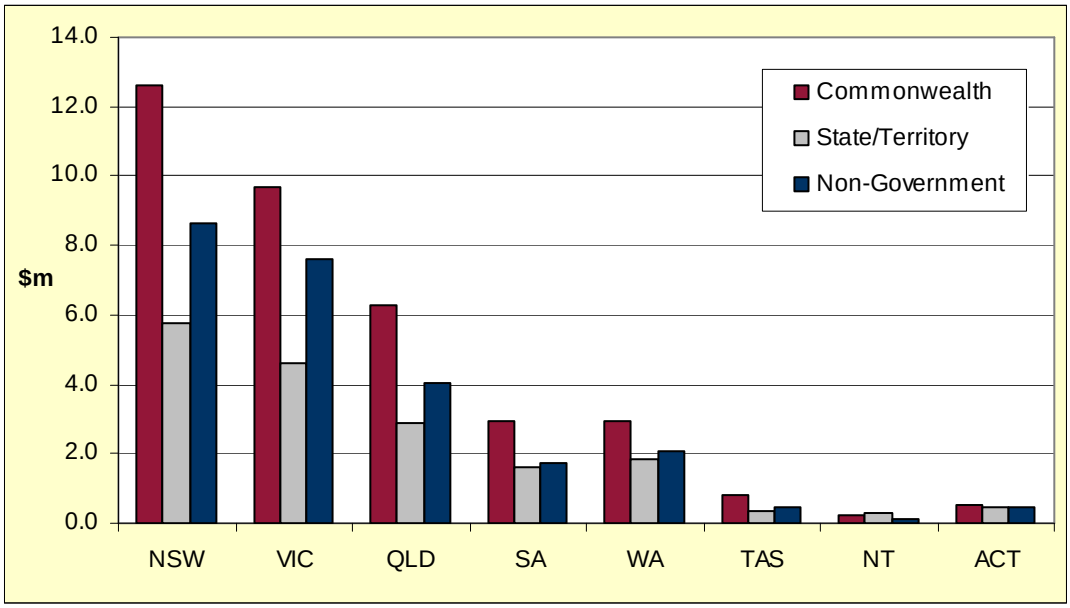
All costs were allocated on the basis of whether they were borne by the Government in each State/Territory, by the Federal Government or by non-Government groups in the community. The latter group includes individuals who have IBD, their families, private health insurance companies, employers, workers compensation insurers and others.

Health system costs were estimated to be borne in accordance with the shares between these three groups for each State and Territory provided in the detailed tables in AIHW (2005) which take account of the financing of health services (including hospitals, out-of hospital medical services, pharmaceuticals, other health professionals and research). These

shares were based on all diseases and funding was split by Commonwealth Government, State and local Government and non-Government.

The distribution of who bears the health system costs is illustrated in Figure 4-4, by State/Territory. In all cases except for the Northern Territory the majority of the costs (a total of 46%) are borne by the Commonwealth Government, followed by the non-Government sector (with a total of 32%).

FIGURE 4-4: HEALTH COST SHARE BY LEVEL OF GOVERNMENT, BY JURISDICTION, 2005



5. OTHER FINANCIAL COSTS

In addition to health system costs, Crohn's and colitis also impose significant other costs on society and the economy, including productivity losses (due to work absenteeism, loss of employment and premature death), carer costs, and deadweight efficiency losses arising from transfer payments to sufferers.

5.1 PRODUCTIVITY LOSSES

Onset of IBD is common in the teens and twenties[11] at a time crucial to educational attainment and when individuals are often making career choices, and may lead to longer-term impacts on future productivity. Chronicity of symptoms impact on productivity throughout life, as do associated higher levels of depression, anxiety and other mental health issues – due to both the symptoms of the diseases and the self-esteem impacts of 'socially unacceptable' symptoms. Drossman (2000) found that adults with IBD are more likely to be diagnosed with a psychiatric disorder (such as anxiety and mood disorders) than healthy adults. Consequently individuals may choose not to work at full capacity by either working part-time or not participating in the workforce.

The requirement to have easy access to a bathroom may restrict the types of jobs an individual can perform. For example, Wyke (1988) found that:

> *"special problems were experienced by those working on production lines, in a restricted environment (out of doors, underground, in special clothing, frequent travelling, or with arthritis)."* (Wyke et al, 1988, 1232-1333)

The reoccurrence of acute episodes and their associated treatment also has temporary productivity impacts while working: repeated hospitalisation results in days off from work or school, as does time off work to attend medical appointments or simply recover from symptoms at home. Workplace discrimination may also reduce promotional opportunities. For example, Stark (2006) found that 47% of people with CD thought their career was affected by IBD as did 39% of people with UC. Similarly Mayberry et al (1992) interviewed people with CD in the UK and found that 37% of people thought that employers should not know about their illness and 30% would actively conceal it. Furthermore up to 24% of people felt their disease had limited their employment prospects and had either prevented them seeking promotion or had actually prevented promotion.

Finally, IBD is a risk factor for other diseases (such as colon cancer) and thus is associated with, in a few rare cases, productivity losses from premature death.

Carers may also take time off work to accompany people with IBD to medical appointments, stay with them in hospital, or care for them at home. Carers may also take time off work to undertake much of the unpaid work otherwise performed by the person with IBD when in remission, such as providing childcare, doing housework, yard work, shopping and so on.

[11] See Australian data in the previous chapter. Yamada et al (1995) report 15% of patients with UC and 25–33% of patients with CD present before age 20 years.

5.1.1 EDUCATION IMPACTS

The onset of IBD during childhood and adolescence can have an impact on educational attainment, leading to longer-term effects on future productivity through reduced wages and a higher probability of being unemployed or out of the labour force. Some of these impacts can be observed through cross-sectional data analysis, as is conducted in the next section. However, longitudinal case-cohort studies are required to observe the true impact of IBD on productivity over time by identifying whether the impact on education has a temporary disruptive effect, or has a more permanent long-term impact.

The onset of IBD in childhood and adolescence poses a significant challenge physically due to the chronicity, unpredictability and severity of symptoms, but also mentally and emotionally.

> *"Children with IBD can be reluctant to talk about their symptoms, and some limit their daily activities to those with ready access to a bathroom. Their frequent visits to the bathroom can be a source of embarrassment, and they may fear becoming the target of the ''bathroom humor'' that is popular among children and adolescents (Casati, Toner, de Rooy, Drossman, & Maunder, 2000). Short stature and delayed puberty can also contribute to feeling different from peers. Steroid medication is commonly used to treat IBD and frequently results in negative side effects such as facial swelling, increased acne, hair growth, and emotional lability, all of which may have additional implications for psychosocial adjustment."* Mackner (2004)

The timing of the onset of CD and UC is crucial for determining the impact on educational attainment. Even if diagnosis occurs after schooling is completed, the disease may still have disrupted educational attainment.

Education may be affected by:

- Temporary absences from school due to hospital admission or while recovering at home.
  - Ferguson (1994) reported that 57% of Scottish juveniles with IBD experienced absences from school of 2 months or greater, with an average of 6.5 hospital admissions (mean of 93 days for UC and 102 days for CD).
  - Mayberry (1992) reported that British juveniles with CD were more likely than buddy and community controls to require hospitalisation for at least 2 weeks (42% versus 4%).
- The inability to study or sit for exams.
  - Ferguson (1994) reported that 7% of Scottish juveniles with IBD did not take their O level exams at the correct time (equivalent to Year 10), and 6% did not take their A level exams at all or at the correct time (equivalent to Year 12).
  - Mayberry (1992) reported that 17% of British juveniles with CD were unable to sit for exams.
- Unawareness or discrimination by teachers or lecturers.
  - Mayberry (1992) reported that 67% of British juveniles with CD reported that teachers were unaware of the student's disease, while 21% reported that teachers were indifferent and 8% reported that teachers were hostile.

Overall Ferguson (1994) reported that 57% of Scottish juveniles with IBD believed that their education was adversely affected by their disease, while Mayberry (1992) reported that 12–

14% of British juveniles with CD believed that their disease prevented the education that they would have liked.

However, Ferguson (1994) and Mayberry (1992) found that overall levels of educational attainment did not statistically differ for people with IBD from that of the general population or a healthy comparison group, respectively. As such, no productivity losses are estimated in this report arising from educational disadvantage caused by the conditions.

5.1.2 ABSENTEEISM (SHORT-TERM PRODUCTIVITY COSTS)

The **friction method** was developed by Koopmanschap et al (1995). This approach estimates production losses[12] for the time period required to restore production to its pre-incident state.

The time period persists until the patient returns to work, or is replaced, if they become unable to work. This method generally assumes that there is unemployment, and that a person who was previously not earning an income replaces the person not working due to IBD.

In the meantime, employers often choose to make up lost production through overtime or employment of another worker that attracts a premium on the ordinary wage. The overtime premium represents lost employer profits. On the other hand, the overtime premium also indicates how much an employer is willing to pay to maintain the same level of production. Thus, if overtime employment is not used, the overtime premium also represents lost employer profits due to lost production. Thus while productivity remains at the same level, the distribution of income between wages and profits changes[13]. For this study it is assumed that the overtime rate is 40%[14].

According to traditional microeconomic theory (in particular the work of Gary Becker in the 1960s), people will work until they are indifferent between the marginal value of the income earned relative to the personal value of the leisure sacrificed. However no-one else tends to value the individual's leisure similarly. The typical approach to overcome this problem is to value leisure time at a discounted proportion of earnings which takes into account taxes that reduce the effective income from work and restrictions on the amount of time that can be used for work (for both biological and governmental regulation reasons).

Average employment rates and AWE are based on ABS data for all calculations on productivity losses (see Table 5-1).

[12] Based on neoclassical theory, wages and other marginal costs are assumed to be equal to the value of the marginal revenue generated by an additional worker under conditions of full employment (Berger and Murray, 2001). Lost production is thus the value of the wages (measured as average earnings) plus other inputs to production (capital, plant and equipment, land, enterprise etc) multiplied by the number of workdays missed.

[13] While the opportunity cost of any overtime employment of another worker is implicitly taken into account through the overtime premium, this methodology does not allow for the choice to use salaried or part-time workers to make up the production at ordinary or no additional wage costs. However, given that workers are assumed to value their leisure time at 30% of their earnings, the difference in estimated economic costs if this choice is taken into account would be small – the only difference would be that “society” would incur these costs rather than the “employer”.

[14] Based on the lower bound of workplace injuries literature – the former National Occupational Health and Safety Commission (now the Office of the Australian Safety and Compensation Council - OASCC) assumed an overtime rate of 40% (Access Economics 2004) and the Industry Commission (1995: 115) assumed an overtime rate of 50%, citing the work by Oxenburgh (1991) who suggested an overtime rate of 50% to 100%.

TABLE 5-1: AVERAGE EMPLOYMENT RATE AND AWE IN THE AUSTRALIAN POPULATION

	Chance of Being Employed (%)		Average Weekly Earnings ($)	
Age	Males	Females	Males	Females
0-4	0.0	0.0	0	0
5-9	0.0	0.0	0	0
10-14	0.0	0.0	0	0
15-19	55.8	58.9	268	201
20-24	85.2	78.8	571	490
25-29	89.9	74.8	917	681
30-34	90.3	68.7	917	681
35-39	90.6	70.8	1065	658
40-44	89.4	75.0	1065	658
45-49	90.0	77.4	1076	679
50-54	86.0	68.7	1076	679
55-59	72.8	52.7	1009	662
60-64	50.8	28.1	862	589
65-69	20.7	8.5	578	389
70-74	5.9	1.3	578	389
75-79	0.0	0.0	578	389
80-84	0.0	0.0	578	389
85-89	0.0	0.0	578	389
90+	0.0	0.0	578	389

Source: ABS 6105.0, ABS 6310.0 (Indexed to $2005).

Literature Review

Relevant studies were identified through the PubMed search engine system. The following keywords were used in various combinations the search: “education”, “employment”, “productivity”, “cost of illness”, “Crohn’s”, “colitis” and “inflammatory bowel disease”. The remaining studies were found by using the references cited in the articles.

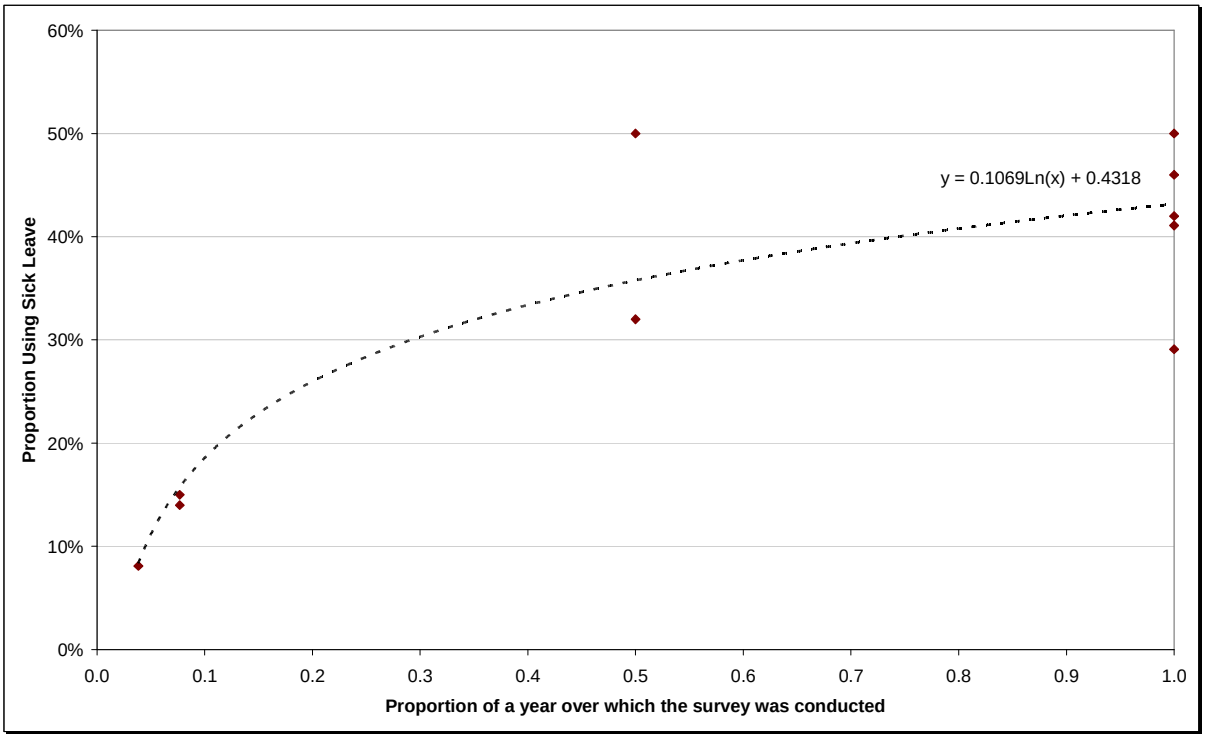
Nine studies were identified that estimate either the proportion of people taking sick leave and/or the average days absent from work, including one Australian study (the National Health Survey). These papers reported an average rate of employment of 60% (see Table 5-3).

National Health Survey, 2004-05

The 2004-05 National Health Survey (NHS) is an Australia, household population-based survey national survey conducted by the ABS on the health of the general population (ie, it does not include people in hospitals, nursing homes etc). Data on long-term health conditions was based on self-identification rather than clinical diagnosis (thus there may be under-reporting of IBD) and time elapsed since diagnosis was not reported, consequently the survey is more likely to identify all people with IBD rather than people with symptomatic IBD.

Many of the studies reported the proportion of employed people with IBD taking sick leave over differing periods of time (2 weeks, 6 months or a full year). In order to convert these studies to a proportion taking time off over a full year, a logarithmic regression line was fitted to all of the studies (see Figure 5-1) comparing the proportion of a year over which the survey was conducted with the proportion reported in that survey using sick leave. The proportion taking time off over a full year could then be estimated for all studies from the regression curve.

FIGURE 5-1: SCATTER PLOT OF PROPORTION USING SICK LEAVE



The analysis found that 43% of employed people with IBD took time off work per year, on average, and **each employed person with IBD took 7.2 days off per year, on average due to IBD** (reflecting that most of the source studies counted IBD-related days off).

For all those who have IBD and are employed, the absenteeism cost was estimated using age- and gender-specific AWE estimates.

Some people may use sick, annual, or long service leave when they are temporarily absent from work. It is estimated that 71.2% of females and 78.1% of males are paid for the days taken off paid work (ABS 6342.0) and the employer incurs wages, on-costs and an overtime premium relating to the paid days off work, while the worker incurs the lost wages relating to the remaining unpaid days off work.

Furthermore, each day a patient is absent from work it is estimated that 30 minutes of management time is lost processing those absent workers[15]. This includes the time of line managers in rearranging work and the time of back-office personnel. The cost of managers' time in 2004 is estimated to be $1,286 for an average working week of 40.2 hours (ABS 6310.0) plus 15.5% on costs (ABS 6348.0.55.001).

[15] The Health and Safety Executive (1999) assume that administrative costs associated with dealing with absences (such as the calculation and payments of benefits, processing of sick leave and extra management time) equates to an average of 30 minutes per day of absence.

The estimated annual costs of absenteeism for people with IBD are $52.3 million ($8.2 million incurred by employees and $44.1 million incurred by employers) in 2005.

Based on the relative prevalence of CD and UC, this includes annual costs of $24.3 million for people with CD and of $28.0 million for people with UC.

Only two studies reported days of leave per year for people with CD and UC separately - Boonen (2002) found a statistically significant difference ($p<0.05$) whereas Stark (2006) did not. Consequently not enough evidence is available to suggest that people with CD and UC experience differing rates of sick leave, and the estimated days off per year is applied to both diseases equally.

In comparison, data collected from the AIHW show that the average length of stay in hospital in 2004-05 for a person with IBD was 0.89 days. Assuming employed and non-employed persons experience a similar length of time in hospital[16] – then hospital stays represent only 12% of the estimated number of days absent from work per employed person, indicating that recovering from symptoms at home is a significant source of productivity loss.

TABLE 5-2: HOSPITAL DAYS AND DAYS ABSENT FROM WORK, AUSTRALIA, 2004-05

	Total Separations	Total Hospital Days	ALOS	Prevalence	Separations per Person	Hospital Days per Person
CD	10,590	31,670	3.0	28,000	0.38	1.13
UC	8,597	22,701	2.6	33,000	0.26	0.69
IBD	**19,187**	**54,371**	**2.8**	**61,000**	**0.31**	**0.89**

ALOS = Average Length of Stay. Source: AIHW (2004-05).

[16] This is a conservative estimate: if employed people with IBD tend to be healthier (and so spend less time in hospital on average) then the proportion of time spent in hospital relative to the total number of days absent from work must be lower.

TABLE 5-3: LITERATURE REVIEW - DAYS ABSENT FROM WORK

	ABS (2004-05)†	Bassi (2004)		Blomqvist and Ekbom (1997)	Boonen (2002)		Pinchbeck (1988)	Sorensen (1987)	Stark (2006)		Wyke (1988)	
Country	Australia	UK		Sweden	Netherlands		Canada	Denmark	Germany		UK	
Year of study	2004-05	2000		1994	2000			1984	2004		1979	1985
Diseases	IBD	CD	UC	IBD	CD	UC	CD	CD	CD	UC	IBD	
Data Sources	Community based	University based hospital		National registers and surveys	Hospital register	Hospital register	Hospital and physician recruited	Hospital recruited	Representative organisation recruited		Hospital recruited	
Number of patients surveyed	-	172	284	na	282	359	2430	106	241	242	170	144
Average age (sd)	43	46 (17)		na	37.3 (11)	43.6 (11)		44	41 (11)	43 (12)	43 (13)	48 (12)
Proportion Male	44%	41%		na	37.9%	52.1%		40%	35%	45%	52%	51%
Proportion employed	65%	39%	39%	-	62%**	69%**		65%	63%	67%	67.6%	65.3%
Proportion of employed people using sick leave	8.1% over 2 weeks	50% over 6 months	32% over 6 months	12% of cases	29.10% over a year	41.10% over a year	50% over a year	72% used less than 11 days	14% over 4 weeks	15% over 4 weeks	42% over a year	46% over a year
Forecasted proportion using sick leave per year	43%	57%	39%	-	29.10%	41.10%	50%	-	41%	42%	42%	46%
Days of leave per sick person	1.61 over 2 weeks	-	-	-	16.7* over a year	10.1* over a year	19.8*** over a year	-	1.4 over 4 weeks	1.7 over 4 weeks	-	-
Days of leave per year per employed person	9.0	-	-	5.4#	4.9	4.2	9.9	-	7.8	9.3	-	-

† National Health Survey *IBD related ** Weighted average of men and women *** Net of provincial average of 6.3 days.

59 episodes of sickness leave per 100,000 population (ie, 5,192 episodes or 0.12 episodes of sickness leave per case). Mean duration = 44 days (ie, 228,448 days or 5.4 days per case).

5.1.3 EMPLOYMENT IMPACTS (LONG-TERM PRODUCTIVITY COSTS)

The **human capital method** estimates production losses based on the remaining expected lifetime earnings for the individual.

Avenues through which IBD can lead to the long-term reduction in the productive capacity of the labour force include long-term absence from employment or reduction in hours of work, long-term reduction in productivity per hour worked, premature retirement[17] and premature mortality (ie, some people may die before they would otherwise retire in the absence of IBD).

A full economic analysis of the effects of a disease on the economy also examines the long-run situation where the lost productive capacity of the labour force (incurred via the worker or the employer) is passed on to society through adjustments in wages and prices. A reduction in the supply of labour would increase wages, which would be passed on to consumers through price increases. At the same time a decrease in the demand for goods and services would decrease prices, which would push down wages. The overall impact on the economy depends on a complex array of elasticities. However, this study assumes that, in the absence of the disease, people with IBD would participate in the labour force and obtain employment at the same rate as other Australians, and earn the same average weekly earnings. The implicit and probable economic assumption is that the numbers of such people would not be of sufficient magnitude to substantially influence the overall clearing of the labour market.

The following methodology is used to estimate lost long-run productivity.

- The expected retirement age by the current age of the worker is calculated based on the participation rates at each age group. Similar to life expectancy, the older the person, the less time it is expected that the person will remain in the workforce but the older they are when they do leave the workforce (see Table 5-4). Note that this methodology takes into account the probability that the patient is working.
- As the person ages, the annual income (based on AWE) is multiplied by the average employment rate at each age group while alive. Income earned at each age is then summed to calculate the expected total income over a person's lifetime (discounted back to present values).

[17] Note that the methodology for premature retirement cannot be used in addition to long-term reduction in employment and premature death due to double counting.

TABLE 5-4: EXPECTED RETIREMENT AGE AND REMAINING LIFETIME EARNINGS (2005 DOLLARS)

	Expected Retirement Age if Employed		Expected Remaining Lifetime Earnings ($m)	
Age	Males	Females	Males	Females
0-4	63	60	1.03	0.57
5-9	63	60	1.12	0.62
10-14	63	60	1.20	0.67
15-19	63	60	1.30	0.72
20-24	63	60	1.36	0.75
25-29	63	60	1.34	0.70
30-34	63	60	1.22	0.62
35-39	63	60	1.10	0.54
40-44	63	60	0.92	0.46
45-49	63	60	0.74	0.36
50-54	63	61	0.53	0.24
55-59	64	62	0.32	0.13
60-64	65	64	0.15	0.05
65-69	68	68	0.04	0.01
70-74	72	72	0.01	0.00
75-79	77	77	0.00	0.00
80-84	82	82	0.00	0.00
85-89	87	87	0.00	0.00
90+	92	92	0.00	0.00

Sources: ABS 6105.0, ABS 6310.0 (Indexed to $2005).

Consequently:

- For permanent disability: the expected remaining lifetime earnings are reduced by the percentage reduction in employment during the period the individual has a lower level of employment.
- For premature death: the entire expected remaining lifetime earnings for the individual are lost. The productivity costs of premature mortality are allocated to the year that the person died.

If an employed person stops working or prematurely dies from IBD, there are also staff turnover costs borne by the employer. These turnover costs are estimated to be equal to 26 weeks salary of the incumbent worker (Access Economics 2004a). However this cost is merely 'brought forward' a number of years because there would be some normal turnover of people with IBD – approximately 15% per annum (which implies that people change jobs, on average, approximately once every 6.7 years (Access Economics 2004b).

Literature Review and Meta-Analysis

Case-control studies were identified through the PubMed search engine system. The following keywords were used in various combinations the search: "education", "employment", "productivity", "cost of illness", "Crohn's", "colitis" and "inflammatory bowel disease". The remaining studies were found by using the references cited in the articles. A meta-analysis of these studies was conducted to estimate the overall impact of IBD on employment.

Five case-control studies were identified that estimated the impact of IBD on employment. Most of these studies controlled for sex and age, while others controlled for a wider range of confounders such as education, marriage etc. Additional unpublished data was also obtained from two ABS surveys – the NHS 2004-05 and SDAC.

Analysis of mean employment rates from NHS reveals (Table 5-5) that overall IBD reduces the probability of employment by 1.7% in males and 14.6% in females (12.2% overall).

However due to small sample sizes, the difference found by the NHS is not statistically significant.

TABLE 5-5: IMPACT OF IBD ON EMPLOYMENT RATES, NHS

	Employment Rate (%)		
	People with IBD	General Population	Difference (%)
Male	79.6%	81.3%	-1.7%
Female	57.2%	71.8%	-14.6%
Total	**65.0%**	**77.2%**	**-12.2%**

Sources: ABS 4364.0, special request.

Survey of Disability, Ageing and Carers, 2003

The 2003 Survey of Disability, Ageing and Carers (SDAC) is a national survey conducted by the ABS to measure disability. In particular it collected detailed information on people with disabilities, older people and those who provided care for older people and people with disabilities.

Information was also collected on people who were not in these populations, allowing for comparison of their relative demographic and socioeconomic situations. In addition to people living in private dwellings, those in cared accommodation, such as nursing homes, were also surveyed. Data on long-term health conditions were based on self-identification rather than clinical diagnosis (thus there may be under reporting of IBD) and time elapsed since diagnosis was not reported. The survey uses questions about activity limitation to screen for respondents before asking questions about conditions present, and thus is likely to miss people with IBD without activity limitation – for example those currently in remission. Consequently the SDAC estimate of prevalence is more likely to identify people currently experiencing symptoms or who have more severe forms of the disease.

Analysis of mean employment rates from SDAC reveals (see Table 5-6) that overall IBD reduces the probability of employment by 15.2%.

TABLE 5-6: IMPACT OF IBD ON EMPLOYMENT RATES, SDAC

	Employment Rate (%)		
	People with IBD	General Population	Difference (%)
People aged 15 - 64	62.7%	77.9%	-15.2%

Sources: ABS 4430.0, special request.

Conducting meta-analysis using a fixed effects model it was found that, on average, **IBD was associated with a 13% (95% CI: 11%-15%) reduction in the probability that the person will be employed** (relative risk of 0.87). This impact was found to be statistically significant.

Based on this estimate, **the annual cost of lost earnings due to workplace separation and early retirement from IBD is $204.2 million** (including $94.3 million for CD and $109.9 million for UC).

The results are dominated largely by the Bernstein (2001) study that used the IBD register. Additional analysis was performed on the relationship between the estimated odds ratio and each sample's average age and proportion of males.

- It was found that the younger the sample's average age the greater the odds ratio.
- It was also found that the less males in the sample the greater the odds ratio. A greater impact on women was also found by Bernstein (2001) with women with IBD having a 15% lower chance of being employed whereas men had a 12% lower chance.

However, neither of these relationships was statistically significant.

Finally, this analysis can only estimate whether people are likely to be employed or not, however individuals may also respond to the disease by changing their hours of employment. For example, Wyke (1988) found that 12.3% had modified their hours, and then 6 years later a further 6.9% had modified their hours (presumably downwards).

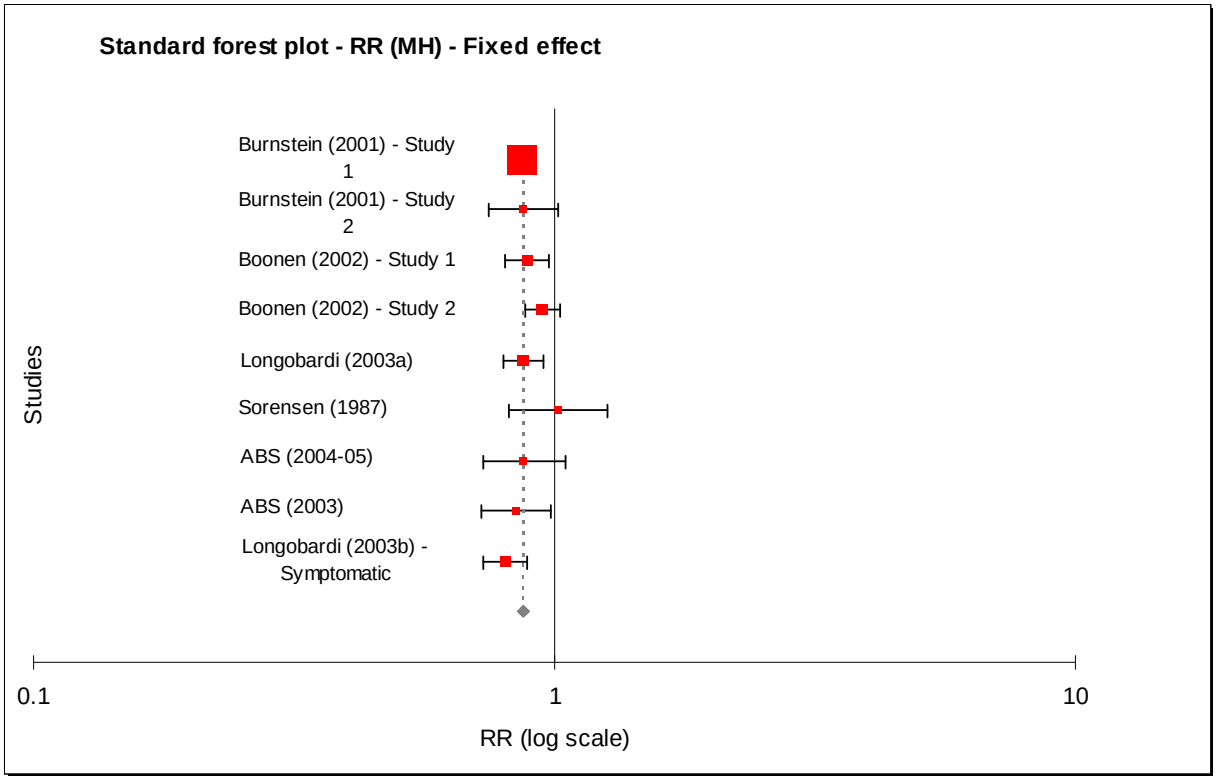
FIGURE 5-2: META-ANALYSIS OF IMPACT OF IBD ON EMPLOYMENT

META-ANALYSIS

General	
Number of studies	9
Number of participants	143332
RR (MH) - Fixed effect model	
Meta-analysis outcome	0.87
95% CI lower limit	0.85
95% CI upper limit	0.89
z	10.29
p-value (two-tailed)	< 0.01
Heterogeneity	
Q	9.75
p-value (two-tailed)	0.28
H	1.1
95% CI lower limit	0.83
95% CI upper limit	1.47
I^2	0.18
95% CI lower limit	0.46
95% CI upper limit	0.54

Source: MIX software meta-analysis.

FIGURE 5-3: FOREST PLOT OF META-ANALYSIS OF IBD IMPACT ON EMPLOYMENT



Source: MIX software meta-analysis.

TABLE 5-7: LITERATURE REVIEW - IMPACT OF IBD ON EMPLOYMENT

	ABS (2003)	ABS (2004-05)	Bernstein (2001)		Longobardi (2003a)	Longobardi (2003b)	Sorensen (1987)	Boonen (2002)	
Country	Australia	Australia	Canada		Canada	US	Denmark	Netherlands	
Year of Study	2003	2004-05	1995-96		1999	1999	1984	2000	
Diseases	IBD	IBD	IBD	IBD	IBD	IBD	CD	CD	UC
Data Sources	SDAC	NHS	IBD Register	Health Administration data linked with census	Canadian National Population Health Survey (NPHS)	National Health Interview Survey (NHIS)	Hospital recruited	Hospital register	
Number of People with IBD	101	65	2476	80	187	187	106	282	359
Number of Controls	36,140	25,841	14177	26082	10704	23462	75	1504	1504
Average Age (sd)	-	43	42	35.9	42.7	42.2	44	37.3 (11)	43.6 (11)
Proportion Male	-	44%	45%	48.2%	36.9%	33.5%	65%	37.9%	52.1%
Proportion Employed (IBD)	62.7	65.0	58.6%	67.1%	71.1%	68.5%	65.0%	62.0%	68.9%
Proportion Employed (Controls)	74	74	67.9%	77.1%	81.5%	85.2%	64.0%	69.9%	72.8%
Estimated Relative Risk	0.84	0.87	0.86	0.87	0.87	0.8	1.02	0.89	0.95
Estimated OR	0.58	0.64	0.67	0.61	0.70	0.83	0.56	0.38	1.04
Controlled for cofounders	No	No	Age	Age	Various	Various	None	Age	Age

5.1.4 PREMATURE DEATH

The production losses arising from premature mortality associated with IBD were estimated based on mortality statistics published by the ABS (2006b). In 2005, there were an estimated 99 deaths due to CD but no additional deaths due to UC, based on the mortality rate in Section 3.6. It was estimated that 20 of those deaths occurred in the 'under 65' age group. The present value of the lost earnings of the share of people who died but would otherwise have been employed was estimated using the employment rates and estimates of average lifetime earnings for the different age groups.

For people aged 15-64 years with IBD the estimated annual cost due to premature death was $10.2 million in 2005.

5.1.5 SUMMARY OF PRODUCTIVITY COSTS

Estimated total productivity costs in 2005 due to IBD were $266.7 million (including $128.8 million for CD and $137.9 million for UC).

Productivity costs were estimated as the sum of the losses due to lower absenteeism ($52.3 million), employment rates ($204.2 million) and premature death ($10.2 million).

Nicole O'Malley, Melbourne VIC (22)

I was diagnosed with Crohn's disease in 1999 not long after I started a hospitality course at a TAFE college. A lump near my rectum, which had previously been treated as a 'local' infection, became aggravated. Soon I had two 'lumps' and I could hardly walk. One night, the pain was so bad, my dad lifted me into the car and drove me to Box Hill Hospital. I underwent surgery for setons to be placed into my lumps, which I found out were called fistulas. From 2001 to 2005 I had another five operations on my fistulas. I still had stomach pains and had developed arthritis. It was very hard to deal with fistulas draining; I would never go out with my friends and basically stayed at home.

I was demoted from my role as a senior administrator for a Superannuation company and told absences due to my illness were not fair on other staff members or my team leader. I was asked to 'step down' from my position which I did. I left the company soon after.

5.1.6 TAXATION REVENUE IMPACTS

Reduced earnings due to lower workforce participation, absenteeism and premature death will also have an effect on taxation revenue collected by the Government. As well as foregone income (personal) taxation, there will also be a fall in indirect (consumption) tax, as those with lower incomes spend less on the consumption on goods and services.

Personal income tax foregone is a product of the average personal income tax rate and the foregone income. With IBD and lower income, there will be less consumption of goods and services, estimated up to the level of the disability pension. Without IBD, it is conservatively assumed that consumption would comprise 90% of income (the savings rate may well be

lower than this). The indirect tax foregone is estimated as the product of the foregone consumption and the average indirect tax rate, derived from the Access Economics macroeconomic model.

In 2005, it is estimated that $97.9 million of potential taxation revenue (37.2% of total productivity costs) **will be lost due to the reduced participation of people with IBD in the paid workforce.** Of this, $56.8 million is lost income tax (based on an average personal income tax rate of 21.2%) and $41.1 million is lost consumption tax (based on an average indirect (consumption) tax rate of 15.51%).

Of the remainder of the potential earnings lost, $140.9 million (52.8%) was borne by the people with IBD and $27.9 million was borne by employers (10.5%).

Lost taxation revenue is considered a transfer payment, rather than an economic cost. However, raising additional taxation revenue does impose real efficiency costs on the Australian economy, known as **deadweight losses**. Administration of the taxation system costs around 1.25% of revenue raised (derived from total amounts spent and revenue raised in 2000-01, relative to Commonwealth department running costs). Even larger DWLs also arise from the distortionary impact of taxes on workers' work and consumption choices. These distortionary impacts are estimated to be 27.5% of each extra tax dollar collected (Lattimore, 1997 and used in Productivity Commission, 2003, with rationale).

Access Economics estimates that **$26.9 million in additional DWL is incurred in 2005** due to the additional taxation required to replace tax foregone due to the lost productivity of people with IBD.

Welfare payments made to people who are no longer working must, in a budget-neutral setting, also be funded by additional taxation. The DWLs associated with welfare transfers are calculated in Section 5.5.2.

5.2 CARERS

Carers are people who provide informal care to others in need of assistance or support. For example, carers may take time off work to accompany people with IBD to medical appointments, stay with them in hospital, or care for them at home. Carers may also take time off work to undertake much of the unpaid work the person with IBD usually does when in remission.

Informal care is distinguished from services provided by people employed in the health and community sectors (formal care) because the care is generally provided free of charge to the recipient and is not regulated by the government. Most informal carers are family or friends of the person receiving care.

While informal care is provided free of charge, it is not free in an economic sense, as time spent caring is time that cannot be directed to other activities such as paid work, unpaid work (such as housework or yard work) or leisure. As such, informal care is a use of economic resources.

There are three potential methodologies which can be used to place a dollar value on the level of informal care:

- the **opportunity cost method** – measures the formal sector productivity losses associated with caring, as time devoted to caring responsibilities is time which cannot be spent in the paid workforce;

- the **self-valuation method** – measures that carers themselves feel they should be paid; and
- the **replacement cost method** – measures the cost of "buying" an equivalent amount of care from the formal sector, if the informal care were not supplied.

The self-valuation method is not commonly used, and there are no reliable Australian studies of the amount Australian carers feel they should be compensated. Interestingly, an Irish study of dementia carers provided a very low figure, of between £2 and £4 per hour (O'Shea, 2000).

Estimates of the value of informal care are very sensitive to the estimation methodology used. In this study, the opportunity cost method is used as data about the age and sex of the carers are available from SDAC and the aim of this report is to estimate the current impacts on people with IBD and their families, rather than a 'what if' scenario if this care were instead provided by formal care providers.

SDAC provides the most recent and comprehensive profile of Australians with IBD and the people who provide them with assistance and support.

SDAC reported that in Australia there are 2,600 primary carers of people whose main condition was disease of the digestive system.[18] Applying AIHW prevalence estimates, 23.3% or 605 of those primary carers care for people with IBD (including 278 primary carers for people with CD and 327 primary carers for people with UC). Thus, on average, there is one carer per 100 people with IBD.

According to SDAC data, a primary carer spends 29.85 hours per week on average caring for people with disabilities. **Overall, in 2005, 939,087 hours of informal care were provided to people with IBD, equivalent to 15.39 hours per person with IBD per year.**

Access Economics has adopted the replacement valuation approach in this section, due to the lack of information about the demographic characteristics of carers of Australians with IBD, noting that the replacement valuation will generally give higher results than the other two methods, for which data are not available.

The estimate of the replacement value of informal community care is sensitive to changes in the estimate of the wage parameter for alternate formal sector care. In this analysis, the unit cost used has been based on the wage of moderately skilled formal sector carers (supervised employees). In May 2004, full-time carers and aides employed in the formal sector received an average wage of $17.20 per hour, or $650.30 for a 37.8 hour week (ABS, 2005b). This average includes payment of overtime for after hours work. However, the hourly rate received by employees does not account for on-costs such as superannuation incurred by employers, the wages of supervisors, managers or administrative support staff or other capital overheads. Loadings are added for each of these additional costs, and for average wage growth between May 2004 (when the survey was last undertaken) and February 2005.

[18] Note that this estimate should be treated with caution as it is based on a very small sample and has a high standard error of 39%.

TABLE 5-8: REPLACEMENT VALUATION OF INFORMAL CARE, UNIT COST COMPONENTS

	% Loading	Hourly rate
Base rate per hour – May 2004		$17.20
Loading for growth in AWE May 2004 to Feb 2005	4.9%	$0.85
Loading for on-costs	15.6%	$2.82
Loading for capital	3.6%	$0.75
Loading for supervision and administration	16.3%	$3.40
Total hourly rate inc. overheads		**$25.01**

The 15.6% loading of on-costs comprises superannuation, workers compensation, payroll and Fringe Benefits Taxation allowances. Loadings for capital (3.6%) and administrative (16.3%) overheads are based on the relative shares of capital expenditure and administration costs compared to other areas of recurrent spending in Australia's formal health sector. When all these loadings are added, the hourly cost of employing a carer in the formal sector to replace an informal carer is $25.01 in 2005 (Table 5-8).

Based on this rate, **the total replacement value of family and other informal care provided to Australians with IBDs is estimated as $23.5 million in 2005** (including $10.8 million for people with CD and $12.7 million for people with UC).

According to Eckardt (1994), the disease impacted the professional career in not only 17% of patients, but also 11% of their spouses, suggesting that the reach of indirect cost and their economic impact must be considered beyond solely the patient, but also family members, friends and other co-workers.

5.3 OUT-OF-POCKET EXPENSES

A broad range of additional out-of-pocket expenses are incurred by people with IBD and their families. Some typical out-of-pocket expenses include:

- **Aids and modifications:** such as incontinence pads, over-the-counter drugs and dietary supplements. However, according to SDAC data, the share of people with a disability in the population of people who have IBD is not significantly higher than the share of all people with a disability in the population (both are around 20%). Hence, it was concluded that no additional costs were incurred due to the use of aids and modifications.
- **Formal care:** A person with IBD may not be able to undertake tasks that they are normally responsible for when they experience a relapse in their disease. During these times additional expenditure on housekeeping, childcare and gardening services may be incurred.
- **Travel and accommodation costs:** Travel costs to medical appointments by both the patient and any accompanying family members. These costs are particularly burdensome for regional and remote patients travelling to metropolitan areas for treatment. However, even if the medical treatment is available locally, travel costs can still be substantial in terms of both distance and time. Potential costs include petrol, road tolls, additional car maintenance, taxi, train, bus and air fares, accommodation costs for both the patient and/or family at hotels/hostels near the treatment facility (although some out-of-town patients may be able to stay with friend/family, additional meal costs; and item duplication, luggage and clothing.

- **Communication costs:** Increased communication costs may be incurred by people with IBD, for example, to obtain information and support from medical specialists and support groups, or stay in touch with friends and family while away. These costs include: mail; mobile, local, and long-distance telephone calls; fax; and email/internet access.
- **Complementary therapies:** Patients may participate in activities to improve their ability to cope with the disease. These costs include membership in self-help groups, yoga courses and book purchases.

Some financial costs incurred by children with IBD and their families may be more burdensome than for adults with IBD. For example, children often require someone to accompany them to medical appointments thus resulting in higher transport costs, whereas many adult patients are able to attend these appointments by themselves. Many children and juveniles with IBD also have siblings that require care. To catch up on schooling missed while admitted to hospital, additional special education expenses (such as tutors) may also be incurred.

For modelling purposes it is assumed that these costs are incurred by the individual, however by-and-large these costs are often borne by the entire family.

No Australian studies were identified that measures out-of-pocket expenses by people with IBD. However, Stark (2006) reported a broad range of costs incurred by people with UC and CD in Germany, which have been converted to A$ using purchasing power parity (PPP).

Consequently it is estimated that people with CD and UC incur additional out-of-pocket expenses of $578.30 per annum and $594.60, respectively.

TABLE 5-9: OTHER FINANCIAL COSTS INCURRED BY PATIENTS WITH CD

Type of Cost	Proportion of Patients (%)	Mean Cost over 4 weeks		Annual Cost per Case (A$)
		Euro (€)	Australian Dollars (A$)	
Dietary	20	17	25.7	66.8
Transport	51	19	28.7	190.4
Household Support	13	18	27.2	46.0
Patient-Initiated Activities	100	14	21.2	275.1
Total				**578.3**

Sources: Stark (2006) inflated using PPP (OECD 2006).

TABLE 5-10: OTHER FINANCIAL COSTS INCURRED BY PATIENTS WITH UC

Type of Cost	Proportion of Patients (%)	Mean Cost over 4 weeks		Annual Cost per Case
		Euro (€)	Australian Dollars (A$)	
Dietary	18%	11	16.6	38.9
Transport	43	13	19.7	109.8
Household Support	13	13	19.7	33.2
Patient-Initiated Activities	100	21	31.7	412.7
Total				**594.6**

Sources: Stark (2006) inflated using PPP (OECD 2006).

The estimated out-of-pocket expenses for people with IBD were $35.8 million (including $16.2 million for people with CD and $19.6 million for people with UC).

Nikole Lowe, Glengai, Walgett, NSW (32)

My family and I live on a property in the upper western part of NSW. I teach our two boys, Izaac (10) and Jaiden (5) by distance education (school of the air). My husband, Brian is maintenance manager of the feedlot and farming enterprise. I used to work with the cattle on the feedlot until I became too ill.

I was diagnosed with Crohn's four years ago, after years of illness, misdiagnosis and invasive tests. Since then I have been treated with many different drugs, most of them with terrible side effects or they simply didn't work for me. The side effects include insomnia, moon face, weight gain, indescribable moods and the sapping of calcium from my body. I need fortnightly blood tests to make sure my liver is functioning. This in itself presents a huge problem for us, as we live 75kms away from town. The travelling is a huge cost for us, something we simply can't afford because I am too sick to work.

I 'flare' every few months. A 'flare' for me is diarrhoea so severe that I can't keep anything in my belly, including fluids (therefore drugs). I bleed from the bowel so much I need blood infusions, with my iron levels low and indescribable stomach pain. Occasionally during a flare my skin develops painful welts; these lesions even appear on my eyeballs. I have permanent scarring and eye problems. I am so unbelievably worn out; dehydrated and low on everything my body needs to function. All I can do is be admitted to hospital for huge doses of medication - not always practical when hospital is so far away and with a family at home who needs me. My family and I can't lead a 'normal life' as everything revolves around 'if Mum is well enough'. My husband and I worry about our future.

My disease is in that many different places in my bowel that surgery isn't an option, unless they take my whole bowel. That is a huge call for someone who is only 32 years old and has a young family. I am one of the lucky few who are able to have access to infliximab infusions. I need to travel 400kms one way for infusions every eight weeks; this is a huge cost both in time and finances, if infliximab was on the PBS I could obtain the infusions in my local hospital. This travelling takes a huge toll on my health.

5.4 FUNERAL COSTS

The 'additional' cost of funerals borne by family and friends of patients is based on the likelihood of death in the five years due to IBD. However, some patients (particularly older patients) would have died during this time anyway, and eventually everyone must die, and thus incur funeral expenses – so the true cost is the cost brought forward (adjusted for the likelihood of dying anyway). The BTRE (2000) calculated a weighted average cost of a funeral across all States and Territories, to estimate an Australian total average cost of $3,200 per person for 1996, or **$3,949 per person in 2005**.

In 2005, total funeral costs associated with premature death due to CD are estimated as $0.4 million in 2005. These costs are paid for by family or friends. Since the mortality rate is not increased for people with UC, no funeral costs are associated with this disease.

5.5 TRANSFER COSTS

Transfer payments represent a shift of resources from one economic entity to another. The act of taxation and redistribution creates distortions and inefficiencies in the economy, so transfers also involve real net costs to the economy.

5.5.1 WELFARE AND INCOME SUPPORT

A number of welfare payments are available to people with IBD, and can sometimes be back-dated to when costs began to be incurred (ie, when the person stopped working). The cost of welfare payments in this section relate to those directly attributable to IBD.

In January 2007 there were around 1,316[19] people listed to have received the Disability Support Pension, Newstart, or Sickness Allowance due to IBD (see Table 5-11). However this estimate is an underestimation of the number of people who received welfare payments because:

- people aged over 65 years would be eligible for the aged pension instead[20];
- it does not include people who did not indicate IBD as a reason for receiving the payment; and
- some individuals after recovering from a relapse in IBD may still experience prolonged absence from the labour force, thus continuing to receive welfare payments such as Newstart.

Furthermore there is a range of additional payments available that have not been costed in this section.

Applying the proportion of recipients who received each of the payments due to IBD to the total annual payments in 2005-06, it is estimated that **$15.0 million in welfare payments was paid to people with IBD** (including $6.9 million for people with CD and $8.1 million for people with UC).

Total welfare payments for people with IBD include $12.1 million in disability support, $2.6 million in Newstart Allowance and $0.3 million in Sickness Allowance. If it is assumed that all of these people are aged between 15 and 65 (working age and not yet eligible for the aged pension) then **only 3% of all working aged people with IBD received welfare payments.**

[19] Recipients of the DSP is only available for individuals with Gastro-intestinal disorders. 43% of these participants were assumed to have IBD based on prevalence estimates of diseases of the digestive system (excluding peptic ulcers) from Mathers, Vos and Stephenson (1999).

[20] Note some women aged between 55 and 65 are currently eligible for the age pension, but this is being slowly phased out.

TABLE 5-11: WELFARE PAYMENTS, 2005-06

	All People		People with IBD	
	No. Recipients (December 2005)	Payments ($m) (2005-06)	No. recipients (January 2006)	Payments ($m) (2005-06)
Disability Support	711,781	8,286.6	1,039	12.1
Newstart Allowance	437,688	4,531.5	252	2.6
Sickness Allowance	8,073	85.0	25	0.3
Total	**1,157,542**	**12,903.1**	**1,316**	**15.0**

Sources: Centreline special request, DEWR (2005-06).
http://www.annualreport.dewrsb.gov.au/chapter2_1/0803.htm

However some of these people would have ordinarily received welfare payments which must be netted out to estimate the *additional* welfare payments due to IBD, using a Melbourne University study (Tseng and Wilkins 2002) about the 'reliance' of the general population (aged 15-64 years) on income support.

TABLE 5-12: WELFARE PAYMENTS TO PEOPLE WITH IBD DUE TO IBD, 2005-06

	Average Reliance (%)			Additional Payments ($m)
	Males	Females	Persons*	2005-06
Disability Support	10.2	14.9	12.0	10.6
NewStart Allowance	14.0	10.2	12.9	2.3
Sickness Allowance	10.2	14.9	11.7	0.2
Total				13.1

* Weighted average based on statistics of demographics of income support customers.

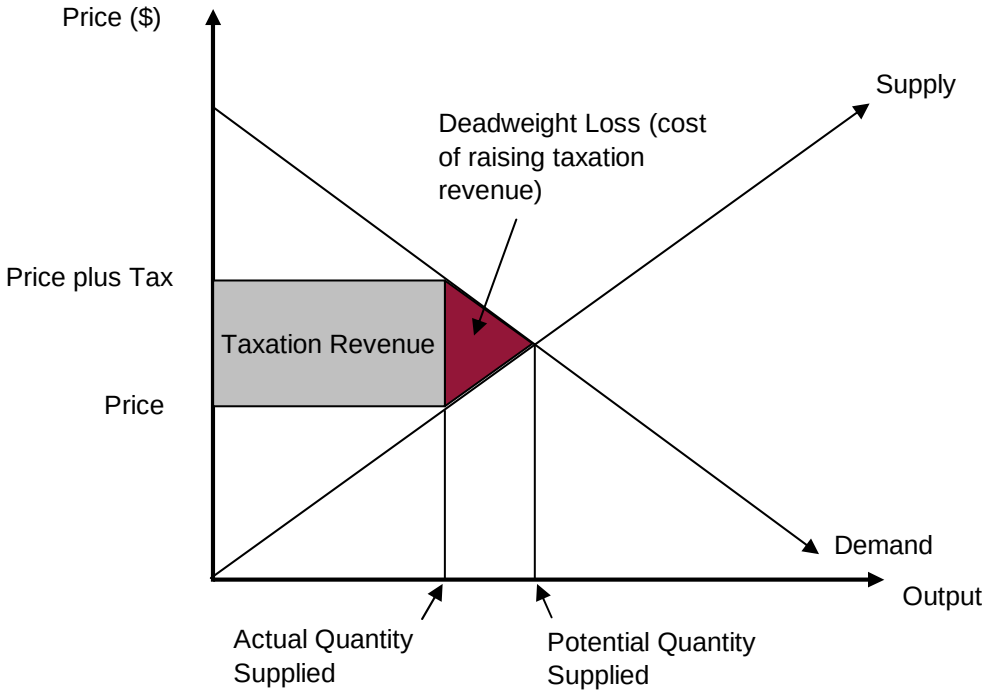
Sources: FACS (2006) and Tseng and Wilkins (2002).

5.5.2 SUMMARY OF DEADWEIGHT LOSSES

As discussed earlier, transfer payments (Government payments/services and taxes) are not a net cost to society, as they represent a shift of consumption power from one group of individuals to another in the community. If the act of taxation did not create distortions and inefficiencies in the economy, then transfers could be made without a net cost to the community. However through these distortions taxation does impose a DWL on the economy.

Deadweight loss is the loss of consumer and producer surplus, as a result of the imposition of a distortion to the equilibrium (society preferred) level of output and prices. Taxes alter the price and quantity of goods sold compared to what they would be if the market were not distorted, and thus lead to some diminution in the value of trade between buyers and sellers that would otherwise be enjoyed. The principal mechanism by which a DWL occurs is the price induced reduction in output, removing potential trades that would benefit both buyers and sellers. In a practical sense, this distortion reveals itself as a loss of efficiency in the economy, which means that raising $100 of revenue requires consumers and producers to give up more than $100 of value.

FIGURE 5-4 DEADWEIGHT LOSS OF TAXATION



The rate of DWL used in this report is 0.275 per $1 of tax revenue raised, based on Productivity Commission (2003), plus 0.0125 per $1 of tax revenue raised for Australian Taxation Office (ATO) administration (Access Economics 2004b: Part II, 66). Strictly speaking, some change in costs for the administration of the welfare payment agencies should be included. However, given that the total induced change in welfare payments is such a relatively small estimate, there are unlikely to be significant cost savings in administering less payments. The total extra tax dollars required to be collected include:

- the calculation for the loss of income tax from people with IBD, carers and employers;
- the additional induced social welfare payments required to be paid; and
- the value of Government services provided (eg, health system costs, counselling etc).

For people with IBD in 2005, the expected total DWL is $91.3 million (including $43.1 million for people with CD and $48.2 million for people with UC).

5.6 SUMMARY OF OTHER FINANCIAL COSTS

In 2005, other (non-health) financial costs for people with IBD were $417.7 million (including $199.3 million for people with CD and $218.4 million for people with UC).

Almost two thirds (64%) of these other financial costs for people with IBD were due to productivity losses. A further 22% was due to DWLs from transfers, while 9% were due to out-of-pocket expenses and funeral costs and 6% were due to carer costs (Table 5-13). Shares are similar for CD and UC individually.

TABLE 5-13: SUMMARY OF OTHER FINANCIAL COSTS ($M) 2005

Costs in $ million	CD	UC	IBD
Productivity Losses	**128.8**	**137.9**	**266.7**
- Absenteeism	24.3	28.0	52.3
- Employment Impact	94.3	109.9	204.2
- Premature Death	10.2	---	10.2
- Hiring costs	0.01	---	0.01
Carers	**10.8**	**12.7**	**23.5**
Out-of-Pocket Expenses and Funeral Costs	**16.6**	**19.6**	**36.2**
DWLs from Transfers	**43.1**	**48.2**	**91.3**
TOTAL	**199.3**	**218.4**	**417.7**

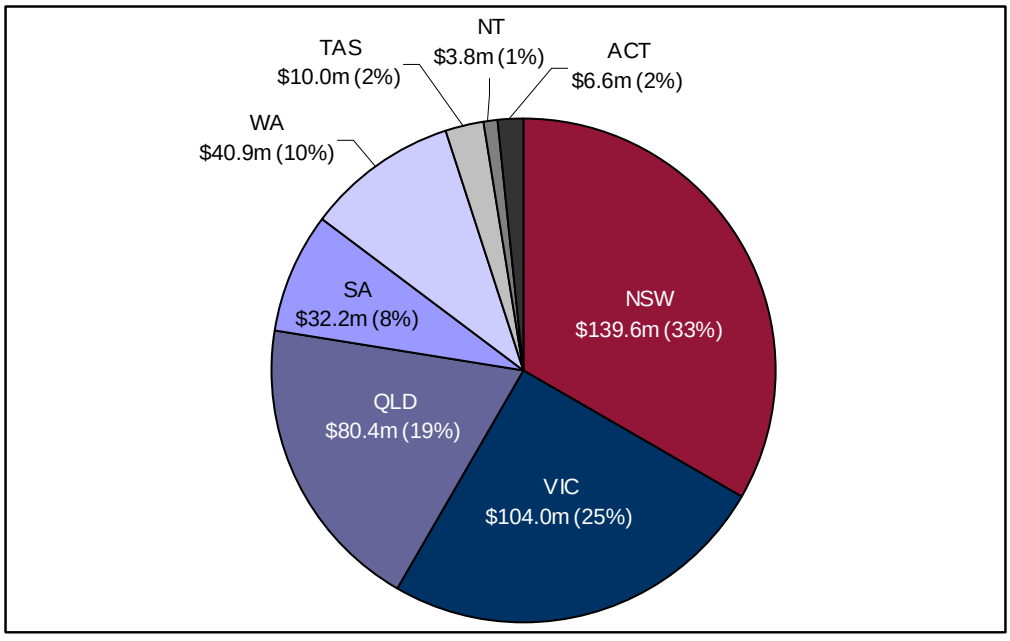
5.7 OTHER FINANCIAL COSTS BY JURISDICTION

In the same way as was done with health costs, other financial costs of IBD were then allocated to States and Territories. The distribution is summarised in Table 5-14 and Figure 5-5.

TABLE 5-14: OTHER FINANCIAL COSTS BY JURISDICTION, 2005 ($M)

IBD	Australia	NSW	VIC	QLD	SA	WA	TAS	NT	ACT
Other Financial Costs									
Lost earnings	266.7	89.2	66.4	51.3	20.6	26.1	6.4	2.4	4.2
Deadweight losss	91.3	30.5	22.7	17.6	7.0	8.9	2.2	0.8	1.4
Carer costs	23.5	7.9	5.9	4.5	1.8	2.3	0.6	0.2	0.4
Out-of-pocket and funeral expenses	36.2	12.1	9.0	7.0	2.8	3.5	0.9	0.3	0.6
Total other financial costs	**417.7**	**139.6**	**104.0**	**80.4**	**32.2**	**40.9**	**10.0**	**3.8**	**6.6**

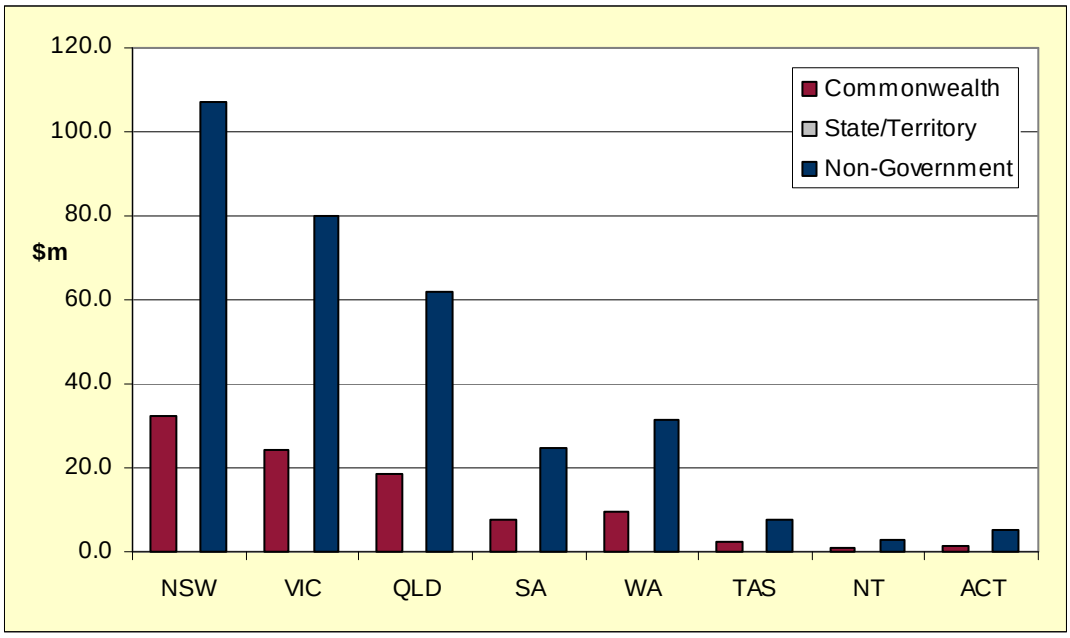
FIGURE 5-5: IBD OTHER FINANCIAL COSTS BY JURISDICTION, 2005



The distribution of who bears the costs is illustrated in Figure 5-6 by State/Territory. In all cases the majority of the costs are borne by the individual. While the Commonwealth

Government bears some of the costs (lost taxation revenue, welfare payments), the (non-health) costs to the State/Territory Governments are estimated as zero.

FIGURE 5-6: OTHER FINANCIAL COSTS BY LEVEL OF GOVERNMENT, BY JURISDICTION, 2005



6. BURDEN OF DISEASE

Burden of disease refers to the loss of wellbeing or healthy life experienced by people with IBD. Various methods have been devised to quantify this loss in monetary terms.

6.1 METHODOLOGY – VALUING LIFE AND HEALTH

Since Schelling's (1968) discussion of the economics of life saving, the economic literature has properly focused on **willingness to pay** (willingness to accept) measures of mortality and morbidity risk. Using evidence of market trade-offs between risk and money, including numerous labour market and other studies (such as installing smoke detectors, wearing seatbelts or bike helmets etc), economists have developed estimates of the **Value of a 'Statistical' Life (VSL).**

> The willingness to pay approach estimates the value of life in terms of the amounts that individuals are prepared to pay to reduce risks to their lives. It uses stated or revealed preferences to ascertain the value people place on reducing risk to life and reflects the value of intangible elements such as quality of life, health and leisure. While it overcomes the theoretical difficulties of the human capital approach, it involves more empirical difficulties in measurement (BTE, 2000, pp20-21).

Viscusi and Aldy (2002) summarise the extensive literature in this field, most of which has used econometric analysis to value mortality risk and the 'hedonic wage' by estimating compensating differentials for on-the-job risk exposure in labour markets, in other words, determining what dollar amount would be accepted by an individual to induce him/her to increase the possibility of death or morbidity by a given percentage. They find the VSL ranges between US$4 million and US$9 million with a median of US$7 million (in year 2000 US dollars), similar but marginally higher than the VSL derived from US product and housing markets, and also marginally higher than non-US studies, although all in the same order of magnitude. They also review a parallel literature on the implicit value of the risk of non-fatal injuries.

> A particular life may be regarded as priceless, yet relatively low implicit values may be assigned to life because of the distinction between identified and anonymous (or 'statistical') lives. When a 'value of life' estimate is derived, it is not any particular person's life that is valued, but that of an unknown or statistical individual (Bureau of Transport and Regional Economics, 2002, p19).

Weaknesses in this approach, as with human capital, are that there can be substantial variation between individuals. Extraneous influences in labour markets such as imperfect information, income/wealth or power asymmetries can cause difficulty in correctly perceiving the risk or in negotiating an acceptably higher wage.

Viscusi and Aldy (2002) include some Australian studies in their meta-analysis, notably Kniesner and Leeth (1991) of the ABS with VSL of US2000 $4.2 million and Miller et al (1997) of the National Occupational Health and Safety Commission (NOHSC) with quite a high VSL of US2000$11.3m-19.1 million (Viscusi and Aldy, 2002, Table 4, pp92-93). Since there are relatively few Australian studies, there is also the issue of converting foreign (US)

data to Australian dollars using either exchange rates or purchasing power parity and choosing a period.

Access Economics (2003) presents outcomes of studies from Yale University (Nordhaus, 1999) – where VSL is estimated as $US2.66m; University of Chicago (Murphy and Topel, 1999) – US$5m; Cutler and Richardson (1998) – who model a common range from US$3m to US$7m, noting a literature range of $US0.6m to $US13.5m per fatality prevented (1998 US dollars). These eminent researchers apply discount rates of 0% and 3% (favouring 3%) to the common range to derive an equivalent of $US 75,000 to $US 150,000 for a year of life gained.

6.1.1 Disability Adjusted Life Years (DALYs) and Quality Adjusted Life Years (QALYs)

In an attempt to overcome some of the issues in relation to placing a dollar value on a human life, in the last decade an alternative approach to valuing human life has been derived. The approach is non-financial, where pain, suffering and premature mortality are measured in terms of DALYs, with 0 representing a year of perfect health and 1 representing death (the converse of a QALY where 1 represents perfect health). This approach was developed by the World Health Organization, the World Bank and Harvard University and provides a comprehensive assessment of mortality and disability from diseases, injuries and risk factors in 1990, projected to 2020 (Murray and Lopez, 1996). Methods and data sources are detailed further in Murray et al (2001).

The DALY approach has been adopted and applied in Australia by the AIHW with a separate comprehensive application in Victoria. Mathers et al (1999) from the AIHW estimate the BoD and injury in 1996 and Begg et al (2007) have recently updated these estimates, including separate identification of premature mortality; Years of Life Lost due to Premature Mortality (YLL), and morbidity; Years of Healthy Life Lost due to Disability (YLD) components. In any year, the disability weight of a disease (for example, 0.18 for a broken wrist) reflects a relative health state. In this example, 0.18 would represent losing 18% of a year of healthy life because of the inflicted injury.

The DALY approach has been successful in avoiding the subjectivity of individual valuation and is capable of overcoming the problem of comparability between individuals and between nations, although nations have subsequently adopted variations in weighting systems. For example, in some countries DALYs are age-weighted for older people although in Australia the minority approach is adopted – valuing a DALY equally for people of all ages.

The main problem with the DALY approach is that it is not financial and is thus not directly comparable with most other cost measures. In public policy making, therefore, there is always the temptation to re-apply a financial measure conversion to ascertain the cost of an injury or fatality or the value of a preventive health intervention. Such financial conversions tend to utilise “willingness to pay” or risk-based labour market studies described above.

The Department of Health and Ageing (based on work by Applied Economics) adopted a very conservative approach to this issue, placing the value of a human life year at around A$60,000 per annum, which is lower than most international lower bounds on the estimate.

> *“In order to convert DALYs into economic benefits, a dollar value per DALY is required. In this study, we follow the standard approach in the economics literature and derive the value of a healthy year from the value of life. For example, if the estimated value of life is A$2 million, the average loss of healthy*

life is 40 years, and the discount rate is 5% per annum, the value of a healthy year would be $118,000.[21] Tolley, Kenkel and Fabian (1994) review the literature on valuing life and life years and conclude that a range of US$70,000 to US$175,000 per life year is reasonable. In a major study of the value of health of the US population, Cutler and Richardson (1997) adopt an average value of US$100,000 in 1990 dollars for a healthy year.

Although there is an extensive international literature on the value of life (Viscusi, 1993), there is little Australian research on this subject. As the Bureau of Transport Economics (BTE) (in BTE, 2000) notes, international research using willingness to pay values usually places the value of life at somewhere between A$1.8 and A$4.3 million. On the other hand, values of life that reflect the present value of output lost (the human capital approach) are usually under $1 million.

The BTE (2000) adopts estimates of $1 million to $1.4 million per fatality, reflecting a 7% and 4% discount rate respectively. The higher figure of $1.4 million is made up of loss of workforce productivity of $540,000, loss of household productivity of $500,000 and loss of quality of life of $319,000. This is an unusual approach that combines human capital and willingness to pay concepts and adds household output to workforce output.

For this study, a value of $1 million and an equivalent value of $60,000 for a healthy year are assumed.[22] In other words, the cost of a DALY is $60,000. This represents a conservative valuation of the estimated willingness to pay values for human life that are used most often in similar studies.[23]" (DHA, 2003, pp11-12)."

As the citation concludes, the estimate of $60,000 per DALY is very low. The Viscusi (1993) meta-analysis referred to reviewed 24 studies with values of a human life ranging between US$0.5 million and US$16m, all in pre-1993 US dollars. Even the lowest of these converted to 2003 Australian dollars at current exchange rates, exceeds the estimate adopted ($1m) by nearly 25%. The BTE study tends to disregard the literature at the higher end and also adopts a range (A$1-$1.4m) below the lower bound of the international range that it identifies (A$1.8-$4.3m).

The rationale for adopting these very low estimates is not provided explicitly. Certainly it is in the interests of fiscal restraint to present as low an estimate as possible.

In contrast, the majority of the literature as detailed above appears to support a higher estimate for VSL, as presented in Table 6-1, which Access Economics believes is important to consider in disease costing applications and decisions. The US dollar values of the lower bound, midrange and upper bound are shown at left. The 'average' estimate is the average of the range excluding the high NOHSC outlier. Equal weightings are used for each study as the:

- Viscusi and Aldy meta-analysis summarises 60 recent studies;

[21] *In round numbers, $2,000,000 = $118,000/1.05 + $118,000/(1.05)^2 + … + $118,000/(1.05).*[40] [Access Economics comment: The actual value should be $116,556, not $118,000 even in round numbers.]

[22] The equivalent value of $60,000 assumes, in broad terms, 40 years of lost life and a discount rate of 5%. [Access Economics comment: More accurately the figure should be $58,278.]

[23] In addition to the cited references in the text, see for example Murphy and Topel's study (1999) on the economic value of medical research. [Access Economics comment. Identical reference to our Murphy and Topel (1999).]

- ABS study is Australian; and
- Yale and Harvard studies are based on the conclusions of eminent researchers in the field after conducting literature analysis.

Where there is no low or high US dollar estimate for a study, the midrange estimate is used to calculate the average. The midrange estimates are converted to Australian dollars at purchasing power parity (as this is less volatile than exchange rates) of USD=0.7281AUD for 2003 as estimated by the OECD.

Access Economics concludes the VSL range in Australia lies between $3.7m and $9.6m[24], with a mid-range estimate of $6.5m. These estimates have conservatively not been inflated to 2004 prices, given the uncertainty levels.

TABLE 6-1: INTERNATIONAL ESTIMATES OF VSL, VARIOUS YEARS

	US$m			A$m
	Lower	**Midrange**	**Upper**	**0.7281**
Viscusi and Aldy meta-analysis 2002	4	7	9	**9.6**
Australian: ABS 1991		4.2		5.8
NOHSC 1997	11.3		19.1	
Yale (Nordhaus) 1999		2.66		**3.7**
Harvard (Cutler and Richardson) 1998	0.6	5	13.7	6.9
Average*	2.9	**4.7**	7.4	**6.5**

* Average of range excluding high NOHSC outlier, using midrange if no data; conservatively not inflated

A$m conversions are at the OECD 2003 PPP rate

6.1.2 DISCOUNT RATES

Choosing an appropriate discount rate for present valuations in cost analysis is a subject of some debate, and can vary depending on which future income or cost stream is being considered. There is a substantial body of literature, which often provides conflicting advice, on the appropriate mechanism by which costs should be discounted over time, properly taking into account risks, inflation, positive time preference and expected productivity gains.

The absolute minimum option that one can adopt in discounting future income and costs is to set future values in current day dollar terms on the basis of a risk free assessment about the future (that is, assume the future flows are similar to the certain flows attaching to a long term Government bond).

Wages should be assumed to grow in dollar terms according to best estimates for inflation and productivity growth. In selecting discount rates for this project, we have thus settled upon the following as the preferred approach.

- **Positive time preference**: We use the long term nominal bond rate of 5.8% pa (from recent history) as the parameter for this aspect of the discount rate. (If there were no positive time preference, people would be indifferent between having something now or a long way off in the future, so this applies to all flows of goods and services.)

[24] Calculated from the non-indexed studies themselves. Converting the Access Economics average estimates from USD to AUD at PPP would provide slightly higher estimates - $3.9 million and $10.2m, with the same midrange estimate.

- **Inflation:** The Reserve Bank has a clear mandate to pursue a monetary policy that delivers 2 to 3% inflation over the course of the economic cycle. This is a realistic longer run goal and we therefore endorse the assumption of 2.5% pa for this variable. (It is important to allow for inflation in order to derive a real (rather than nominal) rate.)
- **Productivity growth**: The Commonwealth Government's Intergenerational report assumed productivity growth of 1.7% in the decade to 2010 and 1.75% thereafter. We suggest 1.75% for the purposes of this analysis.

There are then two different discount rates that should be applied:

- to discount income streams of future earnings, the discount rate is:
  5.8 - 2.5 - 1.75 = 1.55%.
- to discount other future streams (healthy life, health services, legal costs, accommodation services and so on) the discount rate is:
  5.8 – 2.5 = 3.3%

While there may be sensible debate about whether health services (or other costs with a high labour component in their costs) should also deduct productivity growth from their discount rate, we argue that these costs grow in real terms over time significantly as a result of other factors such as new technologies and improved quality, and we could reasonably expect this to continue in the future.

Discounting the VSL of $3.7m from Table 6-1 by the discount rate of 3.3% over an average 40 years expected life span (the average from the meta-analysis of wage-risk studies) provides an estimate of the value of a life year of $162,561.

6.2 ESTIMATING THE DISEASE BURDEN OF CD AND UC

6.2.1 YEARS OF LIFE LOST DUE TO PREMATURE DEATH

Based on a mortality risk of 1.47 for CD, there were an estimated 99 deaths (44 males and 55 females) associated with CD in 2005. There were no additional deaths associated with UC, as no significant increase or reduction of the mortality risk could be observed. In comparison, there were an estimated 211 deaths (93 males and 118 females) due to other causes in the population affected by CD and an estimated 379 deaths (227 males and 152 females) due to other causes in the population affected by UC.

YLL was then calculated from the age-gender distribution of deaths by the corresponding YLL for the age of death in the Standard Life Expectancy Table (West Level 26) with a discount rate of 3.3% and no age weighting. For the age-gender distribution of deaths, the total YLL in 2005 was estimated as 939 DALYs for CD (Table 6-2) and 0 DALYs for UC.

TABLE 6-2: DEATHS AND YLL ASSOCIATED WITH CD, 2005

	0-9	10-19	20-29	30-39	40-49	50-59	60+	Total
Deaths, Males	0	0	1	2	2	3	35	**44**
Deaths, Females	0	0	1	1	2	3	48	**55**
Deaths, Persons	0	0	2	3	4	6	83	**99**
YLL, Males	0	3	27	42	50	61	265	**448**
YLL, Females	0	1	14	31	43	58	343	**491**
YLL, Persons	0	4	41	73	93	119	608	**939**

Source: Access Economics.

6.2.2 YEARS OF HEALTHY LIFE LOST DUE TO DISABILITY

The disability weight used in this study is based on the AIHW estimate for CD and UC of 0.224 (Begg et al, 2007; Mathers et al, 1999). The number of people experiencing loss of wellbeing due to disability from CD and UC is estimated by gender as shown in Table 6-3, totalling 6,272 DALYs and 7,392 DALYs respectively.

TABLE 6-3: ESTIMATED YLD FOR CD AND UC, 2005

	Disability weight	Number of people with CD	YLD (CD)	Number of people with UC	YLD (UC)
Males	0.224	11,548	2,587	17,048	3,819
Females	0.224	16,452	3,685	15,952	3,573
Persons	0.224	28,000	6,272	33,000	7,392

Source: Access Economics

6.2.3 TOTAL DALYS DUE TO CD AND UC

Figure 6-1 and Figure 6-2 illustrate YLD and YLL due to CD and UC, which total 7,211 DALYs and 7,392 DALYs respectively. The greatest impact of both CD and UC is in the 60+ age group – in the case of CD due to the high disability burden for women (1,055 DALYs for females compared with 724 DALYs for males) and in the case of UC due to the disability burden for men (1,255 DALYs for males and 933 DALYs for females).

The estimated gross cost of lost wellbeing due to CD is $1,172 million in 2005 (calculated by multiplying 7,211 DALYs by the VLY of $162,561), while the estimated gross costs of lost wellbeing due to UC is $1,201 million in 2005 (based on 7,392 DALYs).

For IBD, **the estimated gross cost of lost wellbeing is $2.4 billion in 2005** (including $1.2 billion for CD and $1.2 billion for UC).

FIGURE 6-1: LOSS OF WELLBEING DUE TO CD (DALYS), BY AGE AND GENDER, 2005

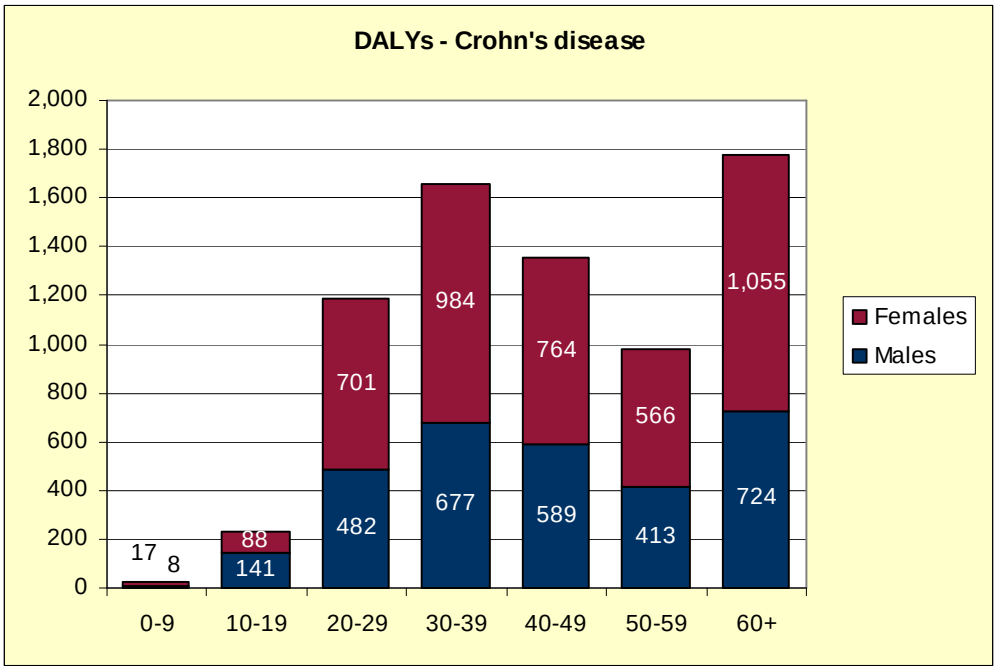
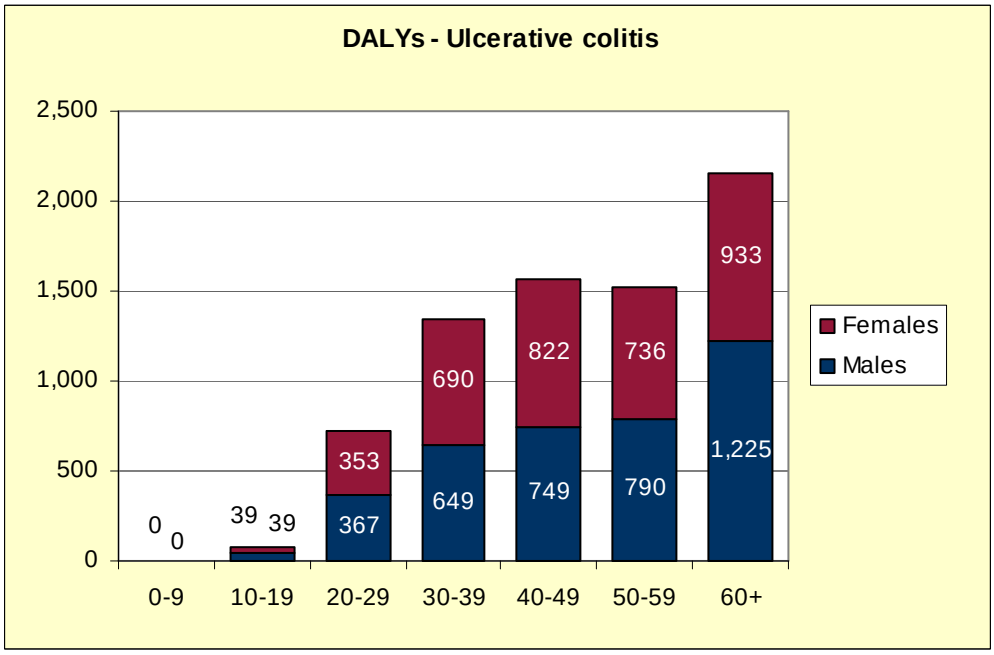


FIGURE 6-2: LOSS OF WELLBEING DUE TO UC (DALYS), BY AGE AND GENDER, 2005



6.2.4 NET VALUE OF HEALTHY LIFE LOST

Bearing in mind that the wage-risk studies underlying the calculation of the VSL take into account all known personal impacts – suffering and premature death, lost wages/income, out-of-pocket personal health costs and so on – the estimate of $2.4 billion should be treated as a 'gross' figure. However, costs specific to CD and UC that are unlikely to have entered into the thinking of people in the source wage/risk studies should *not* be netted out (eg, publicly financed health spending, care provided voluntarily). The results after netting out are presented in Table 6-4.

TABLE 6-4: NET COST OF LOST WELLBEING, CD AND UC, $M, 2005

	Individual (CD)	Individual (UC)	Individual (IBD)
Gross cost of lost wellbeing	**1,172**	**1,202**	**2,374**
Minus production losses net of tax	69	72	141
Minus health costs borne out-of-pocket	8	8	15
Net cost of lost wellbeing	**1,096**	**1,122**	**2,218**

The net cost of lost wellbeing due to CD was thus $1,096 million in 2005, while the net cost of lost wellbeing due to UC was $1,122 million.

The **net cost of lost wellbeing due to IBD was $2.2 billion in 2005.**

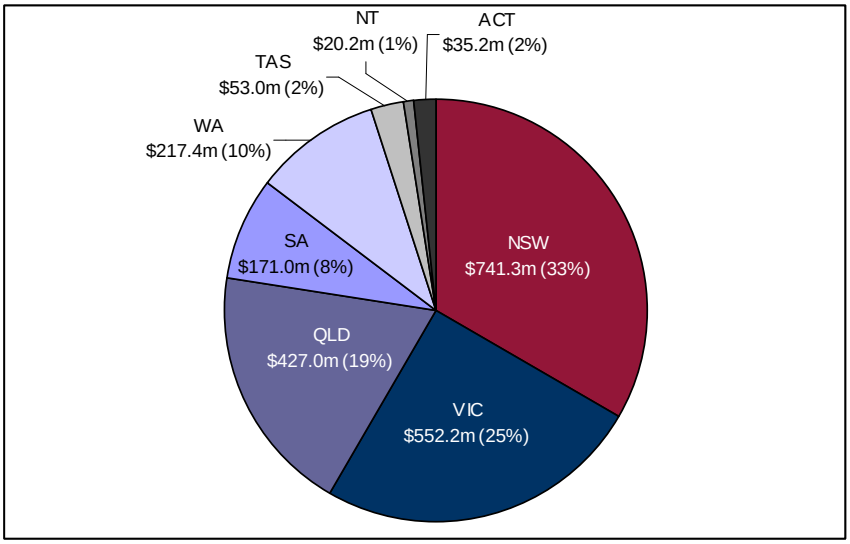
6.3 NET COST OF WELLBEING BY JURISDICTION

Net costs of wellbeing of IBD were then allocated to States and Territories. The distribution is summarised in Table 6-5 and Figure 6-3. All of the wellbeing costs are borne by individuals.

TABLE 6-5: OTHER FINANCIAL COSTS, BY JURISDICTION, 2005 ($M)

IBD	Australia	NSW	VIC	QLD	SA	WA	TAS	NT	ACT
Net cost of suffering	2,217.6	741.3	552.2	427.0	171.0	217.4	53.0	20.2	35.2

FIGURE 6-3: IBD, OTHER FINANCIAL COSTS, BY JURISDICTION, 2005



Matthew Tulk, Hornsby, NSW

I was diagnosed with Crohn's disease in March 2001 after months of treatment for a 'cyst' that turned out to be a painful fistula. I had lost weight very quickly,

from being around an 80Kg person to 60Kg. It was becoming noticeable where I worked at the time, with people asking if I was all right and saying I didn't look healthy.

Another fistula opened up on my other side and I had more surgery. The doctors told me my perianal disease and Crohn's was quite severe and that it was a major concern. My family was worried with my worsening condition because I was now bed-ridden. I went back into hospital to have larger tubes inserted into my bottom as the fistulas had opened up and I was in terrible pain. Even taking strong pain killers around the clock didn't help, not to mention the constant infections.

I had ulcerations from my mouth down through my oesophagus. I could not eat. I was in constant pain. I was forever taking salt baths to numb the pain and clean out any infections from the open fistulas. I was doing this around 6-8 times a day and during the night as this would ease the pain for about ten minutes at a time.

I faced the prospect of losing my lower colon as all other forms of treatment had failed. I had to stop working and started to fight for my life to overcome this illness.

7. CONCLUSIONS

This concluding chapter provides a summary of all costs associated with Crohn's and colitis, the distribution of these costs (across various levels of government, individuals and organisations), a comparison of IBD with other medical conditions (in terms of prevalence, health expenditures and burden of disease), and highlights key issues and strategies for ACCA going forward.

7.1 SUMMARY OF THE COSTS OF IBD

The economic cost of IBD in Australia is summarised in Figure 7-1, Figure 7-2 and Table 7-2.

- The total financial cost of IBD in 2005 was estimated as $496.8 million.
  - Of this, productivity costs were estimated as $266.7 million (55%), health system costs were $79.0 million (16%) and carer costs were $23.5 million (5%).
  - DWLs from transfers (taxation revenue foregone, welfare and other Government payments) were $91.3 million (18%) and out-of-pocket and funeral expenses were $36.2 million (7%).
- The net cost of lost wellbeing was valued at a further $2.2 billion, bringing the total economic cost of IBD in 2005 to $2.7 billion.

FIGURE 7-1: FINANCIAL COSTS OF IBD BY TYPE OF COST, 2005 (% TOTAL)

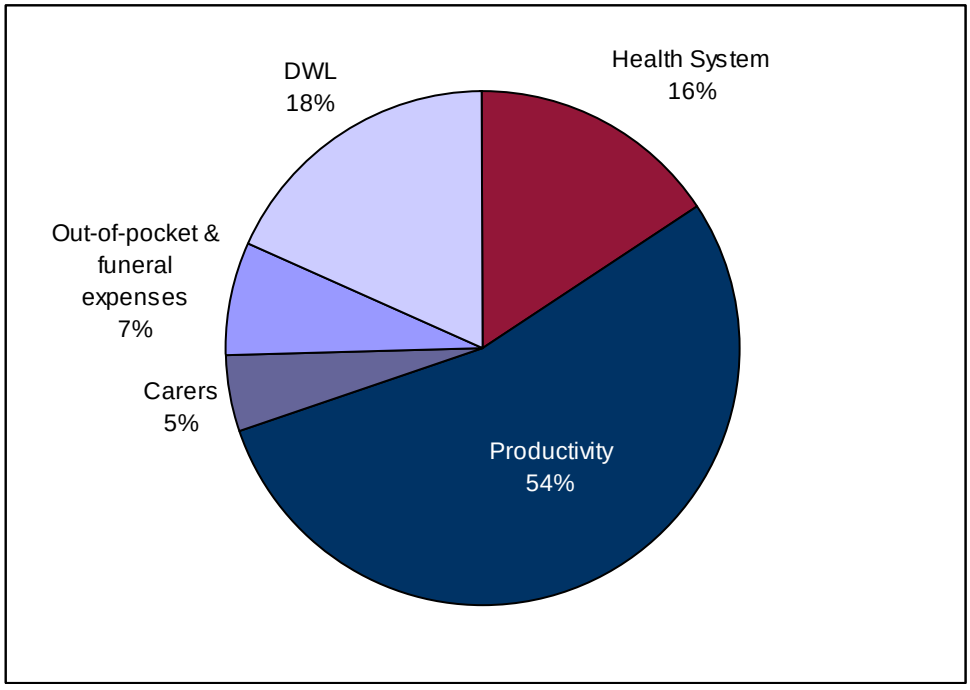
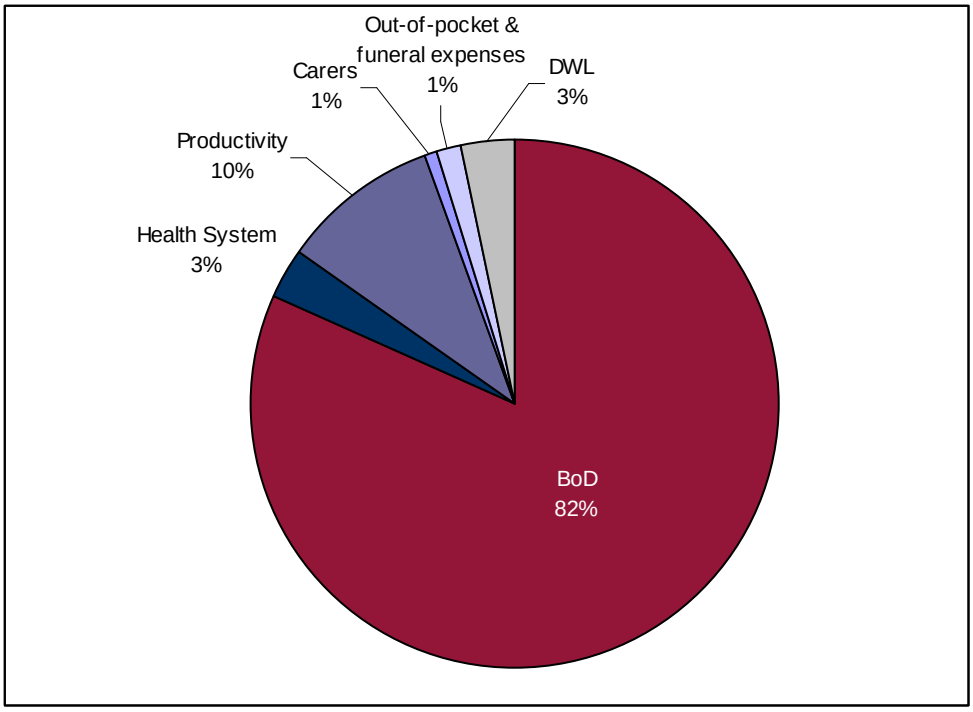


FIGURE 7-2: TOTAL COSTS OF IBD BY TYPE OF COST, 2005 (% TOTAL)



Different costs of diseases are borne by different individuals or sectors of society. Clearly the person with IBD bears costs, but so do employers, government, friends and family, co-workers, charities, community groups and other members of society.

It is important to understand how the costs are shared in order to make informed decisions regarding interventions. While the person with IBD will usually be the most severely affected party, other family members and society (more broadly) also face costs as a result of Crohn's and colitis. From the employer's perspective, depending on the impact of Crohn's and colitis, work loss or absenteeism will lead to costs such as higher wages (ie, accessing skilled replacement short-term labour) or alternatively lost production, idle assets and other non-wage costs. Employers might also face costs such as rehiring, retraining and workers' compensation.

While it may be convenient to think of these costs as being purely borne by the employer, in reality they may eventually be passed on to end consumers in the form of higher prices for goods and services. Similarly, for the costs associated with the health system and community services, although the Federal and State/Territory Governments meet a large component of this cost, taxpayers (society) are the ultimate source of funds. However, for the purpose of this analysis, a 'who writes the cheque' approach is adopted, falling short of delving into second round or longer term dynamic impacts.

Society bears both the resource cost of providing services to people with IBD, and also the 'deadweight' losses (or reduced economic efficiency) associated with the need to raise additional taxation to fund the provision of services and income support.

Typically the groups who bear costs and pay or receive transfer payments are:

- people with IBD;
- friends and family (including informal carers); } The Household
- employers;

- Federal Government;
- State and Local Government; and
- the rest of society (non-government, ie, not-for-profit organisations, workers' compensation groups etc).

Classifying costs by type and allocating them by who bears the costs enables a framework for analysis (see Table 7-1).

TABLE 7-1: SCHEMA FOR COST CLASSIFICATION

Conceptual group	Subgroups	Bearers of Cost	Comments
1. Health System Costs	Costs by type of service and prevalence	individual*, governments and society	
2. Other Financial Costs			
Productivity Costs	Lost productivity from temporary absenteeism	individual, employer and government#	
	Lost management productivity	Employer and government#	
	Long-term lower employment rates	individual and government#	Includes premature retirement
	Premature death	individual and government#	Loss of productive capacity
Carer Costs	Lost carer productivity	Friends and family, and employer#	Includes both paid and unpaid work
Transfer costs	DWL	Society	Relate to transfers from taxation, welfare etc
Other costs	Various, as able to be measured, but tend to be relatively small	Governments, individual, Friends and family and society,	Aids, modifications, travel, accommodation, respite/ palliative care, funeral costs etc
3. Non-financial (loss of wellbeing)	BoD (YLLs, YLDs, DALYs).	individual*	The net value of BoD should exclude other costs borne by the individual to avoid double counting

* Friends/family may also bear loss of wellbeing, health costs and lower living standards as a result of Crohn's and colitis; however, care is needed to assess the extent to which these are measurable, additional (to avoid double counting) and not follow-on impacts. For example, a spouse may pay a medical bill and children may share in lower household income when the individual's work hours are reduced – but as this is simply redistribution within family income it is not measured here. Moreover, if a family carer develops depression or a musculoskeletal disorder, it would be necessary to estimate the aetiological fraction attributable to Crohn's and colitis, allowing for other possible contributing factors.

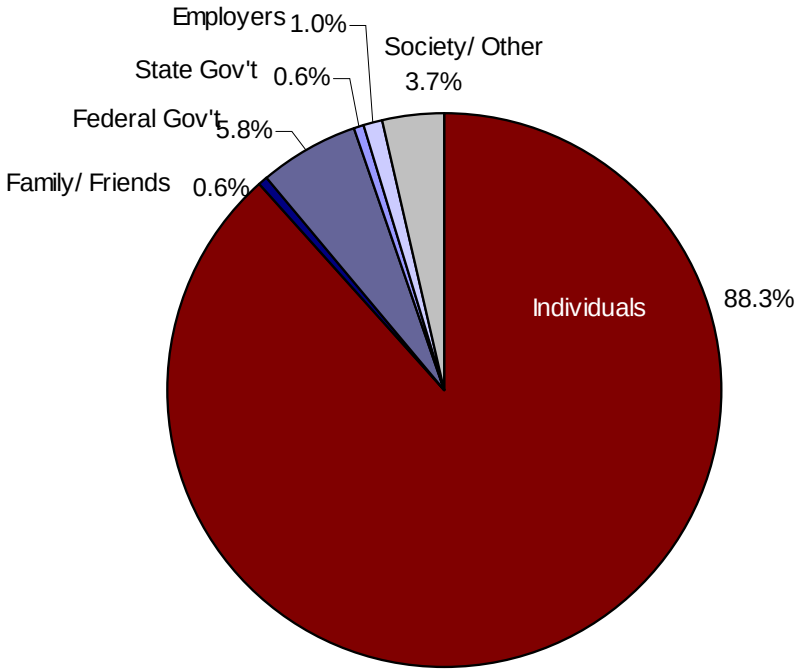
Where earnings are lost, so is taxation revenue and frequently also there are other transfers, such as welfare payments for disability/sickness/caring etc, so Governments share the burden.

TABLE 7-2: COST SUMMARY, CD, UC AND IBD ($M), 2005

	Individuals	Family/ Friends	Federal Gov't	State Gov't	Employ-ers	Society/ Other	Total
CD							
BoD	1,096.0	-	-	-	-	-	1,096.0
Health System	7.7	0.1	18.2	8.5	-	4.9	39.4
Productivity	68.6	-	47.3	-	12.9	-	128.8
Carers	-	6.8	4.0	-	-	-	10.8
Out-of-pocket & funeral expenses	16.2	0.4	-	-	-	-	16.6
DWL	-	-	-	-	-	43.1	43.1
Transfers	-6.0	-	6.0	-	-	-	-
Total financial	**86.4**	**7.3**	**75.5**	**8.5**	**12.9**	**48.0**	**238.7**
Total inc. BoD	**1,182.4**	**7.3**	**75.5**	**8.5**	**12.9**	**48.0**	**1,334.7**
UC							
BoD	1,121.6	-	-	-	-	-	1,121.6
Health System	7.7	0.1	18.3	8.6	-	5.0	39.7
Productivity	72.3	-	50.6	-	15.0	-	137.9
Carers	-	8.0	4.7	-	-	-	12.7
Out-of-pocket & funeral expenses	19.6	-	-	-	-	-	19.6
DWL	-	-	-	-	-	48.2	48.2
Transfers	-7.1	-	7.1	-	-	-	-
Total financial	**92.5**	**8.1**	**80.7**	**8.6**	**15.0**	**53.2**	**258.1**
Total inc. BoD	**1,214.1**	**8.1**	**80.7**	**8.6**	**15.0**	**53.2**	**1,379.7**
Total (IBD)							
BoD	2,217.6	-	-	-	-	-	2,217.6
Health System	15.4	0.2	36.5	17.1	-	9.9	79.0
Productivity	140.9	-	97.9	-	27.9	-	266.7
Carers	-	14.9	8.6	-	-	-	23.5
Out-of-pocket & funeral expenses	35.8	0.4	-	-	-	-	36.2
DWL	-	-	-	-	-	91.3	91.3
Transfers	-13.2	-	13.2	-	-	-	-
Total financial	**178.9**	**15.5**	**156.2**	**17.1**	**27.9**	**101.2**	**496.7**
Total inc. BoD	2,396.5	15.5	156.2	17.1	27.9	101.2	2,714.3

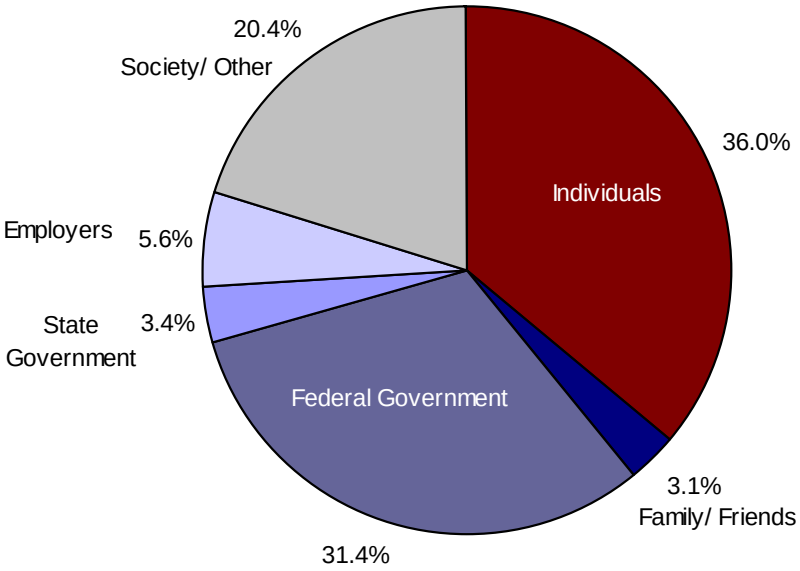
Of total IBD costs, 88.3% are borne by the individual, 0.6% by family and friends, 5.8% by Federal Government, 0.6% by State Government, 1.0% by employers and 3.7% by the rest of society (Figure 7-3).

FIGURE 7-3: TOTAL COSTS OF IBD BY BEARER, 2005 (% TOTAL)



However, of the financial costs only, the respective shares are 36.0%, 3.1%, 31.4%, 3.4%, 5.6% and 20.4% (Figure 7-4).

FIGURE 7-4: FINANCIAL COSTS OF IBD BY BEARER, 2005 (% TOTAL)



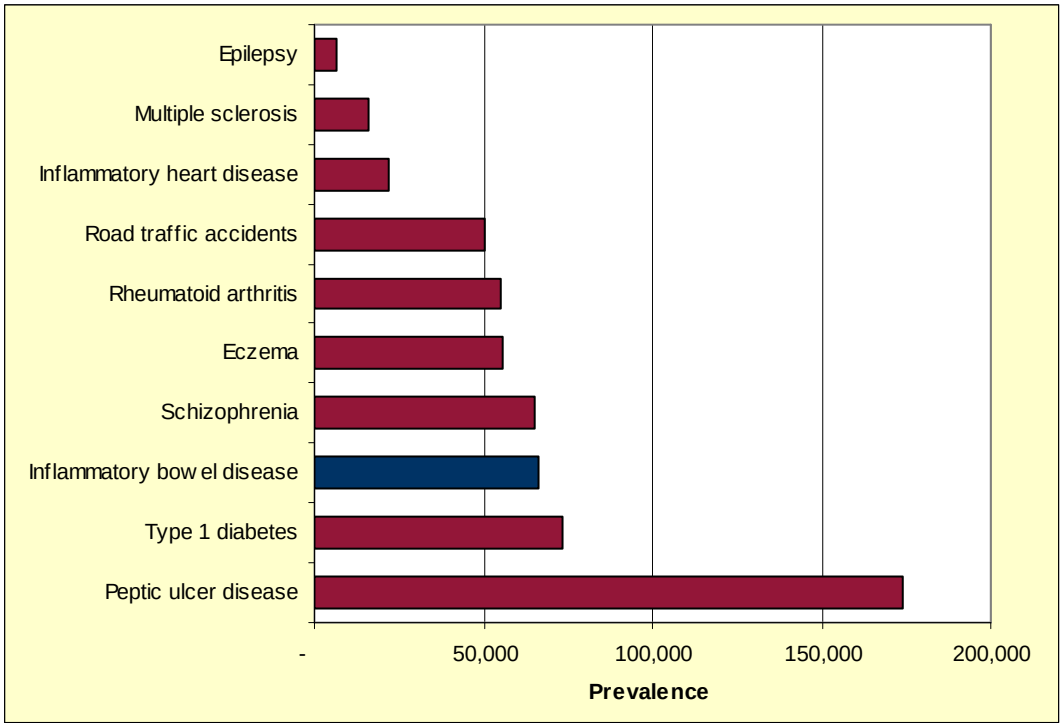
7.2 COMPARISON WITH OTHER CONDITIONS

This section compares IBD with other medical conditions in terms of prevalence, health expenditures and burden of disease.

7.2.1 PREVALENCE COMPARISONS

Figure 7-5 provides a comparison of the prevalence of IBD with that of other conditions, showing it to be more common than epilepsy or road traffic accidents. Its prevalence is comparable with Type 1 diabetes and schizophrenia.

FIGURE 7-5: COMPARISON OF PREVALENCE WITH OTHER CONDITIONS



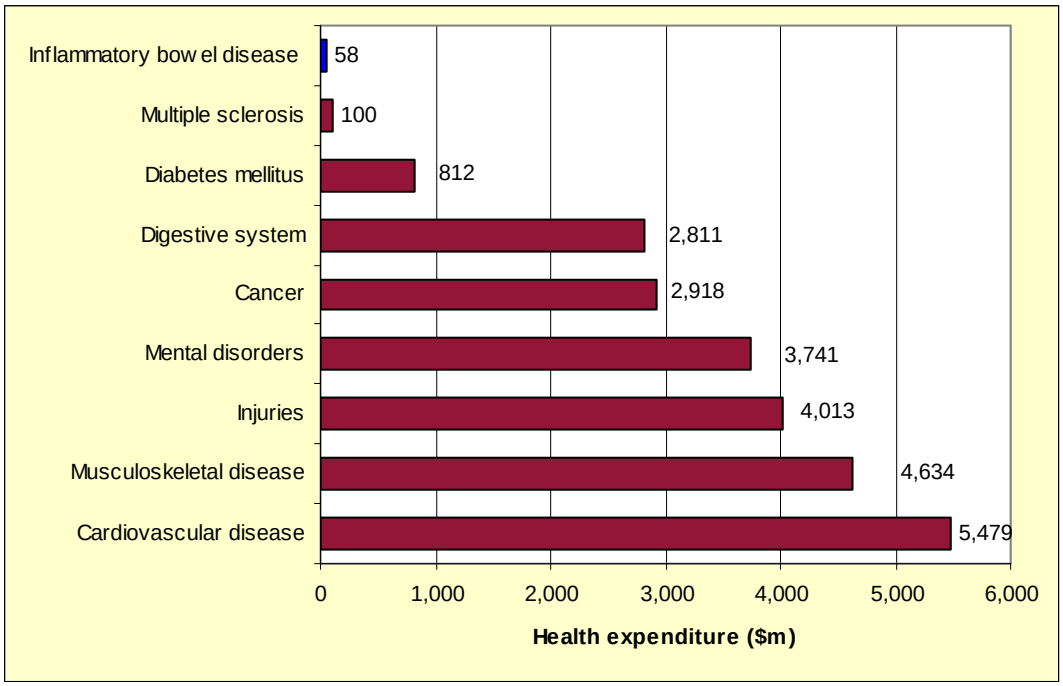
Source: Mathers et al (1999).

7.2.2 HEALTH COST COMPARISONS

Figure 7-6 compares allocated health expenditure for IBD with the national health priority areas. The year 2000-01 was used as the year of comparison as this provides the most recent data available for all disease areas.

Health expenditure on IBD was only 0.1% of the total allocated recurrent health expenditure in Australia.

FIGURE 7-6: HEALTH EXPENDITURE COMPARED WITH NATIONAL HEALTH PRIORITIES, 2001

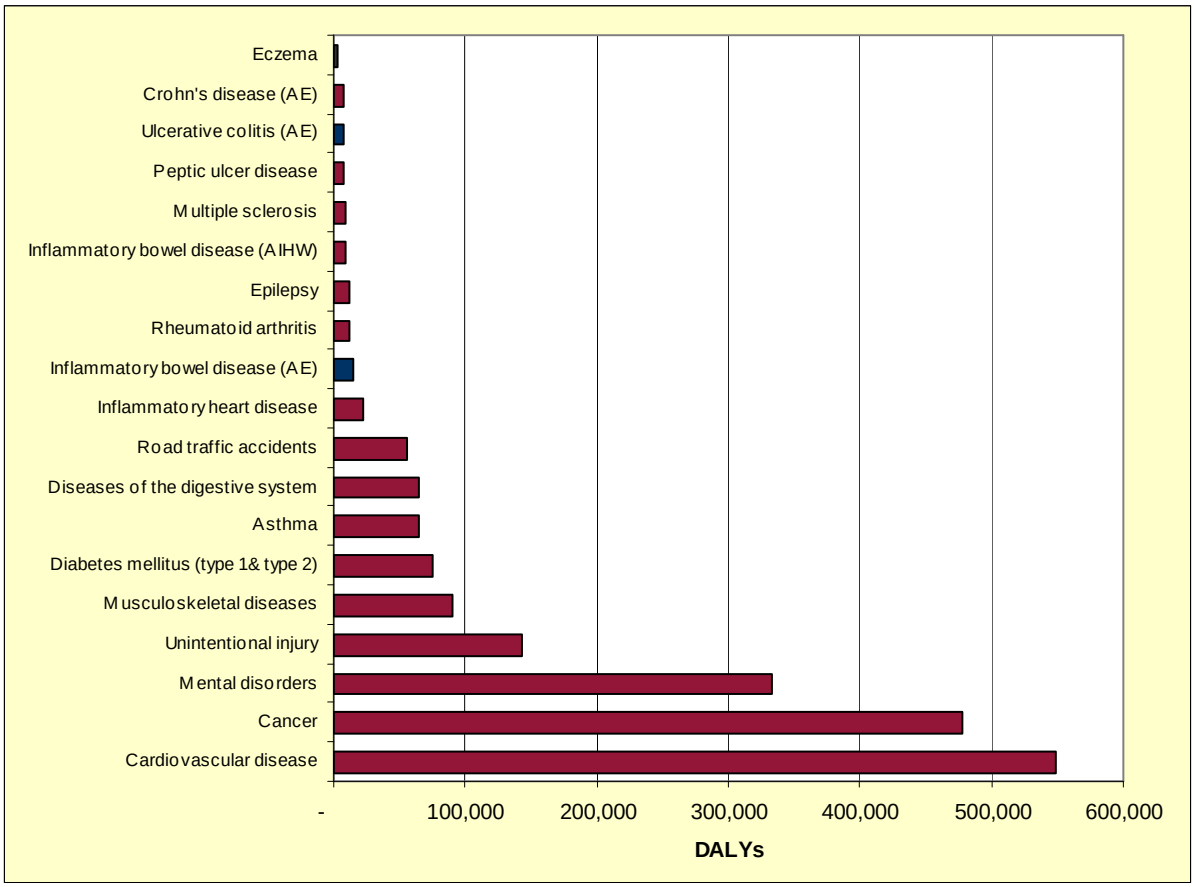


Source: AIHW (2005).

7.2.3 BoD COMPARISONS

Figure 7-7 compares DALYs lost due to IBD with other conditions. Within the original assessment of BoD by Mathers et al (1999) IBD accounted for about 0.4% (9,307) of all DALYs. Based on our estimates, the BoD from IBD is 14,603 DALYs, which is lower than that of the National Health Priority Areas except for rheumatoid arthritis, but higher than that of other conditions such as epilepsy, peptic ulcer disease or eczema.

FIGURE 7-7: COMPARISON OF DALYS WITH OTHER CONDITIONS

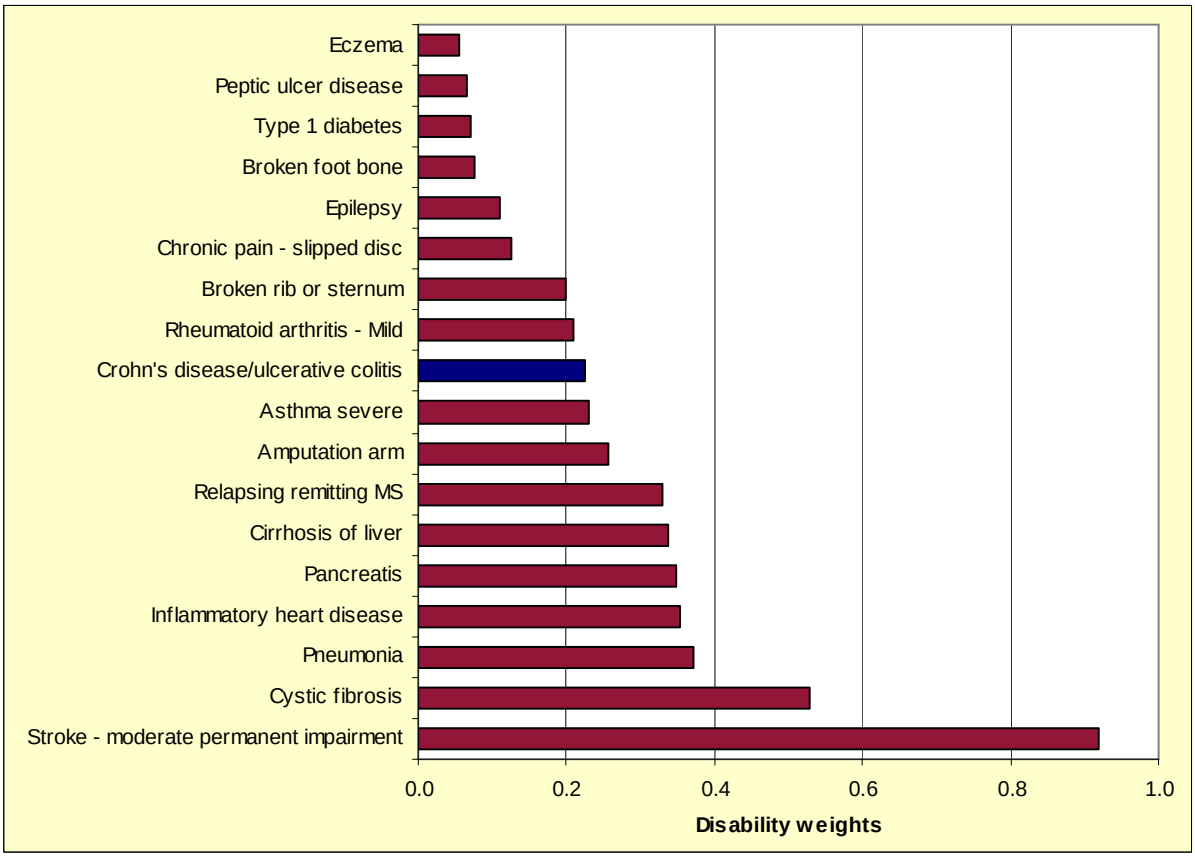


Source: Mathers et al (1999).

Another informative comparison of the burden of disability associated with IBD can be gleaned from a comparison of disability weights, reflecting the severity given to differing conditions. The comparison (based on AIHW data) is depicted in Figure 7-8.

CD and UC were evaluated by the severity against other conditions. It is comparable, for example, with a broken rib or sternum, mild arthritis, severe asthma or the amputation of an arm and disability is more severe than Type 1 diabetes or epilepsy.

FIGURE 7-8: DISABILITY WEIGHTS, CD, UC AND SELECTED COMPARATORS



Source: Mathers et al (1999).

7.3 CONSTRAINTS AND CHALLENGES

This section provides a qualitative overview, based on consultation with stakeholders, of current service delivery constraints and other challenges faced by people with IBD and their carers in relation to community awareness, diagnosis and assessment, services (eg, medical, pharmaceutical, community programs), research and evaluation, policy and planning.

7.3.1 COMMUNITY AWARENESS

The following problems were identified in relation to awareness.

- Community awareness levels are not high, with frequent misunderstanding between IBD and irritable bowel syndrome (IBS).
- Stigma is often associated with the conditions because of the nature of symptoms.
- Toilet access can be an issue, especially when toilets in social settings are kept locked and a key is required (eg, restaurants), that may take time to acquire. In a school setting, misperceptions (eg, teacher perceptions that a child to be trying to skip class rather than having a genuine need) are perhaps best resolved by conversations between parents and teachers, but in a community setting there may be a need for an action plan eg, a national “Can’t Wait” campaign to raise awareness of the urgency related to the disease and the need for immediate access to toilet facilities.

7.3.2 DIAGNOSIS

The evidence suggest that late diagnosis and inappropriate investigation and management are substantial problems with IBD. Spray et al (2001) found, based on referrals to specialists, a median delay of 47 weeks for CD and 66 weeks for those without diarrhoea; in UC the median was 20 weeks but was three years in the worst cases. In a similar setting but for children only, Heikenen et al (1999) had similar findings (7.1 months for CD and 6.7 months for UC) Barton et al (1990) found a median delay less than six months in a hospital setting. In terms of symptoms, Rath et al (1998) found that 38% of CD patients had an interval of more than a year between onset of symptoms and diagnosis. Pimentel et al (2000) found people could be symptomatic for years before diagnosis (a prodromal period of 7.7+/-10.7 years for CD and 1.2+/-1.8 years for UC), due to insidious onset as well as delays after presentation.

- Patients may be slow to present in part due to lack of information/awareness and stigma (Grandbastien et al, 1999).
- Symptoms may mimic functional disease (IBS) leading to misdiagnosis and delays.
- There can be a lack of awareness within the primary care community and Emergency Departments, which can impede diagnosis. At least some of the delay in diagnosis is due to the patient and the GP not recognising the symptoms and emphasises the importance of education.
- Differential diagnosis may be difficult for CD and UC.
- The disease is increasing in incidence, so health professionals may not have seen much of it previously.
- Access to endoscopy, gastroenterologists and radiology may be poor, particularly for regional or socioeconomically disadvantaged Australians.

7.3.3 ACCESS TO PHARMACEUTICALS

- Currently available treatments can have substantial side effects causing other chronic illnesses such as osteoporosis and arthritis.
- The cost of pharmaceuticals can be prohibitive, with difficulty in getting some drugs listed for reimbursement on the PBS, forcing some patients into surgeries (with their associated impacts) that might otherwise be avoidable.
- Particular access issues relate to biological therapies, due to the high cost and differential equity of access patterns in different jurisdictions. Access may depend on the insurance status of the patient – those with private health insurance may be able to obtain a limited supply – while those without depend on the local policies of the regional hospital.

7.3.4 HEALTH SERVICES

- There are geographical inequalities for diagnosis and treatment, and it would be worthwhile identifying the worst areas of need.
- There may be poor referral practices to IBD specialists.
- Access to endoscopy through the public sector is constrained (quantity rationed ie, through queuing).

7.3.5 EMPLOYMENT ISSUES

- Crohn's disease and colitis can have long term impacts on employment prospects, particularly due to the age of onset early in life; these demographic factors also mean that the person may not have built up adequate leave entitlements and superannuation, in comparison to diseases with later onset where more leave is able to be taken, which can then act to impede dismissal.
- There is poor employment protection against redundancy and demotions due to time required away from work, and reports of job loss due to illness are common.
- The effect of symptoms – fatigue, diarrhoea, pain and the secondary effects of medications – are not well understood or catered for in the workplace.
- There can be poor information and support for employers and employees in relation to IBD.

7.3.6 SUPPORT FOR PEOPLE WITH IBD AND THEIR CARERS

- There is a need for support for families dealing with a child with IBD, in particular in relation to sibling issues and strain on the parents' relationship with each other.
- Currently there is no public funding of community based delivery of support services for people with Crohn's and colitis (eg, ACCA relies on donations, sponsorship and membership fees).

7.3.7 RESEARCH AND DEVELOPMENT

- There is a need for more research into the 'cause, care and cure' of IBD, given current knowledge limitations, the scope for future gains and the trends towards increasing incidence.
- There is a need to further investigate the epidemiological observation that the incidence of CD is increasing (reasons are currently unknown) fairly rapidly ie, within generations rather than over generations.
- Environmental trigger research is a promising area for R&D – these factors may be modifiable.

7.4 NATIONAL STRATEGY

This section provides a framework for elements of a longer term national vision about future action that government, academia and the private sector could jointly pursue in disease management of Crohn's and colitis, following from the constraints and challenges identified in the previous section.

7.4.1 COMMUNITY AWARENESS

It is recommended that programs are developed and implemented to raise awareness and common understanding of CD and UC across Government, media and the general community. In particular such programs should aim for a change in community perceptions and attitudes to IBD and a reduction in stigma.

7.4.2 DIAGNOSIS

It is recommended that education programs are developed and implemented to raise awareness and knowledge across the medical and health sector, and particularly for GPs

and Emergency Departments to assist with earlier differential diagnosis, reduce misdiagnosis and reduce the long lags between onset of symptoms and diagnosis with treatment.

7.4.3 ACCESS TO PHARMACEUTICALS

It is recommended that biological therapies are considered for listing on the PBS, taking into account the full costs of CD, not just the health system expenditures. Better access to biological therapies can improve management of some of the most debilitating symptoms of IBD that prevent participation in employment and other forms of community life.

7.4.4 HEALTH SERVICES

It is recommended that referral practices to IBD specialists are reviewed to ensure timely access to specialist care, and geographical areas of need are identified, together with strategies for enhancing services to meet the specific needs of Australians disadvantaged in terms of geographical location (ie, rural and remote Australians), ethnicity or in terms of socioeconomic status. There needs to be continuing attention to workforce development in outer metropolitan and rural locations. Access to endoscopy in the public sector should be a particular focus. It is also recommended that community care is better coordinated, in particular across Australian and jurisdictional governments to result in more seamless, flexible and multidisciplinary care with the aim of supporting people in the community; any need for institutional accommodation should be age-appropriate and incorporate specific care for disease related symptoms.

7.4.5 EMPLOYMENT ISSUES

It is recommended that programs are developed aimed at retention and adaptation of existing jobs for people with CD and UC and other chronic illnesses. Such programs should involve innovative strategies such as workplace environment adaptation, job restructuring or tailoring, part-time and flexible work-from-home options, and transport assistance, as appropriate. Rehabilitation and workers' compensation models should be considered for integration into job retention policy and programs. Existing employer incentive schemes could be extended to include employers supporting workers with IBD and other disabilities in job retention programs. Education and awareness strategies should be developed to counter workplace misperceptions and discrimination against people with disabilities (including CD and UC) and encourage employers and employees to identify and implement positive long term solutions.

7.4.6 SUPPORT FOR PEOPLE WITH IBD AND THEIR CARERS

It is recommended that counselling, support, youth and family programs are designed and delivered to assist people with IBD and their family and carers, particularly respite care to assist employed carers. Support and respite services should be flexible, age-appropriate, lifestyle-friendly, timely and available over the long term. Improved case management input would help ensure good planning and packaging of services.

7.4.7 RESEARCH AND DEVELOPMENT

It is recommended that R&D efforts further investigate the epidemiological observation that the incidence of IBD is increasing, with particular emphasis on environmental trigger research as these factors may be modifiable.

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