

Improving the State of the Nation in Inflammatory Bowel Disease – Information for Decision Makers



What is inflammatory bowel disease and who are CCA?

Inflammatory bowel disease (IBD) refers to a group of chronic, relapsing immune-mediated conditions that cause severe inflammation in the gastrointestinal tract. The two most common IBD conditions are Crohn's disease and ulcerative colitis. IBD is incurable and has severe symptoms such as abdominal pain, weight loss, fever, diarrhoea, rectal bleeding, vomiting, and fatigue. Often, people require surgery and/or long-term medication to achieve disease remission (a period of good health, free of active disease, with few or no symptoms).

Crohn's & Colitis Australia (CCA) is a not-for-profit, patient organisation with a vision that ***All Australians living with IBD are diagnosed in a timely way and empowered to equitably access best practice, integrated care so that they can live fearlessly and to their full potential.***

In 2024, CCA commissioned Insight Economics to review the incidence, prevalence, economic, and disability burden of IBD in Australia. The report highlights the true extent of IBD, the personal and economic impacts on individuals, and the effect on our health system and the economy more broadly. **IBD stands out as the only chronic condition with a National Action Plan that has not received any investment in patient support services or care coordination.** There is a clear need for change in the health system, which requires action across all sectors, including investment from the Australian Government.

You can read the full IBD State of the Nation Report at <https://crohnsandcolitis.org.au/ibd-state-of-the-nation/>

Why is improving IBD care important?

There are nearly 180,000 Australians living with IBD. In contrast to other chronic conditions, IBD disproportionately affects Australia's working population due to the peak age of onset occurring between 15 to 29 years. Currently, 145,000 people living with IBD are working age adults. Outside the typical gastrointestinal IBD symptoms, 70% of people experience fatigue and/or brain fog which makes it hard to complete usual daily activities, and 48% have anxiety and/or depression.

The incidence of IBD is increasing globally, but Australia is leading the pack among similar nations. People experience significant delays to diagnosis, with more than 1 in 3 people



experiencing symptoms for over a year before diagnosis, and more than 1 in 10 people taking over 5 years to get diagnosed.

After fighting to get a diagnosis, 41% of people experience over 5 years of active, debilitating disease before achieving remission. **IBD patients are ‘frequent flyers’ of the hospital system, having a higher rate of hospitalisation and emergency department presentations per prevalent case than cancer or heart disease.** It is essential to improve the quality of care for people living with IBD so they can achieve remission sooner and live to their full potential.

IBD also has an extreme cost to individuals, workplaces, the healthcare system, and the government. Someone living with IBD spends an average of \$5,900 managing their disease each year. However, the cost is approximately \$19,000 for someone with severe disease when considering the loss of income from being unable to work. With the current cost of living pressures, the cost to individuals is unfair and unsustainable.

IBD has a total economic burden of **\$7.8 billion** estimated in 2025. The main contributors include \$759 million from hospital and emergency department visits, \$1.7 billion lost from years lived with disability, and \$1.6 billion in lost wages from being too ill to work. **Without government action, the costs will continue to rise year on year.**

What can the government do to help?

We need your assistance to stop IBD patients from falling through the cracks of our Australian federated health system. CCA, with support from health professional peak bodies, propose a Living Well with IBD program in primary care to support priority population groups to access multi-disciplinary care, which is the pillar of high-quality care. Priority population groups include paediatric patients, regional patients, Aboriginal and Torres Strait Islanders, Culturally and Linguistically Diverse Australians, elderly Australians, people with severely active disease, and people with severe mental health challenges that would not otherwise have access to care coordination. The Living Well with IBD program would be funded by the Australian Government through primary care and complement existing access to IBD services nationally. The program would also facilitate:

- One-on-one discussions with an IBD Care Coordinator, who could be a GP with IBD experience or a qualified IBD nurse.
- Medication reviews by a national panel of IBD pharmacists.
- Access to a group education and support program.
- A tailored plan of allied health services to improve wellness, including dietitian and mental health support.
- Timely support by an IBD Care Coordinator in the event of a flare-up.



Alongside the Living Well with IBD program, CCA seek support to establish a virtual multidisciplinary team network, enable national access to a clinical quality registry, invest in workforce development, allow streamlined specialist referrals for dietitians and psychologists to reduce the need for GP visits, and allow streamlined prescribing for new biologic medications.

At a cost of \$34.1 million over four years, funding the Living Well with IBD program and these supporting initiatives represents less than 0.01% of the total health budget. The proposed actions present a holistic strategy providing time-limited options that strongly align with government policy, objectives and agendas.

What difference would this make?

If the Commonwealth government were to fund the Living Well with IBD program for priority populations alongside implementing a virtual multidisciplinary team network, national clinical quality registry, workforce development, streamlined referrals and streamlined prescribing, the following impacts would be realised:

For the Commonwealth government

The proposed strategy will pay for itself from a Commonwealth perspective, providing nearly \$200 million of benefits from 2025-2035. **The benefit cost ratio (BCR) to the Commonwealth over 10 years is estimated to be 1.7** after taking into account the expected uplift in MBS claiming for allied and psychology health services that would be triggered based on improved access to multi-disciplinary care. If the proposed program benefits were considered only against the new, four year and time limited funding request, the BCR increases to 7.1. This number would be even higher if it were to include the benefits to households from avoided out-of-pocket costs and increased household wages.

Costs to the Commonwealth would be significantly reduced in the form of direct healthcare and income support costs. These costs are in the order of \$9,900 per person for all active disease and increase to \$15,400 per person for moderately to severely active disease. This represents a significant saving for each patient who can achieve remission sooner.

There would also be benefits from improved health service efficiencies as specialists would be able to refer patients to other services, reducing the need for patients to go back to the GP and make a Medicare claim. Investing in digital health infrastructure and a clinical quality registry would also facilitate improvements in clinical practice, leading to additional health service implementation improvements and attracting private sector investment in research.



For people living with IBD

The Living Well with IBD Program would greatly improve patient care and reduce government costs through allowing an additional 23,400 people to access a multi-disciplinary team.

Through accessing a multi-disciplinary team:

- The probability of achieving remission increases four-fold from 15% to 58%.
- Hospitalisation risk reduces by 30%.
- The risk of emergency department presentations reduces by 78%.
- A person's probability of working improves by 26%.
- The probability of a student staying in school triples.

Furthermore, 9,360 people would achieve remission at least one year sooner than they would have without extra access to care. Achieving remission sooner would see patients experience significant cost reduction as the cost of living with severe active disease is 2.5x the cost of living in remission. If the proposal is funded, the avoided financial costs to households in absolute terms are expected to be \$151 million because of earlier access to multi-disciplinary teams and the Living Well with IBD Program.

For Australia

Through the Living Well with IBD Program, Australia could become a global leader in IBD care and make real change to the lives of people living with IBD. Furthermore, having improved digital health infrastructure and a clinical quality registry would attract clinical trials and research investment in Australia.

For more information on this proposal you can meet with Leanne Raven, CEO at Crohn's & Colitis Australia.

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