State of the Nation in Inflammatory Bowel Disease in Australia

Final Report

February 2025

Crohn's & Colitis Australia

Insight Economics
Public Policy ■ Corporate Strategy

[This page is intentionally left blank]

Contents

Foreword

We are often asked the question: "How many people in Australia have inflammatory bowel disease and is it increasing?" Unfortunately, there is no national register of people with Crohn's disease or ulcerative colitis in Australia and the most recent report of national estimates was commissioned by Crohn's & Colitis Australia over 12 years ago.

Crohn's & Colitis Australia (CCA) has raised funds to commission studies by Access Economics in 2007 and by Pricewaterhouse Coopers in 2013. Since then, we have focused on quality of care publishing the Australian IBD Standards 2016, national audits of adult and paediatric hospital care in 2017 and 2023, studies of the patient experience of care for adults and children in 2018 and 2024, identifying consumer-driven research priorities for IBD, preparing the IBD National Action Plan for the Australian Government in 2019, and improving health information on IBD and education for health professionals via our GutSmart platform. Our focus has been to help our community live their lives more fully – or as we say fearlessly.

Understanding the prevalence and incidence of inflammatory bowel diseases (IBD) and its burden on individuals and the Australian community is essential for improving quality, equity and access to services for people living with these life-long, chronic inflammatory gut conditions. Current estimates are outdated and there is a need to establish new evidence from which to plan the next important steps to improve quality of life for people living fearlessly with IBD.

In 2024, we decided it is now time to revisit the prevalence and economic burden of IBD in Australia, given the significance for stakeholders to inform policy development, research, improvements in care pathways and quality of life for people with IBD. With this information in hand, we now have an opportunity to work with people with IBD, clinicians, researchers, policy makers, funders and other stakeholders to develop an economic impact analysis of the costs and benefits of specific priority actions to drive changes in our health system for improved outcomes. The State of the Nation report clearly highlights the true extent of IBD, the personal and economic impacts on individuals, on our health system and the economy more broadly. It provides a powerful base for the development of new care and business cases to improve the lives of the IBD community and enhance the productivity of the economy.

A report of this quality and importance only comes together with the best expertise and the right stakeholders around the table. We would like to acknowledge the skilled formulation of this report by Insight Economics, the stakeholder knowledge generously shared by our volunteer Advisory Committee and workshop participants and our project team at CCA.

We are grateful to our supporters without whom this milestone report would not be possible: health industry sponsors Pfizer Australia, Takeda Australia, Bristol Myers Squibb Australia, Abbvie and GSK as well as generous anonymous philanthropic donors.

Most importantly, we would like to thank the hundreds of people living with IBD who generously participated in the survey and contributed expert consumer input and feedback to this report.

Bruce Rosengarten
Chair
CCA

A/Prof Greg Moore
Chair
Scientific, Medical and Quality of Care Committee
CCA

Leanne Raven
CEO
CCA

[This page is intentionally left blank]

Executive Summary

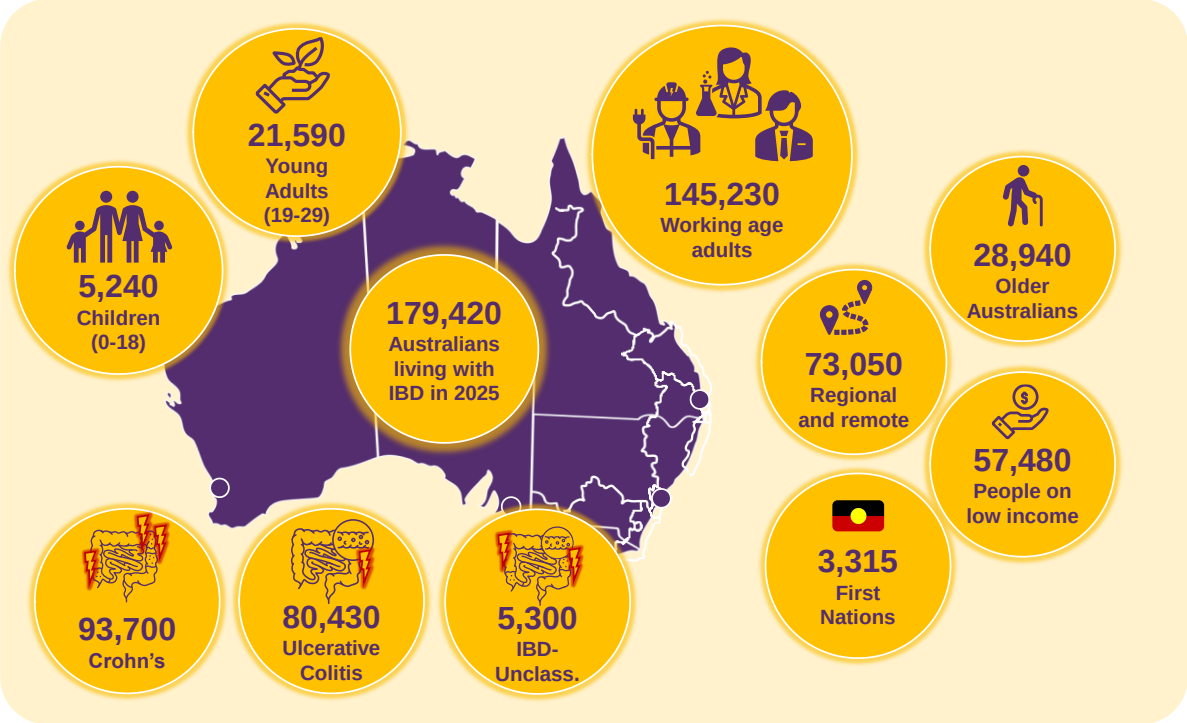
Understanding inflammatory bowel disease

Inflammatory bowel disease (IBD) describes chronic, relapsing, immune-mediated conditions involving inflammation of the gastrointestinal tract. The two predominant IBD conditions are:

- Crohn's disease, which involves inflammation in any part of the gastrointestinal tract
- Ulcerative colitis, which involves inflammation limited to the colon or large intestine.

It is estimated that nearly 180,000 Australians are living with IBD today, and within this, just over 91,000 are experiencing active disease (Figure ES.1).

Figure ES.1: Inflammatory bowel disease impacts young and working age Australians



Source: Insight Economics, see Appendix C.

The incidence of IBD is increasing globally, and Australia is leading the pack – the growth in prevalence for Australia is expected to outpace growth in Canada, the UK and New Zealand.

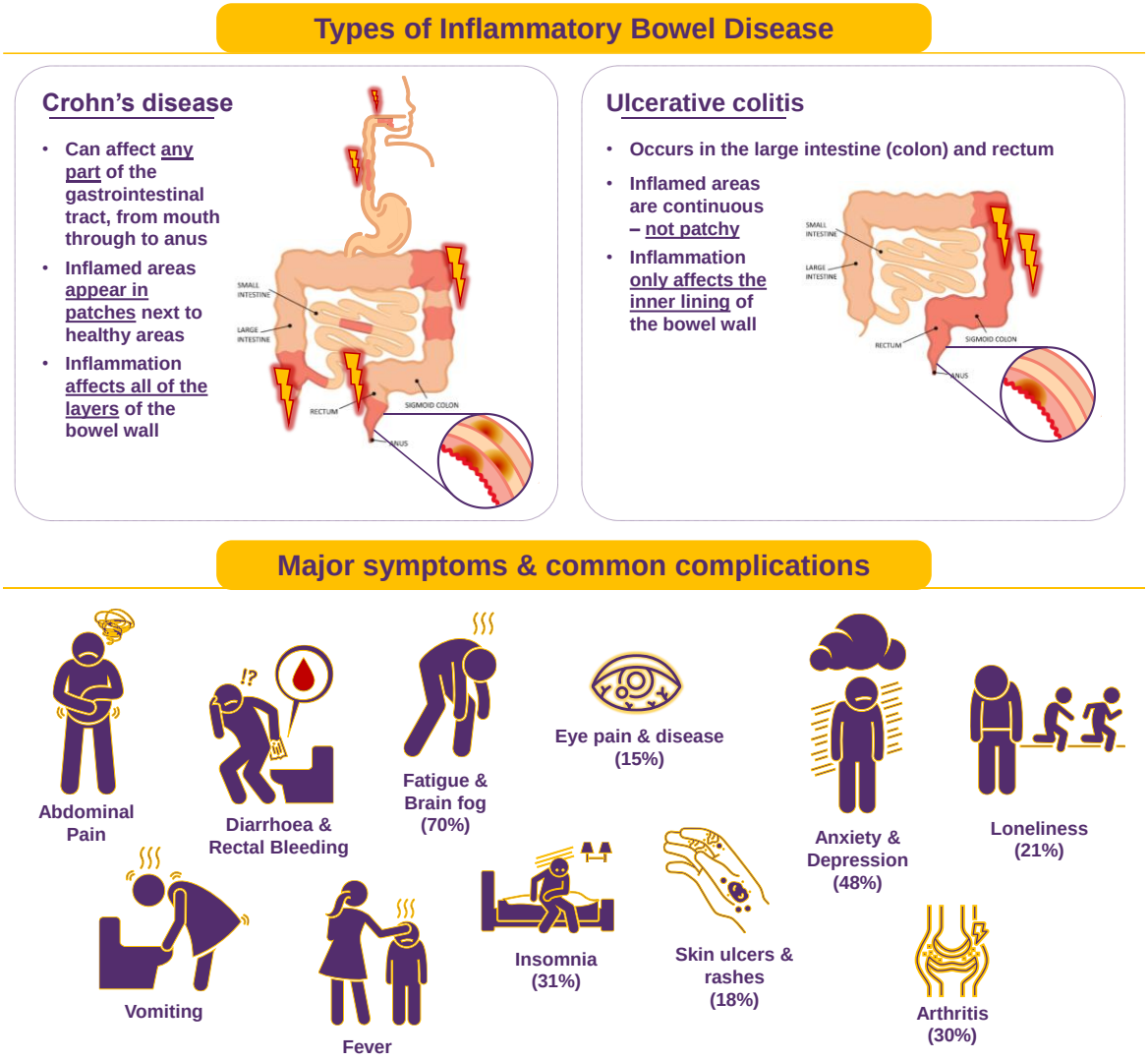
In contrast to other chronic conditions, the increasing prevalence of IBD is projected to disproportionately impact Australia's working population, with the peak age of onset occurring between 15 to 29 years.[1] The timing of the onset of the disease can therefore have an outsized impact on a person's life trajectory – impacting their ability to undertake or

[1] Gastroenterological Society of Australia, editor. 2018. *Clinical update for general practitioners and physicians : Inflammatory Bowel Disease* Gastroenterological Society of Australia, [Melbourne, Vic.] viewed 9 May 2024 http://nla.gov.au/nla.obj-2712116930.

complete education, on their ability to participate in the labour force and their ability to enjoy social connectedness.

People living with IBD experience an unpredictable pattern of relapse and remission, with symptoms including abdominal pain, weight loss, fever, diarrhoea, rectal bleeding, vomiting and fatigue (Figure ES.2).[2]

Figure ES.2: Understanding inflammatory bowel disease – major types, symptoms and complications



Source: Insight Economics, synthesising Gastroenterological Society of Australia, editor. 2018, Clinical update for general practitioners and physicians: Inflammatory Bowel Disease Gastroenterological Society of Australia, http://nla.gov.au/nla.obj-2712116930. Complication rates based on the State of the Nation Survey of People Living with Inflammatory Bowel Disease; see Appendix B.

In addition, IBD is also often associated with serious symptoms outside the bowel. Extraintestinal manifestations occur in 17 per cent of patients with UC and 37 per cent of patients with CD, including anemia, eye disease (uveitis and episcleritis), liver disease and scarring (cirrhosis), skin ulcers and psoriasis, and arthritis.

Patients also report severe fatigue and brain fog and a high mental health burden of disease. Many patients also experience severe anxiety and depression as a result of their IBD; in the Survey of Patients and Carers roughly one in two people reported experiencing

[2]Gastroenterological Society of Australia, editor. 2018. *Clinical update for general practitioners and physicians : Inflammatory Bowel Disease* Gastroenterological Society of Australia, [Melbourne, Vic.] viewed 9 May 2024 http://nla.gov.au/nla.obj-2712116930.

anxiety and one in three reported experiencing depression, as well as high rates of insomnia (Figure 1.3). Patients with IBD are also more likely to develop colorectal cancer than the general population.[3]

The experience of active disease not only causes physical suffering, but also prevents people from participating in the workforce and having an active social life. For example, around one in five people reported they had severe problems or were unable to enjoy or undertake important activities that most people take for granted:

- 17 per cent had severe problems or were unable to date or have intimate relationships
- 21 per cent had severe problems or were unable to participate in sports
- 20 per cent had severe problems or were unable to travel overseas.

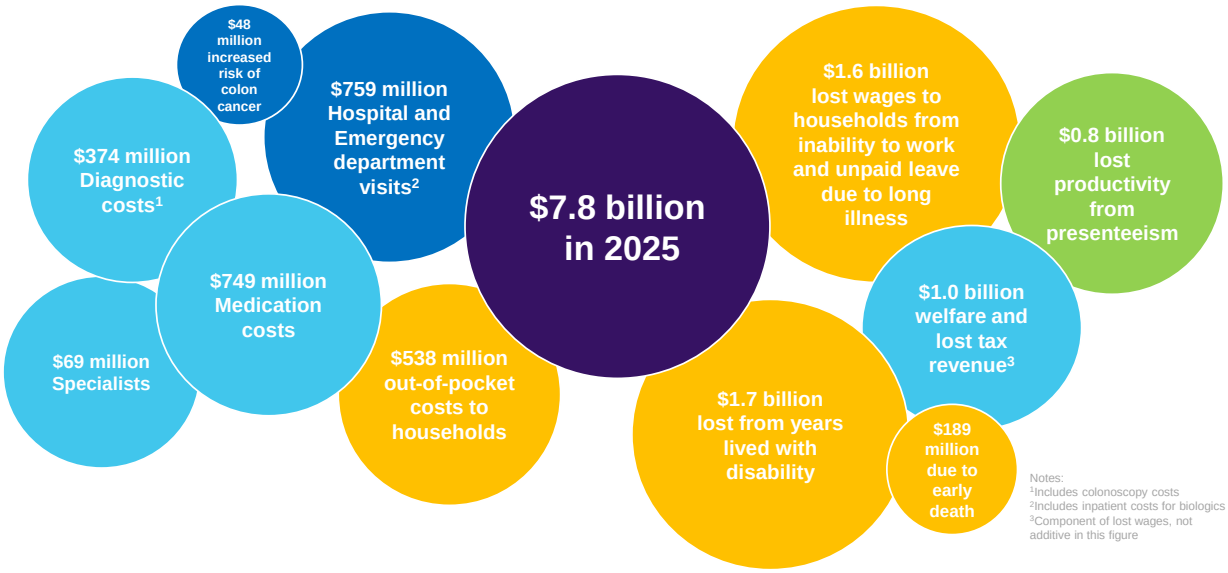
A similar pattern was observed for children with their parents reporting that their IBD created serious challenges for having an active social life, including their ability to participate in sports, their ability to sleep well at night, their ability to go to school and their ability to have friends. Significantly, parents reported:

- 18 per cent of children with IBD had severe problems or were unable to participate in sports
- 19 per cent of children with IBD had severe problems or were unable to sleep well at night
- 22 per cent of children with IBD had severe problems or were unable to go to school.

The health, economic and social costs of IBD to Australia

Taken together, the total economic impact of IBD to the community in 2025 is expected to be in the order of $7.8 billion (Figure ES.3).

Figure ES.3: Counting the economic costs of IBD in 2025



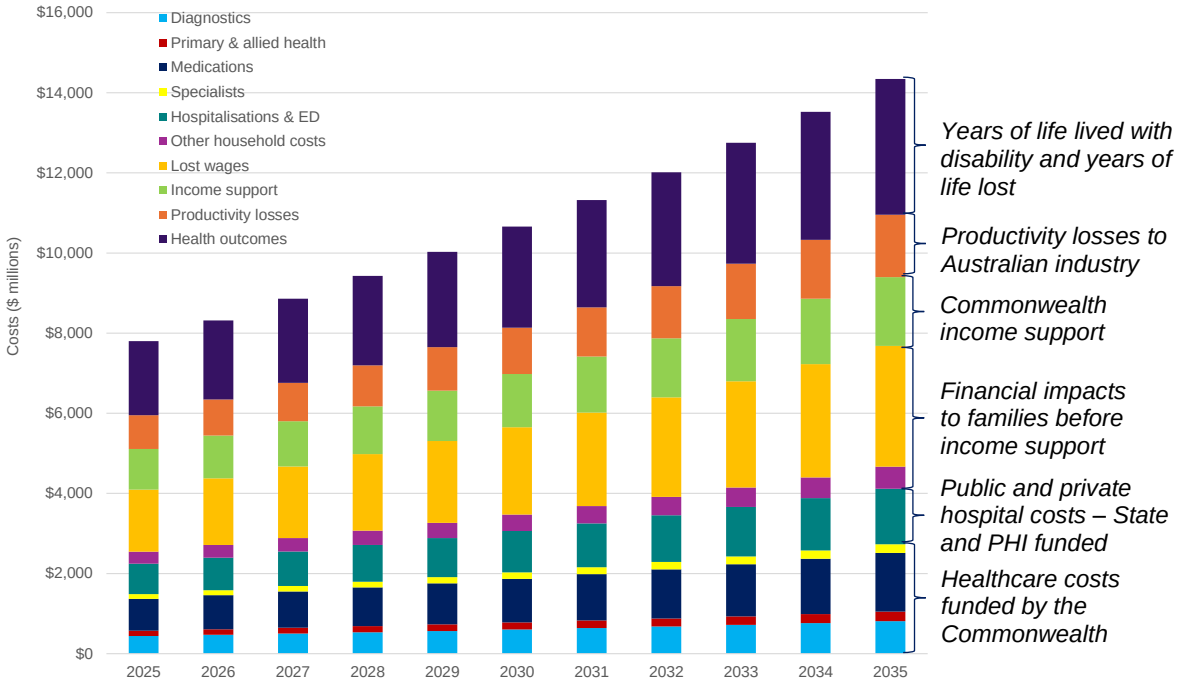
Source: Insight Economics; see Appendix C for method, data sources, key assumptions and calculations.

[3]Mattar, M. C., Lough, D., Pishvaian, M. J., & Charabaty, A. (2011). Current management of inflammatory bowel disease and colorectal cancer. Gastrointestinal cancer research : GCR, 4(2), 53–61; and Carchman E. (2019). Crohn's Disease and the Risk of Cancer. Clinics in colon and rectal surgery, 32(4), 305–313. https://doi.org/10.1055/s-0039-1683923.

Consistent with previous studies, and other chronic disease analysis, approximately one third of the cost is direct healthcare costs, with the balance, and majority of the impact is in the potentially preventable health impacts and wider economic costs arising from lower workforce participation, presenteeism and welfare support.

Over the next decade, in light of the increasing prevalence of IBD, the total economic burden is estimated to be a staggering $77.9 billion in net present value (NPV) terms, discounted at a social discount rate of 7 per cent ($NPV_{7\%}$) terms over the 2025-2035 period (Figure ES.4).

Figure ES.4: The costs of IBD to 2035 without action



Source: Insight Economics; see Appendix C for method, data sources, key assumptions and calculations.

Critically, the costs of IBD are high not only for governments, but for families. The out-of-pocket costs for people living with IBD and their families can be overwhelming given the need for frequent specialist visits, medications, diagnostic tests, allied health services and other out-of-pocket costs. On average, a person living with IBD can spend $5,900 each year managing their disease, which equates to around 10 per cent of the average Australian household's disposable income.[4]

The financial impact only compounds further if the disease becomes so severe that a person needs to reduce their working hours or leave the workforce altogether as a part of a recovery strategy. The average loss of income per active prevalent case was estimated to be in the order of $19,000. After factoring in the expected loss of income, out-of-pocket costs rise to be 15 per cent of disposable household income. For families from low-socioeconomic backgrounds the risk of financial hardship is high.

Poorly managed, IBD can be debilitating and expensive for the patient, their family and Australian governments

IBD is a complex condition that requires a multi-disciplinary approach involving gastroenterologists, IBD nurses, dietitians, psychologists, surgeons, pharmacists, GPs and

[4] Average disposable income was $1,124 in 2020 (Latest release); See ABS, 2022. Household Income and Wealth, Australia accessed at: https://www.abs.gov.au/statistics/economy/finance/household-income-and-wealth-australia/latest-release.

other healthcare providers to ensure comprehensive care to achieve remission and support a patient in the event of relapse.

While there is no cure for IBD, effective treatment can see a patient's IBD go into remission, with a patient experiencing few or infrequent symptoms and enjoying a quality of life in line with their peers. Poorly managed IBD, however, can result in a chronic cycle of disease flares, relapse, progression and surgery.

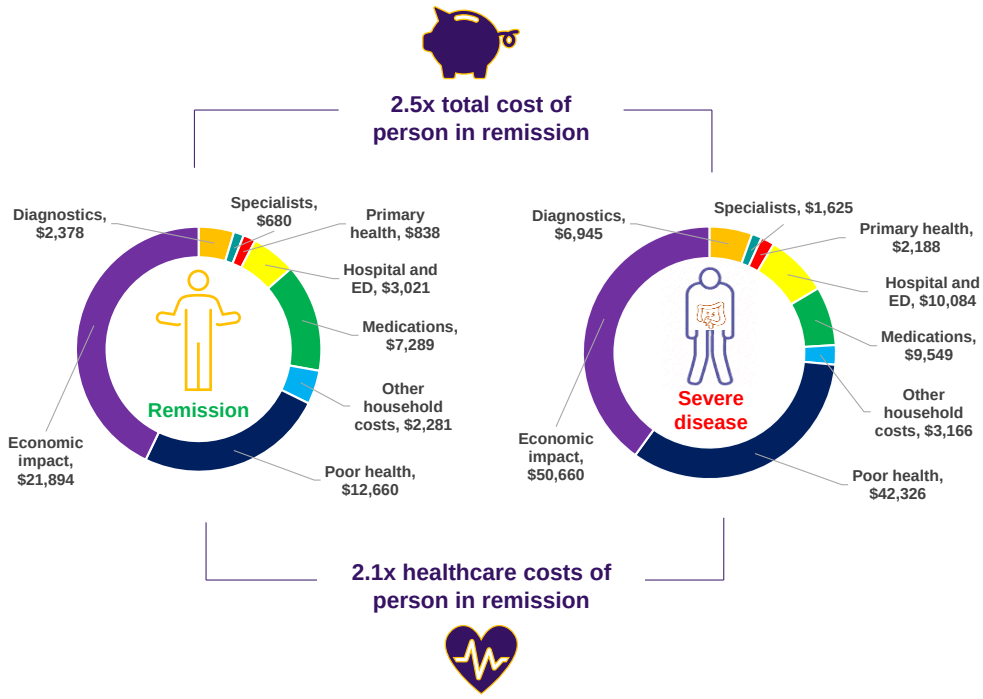
High-quality care for IBD should prioritise sustaining long-term remission through comprehensive, patient-centred management plans that include regular monitoring, early proactive treatments and personalised treatment adjustments.[5]

For example, data from the State of the Nation Survey of People Living with IBD showed for a person with moderate to severely active disease, compared to a person in remission:

- The risk of hospitalisation increases by 67 per cent
- The risk of emergency department presentations triples
- The number of sick days increases five-fold
- The probability of workforce participation halves
- The number of days missed from school triples
- The risk of dropping out of school triples
- A person's ability to have an active social life halves
- A person's quality of life reduces by 22 per cent
- Their carer's quality of life reduces by 14 per cent.

Taken together, the total economic cost of a person living with severely active disease is 2.5 times that of a person in remission (Figure ES.5).

Figure ES.5: The economic cost of severely active disease



Source: Insight Economics. See Appendix C.

[5] Mehta, F., 2016. Report: economic implications of inflammatory bowel disease and its management. *The American journal of managed care*, *22*(3 Suppl), pp.s51-60

IBD patients are 'crowded out' and falling through the cracks of Australia's federated healthcare system

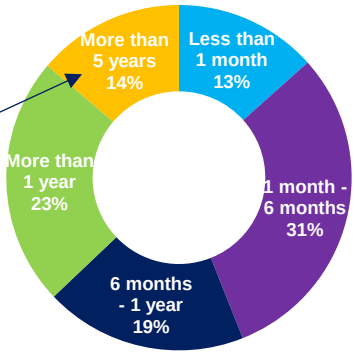
In spite of these high health and economic costs associated with poor disease management, there is evidence to suggest that Australian IBD patients are falling through the cracks.

For example, the average time-to-diagnosis for people living with IBD is astonishingly long. More than 1 in three patients experience symptoms *over a year* before receiving diagnosis. Just over one in 10 patients experienced symptoms *for over five years* before receiving a diagnosis (Figure ES.6).

Figure ES.6: Long time to diagnosis

More than 1 in 3 patients experience symptoms for over a year before receiving a diagnosis…

… and within this, more than 1 in 10 people reported it took more than 5 years to get a diagnosis.

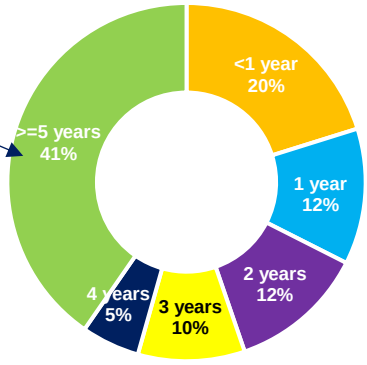


Source: State of the Nation Survey of People Living with Inflammatory Bowel Disease (See Appendix B).

Following the long delay to diagnosis, there are then often further delays in the time to remission (Figure ES.7). The weighted average time from diagnosis to disease remission was conservatively three years, with *more than 40 per cent of people reporting it took more than 5 years to bring their disease under control.*

Figure ES.7: Long time to remission

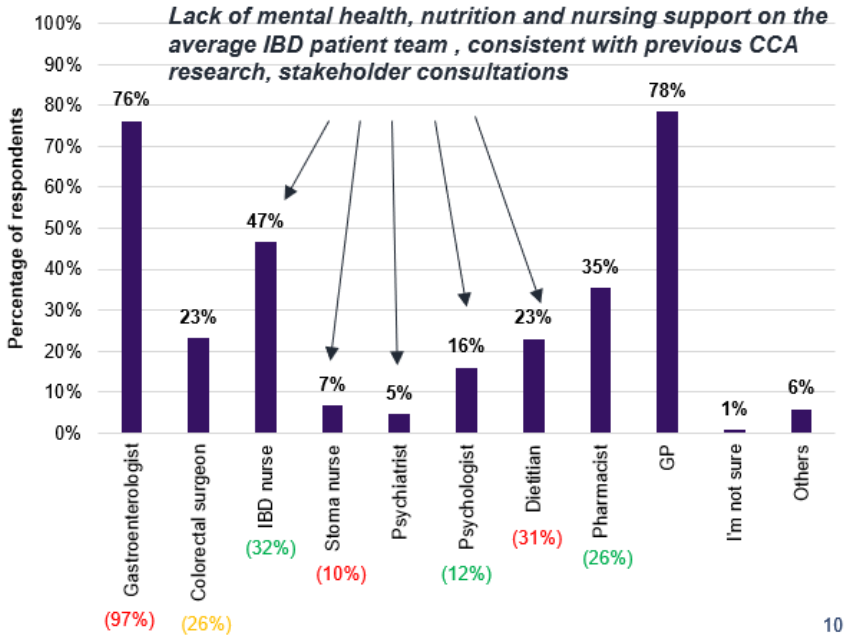
41% of patients reported it took more than 5 years before their IBD symptoms were under control (in remission)



Source: State of the Nation Survey of People Living with Inflammatory Bowel Disease (See Appendix B).

This is a function of inconsistent access to multi-disciplinary teams (Figure Es.8), as well as variation in clinical practice and challenges in the timely access to medicines, particularly for paediatric patients.

Figure ES.8: Poor access to multi-disciplinary health team persists, and in some cases has worsened



Source: Crohn's & Colitis Australia. (2018). My IBD Experience: Australian Inflammatory Bowel Disease Patient Experience of Health Care, Research report 2018, *2018 My IBD Experience results in parentheses, Figure 4, p12.

As a result, IBD patients are among the most 'frequent flyers' of the hospital system, having a higher rate of hospitalisation and emergency department presentation than even cancer.

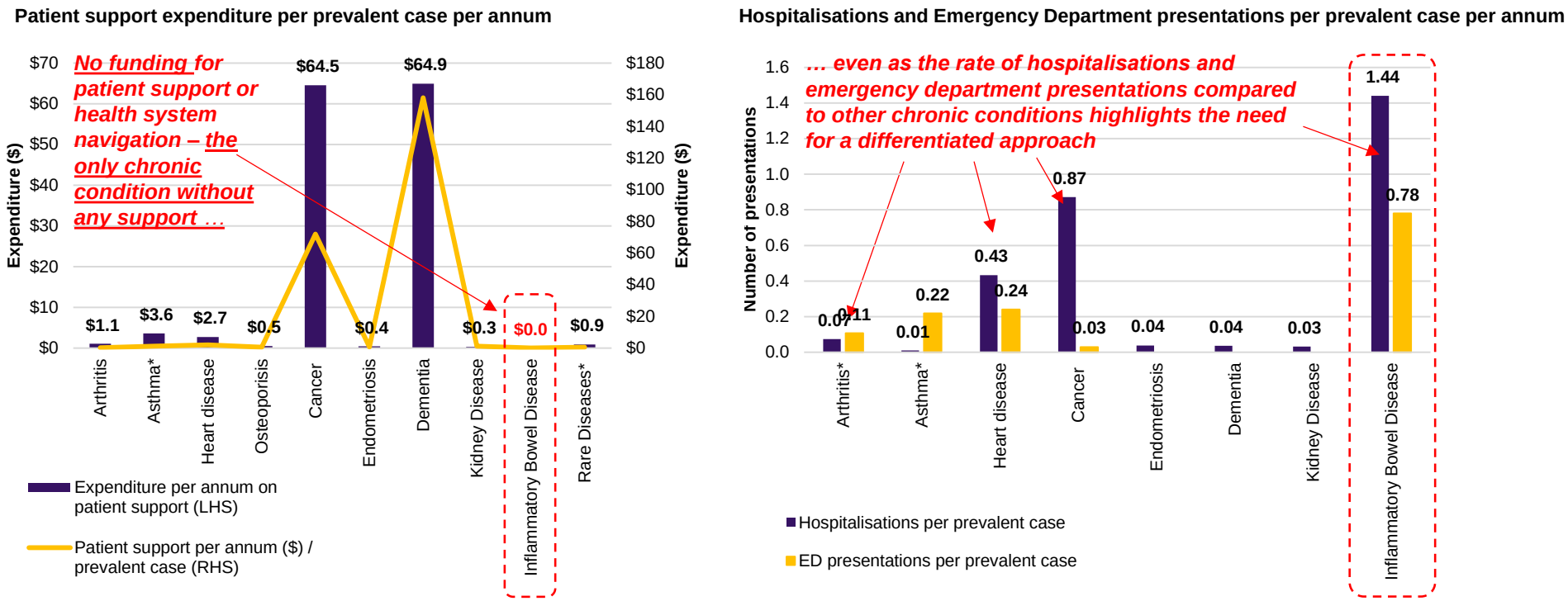
And yet, it is the only condition for which there has been no funding for patient support over the past 10 years, even as key items in the National Action Plan for IBD, launched in 2019, recommended improved access to multi-disciplinary care (Figure ES.9).

In a similar vein, IBD has also seen the least amount of research funding of any chronic condition over the past 10 years, in spite of these high rates of health service utilisation and disease burden.

These data raise questions of whether IBD is being 'crowded out' by other chronic conditions, which get more policy focus and funding by virtue of their patient volumes. Even on a lifetime prevalence basis, which includes people who may have achieved long run remission of their IBD, the prevalence of IBD is dwarfed by other conditions. In practice this can make it relatively easier to overlook or ignore compared to other conditions, particularly when the patient community may feel a stigma or shame associated with their condition, which may tend to mute their advocacy relative to others.

Apart from the National Action Plan in IBD, which did make important investments in GP awareness, consumer education and paediatric research, there is little to no policy reform or investment on the agenda for IBD at any level of government beyond more general strategies for healthy eating, smoking cessation and other general public health strategies for chronic condition management.

Figure ES.9: Benchmarking chronic conditions in Australia — Rates of hospitalisations and emergency department presentations per prevalent case compared to patient support per prevalent case



Source: Patient support data based on Grants Connect data, 2014-2024; hospitalisations per prevalent case based on AIHW data.

Research has shown evidence-based solutions are available to improve outcomes for people living with IBD

There is very substantial evidence, however, to show that the implementation of these action still has merit, with very significant health and economic benefits expected from improving access to multi-disciplinary teams. For example, research has shown that access to multi-disciplinary team care:

- Increases the probability of achieving remission nearly four-fold, from 15 per cent to 58 per cent probability of being in remission[6]
- Reduces the risk of hospitalisations by 30 per cent.[7]
- Reduces the risk of surgeries by 44 per cent[8]
- Reduces the risk of corticosteroid dependence by 61 per cent[9]
- Reduces the risk of emergency department presentations by 78 per cent[10]
- Improves a person's probability of working by 26 per cent[11]
- Triples the probability of a student staying in school
- Improves a person's ability to have a more active social life by 50 per cent.

Improving access to multi-disciplinary care will be a multi-step process involving reform and investment by federal and state governments working together to address care coordination challenges. Key opportunities to facilitate improved access to multi-disciplinary care include:

- Introducing a clinical care standard for inflammatory bowel disease
- Developing a national, virtual network of multi-disciplinary teams
- Improving access to care coordination, potentially through a Living Well with IBD program that could be delivered through Primary Health Networks
- Other foundational investments and reforms, including workforce development, digital health technologies to support shared care and reforms to streamline prescribing and referrals by clinicians to free up time to be redirected to higher, better uses.

In addition to improving access to multi-disciplinary care, other major opportunities to improve outcomes for people living with IBD include:

- Improving access to novel therapies through engagement by the IBD community with regulators following the release of the Health Technology Assessment review

[6] Ferman, M. et al., (2018). Multi-disciplinary team meetings appear to be effective in inflammatory bowel disease management: an audit of process and outcomes, Intern Med J, 48: 1102-1108. https://doi.org/10.1111/imj.13965
[7] Sack, C., Phan, V. A., Grafton, R., Holtmann, G., van Langenberg, D. R., Brett, K., Clark, M., & Andrews, J. M. (2012). A chronic care model significantly decreases costs and healthcare utilisation in patients with inflammatory bowel disease. *Journal of Crohn's & colitis*, *6*(3), 302–310. https://doi.org/10.1016/j.crohns.2011.08.019
[8] Peña-Sánchez, J. N., Lix, L. M., Teare, G. F., Li, W., Fowler, S. A., & Jones, J. L. (2017). Impact of an Integrated Model of Care on Outcomes of Patients With Inflammatory Bowel Diseases: Evidence From a Population-Based Study. *Journal of Crohn's & colitis*, *11*(12), 1471–1479. https://doi.org/10.1093/ecco-jcc/jjx106
[9] Ibid.
[10] Goren, I., Barkan, R., Biron, I. A., Leibovitzh, H., Golan, M. A., Eran, H. B., Snir, Y., Broitman, Y., Konikoff, T., Amir-Barak, H., Yafee, H., Adani, E., Shiber, S., Steiner, H., Drescher, M. J., Dotan, I., Yanai, H., & Israeli IBD Research Nucleus (IIRN) (2022). Specialized Emergency Department Assessment and Multi-disciplinary Intervention After Discharge Improve Management of Patients With Inflammatory Bowel Diseases. *Journal of clinical gastroenterology*, *56*(2), 148–153. https://doi.org/10.1097/MCG.0000000000001490
[11] Survey of People Living with Inflammatory Bowel Disease, See Appendix B.

- Investing in research into the prevention, symptom management, treatment and lived experience of IBD
- Reducing out-of-pocket costs through reforms to funding models for selected diagnostics, increased investment in co-located public and private IBD clinics
- Improving income support for people living with IBD, particularly for low-income households against the backdrop of ever-increasing cost of living.

For people living with IBD, the State of the Nation Survey of People Living with Inflammatory Bowel Disease revealed the highest priorities for consumers are:

- Improving access to medicines through the PBS (#1 priority)
- Investing in research to develop new treatments (#2 priority) and to prevent the onset of IBD (#3 priority)
- Improving access to specialists (#4 priority) and multi-disciplinary teams (#8 priority)
- Reducing out-of-pocket costs (#5 and #9 priority) and improved access to diagnostics on the Medical Benefits Scheme (MBS) (#6 priority)
- Improving awareness of IBD (#7 priority)
- Improving access to care closer to home (#10 priority).

A 2030 vision for people living with IBD

Five years on from the National Action Plan for IBD, and in light of these existing challenges and potential opportunities for improvement, it is timely to refresh and refocus the policy agenda for IBD. In partnership with the IBD community Crohn's & Colitis Australia have set a vision for 2030 for all people living with IBD.

Figure ES.10: A refreshed vision for IBD in 2030

Source: Policy prioritisation workshop with IBD consumers and clinicians October 2024.

This vision, developed with the IBD community, emphasises the need for:

- Improved *timeliness* of diagnosis

- Improved *equity* of access – including for children and people living in regional areas
- The *empowerment* of consumers through information and support
- Delivery of *best practice, integrated* care so that no one living with IBD suffers unnecessarily.

In line with the *Measuring What Matters* framework, this will help Australians to live fearlessly and *to their full potential.*

Top 3 priorities for the next horizon

To realise this vision, the following three major priorities have been identified for implementation within the next five years (Figure ES.11). These include:

- *Priority 1: Improve access to multi-disciplinary care* — Together with the IBD community, Australian governments should work together to progressively increase access to multi-disciplinary team care. Because of the proven benefits that can be realised from such an approach in the short term, the goal would be to see action on this priority within the next three years. Ideally, a robust package of reforms could be implemented to build the foundations for quality, safe and coordinated care, including the implementation of a clinical care standard, support for the development of a national network of multi-disciplinary teams, a Living Well with IBD program, delivered through the Primary Healthcare Networks, and national access to a shared patient record, with reporting into a clinical quality registry for IBD.
- *Priority 2: Improve access to novel therapies* — Following on from the release of the Health Technology Assessment (HTA) review, the IBD community could engage with the Department of Health and Aged Care, HTA Implementation Committee and regulators to progress improved access for novel therapies, including in particular for paediatric patients.
- *Priority 3: Invest in IBD research* — In light of the low levels of funding for IBD research compared to other chronic conditions and high unmet needs of the community, a competitive call for Medical Research Future Fund research for IBD could be issued, similar to other areas of research priority. This would include investment in basic science and clinical research to improve the potential for disease prevention, new treatment options, better symptom management and understanding of the lived experience and outcomes of people living with IBD. Australia has the potential to develop a strategic, structured data asset in IBD if it were to support access to a shared patient record linked to a clinical quality registry. While the data asset could deliver improvements in patient care in its own right, it could also see the attraction of additional private sector investment in research.

Benefits of action

Because the cost of active disease is so great, preventing even one year of disease, for even a small number of people, would be expected to yield considerable health, economic and social benefits. Each of these priority actions would be expected to improve the probability of more people living with IBD achieving disease remission.

For example, improving access to multi-disciplinary care today would deliver a rapid, step change improvement in outcomes in the short term – with research showing that access to multi-disciplinary team care is associated with a 3.9 times higher probability of achieving remission.

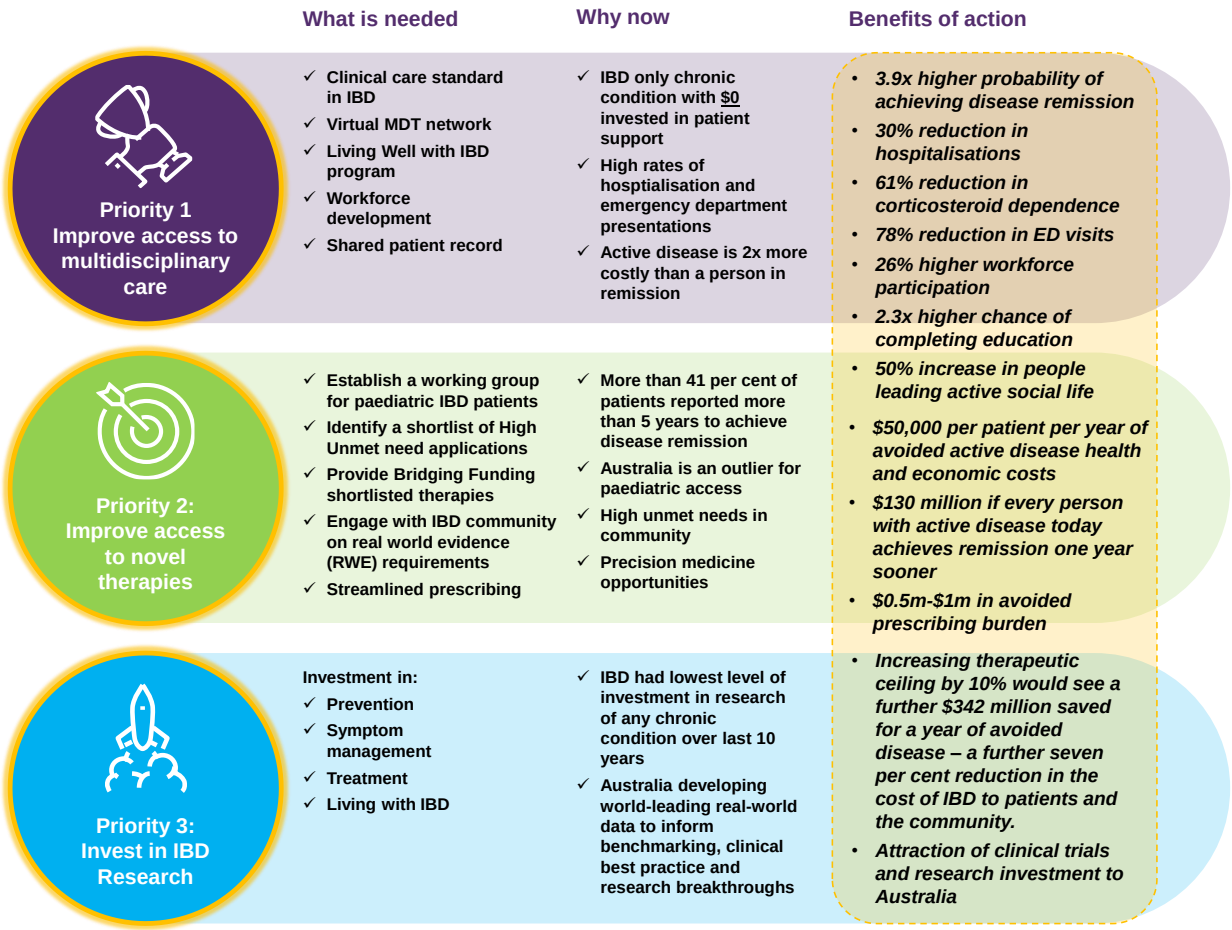
For every person who avoids one year of active disease, $50,000 is saved – through avoided healthcare utilisation, avoided income support, avoided out-of-pocket costs to households, increased workforce participation, increased workforce productivity and avoided suffering for the person living with IBD.

The value of an avoided year of disease increases to $75,000 for people experiencing severely active disease. Preventing a year of severely active disease nearly doubles the probability of a person being able to work and triples the chance of a person – often at an important phase of life – completing their education. It also doubles their probability of having an active social life and restores their life satisfaction to be in line with their age matched peers.

Similarly, improved access to medicines and research would also be expected to improve the probability of people achieving disease remission, by improving treatment options for patients and lifting the therapeutic ceiling through time.

On top of this, a data and research strategy for IBD would be expected to attract additional private sector research to Australia in the form of clinical trials, health implementation science research leveraging real-world data assets and other discovery research.

Figure ES.11: Priorities for the next five years



Source: Policy prioritisation workshop with IBD consumers and clinicians October 2024. Benefits based on active disease (all severity) are relative to a person in remission or having rarely active disease.

Together, we can effect change and prevent unnecessary suffering and financial burden to people living with IBD and their families – with the benefit of freeing up scarce public dollars to be used in other parts of the health and social services systems. But these benefits can be realised if we come together to make IBD a priority and to act today.

Chapter 1

Inflammatory bowel disease: a serious, life-long condition impacting Australians of all ages

Inflammatory bowel disease is a life-long, chronic relapsing disease affecting Australians young and old but significantly children and Australians of working age.

With the peak age of onset occurring between 15 to 29 years, the effective control of this potentially debilitating disease can have a very significant impact on the life trajectory and wellbeing of young Australians entering and participating in the workforce. Poor control of IBD is associated with exponentially increasing healthcare costs, out-of-pocket costs and disease complications.

This chapter provides a short primer in the main types of inflammatory bowel disease – not to be confused with irritable bowel syndrome: what it is, its impact on everyday life, and how it is treated today.

1.1 What is inflammatory bowel disease? It's *not* irritable bowel syndrome

Inflammatory bowel disease (IBD) describes chronic, relapsing conditions involving inflammation of the gastrointestinal tract. The two predominant IBD conditions are:

- Crohn's disease, which involves inflammation in any part of the gastrointestinal tract
- Ulcerative colitis, which involves inflammation limited to the colon or large intestine.

In addition to the two primary types of IBD, a further five to fifteen per cent of patients exhibit characteristics of both conditions; these patients are diagnosed to have 'IBD unclassified' (IBD-U) disease when a clear distinction between the two conditions cannot be made.

IBD is an immune-mediated condition, caused by the body's natural defences (the immune system) mistakenly attacking healthy cells in the bowel walls of the gastrointestinal tract. While more research is needed into the causes and triggers of IBD, researchers have shown that IBD occurs as a result of interactions between a person's genetics and the environment:

- *Genetics* — More than 200 genetic mutations are thought to potentially play a role in developing IBD.[12] Sharing genes with someone that already has IBD, like a parent, sibling or child, can also increase risk.
- *Environment* — The environment plays a significant role in how genes are expressed and, in turn, the potential for IBD to arise. Major environmental factors understood to impact the risk of IBD include more processed diets in industrialised countries; the use of oral contraceptives, and the more prevalent use of non-steroidal anti-

[12] El Hadad, J., Schreiner, P., Vavricka, S. R., & Greuter, T. (2024). The Genetics of Inflammatory Bowel Disease. *Molecular diagnosis & therapy*, *28*(1), 27–35. https://doi.org/10.1007/s40291-023-00678-7

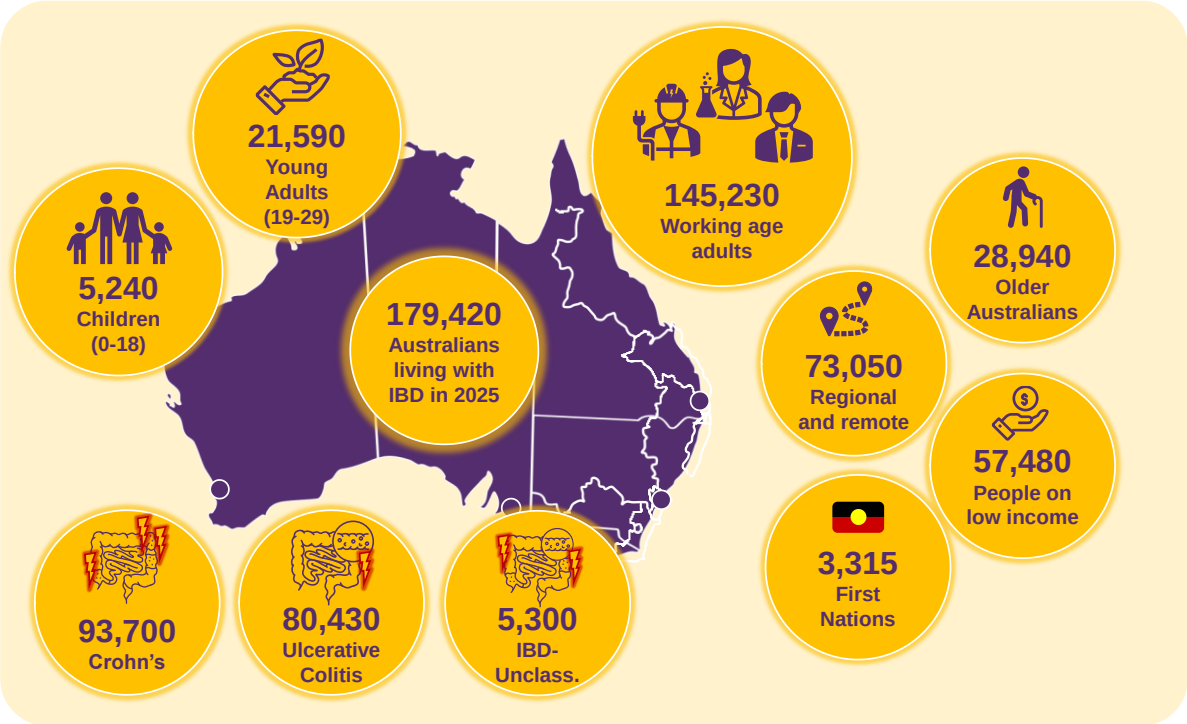
inflammatory drugs.[13] As a result, the risk of IBD is increasing more rapidly in wealthy, industrialised nations.

Environmental factors combined with a person's genetic risk come together to influence the bacterial balance in a person's gut (the microbiome), how the immune system responds to infections and how the body responds to events that cause inflammation.[14]

1.2 Who gets IBD? Australians of all ages

It is estimated that nearly 180,000 Australians are living with IBD today, and within this, just over 91,000 are experiencing active disease (Figure 1.1).[15]

Figure 1.1: Inflammatory bowel disease impacts young and working age Australians



Source: Insight Economics

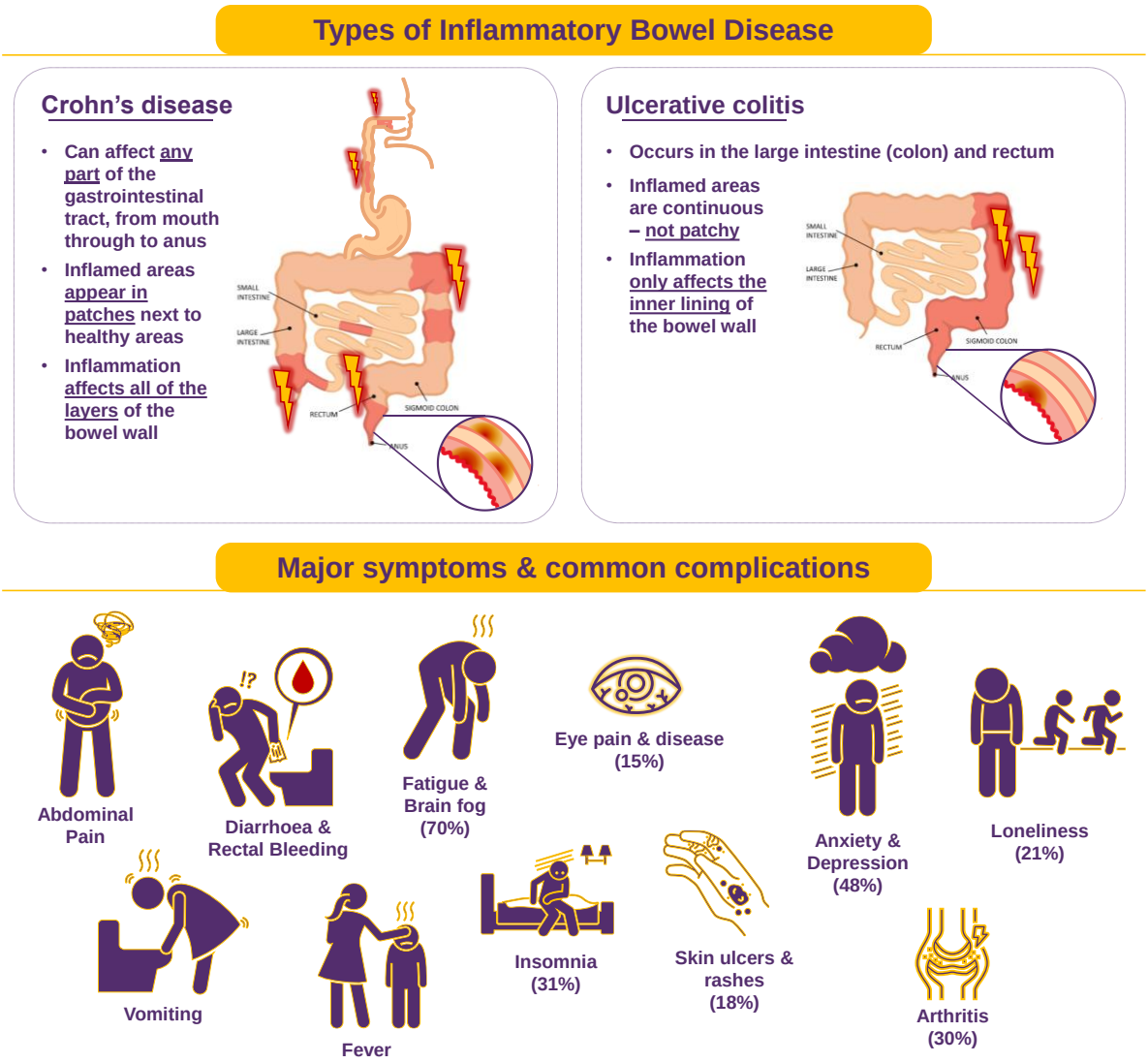
Whereas most chronic conditions tend to increase in prevalence with age, IBD is distinguished by its impact on children, adolescents and working age adults. The majority of new IBD diagnoses appear in adolescence and young adulthood, with the peak age of onset occurring between 15 to 29 years.[16] The timing of the onset of the disease can therefore have an outsized impact on a person's life trajectory – impacting their ability to undertake or complete education, on their ability to participate in the labour force and their ability to enjoy social connectedness.

[13] Abegunde, A. T., Muhammad, B. H., Bhatti, O., & Ali, T. (2016). Environmental risk factors for inflammatory bowel diseases: Evidence based literature review. *World journal of gastroenterology*, *22*(27), 6296–6317. https://doi.org/10.3748/wjg.v22.i27.6296; Kaplan, G. G., and Ng, S. C. (2017). Understanding and Preventing the Global Increase of Inflammatory Bowel Disease,
Gastroenterology, Volume 152, Issue 2, 2017, https://doi.org/10.1053/j.gastro.2016.10.020.
[14] Hasan, N., & Yang, H. (2019). Factors affecting the composition of the gut microbiota, and its modulation. *PeerJ*, *7*, e7502. https://doi.org/10.7717/peerj.7502; Khor, B., Gardet, A. & Xavier, R. Genetics and pathogenesis of inflammatory bowel disease. *Nature* 474, 307–317 (2011). https://doi.org/10.1038/nature10209
[15] See Appendix C for epidemiological modelling.
[16] Gastroenterological Society of Australia, editor. 2018. *Clinical update for general practitioners and physicians : Inflammatory Bowel Disease* Gastroenterological Society of Australia, [Melbourne, Vic.] viewed 9 May 2024 http://nla.gov.au/nla.obj-2712116930.

1.3 Understanding the health, economic and social impacts of IBD

People living with IBD experience an unpredictable pattern of relapse and remission, with symptoms including abdominal pain, weight loss, fever, diarrhoea, rectal bleeding, vomiting and fatigue (Figure 1.2).[17]

Figure 1.2: Understanding inflammatory bowel disease – major types, symptoms and complications

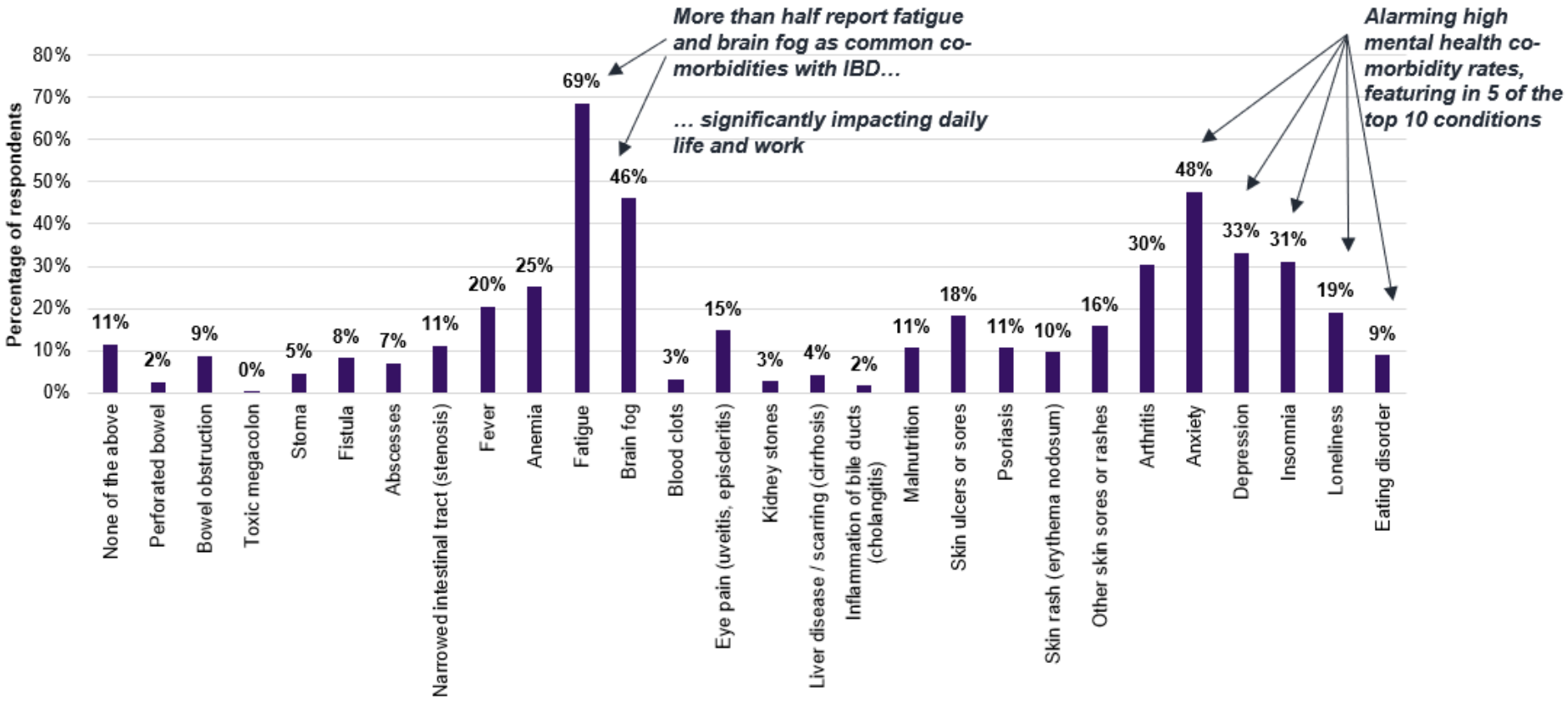


Source: Insight Economics, synthesising Gastroenterological Society of Australia, editor. 2018, Clinical update for general practitioners and physicians: Inflammatory Bowel Disease Gastroenterological Society of Australia, http://nla.gov.au/nla.obj-2712116930. Complication rates based on the State of the Nation Survey of People Living with Inflammatory Bowel Disease; see Appendix B.

In addition, IBD is also often associated with serious symptoms outside the bowel. Extraintestinal manifestations occur in 17 per cent of patients with UC and 37 per cent of patients with CD, including anemia, eye disease (uveitis and episcleritis), liver disease and scarring (cirrhosis), skin ulcers and psoriasis, and arthritis. The range of complications and co-morbidities associated with inflammatory bowel disease reported in the Survey of People Living with IBD is summarised in Figure 1.3.

[17]Gastroenterological Society of Australia, editor. 2018. *Clinical update for general practitioners and physicians : Inflammatory Bowel Disease* Gastroenterological Society of Australia, [Melbourne, Vic.] viewed 9 May 2024 http://nla.gov.au/nla.obj-2712116930.

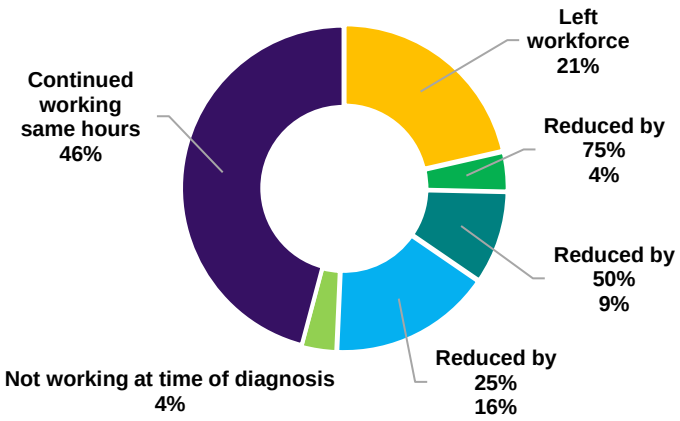
Figure 1.3: High rates of complications and co-morbidities for people living with IBD



Source: State of the Nation Survey of People Living with Inflammatory Bowel Disease. See Appendix B.

These poor health outcomes lead to poor economic outcomes. Many IBD patients of working age leave the workforce as a result of the severity of their symptoms and to support recovery due to the relationship between stress and IBD. The State of the Nation Survey of People Living with Inflammatory Bowel Disease revealed that unlike other chronic conditions that increase with ageing, most people were working (only four per cent were not in the workforce) and half of these people had seen their working hours reduced to some degree (Figure 1.4). One in five patients had left the workforce all together.

Figure 1.4: Impact of IBD on employment and work capacity



Source: State of the Nation Survey of People Living with Inflammatory Bowel Disease. See Appendix B.

Many patients reported experiencing productivity losses as a result of their illness, with over half reporting lower productivity as a result of their IBD and one in four patients reporting reliance on support payments as a result of IBD's impact on their capacity to work.

In addition to impacts on a person's capacity to work, IBD can have a significant impact on their social connectedness and participation, which is increasingly recognised as a critical priority for social cohesion, community wellbeing and economic growth. Half of adult respondents reported that IBD had seriously impacted on their capacity for a social life and social connectedness, including in particular their ability to participate in sports, their sexual health, and ability to travel overseas (Figure 1.5).

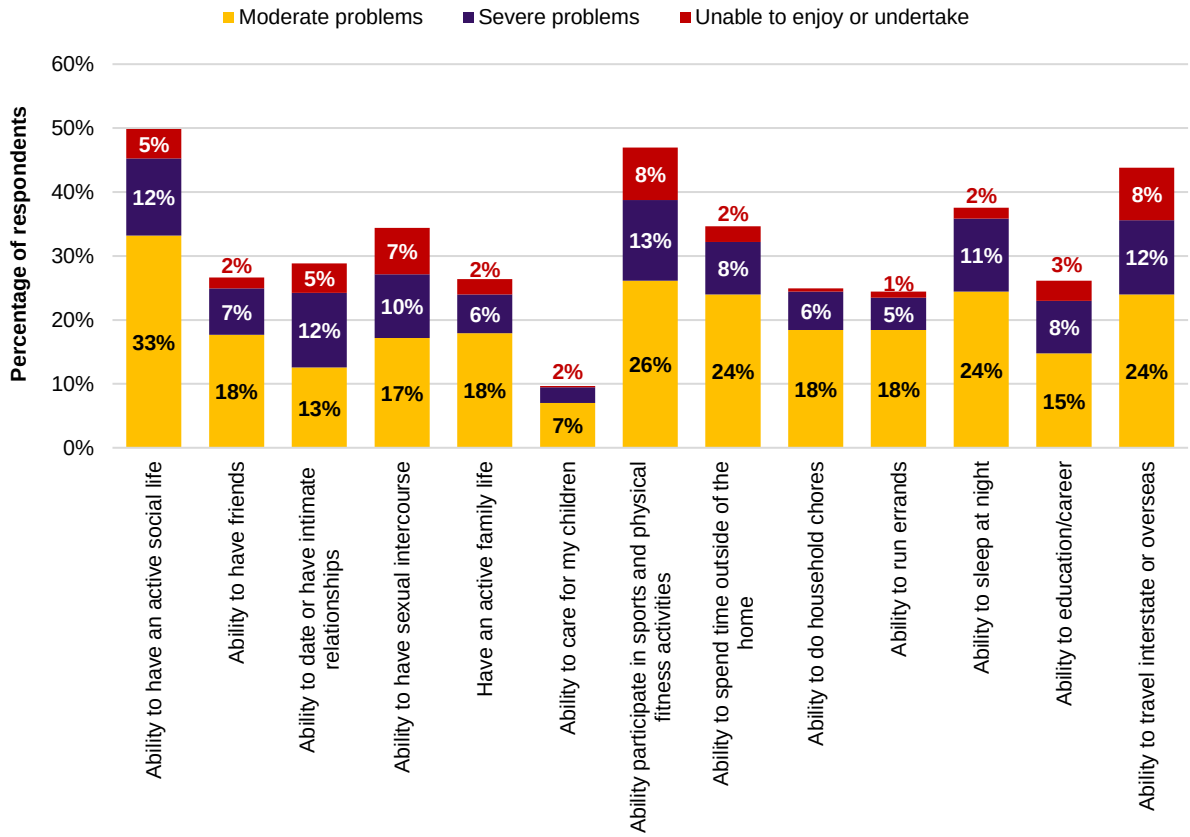
Sadly, as shown in Figure 1.5, around one in five people reported they had severe problems or were unable to enjoy or undertake important activities that most people take for granted:

- 17 per cent had severe problems or were unable to date or have intimate relationships
- 21 per cent had severe problems or were unable to participate in sports
- 20 per cent had severe problems or were unable to travel overseas.

A similar pattern was observed for children (Figure 1.6), with their parents reporting their IBD created serious challenges for having an active social life, including their ability to participate in sports, their ability to sleep well at night, their ability to go to school and their ability to have friends. Significantly, parents reported:

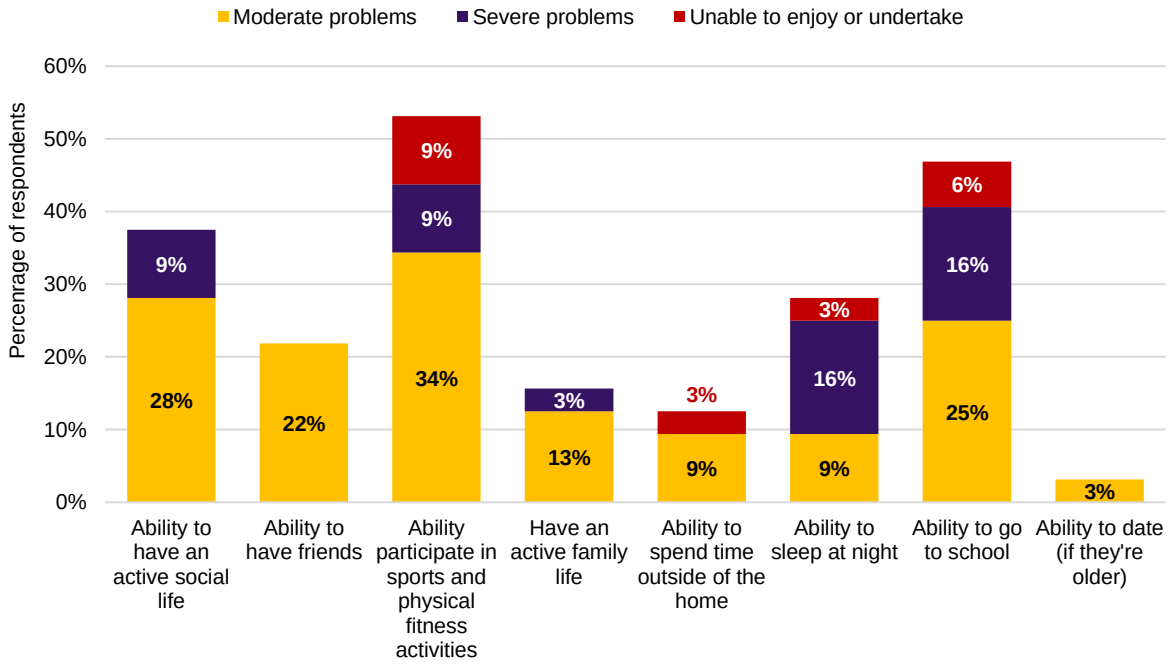
- 18 per cent of children with IBD had severe problems or were unable to participate in sports
- 19 per cent of children with IBD had severe problems or were unable to sleep well at night
- 22 per cent of children with IBD had severe problems or were unable to go to school.

Figure 1.5: Significant impacts on social connectedness and ability to participate in community – adults (>18 years old)



Source: State of the Nation Survey of People Living with Inflammatory Bowel Disease. See Appendix B.

Figure 1.6: Significant impacts on social connectedness and ability to participate in community – children and adolescents (<18 years old)

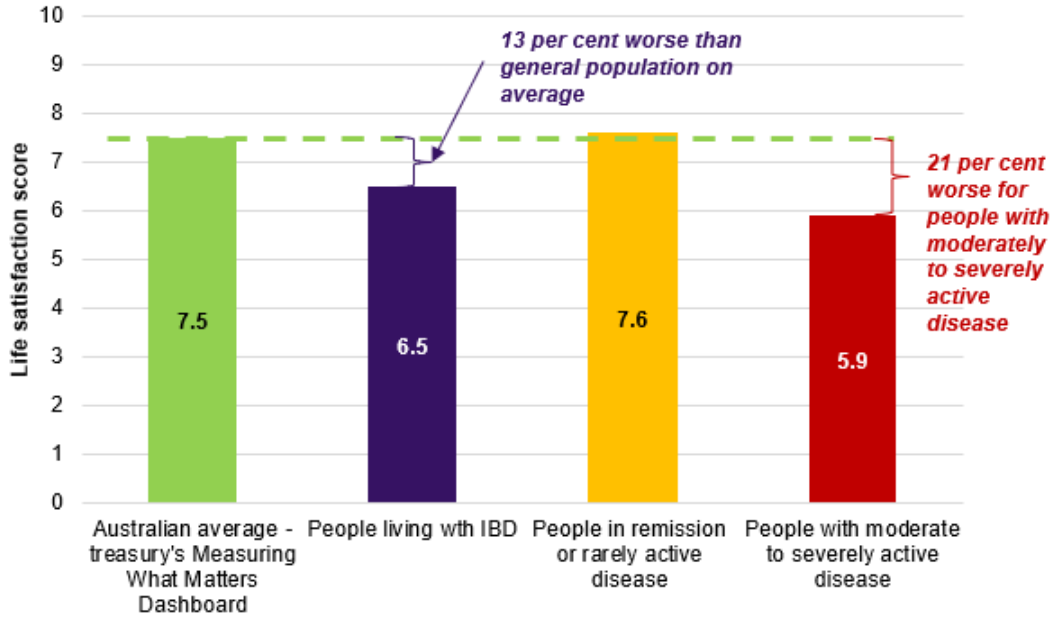


Source: State of the Nation Survey of People Living with Inflammatory Bowel Disease. See Appendix B.

Taken together, these health, economic and social factors add up to a poor quality of life for people living with IBD.

In 2023, the Australian Government launched its first ever wellness framework – called *Measuring What Matters*.[18] This reflects governments' increasing understanding that while economic growth and standards of living are important, they are not the only measures of performance and government has a role to support wider wellbeing and social cohesion. Within the *Measuring What Matters* framework, Life Satisfaction is the first measure identified. Benchmarking IBD patients' life satisfaction with the national average (Figure 1.7) shows that active disease severely compromises people's life satisfaction compared to the national average. Interestingly, for people with their disease in remission outcomes are in line with the population – showing that we can deliver results if we deliver better care.

Figure 1.7: IBD severely impacts on life satisfaction, but when disease is well controlled outcomes match Australian population outcomes



Source: State of the Nation Survey of People Living with Inflammatory Bowel Disease. See Appendix B, and Australian Treasury. (2023). *Measuring What Matters*, accessed at: https://treasury.gov.au/policy-topics/measuring-what-matters.

1.4 The impact of IBD on everyday life, by life stage and priority population

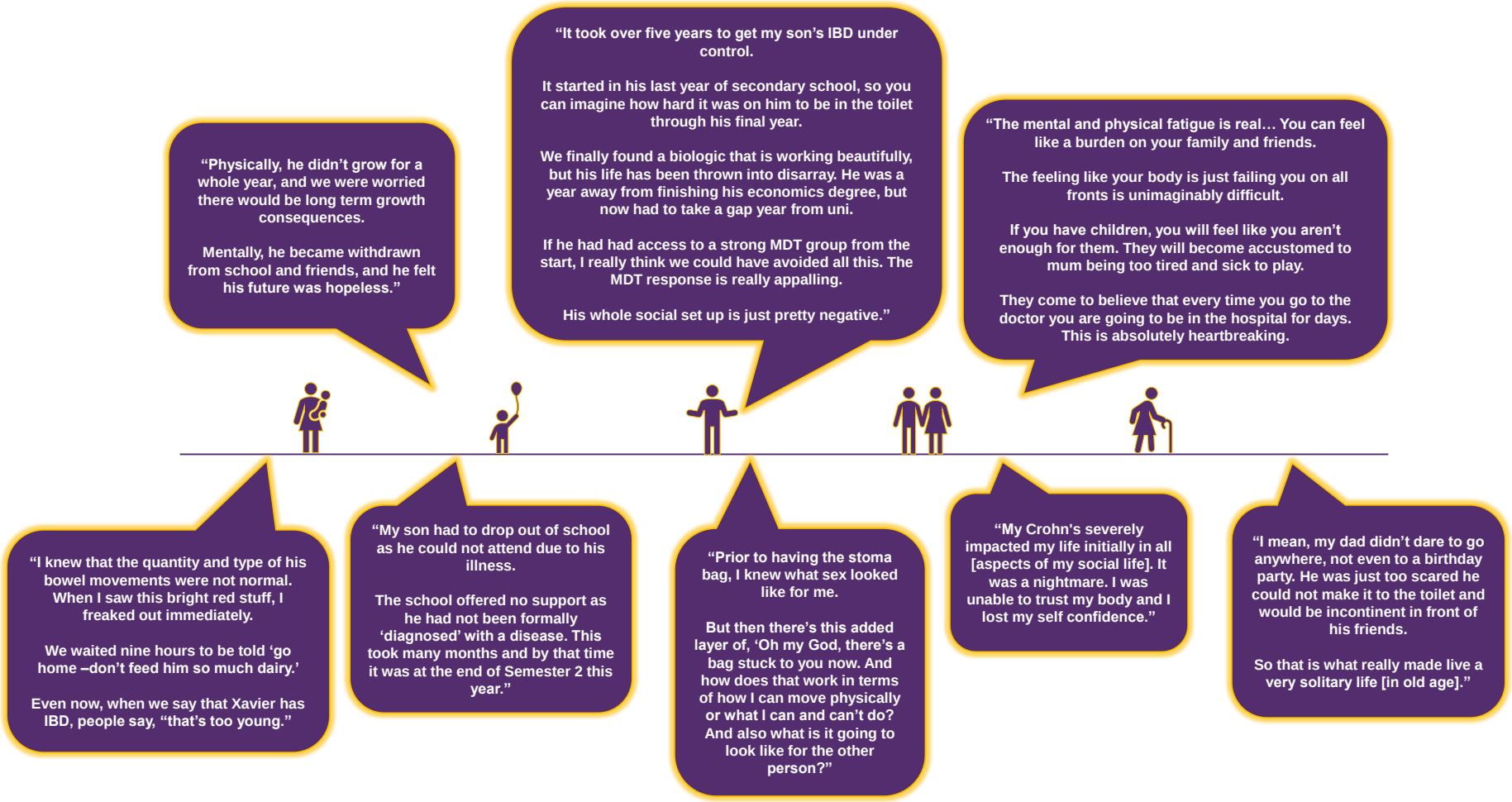
The timing of the onset of the disease can therefore have an outsized impact on a person's life trajectory – impacting their ability to go to school, to complete education, on their ability to participate in the labour force and their ability to enjoy social connectedness (Figure 1.8).

The following sections profile the impacts of IBD for children; adolescents and young adults; women; people living in regional areas; elderly people; First Nations people; and LGBTQIA+ people.

Three patient stories are included in these summaries, highlighting some of the challenges that patients can face in having their symptoms taken seriously and getting the right care.

[18] Australian Treasury. (2023). *Measuring What Matters*, accessed at: https://treasury.gov.au/policy-topics/measuring-what-matters.

Figure 1.8: Impacts of IBD across the lifespan – overview of stakeholder perspectives by life stage



Source: CCA Personal Stories, State of the Nation Survey of People Living with Inflammatory Bowel Disease; Ironmonger, L. (2024). 'I knew what sex looked like for me': Love and dating with Crohn's", Sydney Morning Herald, accessed at: https://www.smh.com.au/lifestyle/life-and-relationships/i-knew-what-sex-looked-like-for-me-love-and-dating-with-crohn-s-20241015-p5kidf.html. Gastro Girl. (2024). The Emotional Impact of IBD: Doctor and Patient Perspectives - Gastro Girl, Meghan, accessed at: https://gastrogirl.com/the-emotional-impact-of-ibd-doctor-and-patient-perspectives/#:~:text=78%20YEAR%20OLD%20WOMAN%20WITH%20ULCERATIVE%20COLITIS; EMJ. (2022). Perspectives on Treatment of Inflammatory Bowel Disease in Older Patients: Applying Gut-Feeling in an Evidence-Based Era?, DOI/10.33590/emj/21-00262. https://doi.org/10.33590/emj/21-00262."

Impact on children and their families

IBD profoundly affects children and their families.

Children often have more extensive disease, higher rates of acute severe colitis, and are at risk for slowed growth, puberty delay, and bone development deficits.[19] Added to this, the symptoms of IBD in children may sometimes be mistaken for other gastrointestinal or emotional disorders, leading to a delayed diagnosis, disease progression and unnecessary suffering for the child and their parents (See Box 1.1: Kelly and Xavier's story).

Children also experience discomfort and anxiety as a result of IBD symptoms and treatments. They also commonly feel 'a sense of vulnerability and diminished control over their lives and future and perceive themselves as 'different' from healthy peers and siblings'.[20] Regular doctor visits, blood tests, colonoscopies, and hospital stays can be especially intimidating for children, and the need for invasive medical procedures can increase anxiety and fear.

As a result, children living with IBD and their families face a unique set of challenges, including the physical burden of managing a chronic illness, the emotional strain of dealing with the uncertainty of flare-ups, and the social difficulties associated with feeling different from their peers:

- *Physical challenges associated with symptoms and flares* — Children with IBD often experience symptoms such as abdominal pain, diarrhea, fatigue, and weight loss. During flare-ups, these symptoms can be severe, leading to frequent absences from school and social activities. The unpredictability of flare-ups can make it difficult for children to engage in normal childhood activities like playing sports, attending school regularly, or participating in social gatherings.

- *Poorer quality of life and mental health than their age-matched peers* — Studies show that children with IBD experience a reduced quality of life compared to their healthy peers.[21] The psychological impact of IBD is particularly significant, with many children experiencing higher levels of anxiety, depression, and stress. Up to 35 % may have clinically significant difficulty in psychosocial functioning.[22]The chronic nature of the illness, combined with the unpredictability of flare-ups, can contribute to feelings of stress, frustration, and sadness. They may worry about their health, how their illness will impact their daily life, and how others perceive them. Social and school-related challenges, as well as the constant need for medical care, contribute to these issues.

- *Poor self-esteem*: Relatedly, many children with IBD struggle with self-esteem, especially if they experience visible symptoms like weight loss or the need for an ostomy. They may feel different from their peers, which can lead to feelings of isolation or embarrassment (See Figure 1.9).

- *Perceptions and experience of social stigma and bullying*: Children with IBD may feel stigmatised due to their condition, especially when they have symptoms like diarrhea, weight loss, or the need for an ostomy, and they may feel embarrassed about explaining their condition to classmates or may avoid participating in activities such as swimming or sleepovers because they are self-conscious about their illness.

[19] Crohn's and Colitis Canada. (2023). Impact of Inflammatory Bowel Disease in Canada, p 98.
[20] Nicholas, D.B., Otley, A., Smith, C. et al. (2007). Challenges and strategies of children and adolescents with inflammatory bowel disease: a qualitative examination. Health Qual Life Outcomes 5, 28, https://doi.org/10.1186/1477-7525-5-28
[21] Ahmed, S., Alam, S., & Alsabri, M. (2022). Health-Related Quality of Life in Pediatric Inflammatory Bowel Disease Patients: A Narrative Review. *Cureus*, *14*(9), e29282. https://doi.org/10.7759/cureus.29282
[22] Mackner, L.M., Crandall, W.V. (2013). Psychological Aspects of IBD in Children and Adolescents. In: Mamula, P., Markowitz, J., Baldassano, R. (eds) Pediatric Inflammatory Bowel Disease. Springer, New York, NY. https://doi.org/10.1007/978-1-4614-5061-0_44

Some children with IBD may face bullying or teasing from their peers, either because of their physical appearance, symptoms, or the fact that they have to take medication or use an ostomy bag.

- *High rates of missed school with impacts on social connectedness and education outcomes* — Children with IBD may experience frequent absences from school due to symptoms, hospital visits, or treatments. One study found children with IBD missed an average of three months of school in the past year; similarly, another found the mean estimate of lifetime school absences was 13 weeks, a rate that was significantly higher than that of a comparison sample.[23] This can affect their academic performance and social relationships, further contributing to social isolation.

- *Slowed Growth* — Children with untreated or poorly controlled IBD often experience growth delays, both in terms of height and weight, and development delays. Slowed growth occurs in 40 per cent of IBD patients, attributed in the main to malnutrition and inflammatory response during the active phase of the disease.[24] Chronic inflammation, poor nutrition due to malabsorption, and side effects from medications (such as steroids) can hinder normal growth, potentially leading to delayed puberty, stunted growth, or weight issues. Inflammation and malabsorption of nutrients can impact a child's ability to thrive physically. Long-term medication use can lead to side effects, including weakened bones (osteoporosis), weight gain, or delayed growth, which can further affect a child's physical and emotional well-being.

- *Family Impact and Stress* — IBD not only impacts the child but also places significant stress on families.[25] Parents of children with IBD often experience high levels of stress due to the need for constant medical monitoring, attending doctor appointments, managing medications, and supporting their child emotionally. In some cases, parents may need to adjust their work schedules or make significant lifestyle changes to accommodate their child's medical needs. Parents often have to manage frequent hospital visits, treatments, and the emotional toll of seeing their child in pain. The financial burden associated with frequent medical care, medications, and potential hospitalisations can also add additional stress for parents and carers. Families may need to adapt holidays, travel plans, and social activities around the child's health, while frequent hospitalisations or the unpredictability of flare-ups may require the family to cancel or modify plans, which can create frustration or resentment.[26]

[23] Mackner, L. M., & Crandall, W. V. (2013). "Health-related Quality of Life in Pediatric Inflammatory Bowel Disease." *Inflammatory Bowel Diseases*, 19(6), 1213-1222. DOI: 10.1097/MIB.0b013e31828c5e91.
[24] Amaro, F., & Chiarelli, F. (2020). Growth and Puberty in Children with Inflammatory Bowel Diseases. *Biomedicines*, *8*(11), 458. https://doi.org/10.3390/biomedicines8110458.
[25] Thapwong, P., Norton, C., Rowland, E., Farah, N., & Czuber-Dochan, W. (2023). A systematic review of the impact of inflammatory bowel disease (IBD) on family members. *Journal of Clinical Nursing*, 32, 2228–2238. https://doi.org/10.1111/jocn.16446
[26] Ibid.

Figure 1.9: IBD through a child's eyes

Source: Nicholas, D.B., Otley, A., Smith, C. et al. (2007). Challenges and strategies of children and adolescents with inflammatory bowel disease: a qualitative examination. Health Qual Life Outcomes 5, 28 (2007). https://doi.org/10.1186/1477-7525-5-28.

Box 1.1. Kelly and Xavier's story

I have four kids, and I knew that the quantity and type of his bowel movements were not normal.

The bleeding started in January 2023, when he was about 18 months old. When I saw this bright red stuff, I freaked out immediately. We went to the local hospital to be told that Xavier had a dairy intolerance, and that we should change his diet. We waited nine hours to be told "go home – don't feed him so much dairy."

But his symptoms continued. We'd see blood in his stool each week. I'd tell my family, "Guys, you can't give him food he can't eat." Then, in June 2023, when he was turning two, he had a birthday party. Two days later, he was so unwell. We thought it was maybe because of what he ate, but the following day, he started vomiting. The day after, he was deteriorating quickly. He was feverish and wasn't responding when we tried to wake him up.

We went straight to the ED. They admitted him for the night and put him on a drip because he was so dehydrated. They discharged him the next day, but we were back at the hospital a few days later. We were treated like we should've been at home looking after him. We were made to feel like Xavier was just a kid with a common tummy bug, and that we were wasting their time. It was an awful feeling.

I was so upset while at the ED. Xavier is usually so vibrant and energetic, but he wasn't himself. My other kids have had tummy bugs and weren't ever this sick. They weren't listening. Fortunately, we had a really nice nurse who spoke to the doctor and got us admitted back into the kid's ward. They stuck a nasal tube down his nose, but the tube was designed for a six-year-old. It made him bleed horrendously; he was so uncomfortable. The whole stay wasn't pleasant.

They didn't do any tests. There was nothing sent to the lab, no stool test taken; nothing. We were discharged from the local hospital after four days. We were waiting until he could eat and stand. Once he stood up, they said he was fine and basically kicked us out.

We went straight from the hospital to our GP in tears, emphasising that there was something wrong with him. Our GP sent us for an ultrasound, he took a few blood tests and asked for a stool test. They quickly saw the inflammation in his nodes and stomach and – two weeks later – we were told his calprotectin levels were over 550, which isn't normal. We were told we had to see a specialist.

We were thrilled that we were taken seriously by a GP who cared.

We were told it could take up to 12 months for the children's hospital to see him. Fortunately, they saw us in two weeks. We were so surprised. The person we saw – who oversees the gastro clinic there – treated us with urgency and care. His inflammation levels were high, and his blood results weren't good, so they booked him in for a procedure. It felt like everyone was finally on our side.

The initial advice was that it was likely polyps, and that there wasn't too much to worry about. After the surgery, they called us into recovery and told us to take a seat. We were told there were no polyps, and they confirmed it was ulcerative colitis.

In February, they changed his medication from Mesalamine to Sulfasalazine – which was going okay – but he suddenly had a melena. He was having a great day, then at 1:30am, he woke up and vomited everywhere. There was vomit every 10 minutes for about an hour, before this awful black poo came out. It was horrendous. I thought that sewerage had leaked throughout the house. I let the clinic know that he had it – but didn't think it was too serious with an email to the gastro team at 10am the next morning, and at 10:04am, I received a call telling me to get him to ED immediately!

He was in hospital for four days. They were worried he had Crohn's and not colitis – they were going to do a colonoscopy and endoscopy, but he didn't have another melena while in hospital and his symptoms resolved quick – his iron levels were terrible, so they gave him an infusion. He was put on steroids from March until August. They tried to wean him off them, but his body resisted, which led to another flare in May.

Cont'd

He's now on Azathioprine, which he takes every morning, as well as Sulfasalazine, which we give him three times a day. We finally weaned him off the steroids. Between November 2023 and March 2024, there'd be blood in his stool every day. We haven't had any blood since May, so we've had a good run. But no one listening to you in hospital is where it hurts. I wonder what his calprotectin test results would've been had they tested earlier.

Even now, when we say that Xavier has IBD, people say, "that's too young." But it's not. The sooner that people are diagnosed, the quicker they can find the right treatments and medications that work for them. Being diagnosed at such a young age will hopefully make it easier for Xavier to process it when he's older.

It was never suggested to us that we should see a dietitian or psychologist.

In recovery, I asked the IBD doctor if there was a diet we should follow – they told us that Xavier would let us know what he doesn't want to eat. Two weeks after his surgery, an IBD Nurse provided a big information pack with online resources and support – including the CCA website. Through CCA, we've grown our support network, and made friends on social media, especially in Perth.

Our family has always been there to support us. During our hospital admissions, they'd be there in a heartbeat and would do everything they could to keep us, and Xavier, entertained. In saying that, no one in the family has had IBD, so we're working out what we can do together.

You want to believe that the local hospital has everyone's best interest at heart – but at the same time, they're overworked and understaffed. They're doing their best, but navigating the system can be a huge challenge.

Source: CCA. (2024). https://crohnsandcolitis.org.au/stories/if-you-feel-something-isnt-right-with-your-body-or-your-childs-stick-to-your-guns-and-dont-back-down-kelly-and-xaviers-story/.

Impact on adolescents and young adults

For adolescents and young adults, the impact of IBD on their social life can compound even further. While effective medical treatment can help manage symptoms and improve quality of life, the emotional and psychosocial aspects of living with a chronic disease are significant in this life stage. Support from healthcare providers, family, and peer groups, along with access to mental health care, are essential in helping young people cope with IBD. Ensuring that adolescents and young adults are empowered with the knowledge and resources they need to manage their condition and lead fulfilling lives is crucial to improving both their physical and emotional outcomes.

Adolescents and young adults living with IBD face very significant challenges to their physical health, emotional well-being, social interactions, and educational or career paths, with delays in diagnosis and time to remission catalysing potentially huge changes in their future life trajectory if their IBD is poorly managed and controlled. Major impacts for adolescents and young adults include:

- *Transitioning to adult care* — One of the key challenges for adolescents and young adults with IBD is the transition from paediatric to adult care. This shift often involves moving from a paediatric gastroenterologist, who may have a closer, more familial relationship with the patient, to an adult gastroenterologist, who may have a more clinical approach. This transition can be difficult, and young adults are at higher risk of poor disease management and complications, which can impact their long-term health.[27] During this life stage young adults increasingly take more

[27] Vernon-Roberts, A., Chan, P., Christensen, B., Day, A. S., Havrlant, R., Giles, E., & Williams, A. J. (2024). Transitional care of adolescents with inflammatory bowel disease to adult services varies widely across Australia and New Zealand. JGH open : an open access journal of gastroenterology and hepatology, 8(1), e13032. https://doi.org/10.1002/jgh3.13032; Bakry, M.,

responsibility for their own care, including learning how to manage medication, recognising signs of flare-ups, and communicating with health providers about their needs as part of increasing autonomy and self-advocacy.

- *Slowed growth and development* — Like children, IBD in adolescence can affect physical growth and development. Chronic inflammation, malnutrition, and delayed puberty may result in the body not absorbing enough nutrients to support growth and development.
- *Social isolation and identity development* — Due to the unpredictability of the disease and the need to manage symptoms, adolescents and young adults with IBD may feel socially isolated or disconnected from their peers. For adolescents, the fear of having to leave class, school activities, or social events to go to the bathroom or deal with a flare-up can create significant stress.[28] This can frustrate the essential process of identity formation during this critical phase of life: young people may struggle with accepting their diagnosis and may feel 'different' from their peers, especially when their illness affects their ability to participate in typical adolescent experiences, such as extracurricular activities, parties, or sports.
- *Stigma and body image issues* — Many adolescents and young adults with IBD experience body image challenges, particularly if they have visible symptoms (e.g., weight loss or ostomy bags). Body image concerns can be exacerbated by the physical changes caused by medication (e.g., steroid-induced weight gain or acne), the visibility of IBD-related scars, or the need for surgical interventions like an ostomy.[29] Adolescents, who are already grappling with self-esteem and appearance concerns as part of their normal development, may find these changes particularly difficult to navigate.
- *Disruption to education and career development* — Adolescents and young adults may miss significant time from school due to flare-ups, hospitalisations, or medical appointments. This can lead to delays in the completion of education and can interfere with their ability to join the workforce, with potentially long-term impacts on earning potential. Adolescents who do not complete year 12 or young adults that are disengaged from the workforce at age 24 see a significant reduction in their lifetime earning potential, with a lifetime economic and social cost of up to $1.1 million per person.[30]
- *Family dynamics in the context of increased autonomy and self-advocacy* — An adolescent or young adult's family can play a key role in providing emotional and practical support through a person's IBD treatment; however, young people with IBD may experience more tension in their relationships with family members during this life stage, particularly if they are still living at home and need assistance managing their health. Sometimes young adults may resist or struggle with taking responsibility for their health;[31] conversely, overprotectiveness from family members or disagreements about treatment plans can sometimes strain these relationships (Figure 1.10).

Hoffmann, P., Prematunga, R., Keightley, P., & Subramaniam, K. (2024). The Transitioning From Pediatric to Adult Inflammatory Bowel Disease Services: A Qualitative Study of Adolescents and Their Parents. *Gastroenterology research*, *17*(3), 146–149. https://doi.org/10.14740/gr1724

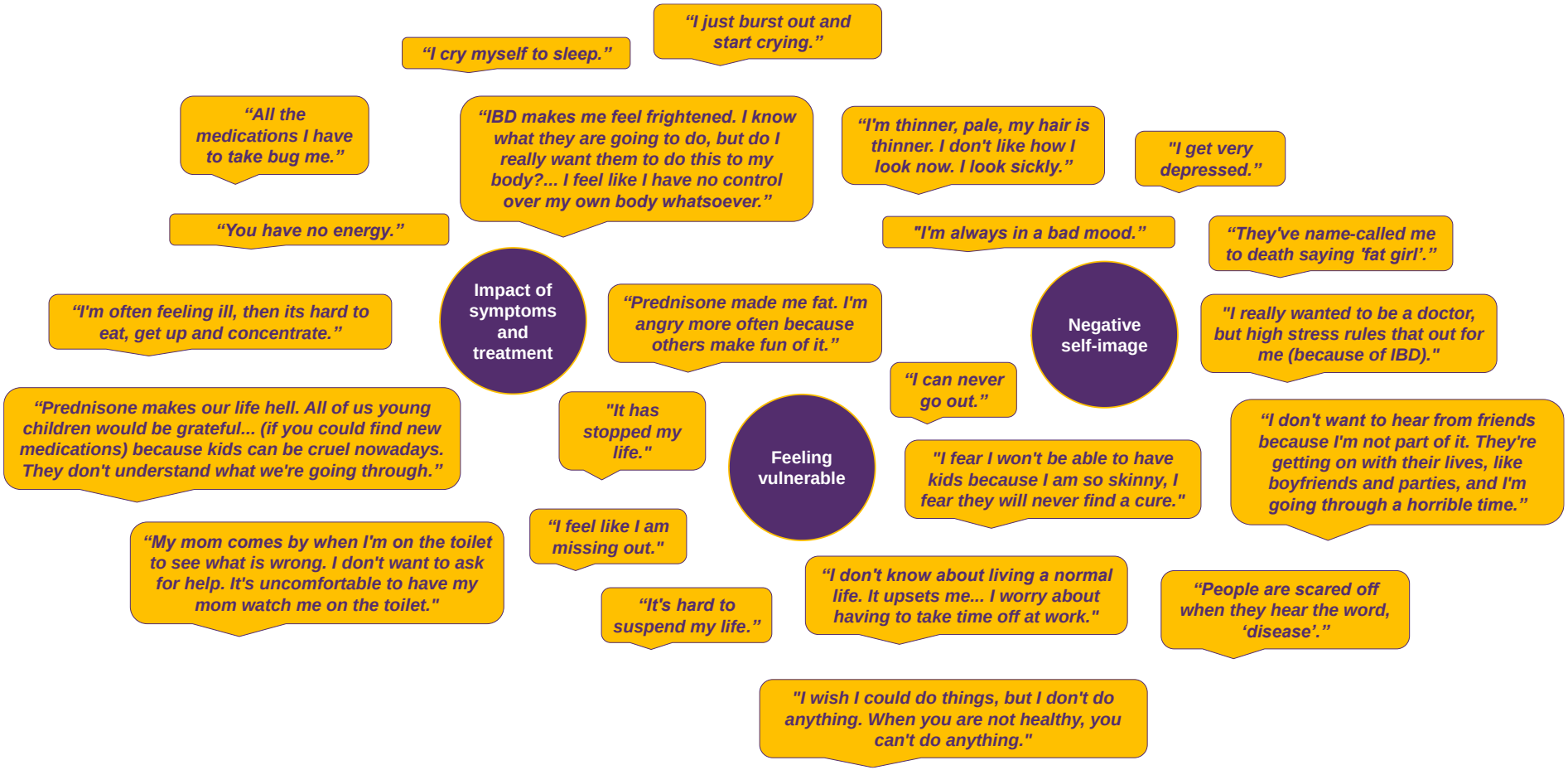
[28] Nicholas, D. B., Otley, A., Smith, C., Avolio, J., Munk, M., & Griffiths, A. M. (2007). Challenges and strategies of children and adolescents with inflammatory bowel disease: a qualitative examination. *Health and quality of life outcomes*, *5*, 28.

[29] Ibid.

[30] Lamb. S., and Ho, S. (2017). Counting the costs of lost opportunity in Australian education https://content.vu.edu.au/sites/default/files/media/counting-the-costs-of-lost-opportunity-in-aus-education-mitchell-institute.pdf

[31] Gumidyala, A., et al. (2018). Moving On: Transition Readiness in Adolescents and Young Adults With IBD, *Inflammatory Bowel Diseases*, Volume 24, Issue 3, March 2018, Pages 482–489, https://doi.org/10.1093/ibd/izx051

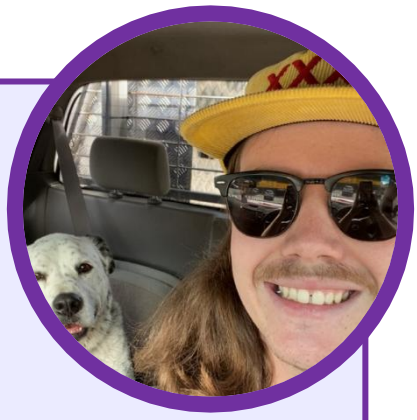
Figure 1.10: Adolescent perspectives on IBD



Source: Nicholas, D.B., Otley, A., Smith, C. et al. 2007. Challenges and strategies of children and adolescents with inflammatory bowel disease: a qualitative examination. Health Qual Life Outcomes 5, 28 (2007). https://doi.org/10.1186/1477-7525-5-28.

- *High rates of mental health concerns* — As a result of the above factors, adolescents and young adults with IBD are at increased risk for mental health issues such as anxiety, depression, and stress (See Box 1.2: Adam's Story). The uncertainty of flare-ups, the burden of chronic illness, and the impact of IBD on their body and social life can lead to feelings of embarrassment, loneliness, anxiety and depression, with the impact of poor mental health outcomes increasing with disease activity.[32]

Box 1.2: Adam's story



My name is Adam Warner, I am 19 and I have recently been diagnosed with ulcerative colitis.

I first became symptomatic in February 2023. It started with excessive urgency to use the toilet – having to go more than 3 or 4 times a day. After about three months of these symptoms, I started to pass mucus. I saw my first GP who got bloods and faecal tests done. I was told that I had two viruses, and they should pass naturally. I returned back to this GP two months later because I started to pass small amounts of blood and more mucus. My GP decided to refer me as a Category 2 in the public system.

After waiting for over seven months for some form of communication from the hospital, I presumed that my referral was lost in the abyss. My symptoms started presenting as more problematic. I was going to the toilet around 8 times a day, passing blood every time I went to the toilet. I always needed a toilet nearby. Work breaks would be spent in the bathroom. I'd go out for a walk and turn around after five minutes because of this urgency.

I then decided to change my GP and take a different approach at navigating the health system. I decided to get referred privately so I could see someone quicker. In June 2024, my symptoms became worse. I was passing a lot of blood and started to become anaemic. It got to the point where I couldn't make it to the toilet, and I started wearing nappies when leaving the house. I started having panic attacks in public and at work. I didn't go out on the weekends or parties because I was scared that I would have to try and explain to everyone why I need to go to the toilet so much. I was able to get two months off work because of the anxiety and depression that I had developed, as well as my UC symptoms. I now take anti-anxiety medication.

After waiting for so long, I saw a specialist and got admitted through the public system. I was then admitted to hospital after a diagnosis, which followed a sigmoidoscopy. I spent a week in hospital and started medication to get me into remission. On my first day in hospital, I went to the toilet 13 times — on the last day, I went once. After three days of being in hospital, I stopped bleeding and started passing solid faeces again. I had to get an iron infusion because of the blood I lost. I am still on oral steroids and don't have any symptoms. I was told by the specialist and my GP before my diagnosis that I could go to the Emergency Department, but I didn't feel I could take priority over someone who needed the help. After talking with the nurses and specialists at the hospital I now feel comfortable that I can go to the emergency department if I need to.

The start of my IBD journey has been highly traumatic and has been filled with anxiety and stress. Just getting the diagnosis was all that I needed to settle me. I urge anyone who is symptomatic and who does not have a diagnosis to push your GP or go to emergency to get the answers you need. No-one should have to live in fear about not knowing what is happening in their body.

Speak up to people around you about your mental and physical health. Do not suffer in silence.

Source: CCA. (2024). https://crohnsandcolitis.org.au/stories/do-not-suffer-in-silence-adams-story/

[32] Qualter, P., Rouncefield-Swales, A., Bray, L., Blake, L., Allen, S., Probert, C., Crook, K., & Carter, B. (2021). Depression, anxiety, and loneliness among adolescents and young adults with IBD in the UK: the role of disease severity, age of onset, and embarrassment of the condition. *Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation*, *30*(2), 497–506. https://doi.org/10.1007/s11136-020-02653-9

Impact of IBD on women

Women living with IBD also face unique challenges – beginning even with achieving a correct diagnosis.

Research has shown that women are more likely to experience IBD, particularly Crohn's disease,[33] but unfortunately, this does not always translate into increased awareness and treatment. Rather, gender bias is prevalent in IBD,[34] women's symptoms can often be misattributed to other conditions, such as menstrual cramping, complications from childbearing (See Box 1.3: Sara's story) or eating disorders, or de-prioritised, with women being told the pain is 'all in their head' (psychosomatic labelling). This is consistent with what is increasingly understood to be part of a broader pattern of dismissal and de-prioritisation of women's health concerns, as highlighted by the *Inquiry into Women's Pain*[35] and research showing women are consistently diagnosed later than men across a multitude of conditions.[36] Box 1.3, for example, highlights how Sara's symptoms were not adequately investigated and required persistent self-advocacy for her GP to take action; when her concerns were finally investigated the specialist was shocked: "I'm so sorry – your bowel is completely littered with ulcers. There's not a section of your large bowel that's okay."

Once diagnosed, women living with IBD face significant challenges; for example:

- *Higher rates of mental health issues* — Women living with IBD are more likely than their male counterparts to report anxiety or depression and are at increased risk for a negative body image.[37] Approximately 70% of women with IBD are concerned about their body image, a concern that significantly impairs their quality of life (QOL), which is already reduced in female IBD patients.[38]
- *Challenges for pregnancy* — Pregnancy is also associated with greater risks in people with IBD.[39] About one third of females considering pregnancy reported stopping their medications without discussing it with their physicians due to concerns about safety and uncertainty about the medications during pregnancy.[40]
- *Voluntary childlessness, particularly for women from disadvantaged groups* — There is also a high rate of observed voluntary childlessness among women with IBD, with up to 17 per cent of surveyed females report choosing to remain childless.[41] Factors associated with voluntary childlessness were poorer reproductive knowledge, older age, unemployment, being single, and not seeking medical advice.

[33] Businge D, Pollack A, Chidwick K. (2021). Prevalence of inflammatory bowel disease in the Australian general practice population: A cross-sectional study. PLoS One. May 27;16(5):e0252458. doi: 10.1371/journal.pone.0252458; Colino, S. (2024). *Why Gut Health Issues Are More Common in Women*, https://time.com/7020911/women-gut-health-ibs-ibd/;

[34] Lungaro, L., Costanzini, A., Manza, F., Barbalinardo, M., Gentili, D., Guarino, M., Caputo, F., Zoli, G., De Giorgio, R., & Caio, G. (2023). Impact of Female Gender in Inflammatory Bowel Diseases: A Narrative Review. *Journal of personalized medicine*, *13*(2), 165. https://doi.org/10.3390/jpm13020165.

[35] See: Victorian Government. (2024). Inquiry into Women's Pain, accessed at: https://www.health.vic.gov.au/inquiry-into-womens-pain.

[36] See Novo Nordisk Foundation's Center for Protein Research. (2019). Study: Across Diseases, Women Are Diagnosed Later Than Men, accessed at: https://www.cpr.ku.dk/cpr-news/2019/study-across-diseases-women-are-diagnosed-later-than-men.

[37] Veerisetty, S, et al. (2018). Women's Health in Inflammatory Bowel Disease, The American Journal of the Medical Sciences, Volume 356, Issue 3, doi: 10.1016/j.amjms.2018.05.010.; Lungaro, L., Costanzini, A., Manza, F., Barbalinardo, M., Gentili, D., Guarino, M., Caputo, F., Zoli, G., De Giorgio, R., & Caio, G. (2023). Impact of Female Gender in Inflammatory Bowel Diseases: A Narrative Review. *Journal of personalized medicine*, *13*(2), 165. https://doi.org/10.3390/jpm13020165

[38] Blumenstein, I., et al, (2023). Sex- and gender-related differences in inflammatory bowel diseases, Frontiers in Gastroenterology, https://www.frontiersin.org/journals/gastroenterology/articles/10.3389/fgstr.2023.1199687, DOI=10.3389/fgstr.2023.1199687

[39] Ibid.

[40] Targownik, L. E., Bollegala, N., Huang, V. H., Windsor, J. W., Kuenzig, M. E., Benchimol, E. I., Kaplan, G. G., Murthy, S. K., Bitton, A., Bernstein, C. N., Jones, J. L., Lee, K., Peña-Sánchez, J. N., Rohatinsky, N., Ghandeharian, S., Davis, T., Weinstein, J., Im, J. H. B., Jannati, N., Khan, R., … Seow, C. H. (2023). The 2023 Impact of Inflammatory Bowel Disease in Canada: The Influence of Sex and Gender on Canadians Living With Inflammatory Bowel Disease. *Journal of the Canadian Association of Gastroenterology*, *6*(Suppl 2), S55–S63. https://doi.org/10.1093/jcag/gwad011

[41] Ibid.

Box 1.3: Sara's story

I got diagnosed at 32 after my second child was born. From the moment he was born, I didn't feel right.

About a year after, I really started noticing symptoms. I had perianal issues, and it was getting dismissed by doctors; "you've just had a baby, you've probably got hemorrhoids." But it was quite severe, and going to the bathroom was like passing glass. Then it became stomach issues, which I couldn't ignore.

I was quite used to having IBS symptoms. I also have celiac disease and can't eat gluten. I sort of dismissed some of the early symptoms – thinking that I'd eaten something wrong. Then it felt like I had gastro 24/7. I went to the bathroom 15+ times a day, and I couldn't hold anything in. Once that started, my symptoms escalated very quickly. I didn't know what was going on with me, and no doctor was able to pick it up.

I lost over 15 kilos within about three months. Even then, the response from GPs was, "it's anxiety – you've had anxiety all your life." I had doctors asking me if I was taking laxatives to lose weight. We have a history of bowel cancer in my family, and it reached the point where I basically forced a colonoscopy. I said, "I'm at an age where I want to check this."

I did the colonoscopy – and I'll never forget the specialist's face. He came out and said, "I'm so sorry – your bowel is completely littered with ulcers. There's not a section of your large bowel that's okay." He was certain that I had Crohn's disease, and within a few weeks, the biopsies confirmed this. What followed was the emotional journey in accepting the diagnosis. It's something that I'd personally never heard of. No one in my family has Crohn's Disease, and nobody I knew had Crohn's disease or colitis. At the time, I didn't know what it was.

I remember thinking that I'd just take a tablet and be better. That was me being naïve. Then I went through about 18 months of hell – in and out of hospital. That was during Covid-19. I was diagnosed in February 2020 – a few months before the first lockdown. I was put in an isolation ward, and I couldn't see the kids for a few months. It was really traumatic. I was put on liquid diets in hospital because I couldn't stomach anything. I tried multiple tablet medications, most of which failed. I went through two specialists whom I didn't connect with. They told me I needed a colostomy bag and, after just being diagnosed, I wasn't coping.

I was put into contact with [a specialist], and I call him my angel to this day. He said that he'd try everything not to go down that path straight away. I was put on Stelara, as well as high doses of intravenous steroids. It took about eight or nine months before I noticed any change. My inflammatory markers remained high for a long time, but we eventually saw some movement.

By the two-year mark, I was in remission. I also put myself on a very strict, anti-inflammatory diet which I can't really come off. Every time I try certain things – like red meat or fruit – my markers go straight up. My body also became addicted to the steroids, and it took me a long time to get off them. But now I can live a semi-normal life.

I'd never experienced depression in the past. I've always had anxiety, but feelings of depression kicked in and became very intense when I was in hospital. I got to the point where I couldn't stay at home by myself, so my mum moved in for a while. My brain fog was immense, and it was a dark time.

Cont'd

I received a lot of support from my specialist whom I saw at one point twice a week. I was always in contact with him, and he was great at pointing me in the right direction. Personally, I felt that the nutritionist I did see offered quite a generic approach. I went through a trial-and-error process to find a diet that was right for me. From a nutritional perspective, I did feel quite alone.

Following the diagnosis, I joined online support groups. A lot of my friends didn't understand I took bits and pieces from different people's stories. I went through a period where I found these stories to be quite confronting. I saw a psychologist to work through some of my thoughts, which helped.

My aunt was also a big part of the change in my thought process. She had cancer, and I was talking to her about how she managed ruminating on worst case scenarios. She provided me with great advice – the basis of which was my focus and energy should be on getting through the day. I try not to worry about what this disease could do to me. I just worry about what it's doing right now, and how I'm going to better it today.

I recently had a spike in my inflammation markers and I'm waiting for biopsies to see why that happened. But as far as I know, I'm still in remission.

In terms of how IBD affects me daily, I generally experience more body pains. I've also had issues with my sinuses. I'm almost always sick, which might be a side effect of the medication. My diet is not normal – there's a ridiculous amount of food groups that I can't eat – and my haemoglobin levels are terrible.

My pain levels have dropped compared to previous years, but I still live with constant pain and am generally uncomfortable every day.

I'd also recommend trying to advocate for yourself whenever possible. What you're feeling is legitimate – so don't take the first answer given to you as gospel. Push for further tests if that's what you believe you need.

In terms of the medical side of things, a blanket approach can be harmful. All of our stories are so different, and everyone responds to different things. Treat everyone as a human being, not a textbook case.

Source: CCA. (2024). https://crohnsandcolitis.org.au/stories

Impact on people in regional areas

Living with inflammatory bowel disease in regional Australia presents unique challenges, with people in these areas facing a variety of factors that can exacerbate the physical and psychological impact of the condition. Around 28 per cent of Australians live in rural and remote areas. These Australians face unique challenges due to their geographic location and often have poorer health outcomes than people living in metropolitan areas. Data show that people living in rural and remote areas have higher rates of hospitalisations, deaths and injury and also have poorer access to, and use of, primary health care services, than people living in major cities.[42] Here are some key aspects of the experience:

- *Limited access to specialists with IBD experience* — In regional areas, access to gastroenterologists and other IBD specialists is often limited. Patients may need to travel long distances to receive diagnosis, treatment, or follow-up care, which can be both time-consuming and expensive. Moreover, local hospitals and clinics in regional areas do not have the same specialised resources or medical staff trained in managing

[42] AIHW. (2024). Rural and Remote Health, https://www.aihw.gov.au/reports/rural-remote-australians/rural-and-remote-health.

complex conditions like IBD, making it more difficult to receive high-quality, timely care.

- *Long distances to travel for care* — Travel is often required for essential appointments, diagnostic tests, or emergency care. Patients may also need to travel to receive intravenous infusions of biologics like infliximab, which can be costly and time-consuming. This can be both financially burdensome and physically exhausting, especially during flare-ups when mobility may be limited. Travel expenses (including fuel, accommodation, and time off work) can be a significant barrier, particularly for those on limited incomes or in remote areas where public transport options are scarce. While telehealth services have improved access to healthcare, the quality of these consultations can sometimes be less comprehensive than in-person visits. Regional areas may also face connectivity issues that hinder effective use of telemedicine. As noted by one patient:

  "We live in a regional area and have to travel 4 hours to specialist services. It is impossible to source locally without lengthy delays."

- *Barriers to access to of IBD medications* — While essential medications for IBD, such as biologics and immunosuppressants, are generally accessible through the Pharmaceutical Benefits Scheme (PBS), getting prescriptions and ensuring timely access to medications can be complicated in rural areas due to delays in mail delivery or stock shortages at local pharmacies. Accessing intravenous treatments or infusions, such as biologic therapies, may require travel to major hospitals or clinics in regional hubs, which can be disruptive and exhausting for patients.

Impact on First Nations people

In Australia, there has been relatively little research on the impact of IBD in Aboriginal and Torres Strait Islander people. Overall, IBD is estimated to occur less frequently in First Nations populations than non-Indigenous populations.[43]

While more research is needed, data reported by Australian Indigenous Health*Info*net indicated that gastrointestinal disease was the third highest cause for hospitalisation of Aboriginal and Torres Strait Islander people.[44]

Internationally, more research has been done with regard to the impact of IBD for First Nations people. For example, in Canada, First Nations people living with IBD in Saskatchewan were found to more likely than the general IBD population to be hospitalised for IBD-specific reasons and had a higher risk of surgery for ulcerative colitis than non-Indigenous populations.[45]

Impact of IBD on elderly Australians

While the experience of IBD in elderly adults tends to be less severe than their paediatric and adolescent onset counterparts (though often with a more severe onset episode),[46] elderly Australians face unique challenges as a result of an IBD diagnosis, stemming from increased risk of infections, increased risk of cancer, increased risk from polypharmacy (taking more

[43] Gearry, R.B., et al. (2006). High incidence of Crohn's disease in Canterbury, New Zealand: results of an epidemiologic study. Inflamm Bowel Dis. 2006;12(10):936–43. 10.1097/01.mib.0000231572.88806.b9; Gearry, R.B., et al. (2010). Population-based cases control study of inflammatory bowel disease risk factors. J Gastroenterol Hepatol. 2010;25(2):325–33. 10.1111/j.1440-1746.2009.06140.x; Leach, S.T., et al. (2014). Low rate of inflammatory bowel disease in the Australian indigenous paediatric population. J Paediatr Child Health. 2014;50(4):328–9. 10.1111/jpc.12535.
[44] See Australian Indigenous Health*Info*net. (2024). https://healthinfonet.ecu.edu.au/learn/health-facts/latest-information-and-statistics/hospitalisation/
[45] Crohn's and Colitis Canada. (2023). Impact of Inflammatory Bowel Disease in Canada.
[46] Hong SJ, Katz S. (2021). The elderly IBD patient in the modern era: changing paradigms in risk stratification and therapeutic management. Therap Adv Gastroenterol. 2021 Jul 3;14:17562848211023399. doi: 10.1177/17562848211023399.

than one medication at once) and poor medication adherence, as well as risks arising from co-morbidities and frailty.[47]

The complex healthcare needs of elderly IBD patients can put additional stress on IBD clinics to adequately care for these people, with co-morbidities and frailty potentially limiting possible treatment options. Like other priority populations, the complex healthcare needs of elderly Australians amplify the need for multi-disciplinary healthcare teams that can adequately manage the risks of medical complications.

Impact on LGBTIQA+ people

The experience of LGBTQIA+ people living with inflammatory bowel disease in Australia is shaped by the intersection of their chronic health condition with their gender identity, sexual orientation, and the broader social and healthcare environment. While people with IBD face challenges related to healthcare access, stigma, and the unpredictability of their condition, LGBTQIA+ individuals often encounter additional layers of complexity that can exacerbate these difficulties. These include healthcare discrimination, mental health challenges, and unique social and support needs. Here's a summary of the key factors affecting the experience of LGBTQIA+ people with IBD in Australia:

- *Healthcare disparities and cultural competence of providers* — LGBTQIA+ individuals often report facing healthcare discrimination or lack of understanding from medical professionals. For people with IBD, this can translate into delayed diagnoses, suboptimal care, or avoidance of healthcare altogether due to fear of discrimination. Studies have shown that LGBTQIA+ patients are more likely to experience a lack of cultural competence among healthcare providers, which can result in diminished trust in the healthcare system. For those living with both IBD and LGBTQIA+ identities, the intersection of these two aspects can complicate interactions with healthcare providers. People may experience marginalisation both because of their chronic illness and their LGBTQIA+ status, which can lead to increased anxiety when seeking medical treatment.
- *Higher rates of mental health struggles* — Research has shown that LGBTQIA+ people are more likely to experience mental health issues like anxiety, depression, and stress compared to their heterosexual and cisgender peers. Living with IBD, a chronic and often unpredictable condition, can exacerbate these mental health challenges, especially if the individual is dealing with discrimination or lack of support related to both their identity and illness.
- *Gender identity and body image* — The visible symptoms of IBD, such as bloating, weight loss, or ostomies (when surgical removal of part of the intestine leads to a stoma), can impact self-esteem and body image. For LGBTQIA+ individuals, body image issues may be even more complex, particularly for transgender and non-binary people whose relationship with their bodies may already be strained by dysphoria.

1.5 The incidence of IBD is increasing – and Australia is leading the pack

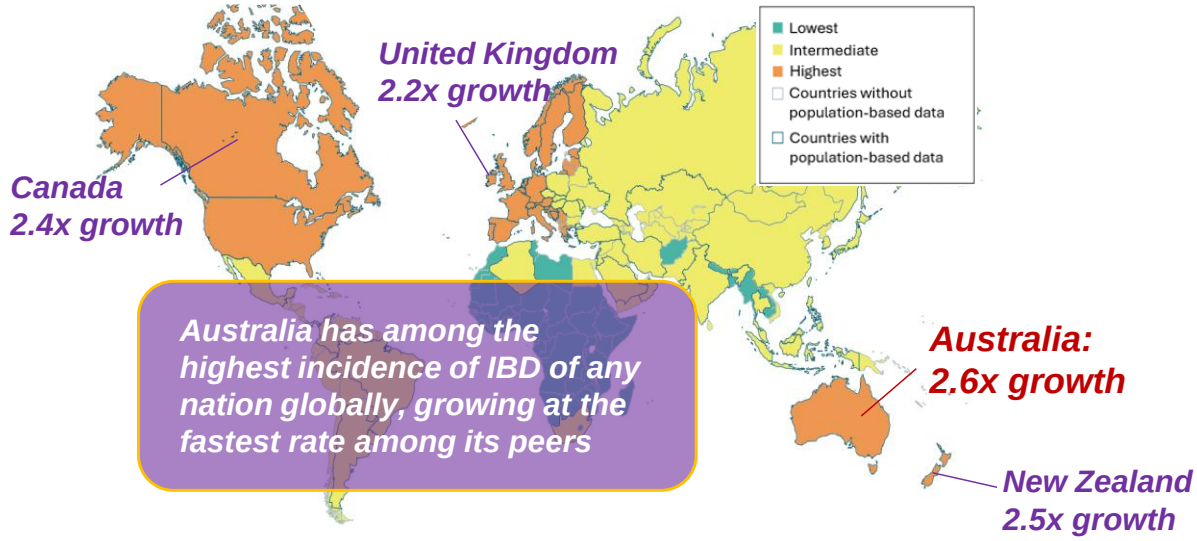
Critically, IBD is a significant and growing health concern for Australian communities.

Recent international studies have revealed a growing prevalence for IBD in Western countries, with Australia projected to experience a 238% increase in prevalence from 2010 to

[47] Crohn's and Colitis Foundation. (2020). Managing Inflammatory Bowel Diseases in the Elderly Population https://www.crohnscolitisfoundation.org/sites/default/files/2020-08/IBD%20and%20elderly%20tip_FINAL_Aug.%202020.pdf

2030 — the highest growth rate when compared to Western country peer groups (Figure 1.11).[48]

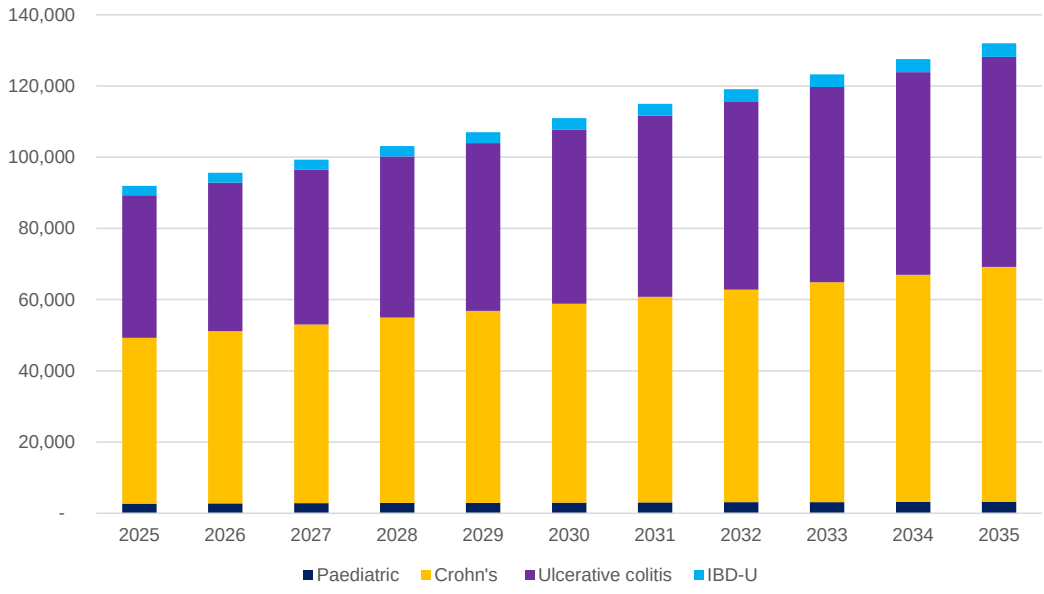
Figure 1.11: Rapidly increasing incidence in advanced economies globally, with Australia expected to experience the highest rate of growth between 2010-2030



Source: Adapted from Kaplan, G.G. and Windsor, J.W., 2021. The four epidemiological stages in the global evolution of inflammatory bowel disease. Nature reviews Gastroenterology & hepatology, 18(1), pp.56-66; and Kaplan, G.G., 2015. The global burden of IBD: from 2015 to 2025. Nature reviews Gastroenterology & hepatology, 12(12), pp.720-727.

Between 2025 and 2030, lifetime prevalence of IBD in Australia is expected to grow from nearly 180,000 people (179,423 people living with IBD today) to more than 200,000 by 2035. Within this, it is estimated that the proportion of prevalence under active management is expected to grow from just over 91,000 patients today to more than 132,000 patients in 2035 (Figure 1.12).

Figure 1.12: Estimated proportion of prevalence under active management in Australia 2025-2035



Source: Insight Economics, See Appendix C.

[48] Kaplan, G.G. and Windsor, J.W., 2021. The four epidemiological stages in the global evolution of inflammatory bowel disease. *Nature reviews Gastroenterology & hepatology*, *18*(1), pp.56-66

1.6 How is IBD diagnosed and treated?

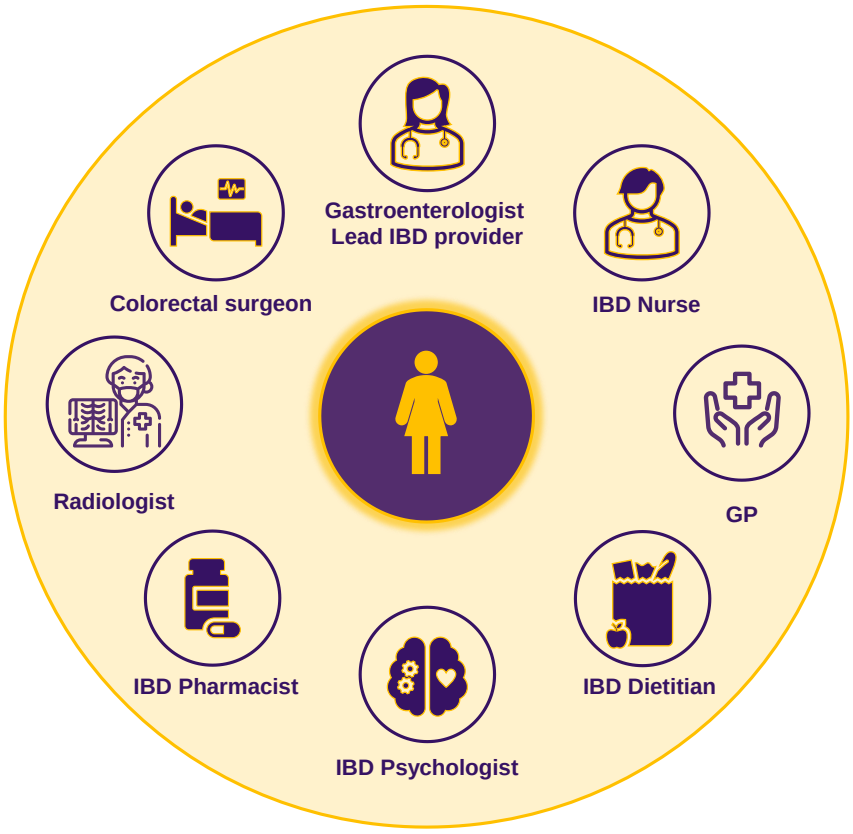
IBD is diagnosed through a combination of clinical assessment, laboratory tests, imaging, and endoscopic procedures. The process is aimed at:

- Distinguishing the disease from other conditions with similar symptoms (such as infections or irritable bowel syndrome)
- Confirming a precise diagnosis
- Determining the extent of the disease in order to inform a treatment plan.

Patients will often initially present to a GP with symptoms, who will order initial tests to rule out other potential conditions and then refer the patient to a gastroenterologist, who typically oversees the diagnosis and treatment planning.

Due to the complexity of IBD and the relapsing nature of the condition, clinical best practice involves a multi-disciplinary approach led by the patient's gastroenterologist but also incorporating IBD nurses, dietitians, psychologists, surgeons, pharmacists, the patient's GP and other healthcare providers to ensure comprehensive care (Figure 1.13). Ideally, once diagnosed, a person has access to an IBD nurse that works as a person's care coordinator, helping to provide a person with information about their IBD, manage flare ups and identify potential allied and mental health supports that might be needed.

Figure 1.13: Clinical best practice through multi-disciplinary team care



Key elements of the diagnostic processes include:

- Clinical Evaluation, including an evaluation of a patient's symptoms, medical history and family history, as well as a physical examination to check for signs of systemic symptoms (fever, weight loss) or abdominal tenderness and distension.

- Blood Tests, which are used to detect signs of inflammation or infection; key blood tests include:
    - C-reactive protein (CRP) and erythrocyte sedimentation rate (ESR), which are elevated during periods of active inflammation
    - Complete blood count (CBC), which may show anaemia (a result of blood loss) or a reduced number of white blood cells (a sign of inflammation)
    - Liver function tests to rule out liver-related conditions or complications often associated with IBD
    - Thyroid function tests to rule out other causes of symptoms.
- Stool Tests, which are also used to detect signs of inflammation or infection; key tests include:
    - A faecal calprotectin test, which measures the level of this protein in a patient's stool. Levels of this protein are elevated in the stool in cases of intestinal inflammation and very high levels indicate IBD.
    - Stool cultures may also be performed to rule out infections (e.g., bacterial or other potential parasitic causes of diarrhea).
- Endoscopy, which involves the insertion of a flexible tube with a camera into the body either via the rectum (colonoscopy or sigmoidoscopy) or the upper GI tract (gastroscopy). The primary diagnostic tool for IBD is colonoscopy, which allows doctors to visually examine the colon and rectum for signs of inflammation, ulcers, and bleeding. Sigmoidoscopy is less invasive and may be used in some cases but is used only to examine the sigmoid colon and rectum.
- Biopsy, which are small tissue samples of the bowel wall taken during the colonoscopy, gastroscopy or sigmoidoscopy, are taken to confirm the diagnosis and assess the extent of inflammation. Pathological examination of these samples can help determine the type of IBD.
- Imaging, including CT/MRIs, x-rays and ultrasounds, which can be used to identify potential complications such as perforation, abscesses, toxic megacolon (a life-threatening dilation of the colon), or severe inflammation. Imaging tests are more commonly used for diagnosing Crohn's disease, they can also be helpful in assessing UC, especially in complicated or severe cases. These scans can identify.

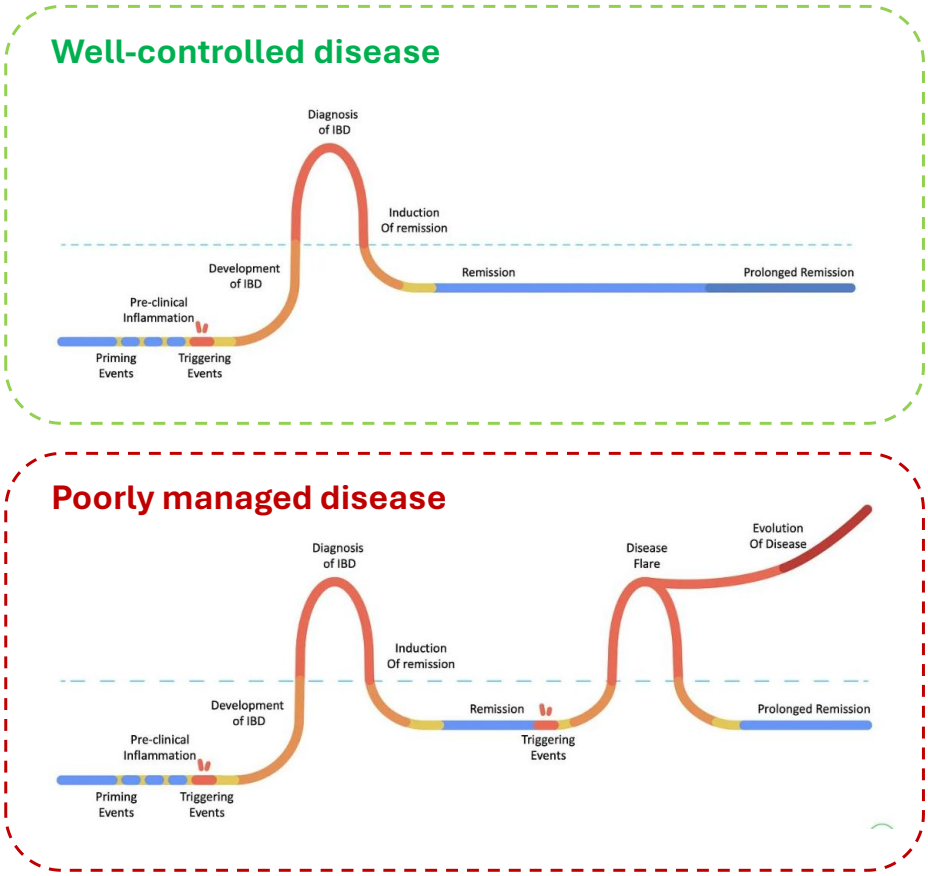
Once diagnosed, effective treatment, monitoring and follow-up care are essential to manage IBD effectively. Because IBD is a relapsing condition, patients require support to proactively respond when symptoms flare to prevent disease progression and unnecessary suffering.

High-quality care for IBD should prioritise sustaining long-term remission through comprehensive, patient-centred management plans that include regular monitoring, early proactive treatments and personalised treatment adjustments.[49] This many be achieved through medication alone or it may also involve surgery, often in combination with other supportive and psychological care services.

While there is no cure for IBD, effective treatment can see a patient's IBD go into remission, sometimes for extended periods, with a patient experiencing few or infrequent symptoms and enjoying a quality of life in line with their peers. Poorly managed IBD, however, can result in a chronic cycle of disease flares, relapse, progression and surgery (Figure 1.14).

[49] Mehta, F., 2016. Report: economic implications of inflammatory bowel disease and its management. *The American journal of managed care*, *22*(3 Suppl), pp.s51-60

Figure 1.14: Treatment outcomes for well-controlled disease compared with poorly controlled disease



Source: Lees, C. (2022). Improving outcomes for IBD in 2022, Atomic IBD, https://charlielees.substack.com/p/improving-outcomes-for-ibd-in-2022.

Treatment is individualised based on the severity of the disease, the affected areas of the digestive tract, and the patient's overall health, typically involve a combination of medication, lifestyle changes, and surgery. For some patients, surgery early may be the optimal treatment path, for others management through medication alone may be the recommended course of treatment. Key components of the treatment plan are likely to include:

- *Medications* — Clinical guidelines recommend commencement of therapy with so-called 'conventional therapies', which are the first-line treatments to reduce inflammation in the digestive tract. For people with mild to moderate disease this may be the only type of medication prescribed to achieve and maintain remission. Conventional therapies include:
    - Anti-inflammatory drugs, such as aminosalicylates (e.g., mesalazine)
    - Corticosteroids, such as prednisone, which are used for short-term flare-ups to quickly reduce inflammation but not suitable for long-term use due to potential side effects
    - Immunosuppressants, including drugs like azathioprine and mercaptopurine that suppress the immune system to reduce inflammation and help prevent relapse.

  If conventional therapies fail to achieve a clinical response, patients will be progressed to other novel therapeutics that are often collectively referred to as biologics but include a range of drugs that work in different ways to target a patient's immune response. Treatment of moderate to severely active IBD with these novel

therapies work by blocking specific molecules involved in the inflammatory process and include:

- TNF-alpha inhibitors, such as infliximab and adalimumab
- Monoclonal antibodies, such as ustekinumab
- Anti-integrin agents, such as vedolizumab
- Janus kinase inhibitors (JAK inhibitors), which are not biologic therapies but synthetic small molecules, such as tofacitinib.

Additionally, antibiotics, such as metronidazole or ciprofloxacin, may be used to treat complications like infections or abscesses. Patients also need to stay up-to-date with vaccinations as medicines that reduce an immune response also put a person at-risk of infection.

- *Surgery* — While most people can manage their condition with medication, surgery may be the optimal treatment for some people, particularly for people diagnosed with Crohn's disease. While the risk of surgery has been declining through time,[50] the overall 5-, and 10-year risk of colectomy for a person diagnosed with ulcerative colitis is estimated to be around 7 per cent (5.7–8.6) and 10 per cent (6.3–14.2), respectively. The overall 5-, and 10-year risks of surgery for a person diagnosed with Crohn's disease have been estimated to be 18 per cent (15.4–21.0) and 26 per cent (23.4–29.4), respectively.[51] Common types of surgery include:
  - Resection, which involves removing a damaged portion of the intestine.
  - Strictureplasty, which involves widening the intestines if there has been a narrowing of the intestines (stricture)
  - The removal of fistulas (the connection of two parts of the body that should not connect) or abscess drainage
  - The creation or closure of an ostomy, which is a surgically created connection between the bowel and skin to allow faeces to drain that can be temporary or permanent depending on the clinical situation.

  In very severe cases, the large bowel (colon) may be removed.
- *Dietary changes* — Patients may need to follow a special diet to manage symptoms, avoid trigger foods, and ensure proper nutrition. In some cases, a low-residue diet or enteral nutrition (liquid feeding) may be recommended. Patients may also be prescribed nutritional supplements (e.g., vitamins and minerals) to address deficiencies, especially during flare-ups when nutrient absorption is compromised.
- *Lifestyle changes* — Patients with active disease will also be counselled to avoiding stress and to quit smoking. Managing stress and quitting smoking are important for controlling symptoms and reducing the frequency of flare-ups.
- *Mental health support* — Recent research has revealed a complex relationship between the brain and the gut, often referred to as the 'gut-brain axis.' Critically, this connection is bi-directional, meaning that not only can gut health influence mental well-being, but mental health can also affect the functioning of the gastrointestinal

[50] Giddings, H. L., Ng, K. S., Solomon, M. J., Steffens, D., Van Buskirk, J., & Young, J. (2023). Reducing rate of total colectomies for ulcerative colitis but higher morbidity in the biologic era: an 18-year linked data study from New South Wales Australia. ANZ journal of surgery, 93(12), 2928–2938. https://doi.org/10.1111/ans.18713

[51] Tsai, L., et al. (2021). Contemporary Risk of Surgery in Patients With Ulcerative Colitis and Crohn's Disease: A Meta-Analysis of Population-Based Cohorts. Clinical gastroenterology and hepatology : the official clinical practice journal of the American Gastroenterological Association, 19(10), 2031–2045.e11. https://doi.org/10.1016/j.cgh.2020.10.039. See also: https://crohnsandcolitis.org.uk/info-support/information-about-crohns-and-colitis/all-information-about-crohns-and-colitis/surgery-and-complications/surgery-for-crohns-disease.

system. An IBD diagnosis can contribute to significant mental health issues with more than half of patients reporting anxiety and/or depression. Cruelly, psychological stress, anxiety, and depression also put patients at a higher risk of flare ups and disease relapse. Access to psychological therapies is essential for these patients to better manage the mental health following an IBD diagnosis.

- *Monitoring and maintenance* — Regular follow-up appointments with a gastroenterologist are important to monitor disease progression, adjust treatments, and manage side effects of medications.
- *Screening for cancer* — People with IBD are at higher risk for colorectal cancer, so regular screening through colonoscopy is recommended.

[This page is intentionally left blank]

Chapter 2

Inflammatory bowel disease is debilitating and expensive – and too many IBD patients fall through the cracks

By 2035, more than 200,000 Australians will be living with IBD.

Epidemiological and economic analysis shows that the health, economic and social costs of IBD increase exponentially with disease severity. The economic cost of moderate to severely active disease is 2.5 times that of a person in remission; bringing forward the time to remission by only one year has the potential to save more than $75,000 per patient in avoided health and economic costs.

And yet, the time to diagnosis and disease remission takes many years for patients, and people living with IBD have hospitalisation and emergency department presentation rates that outstrip all other chronic conditions — even cancer.

Preventing disease progression through more timely diagnosis and effective treatment makes good health and economic sense for patients, their families and governments alike. But unlike other chronic conditions, the last 10 years have seen no investment in patient support services and there is no policy agenda for improving outcomes for people living with IBD beyond the National Action Plan for Inflammatory Bowel Disease.

Increasingly, IBD patients are at risk of being 'crowded out' and ignored by other chronic conditions with higher rates of prevalence.

This chapter takes stock of the economic, health and social impacts of IBD to Australian communities and the current policy landscape for improving the diagnosis, treatment and care of people living with IBD. Ultimately, the chapter concludes that while the Australian Government has advanced important initiatives that significant work remains to be done.

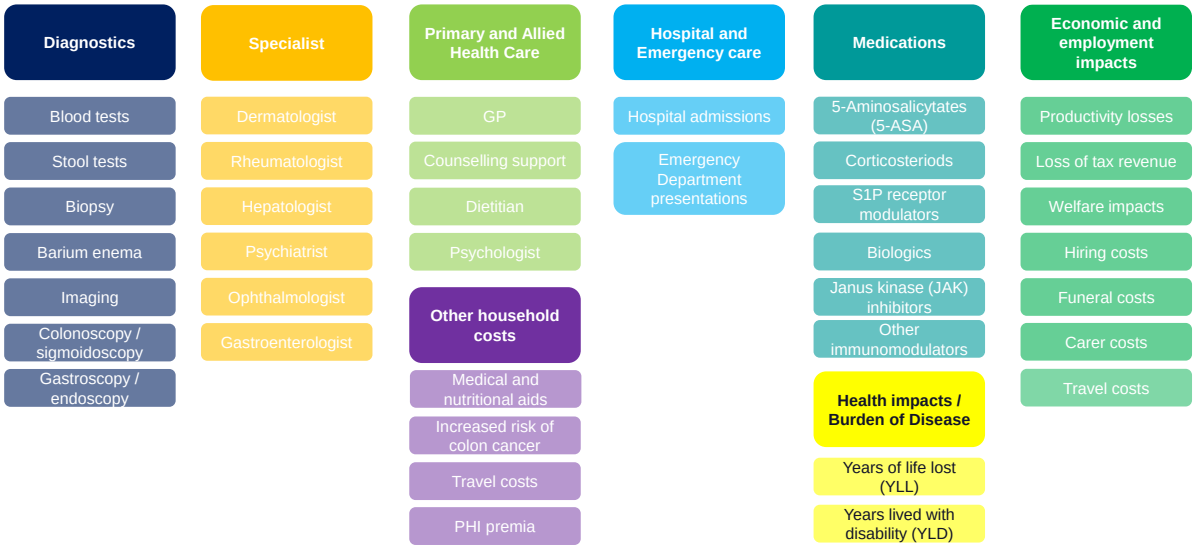
2.1 The health, economic and social impact of IBD to Australian communities

As shown in Chapter 1, IBD has a profound impact on a patient's health and well-being. It impacts their physical health and their emotional wellbeing, as well as their ability to participate in education, the workforce, and social activities.

This results in significant health services utilisation, lost work and productivity, lost tax revenue and increased welfare payments, as well as poor quality of life and, in some cases, premature death. To understand the total burden of these effects on patients, their carers and the wider community, a detailed, bottom-up analysis of health services utilisation, labour force outcomes, welfare supports, morbidity and mortality was developed, based on the State of the Nation Survey of People Living with Inflammatory Bowel Disease (See Appendix B), publicly available data on health and government services utilisation and cost, including data from the Australian Institute of Health and Welfare, Australian Bureau of

Statistics, Medical Benefits Schedule, Pharmaceutical Benefits Schedule, Independent Health and Aged Care Pricing Authority, Department of Health and Aged Care, Services Australia, the Global Burden of Disease Study and other market data where appropriate. The method and assumptions are detailed in Appendix C.

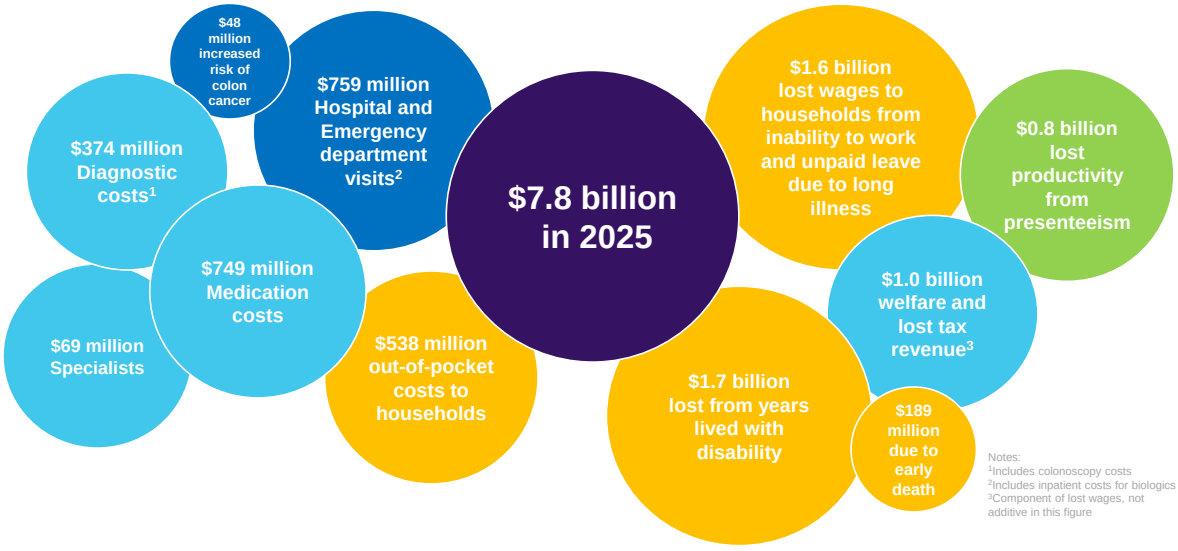
Figure 2.1: Overview of health and economic costs of IBD



Source: Insight Economics

This analysis reveals the total economic impact of Inflammatory bowel disease to be in the order of $7.8 billion in 2025 (Figure 2.2). Consistent with previous studies, and other chronic disease analysis, approximately one third of the cost is healthcare costs, with the balance, and majority of the impact, is in the potentially preventable health impacts and wider economic costs arising from lower workforce participation, presenteeism and welfare support.

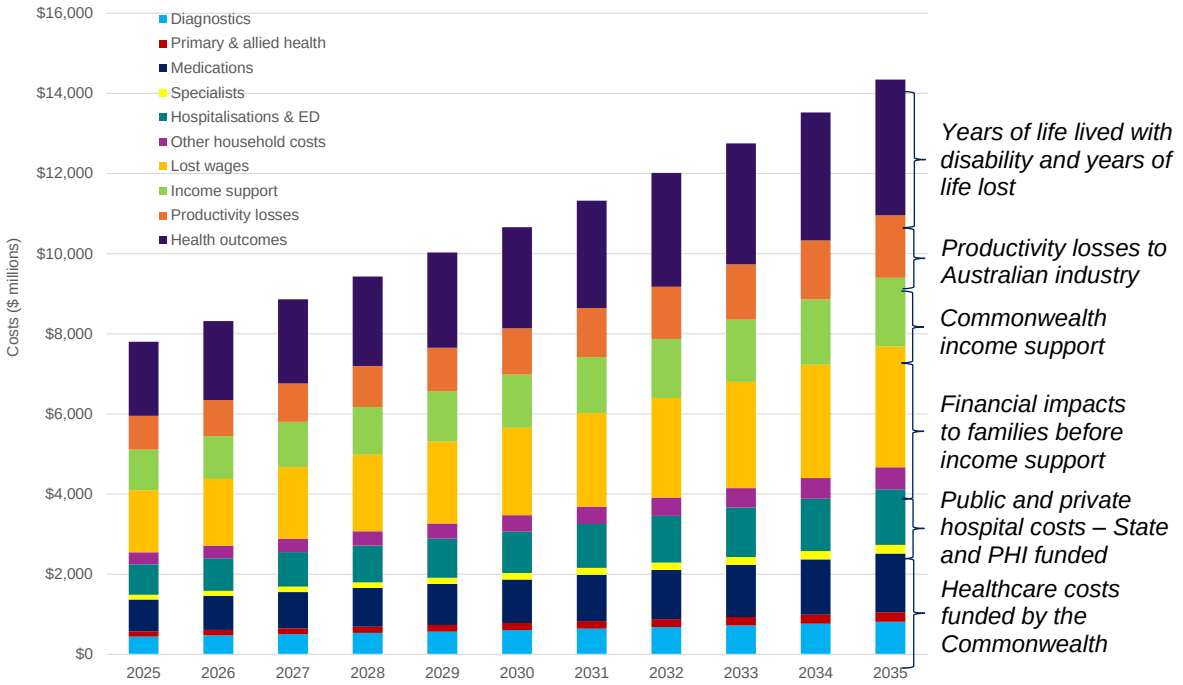
Figure 2.2: Counting the economic costs of IBD in 2025



Source: Insight Economics; see Appendix C for method, data sources, key assumptions and calculations.

Over the next decade, in light of the increasing prevalence of IBD, the total economic burden is estimated to be a staggering $77.9 billion in $NPV_{7\%}$ terms over the 2025-2035 period (Figure 2.3).

Figure 2.3: The costs of IBD to 2035 without action



Source: Insight Economics; see Appendix C for method, data sources, key assumptions and calculations.

This will include:

- $4.3 billion in diagnostics costs, which account for approximately 6% of the economic impact arising from the extensive and frequent tests required to diagnose and monitor disease outcomes, including blood tests, stool tests, colonoscopies, imaging and biopsies
- $1.3 billion in primary and allied health costs, including GP visits, dietitian and psychologist supports, which account for 2 per cent of the economic impact of IBD
- $8 billion in medication costs, including funding for conventional medicines and novel therapeutics, which account for 10 per cent of the economic impact of IBD
- $1.2 billion for specialists, including in the main visits to gastroenterologists, but also dermatologists, rheumatologists (specialists in treatment of arthritis), hepatologists (liver specialists), ophthalmologists or optometrists (eye specialists) and psychiatrists, which account for 2 per cent of the economic impact of IBD
- $7.6 billion in hospitalisations and emergency department presentations, which account for 10 per cent of the economic impact of IBD
- $3 billion in other household costs, which includes the funding of enteral nutrition, supplements, pain medication, skin creams, ostomy bags, PHI excess and increased coverage, and accounts for 4 per cent of the economic impact of IBD
- $15.9 billion in lost wages due in the main to people being unable to work as a result of their symptoms and needing to recover, which accounts for 20 per cent of the economic impact of IBD
- $9.7 billion in income support payments to people unable to work
- $8.4 billion in productivity losses to Australian industry due to presenteeism

- $18.4 billion in poor health outcomes, arising from years lived with a disability and, to a lesser extent, years of life lost due to premature death.

2.2 Crippling out-of-pocket costs for families

Critically, the out-of-pocket costs for people living with IBD and their families can be overwhelming given the need for frequent specialist visits, medications, diagnostic tests, allied health services and other out-of-pocket costs. On average, a person living with IBD can spend $5,900 each year managing their disease, which equates to around 10 per cent of the average Australian household's disposable income.[52]

Taking into account the expected average loss of income of $19,000 (21 per cent of the average household income) from reduced workforce participation and unpaid leave due to illness, the financial impact on families from IBD is enormous. After factoring in the loss of income, out-of-pocket costs rise to be 15 per cent of disposable household income. For people on low income, the risk of financial hardship from active disease is significant.

Major out-of-pocket costs include:

- *Specialist fees* — The cost of seeing a gastroenterologist or IBD specialist in private practice can also be high, and most patients with IBD are treated in the private sector (73 per cent), often due to the long wait times for access to public clinics. For those without private health insurance, the out-of-pocket cost for an initial consultation can range from $150 to $300, with follow-up appointments costing $100 to $200. The average out-of-pocket cost per visit reported by patients in the State of the Nation Survey of People Living with Inflammatory Bowel Disease (See Appendix B) was $130 per visit. In addition, if a person is experiencing other extra-intestinal manifestations, they may also need to see other types of specialists, including a hepatologist (liver specialist), rheumatologist (arthritis specialist), ophthalmologist (eye specialist) or optometrist, a dermatologist (skin specialist) or a psychiatrist; the average out-of-pocket cost per visit for these specialists ranged from $150 to $220 per visit on average. The average annual cost of specialist visits across all specialist types was approximately $510 per annum.
- *Diagnostic tests* — A range of diagnostic tests are used in the diagnosis and monitoring, including blood tests, stool tests, colonoscopy and imaging procedures, such as MRI or CT scans. A number of these investigations involve a hospital admission as well. While many diagnostic tests are partially covered by Medicare, patients may still face significant out-of-pocket costs. The average out-of-pocket cost per visit reported by patients in the State of the Nation Survey of People Living with Inflammatory Bowel Disease (See Appendix B) was approximately $700 per annum.
- *Medication Copayments* — Even for patients who qualify for the PBS subsidy, copayments for medications (including biologics) add to the financial burden for individuals. The average out-of-pocket cost per visit reported by patients in the State of the Nation Survey of People Living with Inflammatory Bowel Disease (See Appendix B) was around $500 per annum, or roughly $40 per month.
- *Hospital admissions* — For IBD patients requiring hospital admissions due to complications, flare-ups, or surgery (such as bowel resections), the out-of-pocket costs can be considerable. Even with Medicare, patients with private health insurance may face gap fees for hospital stays, surgical procedures, and anaesthetist services. Gap fees for surgery can range from $500 to several thousand dollars, depending on the procedure and the patient's health fund coverage. The average

[52] Average disposable income was $1,124 in 2020 (Latest release); See ABS, 2022. Household Income and Wealth, Australia accessed at: https://www.abs.gov.au/statistics/economy/finance/household-income-and-wealth-australia/latest-release.

out-of-pocket cost for hospitalisations and emergency department presentations was estimated to be $400 per prevalent case.

- *Primary care, allied health and mental health services* — IBD patients often require ongoing care from GPs, dietitians, psychologists, and other allied health professionals to manage their condition effectively in the community. These services are only partially covered by Medicare, with many patients needing to pay additional out-of-pocket costs for private consultations. For instance, a dietitian consultation can cost around $80 to $150 per session, and psychology services may cost $100 to $250 per visit, depending on the provider. The average out-of-pocket cost for key allied health were reported to be:
    - $50 per visit to a GP
    - $120 per visit to a dietitian
    - $60 per visit to a physiotherapist
    - $100 per visit to a counsellor
    - $175 per visit to a psychologist.
- *Other household costs* — Other costs are also incurred which may be less obvious. For example, people living with a stoma (16 per cent of respondents) reported spending $70 per month on ostomy bags. Around one third of families reported spending $310 per month on home enteral nutrition for children, while adults can spend $125 per month.

  Added to this, most adults (62%) reported spending $45 per month on oral supplements, while parents spent $85 per month for oral supplements for their children. Approximately 40 per cent of people also spent money on skin care medications and 14 per cent of respondents spent money on continence aids, which cost $130 per month after government subsidy support.

  People living in regional areas (43% of respondents) reported spending more than $1,000 each year on average to access treatment.

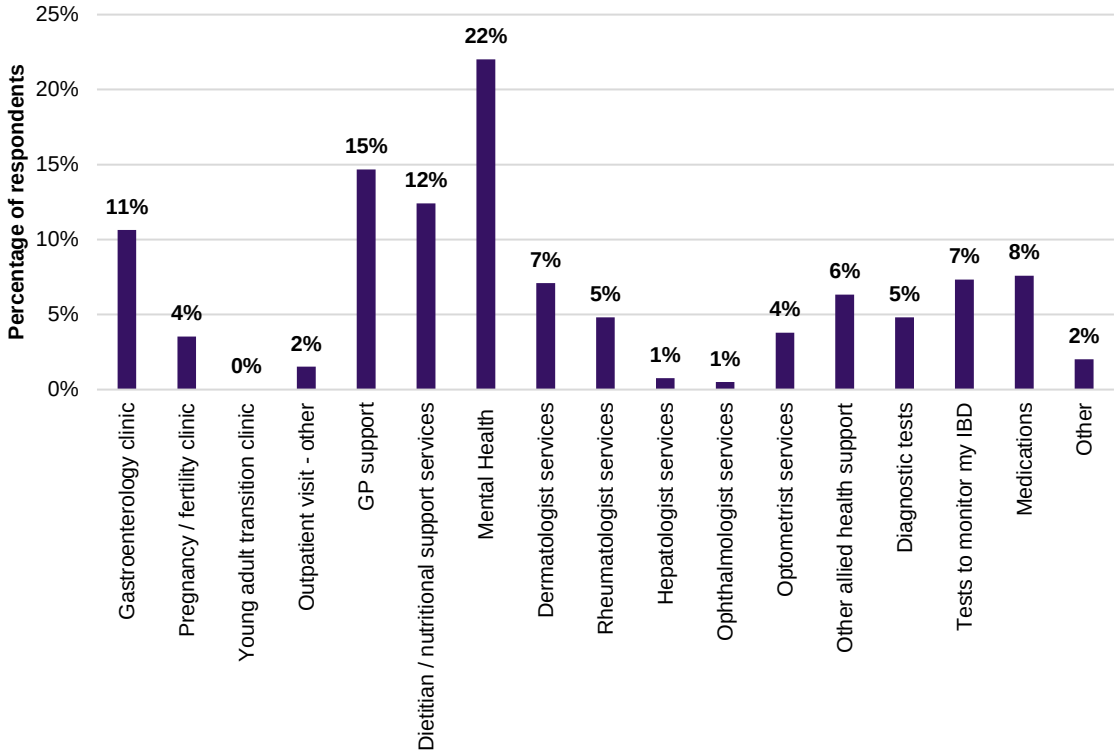
  People living with IBD also have higher levels of private health insurance coverage than the population average.

  Altogether, these other additional goods to support the management of IBD accounted for around half of the expected out-of-pocket costs to families.

In the context of ever-increasing cost of living pressures, many patients reported delaying key services due to cost concerns; for example, as shown in Figure 2.4:

- 1 in 5 patients (22%) put off mental health support
- Just under 1 in 10 patients delayed accessing medications (8%)
- 15% delayed seeing their GP
- 12% delayed accessing nutritional support
- 11% delayed accessing gastroenterology appointments.

Figure 2.4: Proportion of patients that had delayed tests, medications, or services due to cost in last six months



Source: State of the Nation Survey of People Living with Inflammatory Bowel Disease (See Appendix B).

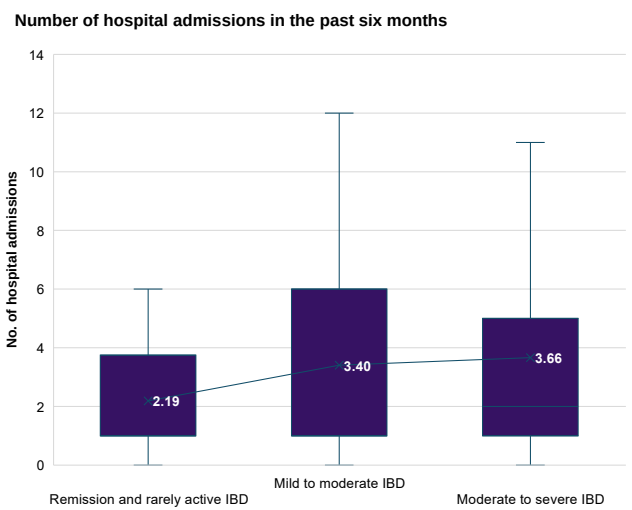
2.3 IBD is debilitating and expensive if poorly controlled

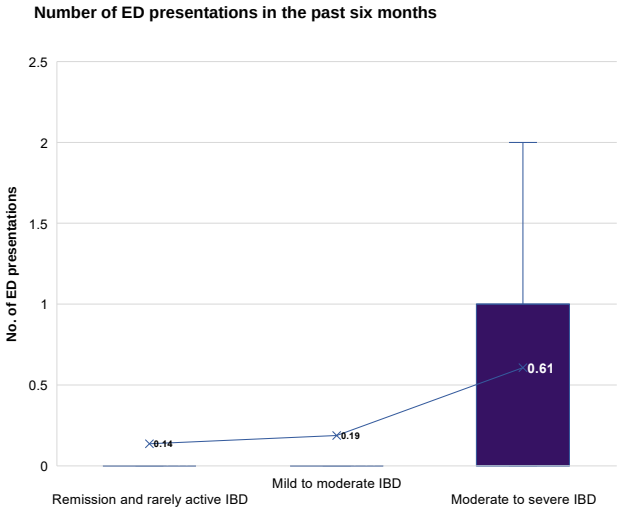
The health, economic and social costs of IBD increase exponentially with disease severity. For a person with moderately to severely active disease, compared to a person in remission:

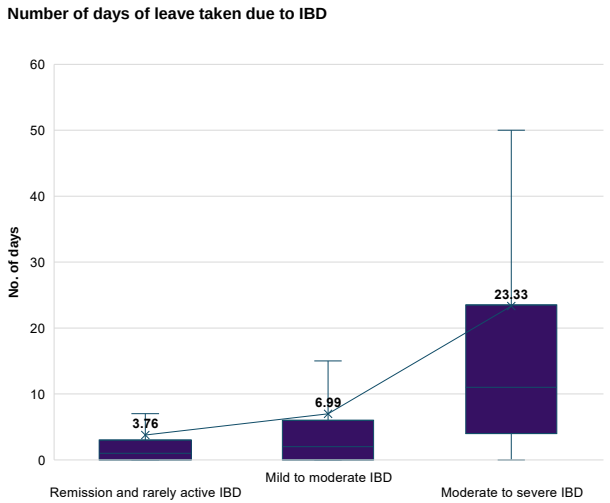
- The risk of hospitalisation increases by 67 per cent
- The risk of emergency department presentations triples
- The number of sick days increases five-fold
- Workforce participation halves
- The number of days missed from school triples
- The risk of dropping out of school triples
- A person's ability to have an active social life halves
- A person's quality of life reduces by 22 per cent
- Their carer's quality of life reduces by 14 per cent.

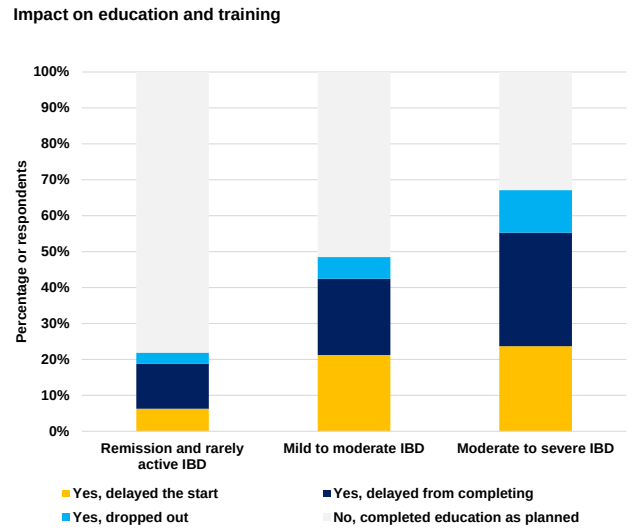
Figure 2.5 shows some of the outcomes for people across various health, economic and social metrics for varying levels of disease severity.

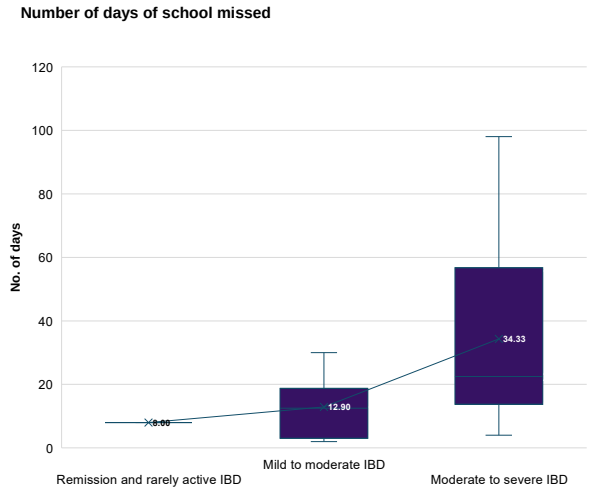
Figure 2.5: Understanding the impact of severe disease across health, economic and social domains

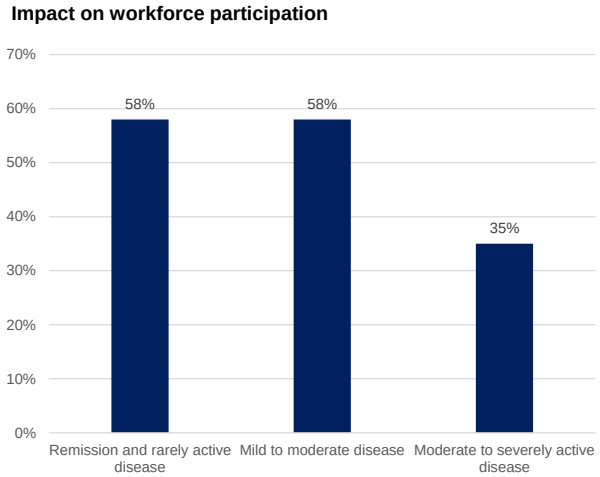




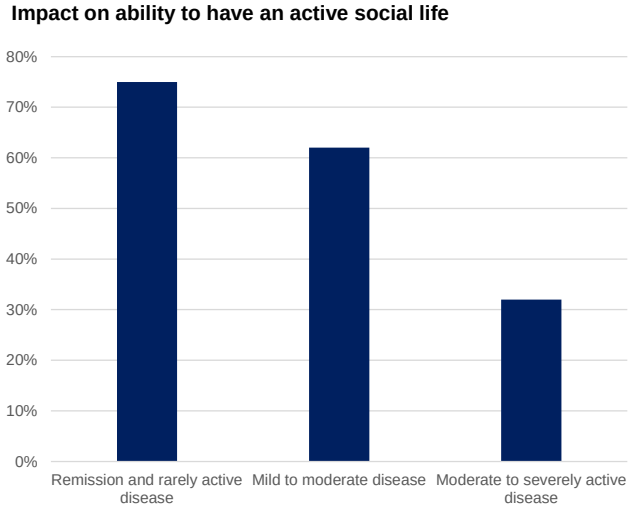


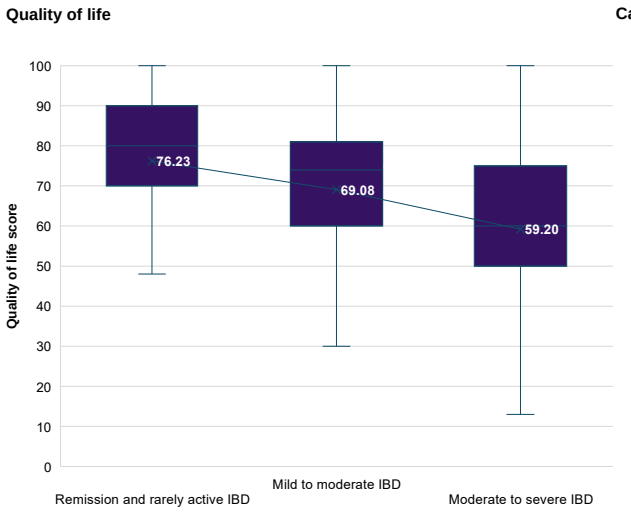


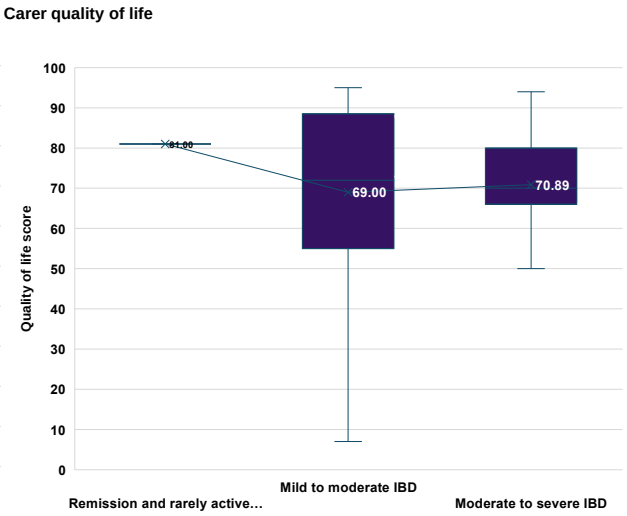




Continued next page



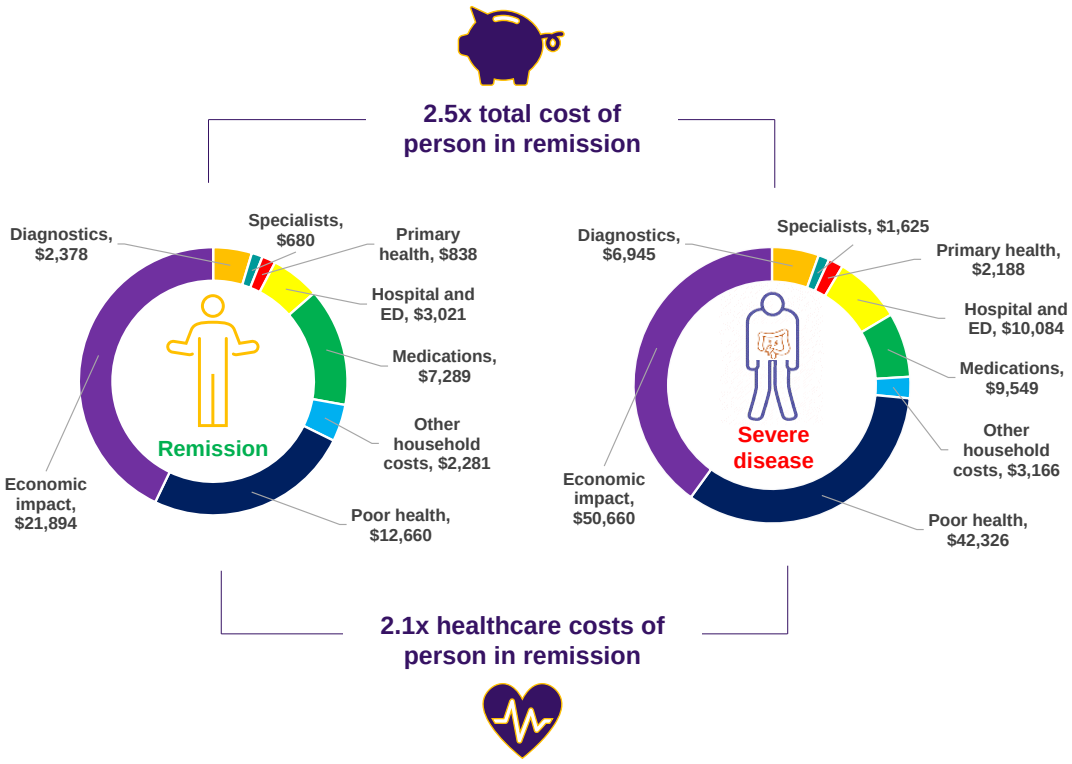




Source: State of the Nation Survey of People Living with Inflammatory Bowel Disease, See Appendix B.

Taken together, the total economic cost of a person living with severely active disease is 2.5 times that of a person in remission.

Figure 2.6: The economic cost of severely active disease



Source: Insight Economics. See Appendix C.

2.4 IBD is at risk of being 'crowded out' and forgotten – with no patient support funding, in contrast to other chronic diseases

In spite of these significant and potentially avoidable costs to patients, their families and governments, IBD increasingly lacks any real policy focus by governments today and is at risk of falling through the cracks.

The need to improve outcomes for people living with IBD was first recognised by the Australian Government though the development of the National Action Plan for IBD, launched in 2019. Through the National Action Plan important progress has been made; as shown in Table 2.1, there has been investment in GP awareness, consumer education and paediatric research as a result of the National Action Plan, but significant issues remain and a number of the key actions in the Action Plan have not been implemented.

Table 2.1: Outcomes from the National Action Plan for IBD

Action	Progress to date
1. A skilled and accessible multi-disciplinary workforce	
1.1 Increased access to specialist IBD nurses	
a. Implement specialist IBD nurse positions to address demand and increase access in areas of need	No action
b. Develop specialist IBD nurse training modules	No action by govt, but GENCA/IBDNA deliver IBD training
1.2 Greater access to multi-disciplinary allied health teams	

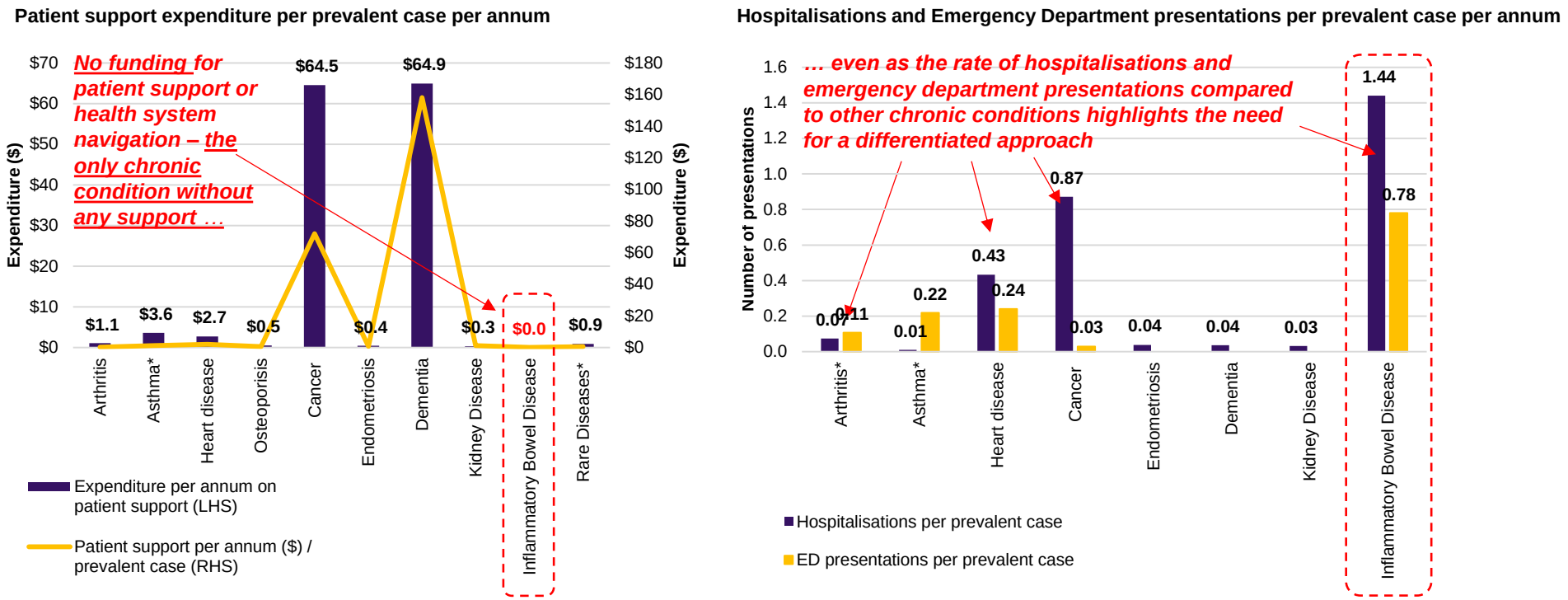
Action	Progress to date
a. Implement IBD psychology roles in multi-disciplinary teams	No action
b. Implement IBD focussed pharmacist roles in multi-disciplinary teams	No action
c. Develop credentialling roles on IBD management for psychologists, dieticians and pharmacists	No action by govt, but CCA funded online dietician and psychologists course
d. Examine Medicare Benefits Schedule (MBS), General Practitioner (GP) care planning utilisation for referral to allied health clinicians for people with IBD	No action
1.3 Increase administrative resources to support case workers in IBD clinics	
a. Study the cost effectiveness and impact of an administrative role	No action
2. Access to responsive IBD helplines	
a. Support for local services to maintain clinically useful helplines	No action
b. Implement a national IBD nurse helpline network available to support individuals without access to a local helpline	No action, modest pilot of nurse navigation at CCA Nurse Line
c. Conduct an awareness campaign for GPs and primary care providers on the availability of local and national helplines for patients and clinicians	No action
3. Support general practitioners to more effectively participate in IBD management	
a. Establish clearer GP referral guidelines and protocols	✓ $700k GPAware for IBD
b. Upskill GPs on contemporary IBD management	
c. Develop individual action plans for IBD patients	
4. Improve patient knowledge	
a. Develop self-management focussed information materials	✓ $1 million Consumer Education & Awareness of IBD Project
5. Increased investment in research and focus on children with IBD	
a. Increased investment in research for children and adults with IBD	No action by govt, but CCA has funded research
b. Improved/streamlined PBS subsidised access to new IBD medications for paediatric patients	No additional listings but improved processes still under review (e.g., HTA reforms)
c. Complete a research audit of IBD paediatric care to measure change and inform future quality improvement	✓ $300k to conduct 2023 Paediatric IBD Audit
6. Support for practice management software, data and audit systems	
a. Support for practice management software (IBD specific auditable clinical management software)	No action by govt, but Crohn's Colitis Care (CCCare) Electronic Medical Record (EMR) and clinical database developed by Crohn's Colitis Cure (CCCure)
b. Research the IBD Quality of Care Audit incorporating data from practice management software	No action
7. Funding faecal calprotectin testing and therapeutic drug monitoring of biological therapies	
a. MBS funding of faecal calprotectin testing (diagnostic indication)	✓ Diagnostic test for patients <50yo
b. Research funding for health economic analysis of faecal calprotectin testing (monitoring indication) and therapeutic drug monitoring of biological therapies	No action by government but GESA has developed additional evidence

Action	Progress to date
8. Explore the potential for effectiveness of medical-home funds bundling	
a. IBD stakeholders should monitor the evidence produced by the healthcare homes initiative and patient-centred medical homes in the US and identify opportunities for application	No action, but CCA & Monash Health have developed Framework for Integrated Care

Apart from the National Action Plan for IBD, a review of the policy landscape shows there is little to no real policy agenda to improve outcomes for people living with IBD. At a state level, policies are primarily focused on strategies to promote general lifestyle change, such as the promotion of healthy diets and reducing smoking. At a federal level, IBD falls within the remit of the National Strategic Framework for Chronic Conditions, and work to advance recommendations of the National Action Plans has been paused in the context of the refresh of the National Strategic Framework for Chronic Conditions.

While finding solutions at scale for common issues shared by all chronic diseases is sound public policy, it also is critical that such an approach does not drift into an inequitable or 'one size fits all' approach, where important differences between diseases are ignored or overlooked. Benchmarking IBD against other chronic conditions with National Action Plans, for example, reveals a disease that has among the highest rates of hospitalisation and emergency department presentation of any chronic disease – even cancer – but also no support for patients (Figure 2.7).

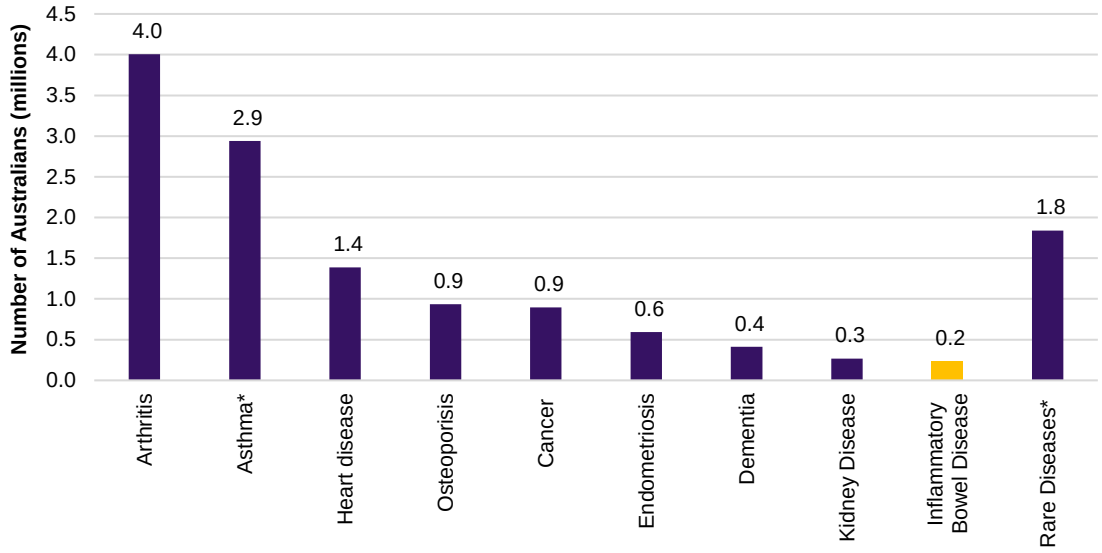
Figure 2.7: Benchmarking chronic conditions in Australia — Rates of hospitalisations and emergency department presentations per prevalent case compared to patient support per prevalent case



Source: Patient support data based on Grants Connect data, 2014-2024; hospitalisations per prevalent case based on AIHW data.

These data raise questions of whether IBD is being 'crowded out' by other chronic conditions, which get more policy focus and funding by virtue of their numbers. Even using the lifetime prevalence estimate, the prevalence of IBD is dwarfed by other conditions (Figure 2.8).

Figure 2.8: Prevalence of chronic conditions in Australia (millions of people)



Source: Australian Institute of Health and Welfare rates of chronic conditions per 100,000 and updated IBD lifetime prevalence estimates based on Insight Economics epidemiological modelling, see Appendix C.

This means it is relatively easier to overlook or ignore, particularly when the patient community may feel a stigma or shame associated with their condition, which may tend to mute their advocacy relative to others.

2.5 Five years on from National Action Plan, time for a refresh and refocus by government

Improving the management of IBD is strongly aligned to government objectives for improved health and wellbeing, improving health system efficiency, and workforce participation and productivity. As a chronic condition that affects young people and the working age population, improving the treatment and care of IBD is strongly aligned to the Government's health and economic reform objectives (See Appendix E). Moreover, against a backdrop of declining employment-to-population ratios and labour productivity growth, as highlighted by the most recent *Intergenerational Report*, the strategic imperative for improved outcomes for people living with IBD is only set to grow.

Five years on from the release of the National Action Plan for IBD and against the backdrop of a refresh of the *National Strategic Framework for Chronic Conditions,* it is timely to consider continued areas of need for people living with IBD and priorities for reform.

[This page is intentionally left blank]

Chapter 3

Barriers to improved outcomes in IBD today

Against this backdrop of rapidly increasing prevalence and debilitating disease burden, there are significant issues related to the consistent adherence and access to best practice treatment and care.

In particular, many patients experience delayed diagnosis due to the lack of awareness and non-specific symptoms of IBD, with delayed diagnosis leading to more severe disease, which doubles a patient's risk of intestinal surgery.

Once diagnosed, current levels of healthcare service provision fail to deliver equitable and comprehensive IBD care. Addressing these gaps would be expected to reduce avoidable healthcare and economic costs for people living with IBD and Australian communities.

This chapter presents a summary of the major barriers to improved outcomes for people living with IBD in Australia today.

3.1 Overview of major barriers to improved outcomes in IBD

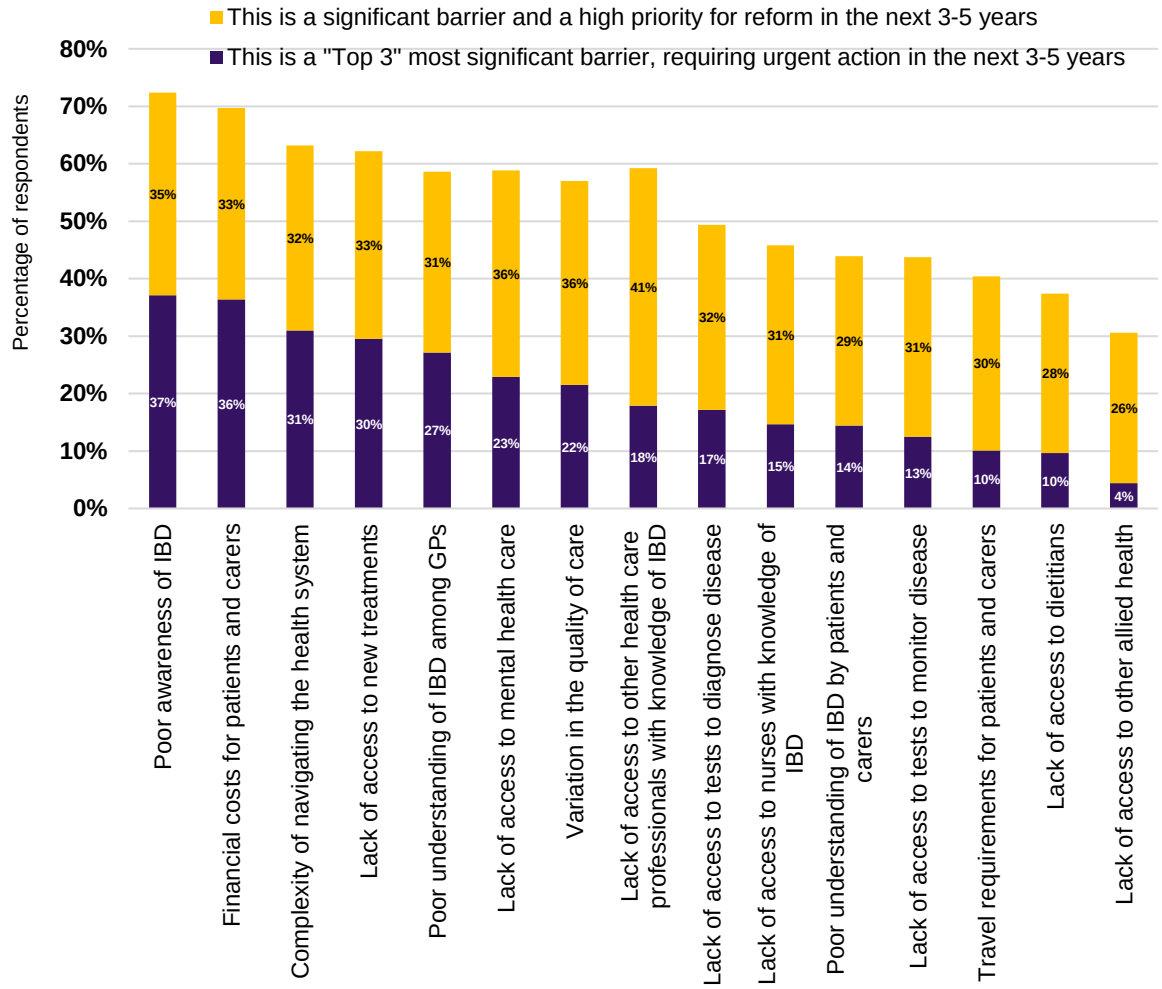
While important progress has been made since the launch of the National Action Plan in 2019, stakeholders indicated that on balance many of the most significant barriers to quality care remained for people living with IBD.

Significant barriers identified through stakeholder consultations and the survey of people living with IBD (Figure 3.1) included:

- Still limited awareness and understanding of IBD, leading to long times to diagnosis and disease remission
- Lack of multi-disciplinary approach to treatment and care, including in particular poor access to allied health and mental health support
- Significant variation in clinical practice
- Poor access and long waiting times for public sector services
- Significant challenges in health system navigation
- Lack of access to novel therapies and inefficiencies in accessing medicines
- High costs of healthcare for people with frequent interactions with health care system, compounded by inability to earn due to burden of disease
- Lack of investment in IBD research.

These are considered in turn.

Figure 3.1: Patient perspectives on the major barriers to improved outcomes for people living with IBD



Source: State of the Nation Survey of People Living with Inflammatory Bowel Disease (See Appendix B).

3.2 Poor awareness and understanding of IBD, leading to long times to diagnosis and disease remission

As shown in the Survey of People Living with Inflammatory Bowel Disease, the number one barrier to improving outcomes reported by patients is poor awareness of IBD, which can contribute significantly to delayed diagnosis, difficulties in disease control, and psychosocial challenges for those living with the condition. Poor awareness was evident, for example, in all three of our patient stories presented in Chapter 1 (See Boxes 1.1-1.3).

The National Action Plan funded GPAware to improve GP awareness and understanding of IBD. Initial evaluations indicate that there has been relatively low take up to date, which may reflect the relative rarity of IBD. For example, there are currently approximately 38,388 GPs working across Australia (30,736 full-time equivalent);[53] with a prevalence under active management of approximately 91,000 people in 2025, that translates to around 2.3 IBD patients per GP per annum. In practice, this means maybe one patient with Crohn's and one with ulcerative colitis. The average GP conducts around 144 patient

[53] AMA. (2022). General practice facts, accessed at: https://www.ama.com.au/articles/general-practice-facts-0#:~:text=In%202020%20-%202021%3A%20%5B1%5D%201%20there%20were,aged%20groups%207%2041.4%25%20of%20GPs%20trained%20overseas

consultations per annum,[54] which equates to approximately 7,488 patient consultations per annum. The utilisation rate of GPs per annum was reported to be six visits to the GP per annum; this would translate into roughly 14 patient consultations on IBD each year, or 0.19 per cent of a GPs typical workload. Research has shown that GPs tend to undertake continuing professional education in the conditions where they are most likely to see patients.[55] It is therefore somewhat unsurprising that GP participation in GPAware for IBD remains low and perhaps points to the need for a new or at least complementary approach.

Poor awareness of IBD contributes to the misinterpretation or dismissal of symptoms for less serious or more common conditions like irritable bowel syndrome (IBS), gastroenteritis, or food poisoning. Primary care providers may also be unaware of the more severe manifestations of IBD, such as extra-intestinal symptoms (e.g., joint pain, skin rashes) or complications like fistulas or strictures, which can lead to delayed treatment. As a result, people may be misdiagnosed for months or even years before receiving the correct diagnosis.

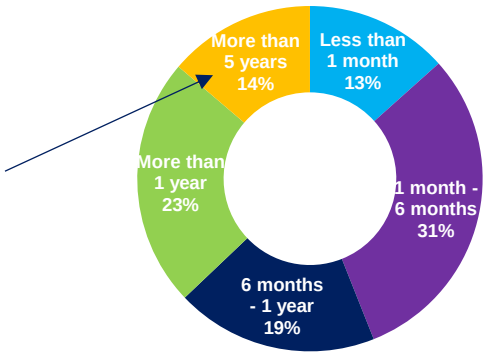
Added to this, low awareness of IBD in the community may mean that individuals with IBD may not seek medical attention early or may lack the confidence to advocate for themselves or seek a second opinion.

As a result of these factors, the average time-to-diagnosis for people living with IBD is astonishingly long. More than 1 in three patients experience symptoms for over a year before receiving diagnosis and for just over one in 10 patients have experienced symptoms for over five years before receiving a diagnosis (Figure 3.2). After this there are long delays to remission, with poor access to MDTs.

Figure 3.2: Long time to diagnosis

More than 1 in 3 patients experience symptoms for over a year before receiving a diagnosis…

… and within this, more than 1 in 10 people reported it took more than 5 years to get a diagnosis.



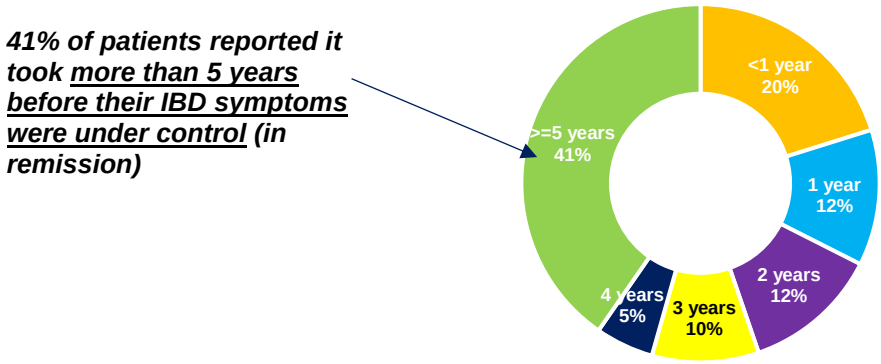
Source: State of the Nation Survey of People Living with Inflammatory Bowel Disease (See Appendix B).

This delay in seeking medical care can allow the disease to progress to a more severe state at the time of diagnosis, leading to complications such as intestinal damage, malnutrition, and slowed growth in children. Without early intervention, patients may experience more extensive inflammation, which can lead to irreversible damage to the gastrointestinal tract and increases the risk of surgery.

Following the long delay to diagnosis, there are then often further delays in the time to remission (Figure 3.3). The weighted average time from diagnosis to disease remission was conservatively three years, with more than 40 per cent of people reporting it took more than 5 years to bring their disease under control.

[54] Glasziou, P., (2013). Common general practice presentations and publication frequency, https://www.racgp.org.au/afp/2013/january-february/common-general-practice-presentations
[55] Ibid.

Figure 3.3: Long time to remission

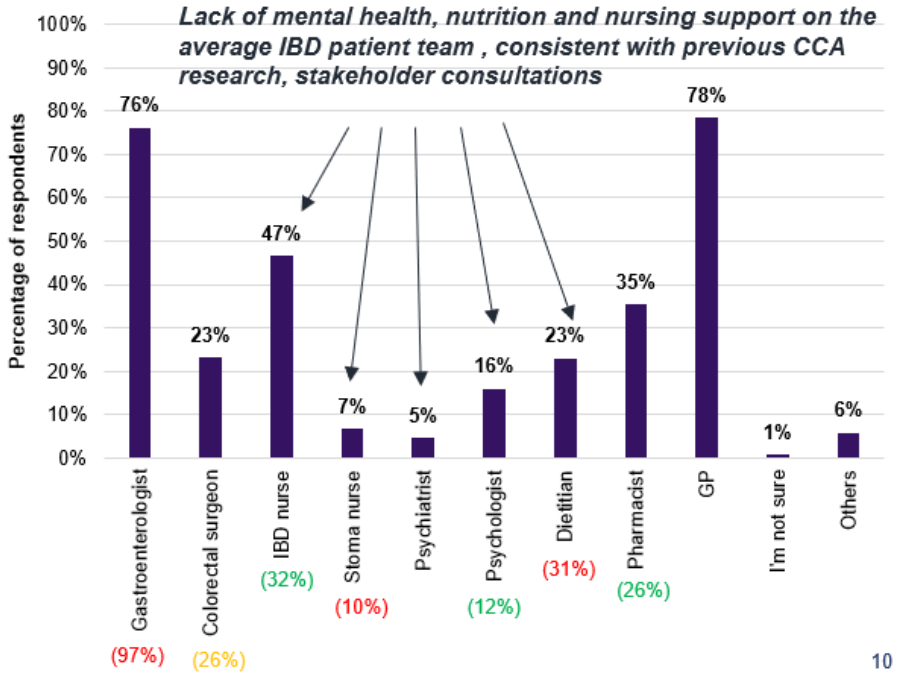


Source: State of the Nation Survey of People Living with Inflammatory Bowel Disease (See Appendix B).

3.3 Lack of quality, integrated approach to treatment and care

Once diagnosed, people lack access to multi-disciplinary teams to support their treatment and care (Figure 3.4), in spite of substantial evidence of the need and cost-effectiveness of a multi-disciplinary approach. Relative to 2018, when the first IBD Hospital Audit was undertaken,[56] there is improved access to IBD nurses but on balance most patients still lack access to the clinical best practice in IBD.

Figure 3.4: Poor access to multi-disciplinary health team persists, and in some cases has worsened

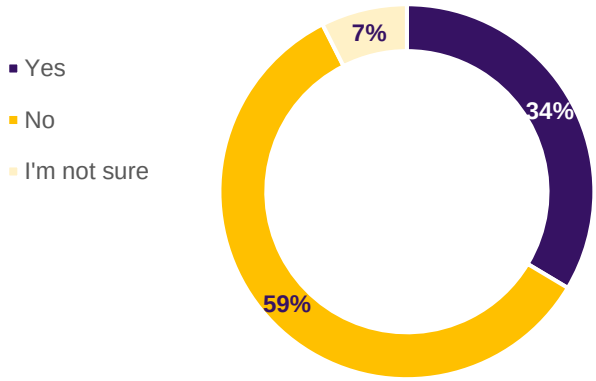


Source: Crohn's & Colitis Australia. (2018). My IBD Experience: Australian Inflammatory Bowel Disease Patient Experience of Health Care, Research report 2018, *2018 My IBD Experience results in parentheses, Figure 4, p12.

[56] Crohn's & Colitis Australia . (2018). My IBD Experience: Australian Inflammatory Bowe Disease Patient Experience of Health Care, Research report 2018.

Similarly, and perhaps unsurprisingly, very few patients have a Chronic Disease Management Plan, with only one third of patients reporting that they had a plan in place.

Figure 3.5: Do you have a Chronic Disease Management Plan?



Source: Crohn's & Colitis Australia Pulse Survey of People Living with Inflammatory Bowel Disease.

IBD is a complex condition and the lack of a coordinated, patient-centered approach to care can lead to fragmented treatment, delayed interventions, and suboptimal outcomes for individuals with IBD. Access to MDTs is recognised as international best practice but inconsistently delivered in Australia. For example:

- Ferman et al in 2018 found the probability of patients being in remission at follow-up (27 months) was 58 per cent for patients with treatment overseen by a successful MDT, and only 15 per cent for people without access to a successful MDT – increasing the probability of remission by nearly four-fold (3.9 times higher probability of remission).[57]
- Sack et al in 2012 found the risk of hospital admission was lowest (30 per cent reduction compared to not MDT) among people with access to specialist gastroenterologist and IBD service.[58]
- A Canadian study from Saskatchewan comparing outcomes between individuals with an MDT and those without demonstrated that individuals with an MDT had a 22 per cent lower risk of IBD-related surgeries, and (for individuals with ulcerative colitis) a 44 per cent lower risk of IBD-related hospitalisations and 61 per cent lower risk of corticosteroid dependence.[59]
- A 2022 study found referral to an MDT following an emergency department presentation significantly reduced ED revisits compared to the standard-care group; there was a 77.8 per cent reduction in the probability of a further ED presentation within the next 30 days, with only 4.4 per cent of people accessing an MDT returning to the emergency department compared to 19.8 per cent of people who were not reviewed by an MDT.[60]

[57] Ferman, M. et al., (2018). Multi-disciplinary team meetings appear to be effective in inflammatory bowel disease management: an audit of process and outcomes, Intern Med J, 48: 1102-1108. https://doi.org/10.1111/imj.13965
[58] Sack, C., Phan, V. A., Grafton, R., Holtmann, G., van Langenberg, D. R., Brett, K., Clark, M., & Andrews, J. M. (2012). A chronic care model significantly decreases costs and healthcare utilisation in patients with inflammatory bowel disease. *Journal of Crohn's & colitis*, *6*(3), 302–310. https://doi.org/10.1016/j.crohns.2011.08.019
[59] Peña-Sánchez, J. N., Lix, L. M., Teare, G. F., Li, W., Fowler, S. A., & Jones, J. L. (2017). Impact of an Integrated Model of Care on Outcomes of Patients With Inflammatory Bowel Diseases: Evidence From a Population-Based Study. *Journal of Crohn's & colitis*, *11*(12), 1471–1479. https://doi.org/10.1093/ecco-jcc/jjx106
[60] Goren, I., Barkan, R., Biron, I. A., Leibovitzh, H., Golan, M. A., Eran, H. B., Snir, Y., Broitman, Y., Konikoff, T., Amir-Barak, H., Yafee, H., Adani, E., Shiber, S., Steiner, H., Drescher, M. J., Dotan, I., Yanai, H., & Israeli IBD Research Nucleus (IIRN) (2022). Specialized Emergency Department Assessment and Multi-disciplinary Intervention After Discharge Improve Management of Patients With Inflammatory Bowel Diseases. *Journal of clinical gastroenterology*, *56*(2), 148–153. https://doi.org/10.1097/MCG.0000000000001490

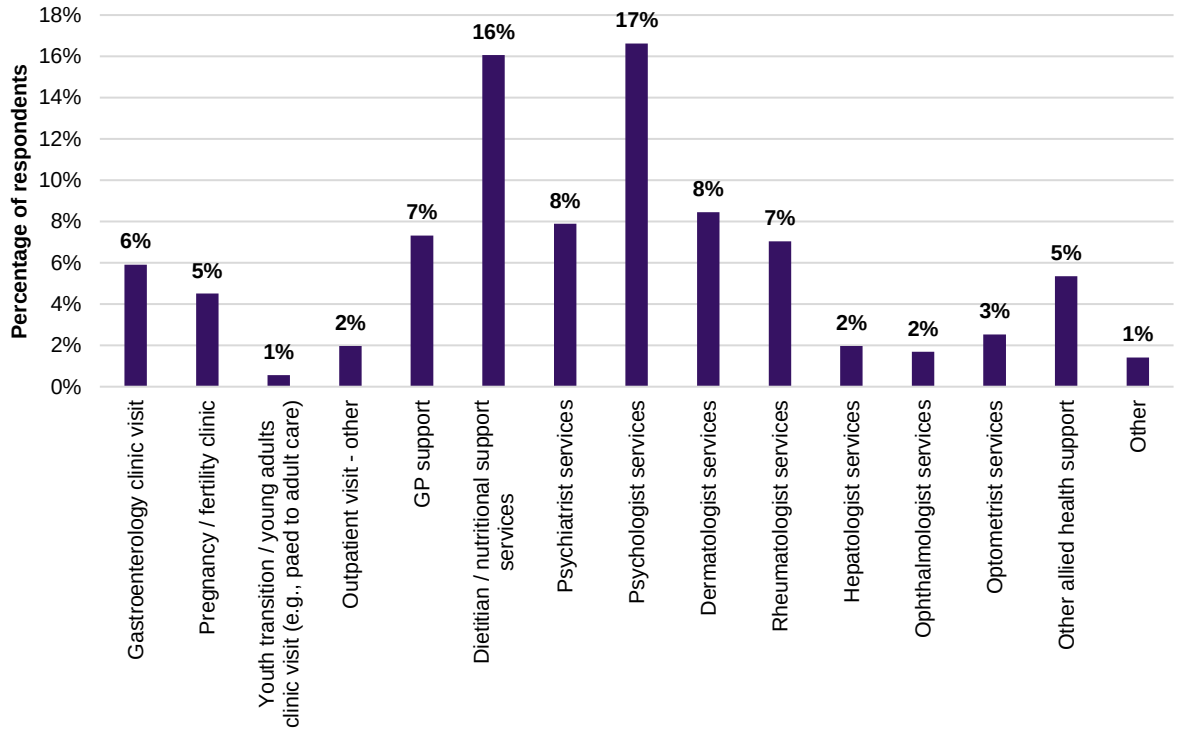
- The CALM study showed that tight control of Crohn's treatment by an MDT using anti-tumour necrosis factor therapy combined with biomarkers in patients can result in better clinical and endoscopic outcomes. A 'significantly higher proportion of patients in the tight control group achieved the primary endpoint at week 48 (56 [46%] of 122 patients) than in the clinical management group (37 [30%] of 122 patients)'.[61]

This results in poor outcomes for the patient, who fail to achieve disease remission, and poor outcomes for governments, with a waste of scarce public dollars used to treat people in emergency departments and hospitals that could have been otherwise avoided.

As shown in Chapter 2, IBD patients are among the most 'frequent flyers' or users of emergency department services; in the context of increasing stress on hospital emergency departments, evident in increasing ambulance ramping across Australia,[62] addressing this barrier would have benefits not just for IBD patients but the wider health system.

Even where patients have sought out multi-disciplinary care independent of an MDT, access to support services was poor. When asked what services patients wanted to access but haven't been able to, nearly one in five reported they were not able to access a psychologist and similarly, 16 per cent of people living with IBD indicated they had wanted additional support from a dietitian but had not been able to (Figure 3.6).

Figure 3.6: What services did you want to access but were unable to?



Source: State of the Nation Survey of People Living with Inflammatory Bowel Disease (See Appendix B).

[61] Colombel, J. F., Panaccione, R., Bossuyt, P., Lukas, M., Baert, F., Vaňásek, T., Danalioglu, A., Novacek, G., Armuzzi, A., Hébuterne, X., Travis, S., Danese, S., Reinisch, W., Sandborn, W. J., Rutgeerts, P., Hommes, D., Schreiber, S., Neimark, E., Huang, B., Zhou, Q., … D'Haens, G. (2017). Effect of tight control management on Crohn's disease (CALM): a multicentre, randomised, controlled phase 3 trial. *Lancet (London, England)*, *390*(10114), 2779–2789. https://doi.org/10.1016/S0140-6736(17)32641-7

[62] Karnon, J. and Partington, A., (2024). Ambulance ramping is getting worse in Australia. Here's why – and what we can do about it, published July 5. (2024). accessed at: https://theconversation.com/ambulance-ramping-is-getting-worse-in-australia-heres-why-and-what-we-can-do-about-it-232720

These access barriers are particularly acute for people living in regional and remote locations. In regional and remote areas of Australia, access to a full multi-disciplinary team can be especially challenging. Gastroenterologists and other specialists are often concentrated in major cities, while people in rural or remote areas may have to travel long distances to access these services. This can result in fragmented care, as patients may only be able to see one or two specialists rather than a complete team.

3.4 Variation in clinical practice

Closely related to poor access to MDTs is the prevalence of unwarranted variation in clinical practice.

There was a strong theme through the consultations that improving access to best practice care and reducing variation in care was among the highest priorities for government. The potential for a clinical care standard to drive systems change was identified often as a major priority given some of the wider barriers to reform.

Australia lacks the data infrastructure to enable benchmark adherence to clinical best practice today; even basic data on hospitalisations and emergency department presentations at the ICD-10 code level are not readily available. This can make variation in care invisible to the community, even as it is apparent to stakeholders.

Through the progressive implementation of an IBD-specific electronic medical record (EMR) at IBD centres across Australasia since 2018, CCCure have been closing this data gap and revealing variation in clinical practice[63] – but further investment is needed to develop a full clinical quality registry.

Analysis of data collected at 10 centres between 1st January 2022 to 31st December 2022 revealed significant disparity in routine IBD care documentation and outcomes (Figure 3.7).

The figure shows outcomes against eight different measures: FCP remission, hospital admission rates, steroid use, rates of surgery, skin care checks, dose escalation, and vaccinations for influenza and Covid (noting that some therapies suppress a person's immune system making them more vulnerable to infection). Depending on where a person is treated, relative to a peer at another hospital, they may be:

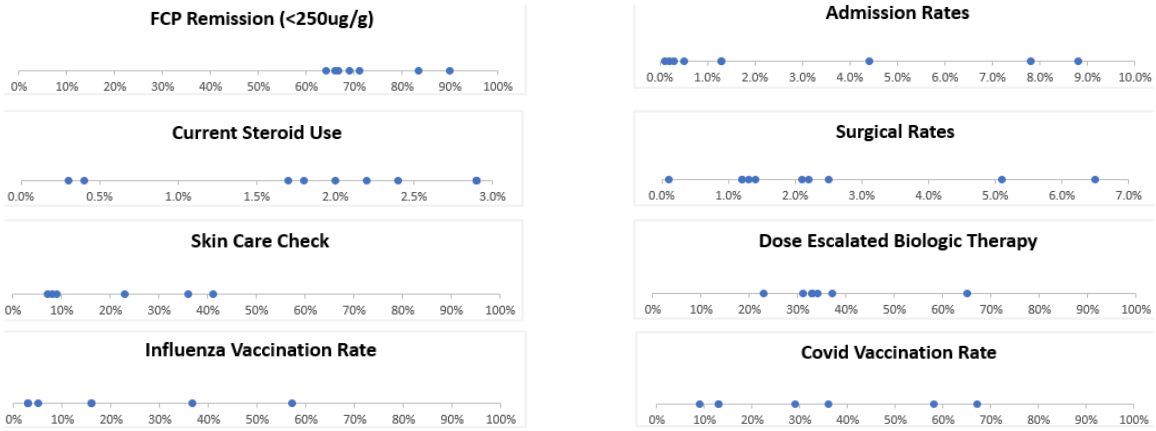
- Roughly nine times more or less likely to be admitted to hospital
- Roughly 6.5 times more or less likely to have surgery
- Roughly 3 times more or less likely to gain access to dose escalation
- Roughly 10 times more or less likely to be on steroids
- Roughly 6 times more or less likely to have had a skin check
- Roughly 8 times more or less likely to be vaccinated against Covid
- Roughly 14 times more or less likely to be vaccinated against influenza.

Unwarranted national variation in care quality and delivery can lead to serious avoidable consequences, including hospitalisations.

To that end, Figure 3.7 also shows that in one treatment centre, a person is roughly 1.4 times more likely to report faecal calprotectin remission (FCP remission) than at the centre with the lowest rate of remission.

[63] Litwin, P. and Andrews, J. (2025). Benchmarking in inflammatory bowel disease: lessons from Australia and New Zealand, Journal of the Canadian Association of Gastroenterology, 2025;, gwae046, https://doi.org/10.1093/jcag/gwae046

Figure 3.7: Variation in of outcomes in IBD disease at ten Australasian centres

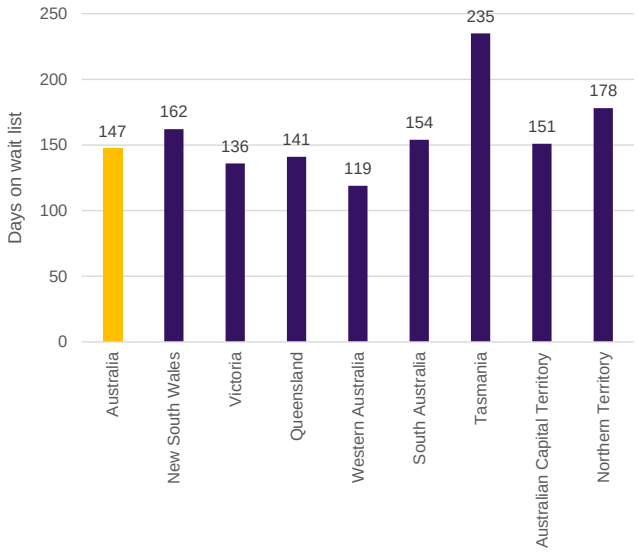


Source: McNamara, J., et al. (2024). Documented Variation in Inflammatory Bowel, Disease Care in Australasia – Crohn's Colitis Cure Data, Insights Program, https://c-c-cure.org/wpcontent/uploads/2024/03/P286_McNamara_CCC_KPI_v2_2024.02.08.pdf

3.5 Poor access and long waiting times for services

Variation in best practice care is also evident in variable wait times for colonoscopy and in particular very long wait times for public patient colonoscopy. Wait times for colonoscopy in public hospitals in Australia can vary significantly depending on several factors, including the urgency of the procedure, the availability of resources, and patient demand by the state or territory. The wait time for a colonoscopy in public hospitals in Australia can range from several months to over a year for non-urgent cases. For example, recent AIHW data for time between a positive screening for blood in a stool and a colonoscopy (Figure 3.8) was reported in 2023 to range from 119 days (four months) to 235 days (7.8 months) depending on the jurisdiction.[64]

Figure 3.8: Average wait times between positive screen for faecal blood and colonoscopy

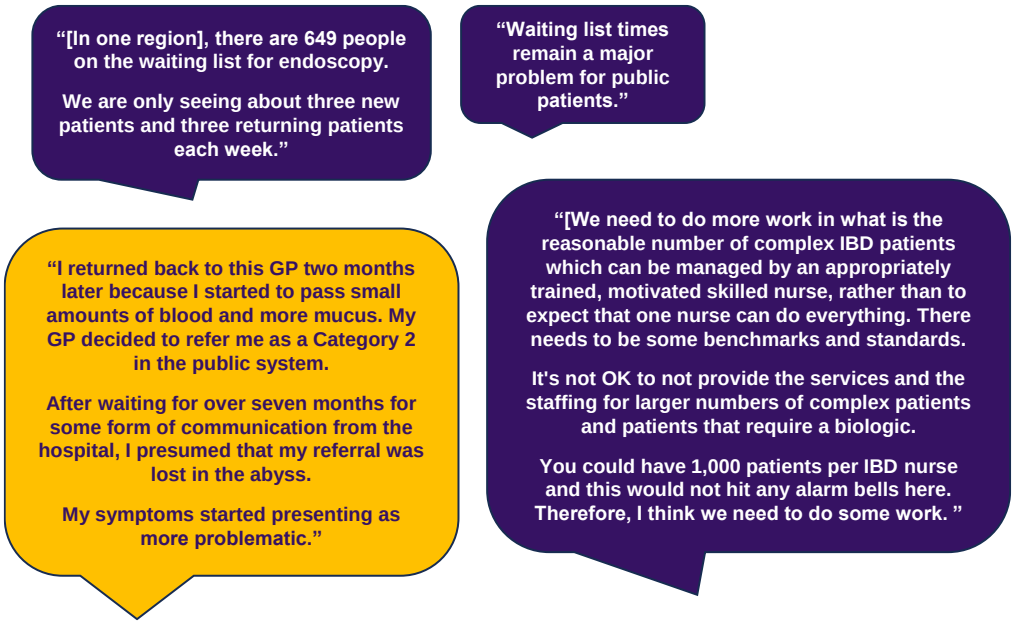


Source: Bowel Cancer Australia. (2024). A Colonoscopy Wait Time and Performance Guarantee, data accessed from AIHW 2023. https://www.bowelcanceraustralia.org/a-colonoscopy-wait-time-and-performance-guarantee.

[64] Bowel Cancer Australia. (2024). A Colonoscopy Wait Time and Performance Guarantee, data accessed from AIHW 2023. https://www.bowelcanceraustralia.org/a-colonoscopy-wait-time-and-performance-guarantee.

These data are consistent with stakeholder consultations (Figure 3.9); amongst all stakeholder groups there was a strong consensus that wait list times were excessive.

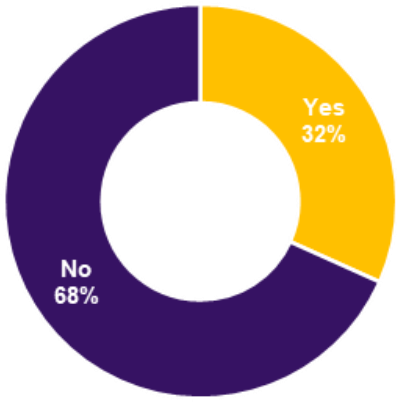
Figure 3.9: Private provider visits for shorter waiting times – 32% of public patients accessed private services due to waiting lists for public services



Source: State of the Nation in Inflammatory Bowel Disease interviews.

Consistent with previous CCA Hospital Audits, these long waiting times had pushed people into accessing services in the private sector. For example, the State of the Nation Survey of People Living with Inflammatory Bowel Disease revealed that one in three public patients had accessed colonoscopies in the private sector to bypass long public waitlists for tests and procedures (Figure 3.10).

Figure 3.10: Private provider visits for shorter waiting times – 32% of public patients accessed private services due to waiting lists for public services



Source: State of the Nation Survey of People Living with Inflammatory Bowel Disease (See Appendix B).

This gives rise to concerns about a two-tiered health system: where those that can afford private health services get more timely care while those that cannot wait, potentially allowing their disease to progress.

3.6 Significant challenges in health system navigation

Health system navigation is a significant challenge for people with complex chronic conditions like IBD and can result in poor health outcomes for patients and their families.

IBD patients must manage input from a range of specialists, from gastroenterologists for medical management, dietitians for nutritional advice, psychologists for mental health support, and surgeons for surgical interventions—these professionals are often not working in a coordinated or integrated manner. In the absence of an MDT or coordination of care, communication between specialists is often minimal in practice. This lack of communication can result in conflicting advice, poor coordination of treatment plans, and missed opportunities for holistic care. For example, a patient might receive treatment for flare-ups from a gastroenterologist but may not receive adequate nutritional support from a dietitian to address malnutrition, or psychological counselling to cope with the emotional burden of chronic illness. Appointments with different specialists can be spread across different locations, creating logistical challenges for patients and leading to delays in receiving comprehensive care.

The need to improve access to multi-disciplinary care and care coordination has been recognised since 2019: improving access to multi-disciplinary care was the first priority action of the National Action Plan, but to date, no action has been against this domain. In fact, IBD stands out as the only chronic condition with an action plan that has received no funding for patient support over the past 10 years.

This in spite of a wealth of evidence — including very substantial *Australian* evidence — showing the health and economic benefits of care coordination through access to an IBD nurse.

The National Action Plan for IBD itself identified that specialist IBD nurses delivered a net economic benefit through avoided hospitalisations and emergency department presentations. Three major Australian studies were identified, including Sack et al (2012), Leach et al (2014), and CHEAP (2015). These studies identified:

- 47 per cent reduction in the re-admission rate for people living with Crohn's (IBD patients with CD had significantly fewer (re-) admissions than controls (1.4 (SD +/−0.83) vs. 2.66 (SD +/−2.47), $p < 0.0001$))
- A 57 per cent reduction in hospitalisation costs, arising from reduced total length offstage and reduced inpatient costs
- Gross avoided costs of $327,678 (A$2012) per patient (Sack et al 2012)
- Net avoided costs of $136,535 (A$2014) per patient (Leach et al 2014)
- Net avoided costs of $111,061 (A$2015) per patient (CHEAP 2015).

Since the launch of the National Action Plan, additional studies have been published, further underscoring the benefits of increased access to IBD nurses. For example:

- A 2024 retrospective review of nurse encounters at St Vincents in Victoria over an 11-month period found 29 emergency department visits, 1,925 outpatient clinic visits and 137 GP visits were avoided, and that after deducting the costs the IBD nursing service had delivered a net saving of $570,838 to the hospital, or an average net healthcare cost savings was $832 per patient supported. Nurses also facilitated faster access to investigations (29%), providing consumer education (28%), delivering of biologic services (25%), and medication changes (19%).[65]

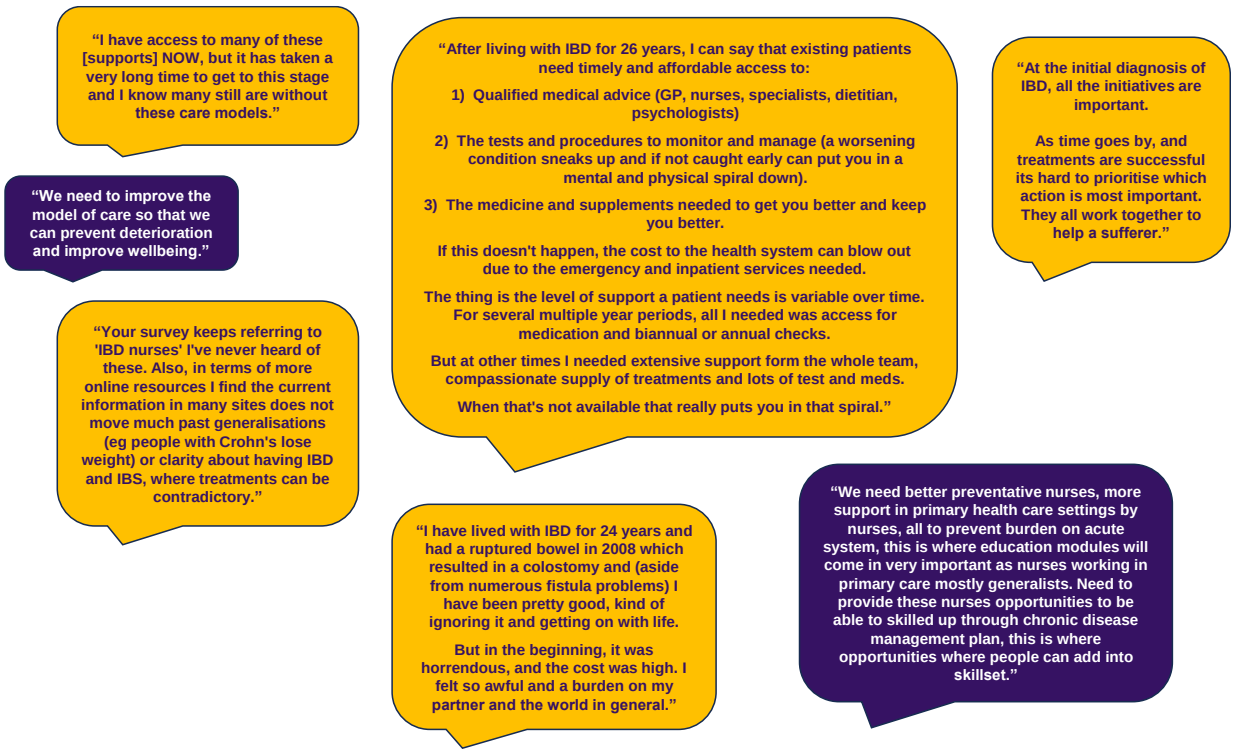
[65] Yu, N. et al., (2024). Outcomes of a Comprehensive Specialist Inflammatory Bowel Disease Nursing Service, Inflammatory Bowel Diseases, Volume 30, Issue 6, June 2024, Pages 960–969, https://doi.org/10.1093/ibd/izad145

- A 2018 study found IBD nurses reduced the risk of hospitalisation by 53 to 64 per cent and released specialist time for other uses.[66]
- A 2020 study of nursing sensitive outcomes identified positive impacts across multiple domains, but also noted the effects often depended on the implementation of other impacts, e.g., an MDT.[67]

Stakeholders highlighted the need for support early on in the diagnosis phase; many patients reported that they had progressively identified needed supports but that there was a significant opportunity to improve the coordination and timeliness of access to the right supports (Figure 3.11). As one stakeholder noted

> *"I have access to many of these [supports] NOW, but it has taken a very long time to get to this stage, and I know many still are without these care models."*

Figure 3.11: The need for care navigation to support access to multi-disciplinary care



Source: State of the Nation Survey of People Living with Inflammatory Bowel Disease (See Appendix B).

3.7 Delays and inefficiencies in access to medicines and other treatments

Access to novel therapies and inefficiencies in access to medicines was also identified as a major barrier to improving outcomes for patients. This was characterised as having two main components:

- Timely access to novel therapies to increase patient choice and treatment options
- Reduced administrative inefficiencies to access medicines that are standard of care.

[66] Molander, P., Jussila, A., Toivonen, T., Mäkkeli, P., Alho, A., & Kolho, K. L. (2018). The impacts of an inflammatory bowel disease nurse specialist on the quality of care and costs in Finland. *Scandinavian journal of gastroenterology*, *53*(12), 1463–1468. https://doi.org/10.1080/00365521.2018.1541477

[67] Spagnuolo, R., Corea, A., Napolitano, D., Nisticò, E., Pagnotta, R., Pagliuso, C., Schiavoni, E., Turchini, L., Fiorino, G., Radice, S., Armuzzi, A., & Doldo, P. (2021). Nursing-sensitive outcomes in adult inflammatory bowel disease: A systematic review. *Journal of advanced nursing*, *77*(5), 2248–2266. https://doi.org/10.1111/jan.14744

These are considered in turn.

Access to novel therapies

The treatment landscape for IBD is improving exponentially, with a range of significant new innovations offering the potential for more effective disease control. Within this, the advent of biologic and JAK inhibitor medicines has been particularly important for expanding treatment options for patients and delivering substantial improvements in patient outcomes.

While many medications for IBD, including biologics like infliximab and adalimumab, are listed on the Pharmaceutical Benefits Scheme (PBS), however, a number of new therapies that are available in other developed nation peers are not (Table 3.1). This is particularly true for newer biologics, where it can take years before they are added to the PBS, limiting patient choice compared to their developed nation counterparts. As a result, patients may have to wait for significant periods before gaining access to affordable treatment options, or they may face high out-of-pocket costs if the medications are not covered by the PBS.

Table 3.1: Benchmarking Australian access to novel medicines against Canadian and UK access

						
Therapy	**CD**	**UC**	**CD**	**UC**	**CD**	**UC**
Adalimumab	✓	✓	✓	✓	✓	✓
Infliximab	✓	✓	✓	✓	✓	✓
Ustekinumab	✓	✓	✓	✓	✓	✓
Vedolizumab	✓	✓	✓	✓	✓	✓
Upadacitinib	✓	✓	✓	✓	✓	✓
Risankizumab	×	×	✓	×	✓	✓
Mirikizumab	×	×	×	✓	*[In dev]*	✓
Tofacitinib	×	✓	×	✓	×	✓
Golimumab	×	×	×	✓	✓	✓
Etrasimod	×	✓	×	✓	✓	✓
Ozanimod	×	✓	×	✓	×	✓

Source: PBS Online, Health Canada and Crohn's and Colitis Canada. (2023). Impact of Inflammatory Bowel Disease in Canada, and National Institute for Clinical Excellence.

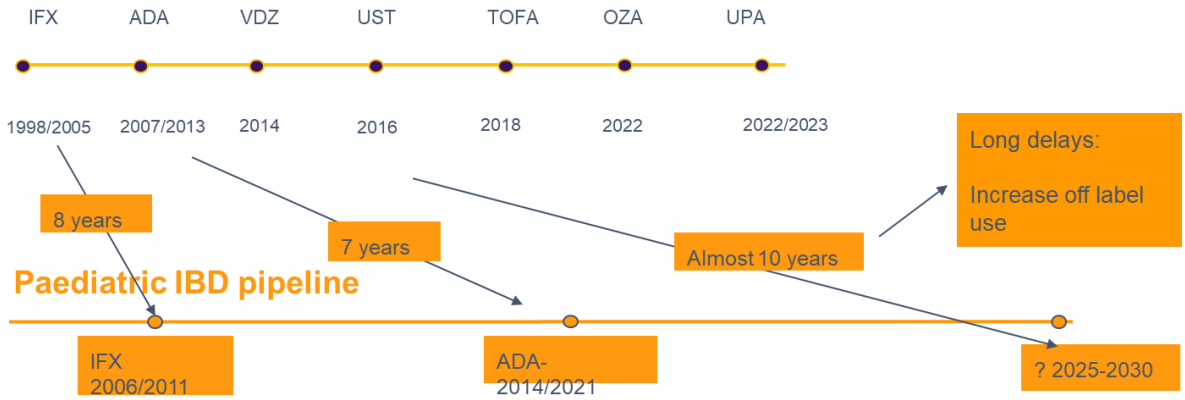
Access delays are particularly acute for paediatric patients as well. Crohn's & Colitis Australia showed huge delays in access for Australian paediatric patients compared to their developed nation peers. New Zealand, Canada, UK and many other countries allow government-subsidised access to advanced therapies for children as soon as approved for adults, but Australia's process sees significant and inequitable delays (Figure 3.12).

For example, paediatric access to key biologics were near decades delayed following the approval in adult populations:

- 8 years delay between adult approval of infliximab and paediatric approval
- 7 years delay between adult approval of adalimumab and paediatric approval

- Potentially more than 10 years delay between adult approval of ustekinumab and paediatric approval (yet to be approved).

Figure 3.12: Outlier delays in access for Australian children



Source: Giles, E. (2023). Access to advanced therapies for paediatric inflammatory bowel disease (IBD) patients in Australia, submission to the Health Technology Assessment Review.

Note: IFX = Infliximab, ADA = Adalimumab, VDZ = Vedolizumab, UST = Ustekinumab, TOFA = Tofacitinib, OZA = Ozanimod, UPA = Upadacitinib.

Delays in accessing PBS-Supported Medications

Even for medications listed on the PBS, not all patients automatically qualify for the subsidy due to authority restrictions and bureaucratic hospital approval processes. For example, eligibility criteria for biologics often require patients to meet specific disease activity thresholds or fail on other treatment options first.

Apart from the potentially debilitating health experience for the patient (Figure 3.13), the process of proving eligibility creates a significant administrative burden for medical teams to complete the necessary medical documentation and approval processes.

This process can involve multiple rounds of paperwork, including requests for prior authorisation, and may require specialist intervention or waiting for approval from external committees, all of which contribute to delays in starting treatment. GESA estimates the clinical time per new prescription is between two and four hours per script. Valuing only two hours of avoided time and applying that to only four per cent of all scripts prescribed each year based on incidence expectations, this could save up to $1 million in clinician time each year. These hours of scarce, senior clinician and nursing time could be usefully redirected towards care coordination and increased access to IBD clinics.

While eliminating the need to ‘fail’ conventional therapies or accessing biologics for patients with less severe disease will require evidence development (as all clinical guidelines globally recommend conventional treatments as first line therapy and biologics are recommended for moderately to severely active disease), significant improvements could be made in the short term to reduce inefficiencies in prescribing that would both speed the patient’s access to treatment and free up scarce health system resources to be redirected to higher, better uses.

Even once prescribed and approved, however, there can *still* be further delays in receiving prescriptions for IBD patients with reports of delays in access to novel therapies being commonplace, preventing patients from filling or refilling medications in a timely manner.

Figure 3.13: Delays in access and inefficiencies in prescribing – stakeholder perspectives

Source: State of the Nation in Inflammatory Bowel Disease stakeholder consultations.

Australian survey data collected by Arthritis Australia (as arthritis being another immune-mediated condition involves the prescription of similar medications) indicates sixty-nine percent of respondents indicated they had experienced delays:[68]

- 39 per cent stated that it was *more than four weeks*
- 32 per cent indicated it was for *3-4 weeks*.

This is particularly problematic for patients who require continuous treatment with biologics, as interruptions to their medication regimen can lead to disease flare-ups and complications

3.8 High out-of-pocket costs and limited income support

As outlined in Chapter 2, the out-of-pocket costs of IBD can substantial, and can arise from a myriad of sources including costs not covered by the Medicare safety net. The risk of financial hardship can compound for a person or family when the person needs to exit the workforce due to symptom severity or to facilitate recovery through the reduction of stress.

Policy reforms to improve access to public services, reduce out-of-pocket costs and gap payments are sorely needed, particularly against the backdrop of increasing cost of living for Australian families.

Added to this, more support could be provided to supplement income for people requiring long term leave from the workforce due to chronic illness. Currently, IBD patients requiring extended leave can access a Disability Support Payment if they expect to be out of the workforce for more than 2 years or JobSeeker if they expect to be out of the workforce for an extended period but less than two years. Given the age profile of IBD patients, most people requiring income support seek JobSeeker support.

But because JobSeeker is structured to encourage people to seek employment, the levels of support are low. The maximum fortnightly payment is $833.20 as of September 2024, which translates into income support of around $21,658 per annum. This is substantially less than the average wage and less than the implied average household running costs of around $34,000 per annum.[69] Taking into consideration average out-of-pocket costs of $5,900 per annum it paints a picture of serious financial challenges for people at their most vulnerable.

Reform to the eligibility criteria for the Disability Support Pension or the JobSeeker program, such as a 'JobKeeper' approach with tightly controlled eligibility criteria could go a long way to supporting people when they need it the most.

3.9 Lack of investment in IBD research

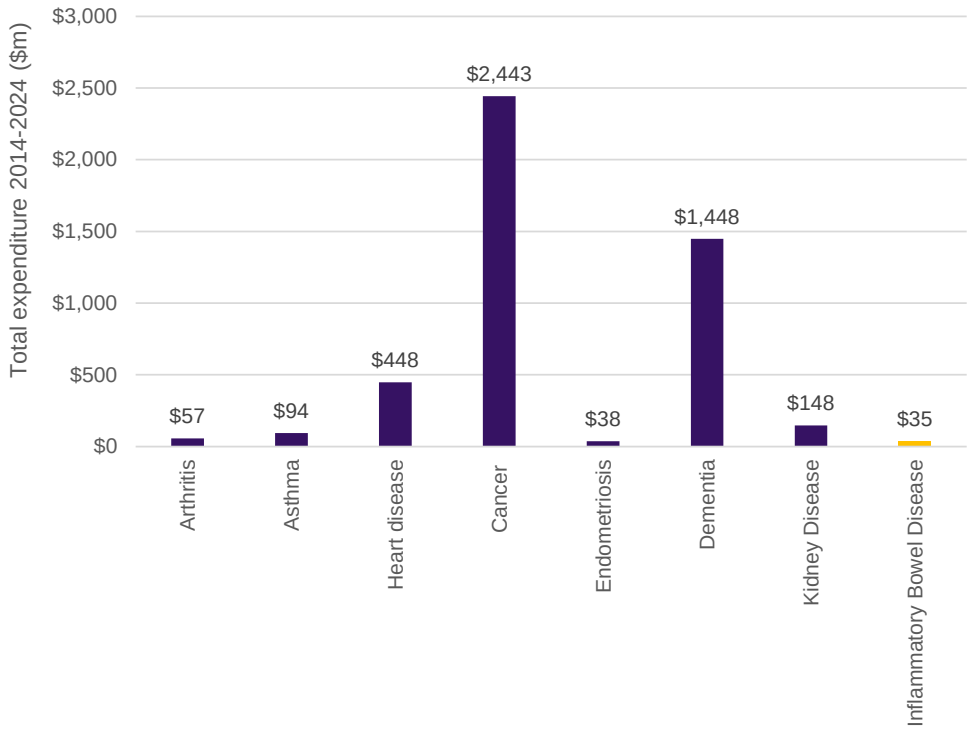
The other significant barrier to improved outcomes is limited investment in IBD research. Very substantial improvements in disease control can be made through better access to clinical best practice, including access to multi-disciplinary teams and novel therapies. But data also suggest there is a therapeutic threshold, where not every patient can achieve remission. Breaking through this therapeutic ceiling will require investment in research.

While funding for research in Australia is not as dire as the complete lack of investment in patient support, funding for IBD research is still dwarfed by the contemporary investments made in other chronic conditions like cancer or dementia, or which have been historically invested in other sectors, like cardiovascular disease. In absolute terms, IBD received the lowest allocation of research investment of any chronic disease: $35 million over the past 10

[68] Musculoskeletal Australia and Arthritis Australia. (2022). Delays in receiving scripts and biologic medication – A national survey.
[69] Calculated as the difference between average gross household income and average disposable household income.

years (Figure 3.14). This compares to investment of over $2 billion in cancer research and nearly $1.5 billion in dementia research.

Figure 3.14: IBD received the lowest level of funding for research of any chronic disease over the 2014-2024 period



Source: Analysis of Grants Connect and MRFF data for cardiovascular disease.

Australia boasts world-leading, high impact research in IBD, particularly in health implementation science (such as the impact of nurse practitioners) and the impact of psychological therapies. Support for a clinical quality registry, enabled by the CCCure EMR could see Australia develop world-leading data infrastructure that could leverage clinical trials, investment in AI and discovery research.

3.10 Conclusions

Taken together, there are a number of important areas of need for policy reform to improve outcomes for people living with IBD. It is clear that this is not only causing unnecessary suffering and poor health outcomes for people living with IBD and their families, but wasting scarce public monies that could be directed to higher, better uses – including better access to treatment and care for people living with IBD. The next chapter sets out some ideas for change.

Chapter 4

Opportunities to improve outcomes for people living with IBD today

Importantly, research has shown that there are huge opportunities to improve outcomes for people living with IBD. Correcting underinvestment in support and driving systems change to improve access to multi-disciplinary care and reduce unwarranted variation has the potential to deliver rapid and significant step change improvements in outcomes today.

This chapter presents opportunities to address the barriers identified in Chapter 3 over the short to medium term. Chapter 5 then identifies from this longer list of opportunities the highest priority areas for action over the next three years.

4.1 Overview of priority actions: stakeholder perspectives

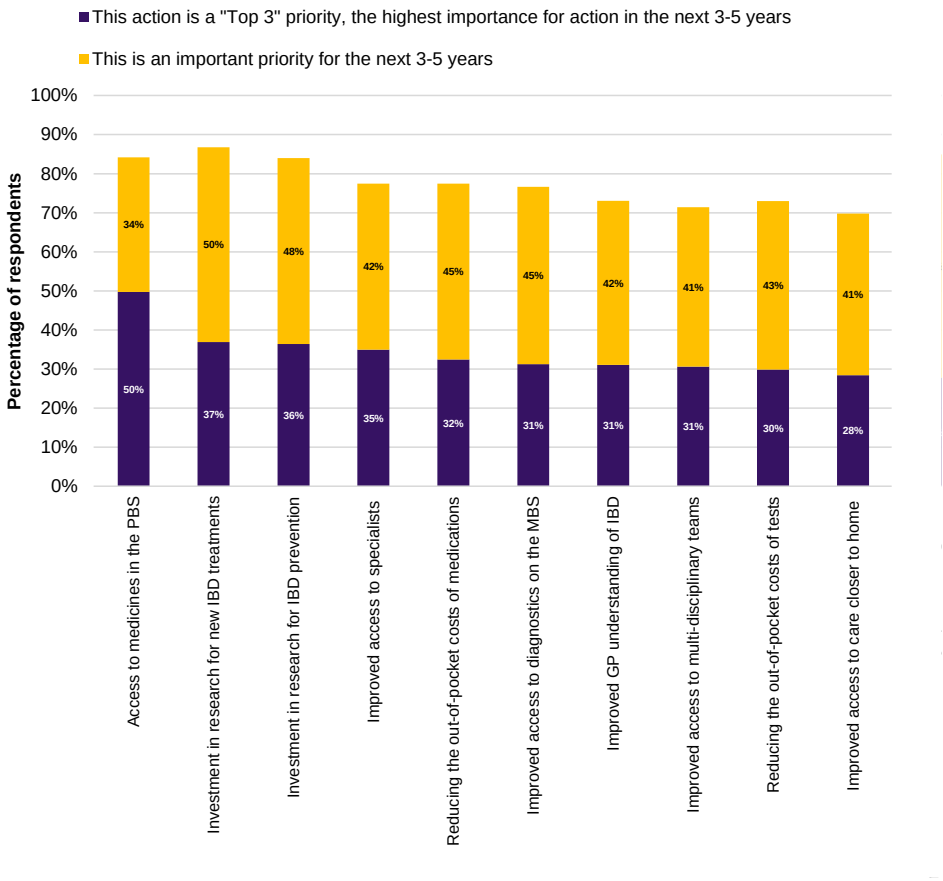
There are a number of significant opportunities to address the challenges identified in Chapter 3 and improve outcomes for people living with IBD. For people living with IBD, the State of the Nation Survey of People Living with Inflammatory Bowel Disease revealed the following top 10 priorities for government to improve outcomes for people living with IBD included (Figure 4.1):

- Improving access to medicines through the PBS (#1 priority)
- Investing in research to develop new treatments (#2 priority) and to prevent the onset of IBD (#3 priority)
- Improving access to specialists (#4 priority) and multi-disciplinary teams (#8 priority)
- Reducing out-of-pocket costs (#5 and #9 priority) and improved access to diagnostics on the MBS (#6 priority)
- Improving awareness of IBD (#7 priority)
- Improving access to care closer to home (#10 priority).

This enjoyed strong alignment with stakeholder interviews with similarly underlined the need to address gaps in access to multi-disciplinary care, to improve timely access to novel therapies and reducing costs of care. As shown in Figure 4.1, most of these initiatives are seen as critical and many of these actions are interdependent: improving access to novel treatments depends in part on having access to specialists with experience in IBD, and improving the optimisation of medicines depends on research and real-world evidence to continually advance evidence-based best practice.

These major opportunities to improve outcomes for people living with IBD are considered in the following sections.

Figure 4.1: Consumer priorities for action in IBD



Source: State of the Nation Survey of People Living with Inflammatory Bowel Disease, See Appendix B.

4.2 Facilitate to nationally consistent, integrated multi-disciplinary model of care

One of the most important opportunities to improve outcomes for people living with IBD is to facilitate more systematic access to integrated, multi-disciplinary team care. This was strongly supported by all stakeholders as a critical area of need and major opportunity (Figure 4.2).

As outlined in Chapter 3, there is very substantial evidence showing the health and economic benefits of such an approach. Multi-disciplinary teams that include an IBD nurse as a care coordinator:

- Increase the probability of achieving remission nearly four-fold, from 15 per cent to 58 per cent probability of being in remission
- Reduce the risk of hospitalisations by 30 per cent
- Reduce the risk of surgeries by 44 per cent
- Reduce the risk of corticosteroid dependence by 61 per cent
- Reduce the risk of emergency department presentations by 78 per cent
- Improve a person's probability of working by 26 per cent
- Triple the probability of a student staying in school
- Improve a person's ability to have a more active social life by 50 per cent.

Figure 4.2: Stakeholder perspectives on the need for policy reform and investment in multi-disciplinary care

Source: State of the Nation in Inflammatory Bowel Disease consultations.

As noted in previous chapters, the average time to diagnosis is 1.5 years and the average time to remission from diagnosis is a further 3 years. Nearly five years of suffering after seeking help is excessive and avoidable for most patients; Australia can do better, and it makes both moral and economic sense to target a reduction in the time to remission.

Because active disease is twice as costly as a person in remission, reducing the time to remission by even one year would make an enormous difference to patients and payers alike. For example, if all people experiencing active disease today that could be expected to achieve remission (taking into account current therapeutic ceilings) had avoided one year of active disease this would have saved $1.4 billion in health and economic costs. Reducing the time to remission for only new cases of IBD would save $54.9 million over the course of a year.

The key challenge is how to bring improved access about in Australia's federated healthcare system. In Australia, the Commonwealth funds services in primary and community care settings, including GP, allied health and psychology visits, while the states fund hospital services. Improving access to multi-disciplinary care requires investment in all settings, and a partnership model that improves coordination of care.

Compounding the challenges presented by Australia's federated health model is IBD's relative rareness. In aggregate, IBD is not a 'rare' condition,[70] although paediatric IBD arguably meets the definition, it is less common than most chronic conditions, accounting for 0.01 per cent of the average GP's typical patient mix in a year, for example. It would not be cost-effective, for example, to build up an IBD clinic in every hospital or region to improve access. This requires innovative thinking in how to achieve scale and quality through service networking and the use of technology.

Improving access will require a coordinated approach to cost-effectively improve access across all care settings. The main pillars of improving access to multi-disciplinary care include:

- Establishing a clinical care standard for IBD
- Establishing a national network of MDTs in IBD
- Funding access to care coordination in IBD
- Allow for specialist referrals to psychology and dietitian services.

Introduce a clinical care standard for IBD

Clinical care standards are developed by the Australian Commission for Quality and Safety in Healthcare (ACQSHC). As noted by the ACQSHC:

> *A clinical care standard describes the care that patients can expect to be offered by clinicians and healthcare services for a specific clinical condition, treatment, procedure or clinical pathway, regardless of where they are treated in Australia, whether it be public or private settings, hospital or community settings.*
>
> *Clinical care standards contain:*
>
> – *Quality statements describing the care that a patient should be offered, regardless of where they are treated in Australia*
>
> – *Information for patients, clinicians and healthcare services about what each statement means*

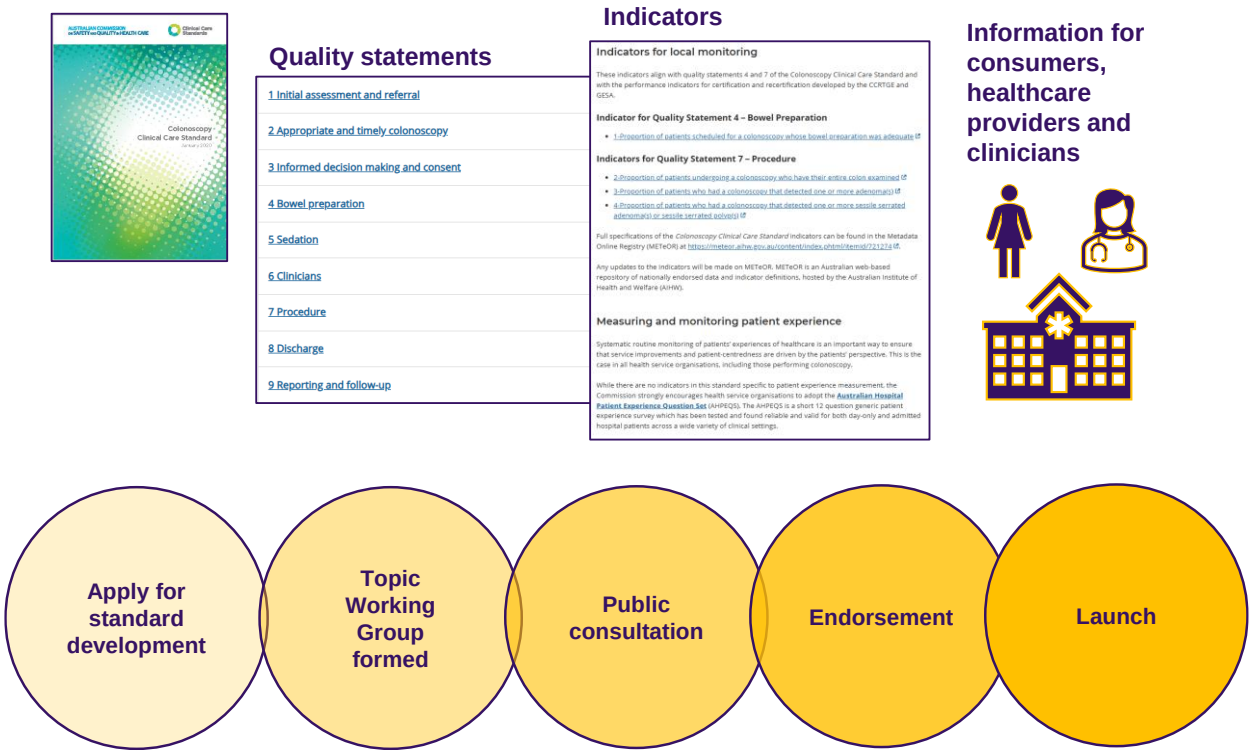
[70] In Australia, the Department of Health and Aged Care has defined a rare condition to be rare if it affects less than 5 in 10,000 people, which equates to approximately 13,000 people in 2023. See: https://www.health.gov.au/topics/chronic-conditions/what-were-doing-about-chronic-conditions/what-were-doing-about-rare-diseases.

– *Indicators to help clinicians and healthcare services monitor the care described in the clinical care standard and to support local quality improvement*

Each clinical care standard is supported by implementation resources for consumers, clinicians, and health services, and in some cases, for Primary Health Networks (PHNs).[71]

Clinical care standards are important tools for ensuring minimum standards in treatment and care. The development of a national clinical care standard for IBD through the Australian Commission for Quality and Safety in Health Care would set out a series of quality statements to improve outcomes for patients at all stages of the care journey and included within this could be a statement around access to MDTs (Figure 4.3).

Figure 4.3: Overview of clinical standards – key elements and process for development



The clinical care standard could make MDTs the standard of care, which would drive investment across the health system to meet these standards, improving access to best practice treatment teams.

Establish a national network of MDTs in IBD

A clinical care standard is an important, system-wide intervention that could drive investment across healthcare settings. But the development of a care standard is a multi-year process and realistically, it will take several years to develop and implement.

In parallel to the development of a clinical care standard, Australian governments could work together to facilitate and co-fund access to MDTs through a virtual network of MDTs in IBD nationally. A national network of MDTs would overcome issues of scale that exist in some areas and care settings – helping to ensure patients' treatment plans have input from people with IBD specialisation.

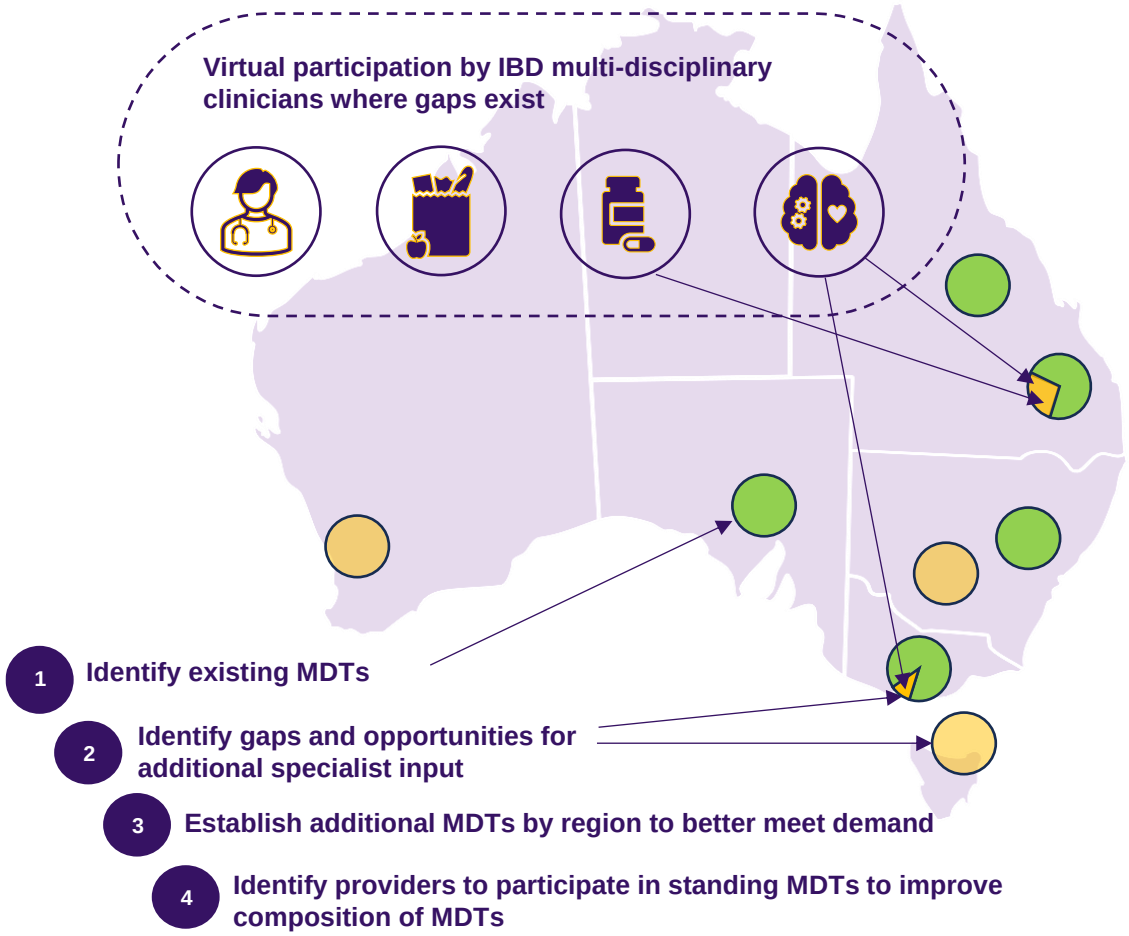
[71] Australian Commission for Quality and Safety in Healthcare. (2024). About the Clinical Care Standards, accessed at: https://www.safetyandquality.gov.au/standards/clinical-care-standards/about-clinical-care-standards.

This would involve first an identification of the gaps in access to MDTs by region. For example, patients that are treated in major public hospitals in urban centres tend to have increased access to more comprehensive multi-disciplinary teams, including IBD nurse care coordination. Stakeholder consultations indicated that public IBD clinics tend to fund a greater number of MDT roles, but noted there was significant variability across services nationally. In regional areas or in private hospitals, access to MDTs was reported to reduce considerably. Most patients being treated by private gastroenterologists will not have access to an IBD nurse or other care coordinator and similarly, expertise in IBD is likely to decline in regional areas.

Currently, some tertiary hospital teams have initiated regional outreach programs to better support quality outcomes for patients being treated in regional hospitals that lack IBD expertise. But these initiatives are *ad hoc* and unfunded, run off the goodwill of clinicians willing to give up their time to support better care for patients.

A major opportunity to improve access to MDTs across all treating teams nationally would be to systematise this virtual MDT approach – identifying gaps where additional MDTs need to be added to meet patient demand in a region and establishing a panel of providers that could participate in the MDTs, including in particular IBD care coordinators, IBD psychologists, IBD pharmacists and IBD dietitians (Figure 4.4).

Figure 4.4: Establish a national network of virtual multi-disciplinary teams in IBD



Through the virtual MDT network, each MDT would be comprised of:

- Gastroenterologist
- Colorectal surgeon

- Radiologist
- IBD nurse
- Stoma nurse (as appropriate)
- Dietitian with IBD experience
- Pharmacist with IBD experience
- Psychologist with IBD experience.

A patient's GP would also be involved as much as possible; if the GP cannot attend a summary would be sent to the GP to promote continuity of care.

The virtual MDT program would address the information gaps and barriers to coordination that exist today to develop the network and provide funding for the full-time-equivalent (FTE) to participate in the MDTs.

Key roles that are not routinely available in MDTs today would be accessed through the virtual model. For example, IBD dietitians would be able to participate virtually in MDTs nationally to support better care.

Improving access to IBD care coordination and multi-disciplinary care in the community

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.

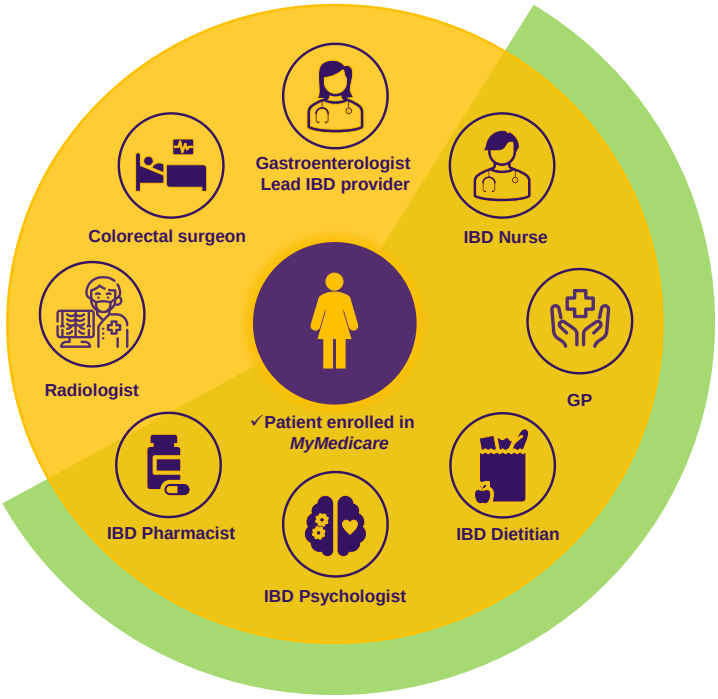
Complementing the national network of MDTs, the Commonwealth could fund through the Primary Health Networks (PHNs) a Living Well with IBD program. Such an approach would be similar to programs like the Living Well with Chronic Pain program, for example, or mental health care coordination programs being delivered through the PHNs. This program could complement existing access to IBD nursing nationally, particularly focused on people living with moderate to severe disease receiving treatment in the community.

Like the Living Well with Chronic Pain Program, the Living Well with IBD program would enable (Figure 4.5):

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

While responsibility for the patient would remain with the gastroenterologist, key roles that are not routinely available would be more systematically accessed through the Living Well program. The IBD Care Coordinator would work with the person living with IBD to help coordinate the support and allied health services needed, provide regular reports to the patient's treatment team and support the patient in the event of a disease flare.

Figure 4.5: Living Well with IBD program



There are significant gaps in the care team today for many patients:

- × *Only 47% per cent of patients reported access to an IBD Nurse*
- × *GPs are often poorly involved in the IBD care team*
- × *Only one third of patients have a Chronic Disease Management Plan*
- × *23% patients have access to dietitian*
- × *16% patients have access to psychologist.*

Living Well with IBD program would complement existing teams, providing access to patients that would not otherwise have access, ensuring:

- ✓ *Patients have access to an IBD Care Coordinator – either an IBD Nurse or GP with IBD experience.*
- ✓ *Medications are reviewed by a pharmacist with IBD experience*
- ✓ *Patients access dietitian and psychology services.*

Streamlined specialist referrals for dietitians and psychologists

To facilitate more timely and efficient access to multi-disciplinary care, the Commonwealth could also allow for gastroenterologists to directly refer patients to psychologists or dietitians.

Figure 4.6: Stakeholder perspectives on the potential to improve outcomes through streamlined referrals to mental health and nutritional support

Source: State of the Nation in Inflammatory Bowel Disease, stakeholder consultations.

Currently, patients must see a GP to obtain a referral in order to access MBS-subsidised treatment by a psychologist or dietitian. There was strong consensus that this created inefficiencies and delays to treatment support and a simple opportunity to improve access would be to allow for direct referrals by specialists. This would allow for the more efficient allocations of Commonwealth monies towards the actual service delivery.

4.3 Invest in core enabling capabilities for multi-disciplinary care: Workforce development and digital health technology

Improving access to multi-disciplinary care, particularly in community settings, depends on access to a skilled workforce in IBD and the use of technologies that provide a shared medical record across care settings and treating teams. To this end, two important actions to facilitate access to multi-disciplinary care include:

- IBD workforce development
- Digtial technologies for shared care in IBD, linked to a clinical quality registry
- An IBD dashboard managed by the Australian Institute of Health and Welfare.

Workforce development

Given the significant role of IBD nurses and pharmacists to improve outcomes for people living with IBD, stakeholders indicated that the development of clear career pathways and training to support the specialist skills required to support IBD patients to better manage their IBD was core enabling infrastructure. Supporting the upskilling of the IBD workforce was seen as particularly important for the delivery of care in the community and is strongly aligned with the Commonwealth's Draft Nursing Strategy (Box 4.1) and Scope of Practice review. Crohn's & Colitis Australia have developed a number of education and training modules for IBD skills development for GPs, psychologists and dietitians.[72] This could be extended to nurses and pharmacists as core members of the multi-disciplinary team.

[72] Crohn's & Colitis Australia . (2024). Gut Smart Courses: see https://gutsmart.com.au/all-courses/

Box 4.1: Alignment of IBD workforce development to the National Nursing Workforce Strategy

The *National Nursing Workforce Strategy* is currently under development, with the draft Strategy released for public consultation in September 2024. The Strategy will establish priorities to guide the current and future nursing workforce, providing a strategic approach to future workforce planning, investment and reform. The Strategy's framework and actions will align with areas that are crucial for nursing support of patients living with IBD, including supporting nurses to work at their full scope of practice, enabling nurses to deliver quality, evidence-based, person-centred care, and sustaining a nursing workforce including in regional, rural and remote areas.

The Draft Strategy identified the following actions relevant to IBD:

Value

1.1 Invest in nurse leadership.

1.4 Support internationally qualified nurses to transition into Australia's health and aged care system.

1.5 Modernise the identity of nursing.

Plan

2.1 Implement nationally coordinated nursing workforce data, modelling and planning.

2.2 Implement strategies that enhance workforce mobility and flexibility.

Design

3.1 Prepare and engage the nursing workforce to drive the innovation and use of emerging technologies.

3.2 Grow nurse leadership and involvement in the design and delivery of innovative models of care.

3.4 Create and embed funding models that drive evolution and enhancement of nursing practice.

3.5 Enable nurses to work to their optimum scope of practice in all settings.

Deliver

4.2 Develop a national professional development framework.

4.4 Develop a national career framework.

4.5 Build and grow nurse clinical-academic/research career pathways.

4.6 Develop a dedicated rural and remote recruitment and retention strategy (inclusive of students)

Source: Department of Health and Aged Care, 2024, Draft National Nursing Strategy

Digital health technologies and data infrastructure to support cost effective service delivery

Another important opportunity to improve the quality of care through multi-disciplinary teams is national access to consumer and clinical digital health infrastructure, including a national electronic health record in IBD and a clinical quality registry that would enable a range of basic, clinical and health implementation science research to enable research breakthroughs and improvements in clinical practice.

CCCure, for example, has been advancing the development of an electronic medical record[73] which integrates into the MyHealthRecord and allows for the sharing of patient information across care settings (Box 4.2).

Box 4.2: CCCare – a shared patient record in IBD that integrates with the MyHealthRecord

CCCare is used to directly document routine care as an Electronic Medical Record (EMR). It also incorporates a consumer portal so people with IBD can self-report and share important information directly with the clinical teams.

CCCare has over 330 clinical users and 15,300 records from people with IBD, representing over 60,000 clinical encounters and around 70,000 years of people's data (as of August 2024). It is the largest dynamic structured dataset in Australia and one of the largest and most detailed globally. With every clinical interaction, CCCare refreshes and grows, becoming an ever-expanding source of knowledge for researchers, policymakers, funders and others in the IBD space.

CCCare is most beneficial and available for the following users:

- *People living with IBD* — Patients with IBD benefit from the consumer-facing portal that enables self-reporting, record management anywhere and anytime, and will soon provide new, world-first access to features like personalised IBD information and direct communication with treating teams.
- *Clinicians* — Clinicians benefit from the data reporting that provides the most up-to-date, accurate and immediate access to clinical quality, holistic information on people living with IBD for enhanced consultations and care.
- *Researchers and governments* — IBD researchers have the potential to benefit from the most granular, ever-expanding, real-world consumer IBD data and analytics derived from the platform's EMR and data assets. This unique information will benefit healthcare practice and policy creators, service providers, hospitals, insurers, pharmaceutical manufacturers by allowing for real world data analysis.

Source: CCCure, (2024). About Crohn's and Colitis Care, https://c-c-cure.org/cccare/#:~:text=CCCare%20is%20used%20to%20directly%20document%20routine%20care,share%20important%20information%20directly%20with%20the%20clinical%20teams.

Facilitating national access to such a system, which could be linked to a clinical quality registry, could strongly support improved coordination and quality of care across care settings and providers through the ability to access a single shared view of patient records.

Through time, these data, too, should enable improvements in clinical practice and research breakthroughs.

[73] Litwin, P. and Andrews, J. (2025). Benchmarking in inflammatory bowel disease: lessons from Australia and New Zealand, Journal of the Canadian Association of Gastroenterology, 2025;, gwae046, https://doi.org/10.1093/jcag/gwae046

Because the costs of IBD are so significant, even a small improvement in service delivery would generate huge health and economic savings. Even a one per cent improvement in the costs of healthcare services would deliver a benefit of more than $223.9 million over the next 10 years.

A clinical quality registry is also critical enabling infrastructure for research and has supported breakthroughs in a range of other conditions such as cancer and respiratory conditions. Importantly, it also substantially influences the competitiveness of the IBD research community when applying for highly-competitive Medical Research Future Fund (MRFF) and National Health and Medical Research Council (NHMRC) grants where better-funded researchers are able to mount more detailed cases for investment if they have access to a clinical quality registry or richer data sets.

Added to this, these data would also be expected to attract additional investment as the development of a world-leading dataset in IBD would be highly valuable to industry and academic researchers alike and supporting research breakthroughs. For example, the application of AI technologies to IBD is a major area of research (See Section 4.6) that could be explored further in the context of a national, structured data asset in IBD.

Australia could pursue an 'AI Mission in IBD', in collaboration with the Commonwealth Scientific and Industrial Research Organisation (CSIRO), for example, and similar to the model that has been pursued in Canada, through the AI with Roche (AIR) Centre for Healthcare Transformation.

Seed investments by government in research programs or centres of excellence often attract matched funding or co-investment by the private sector. Australian Research Council Centres of Excellence in 2023, for example, attracted private sector investment at a rate of 4:1.[74]

[74] Australian Research Councils. (2023). Selection Report: ARC Centres of Excellence for Funding Commencing in 2023, accessed at: https://www.arc.gov.au/funding-research/funding-outcome/selection-outcome-reports/Selection-Report%3A-ARC-Centres-of-Excellence-for-Funding-Commencing-in-2023#leverage-of-arc-funding

Box 4.3: Examples of potential second round opportunities and benefits from data asset development in IBD

CSIRO AI-enabled Missions

The CSIRO Missions Program was established as the key delivery vehicle to coordinate our interdisciplinary science capability and catalyse new forms of collaboration in the innovation system. Health and wellbeing was identified as one of the six domains for missions to be developed, with the goal of enhancing the health and wellbeing of all Australians, by supporting healthier lives, preventing and preparing for future infectious diseases, digital transformation in healthcare and health technology solutions.

CSIRO aims to create novel AI research and develop large technology platforms that will enable Missions. The CSIRO is focussed on translation and accelerating impact in Missions using AI, including:

- Data centred AI: involves sensing technologies, data generation, information processing and modelling, and analytics
- Human centred AI: focusses on robotics, reasoning, natural language processing and augmented reality
- Scientific AI: develops novel AI methods to accelerate scientific discovery and engineering

The CSIRO works with the National AI Centre to develop collaborative projects to foster innovation across the Australian AI ecosystem.

AIR Centre of Excellence in Canada

AI with Roche (AIR) is a centre of excellence with a core purpose to deliver to people in Canada and beyond better health outcomes through the discovery and application of artificial intelligence research underpinned by an open and collaborative exchange.

Roche AI CoE has its origins in the Roche Data Science Coalition (RDSC), which formed in April 2020 as a multi-industry coalition lending expertise and resources to tackle challenges presented by COVID-19. Since its formation, the RDSC has contributed to over 100 digital solutions and insights including AI models, advanced analytics, virtual dashboards, market reports, and also deepened relationships with Canadian and international stakeholders.

The CoE seeks to leverage collaboration and specialised expertise to work toward outcomes such as enhancing access to the right diagnostics and treatments at the right time, informing and de-risking healthcare decision making, elevating and scaling up Canadian AI startups, nurturing AI talent, and bringing science closer to citizens.

Source: Quoted from CSIRO Mission driven science and https://www.csiro.au/en/about/challenges-missions and AI enabled Missions https://www.csiro.au/en/about/challenges-missions/AI-technologies-for-Missions; AMII. (2020). Roche Canada Launches National Artificial Intelligence Centre of Excellence, accessed at: https://www.amii.ca/latest-from-amii/roche-ai-centre-of-excellence/

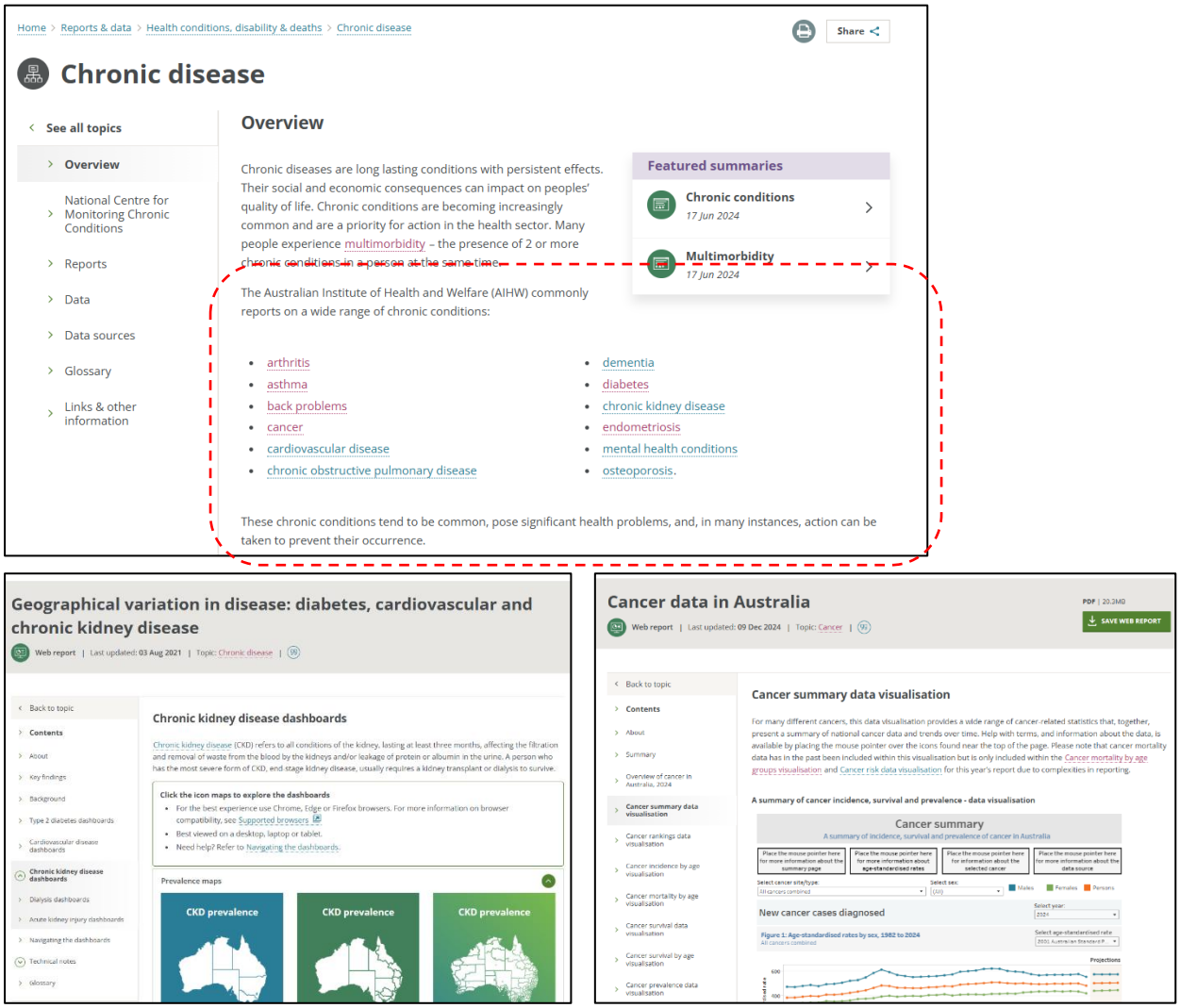
IBD dashboard managed by the Australian Institute of Health and Welfare

The reporting of statistics about chronic diseases and their associated determinants enables the monitoring of outcomes of interventions and health programs and helps to assess the needs for health services in the future.

Consistent with broader patterns of underinvestment in IBD compared to other chronic diseases, the Australian Government has invested significant funds in the development of dashboards for other chronic diseases but not IBD (Figure 4.7). The AIHW reports on these conditions because they tend to be ‘common, pose significant health problems, and in many instances, action can be taken to prevent their occurrence’. IBD is not as common as the other

conditions, but it does pose significant health problems that, in many instances, can be prevented through action.[75]

Figure 4.7: Examples of AIHW chronic disease dashboards – IBD no where in sight



Source: AIHW, 2024, Chronic Disease, https://www.aihw.gov.au/reports-data/health-conditions-disability-deaths/chronic-disease/overview; AIHW. (2024). Geographic variation in disease: diabetes, cardiovascular disease and chronic kidney disease, https://www.aihw.gov.au/reports/chronic-disease/geographical-variation-in-disease/contents/chronic-kidney-disease-dashboards and AIHW (2024).Cancer Data in Australia, https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/contents/summary-dashboard.

This puts the onus back on patients and the not-for-profit sector to develop these data to try to advocate for change. You cannot manage what you cannot measure. Government should address this gap in data to improve awareness and support policy development and investment decisions.

4.4 Improve timely access to medicines

Improving access to medicines was identified as the highest priority action for government identified by consumers in the State of the Nation Survey of People Living with Inflammatory Bowel Disease. It was also reinforced as a major priority by patients, clinicians and researchers

[75] AIHW, 2024, Chronic Disease, https://www.aihw.gov.au/reports-data/health-conditions-disability-deaths/chronic-disease/overview

in stakeholder consultations. In addition to addressing gaps between patient access for novel therapies in Australia with key developed nation counterparts, clinicians also identified the need to streamline prescribing to allow for the redirection or scarce clinician time towards patient care.

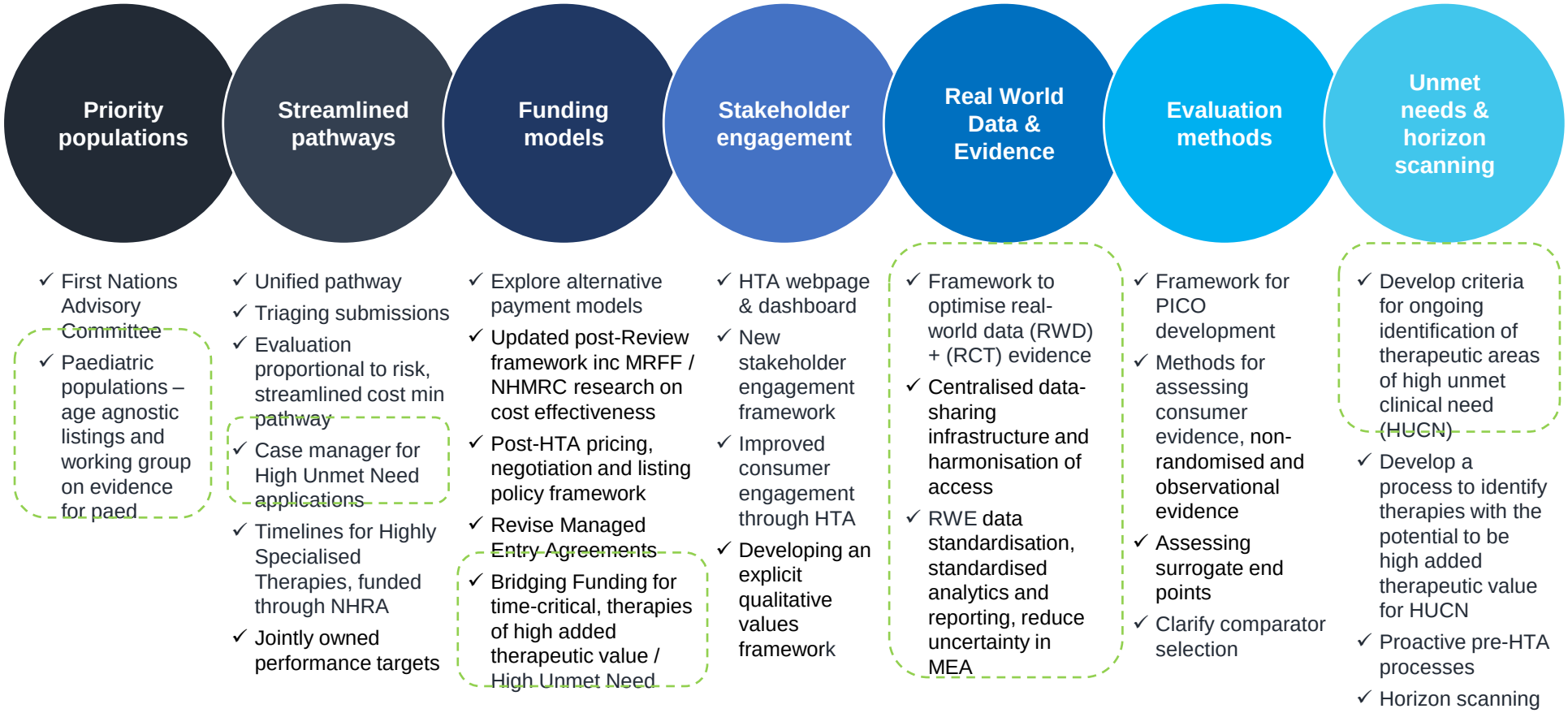
In 2022, the Australian government commissioned a wide-ranging Health Technology Assessment Review (HTA Review) of Australia's HTA system, including its policy and methods. The aim of this review was to improve the performance of the HTA system in the context of technology change, ensuring Australians continue to have timely access to medicines at a cost the community can afford.

The Review handed down its recommendations in 2024 (Figure 4.8); the Australian government has yet to respond to the review. The recommendations provide a framework for the IBD community to engage with government on access to medicines for people living with IBD. For example, key recommendations that may offer opportunities to improve timely access to medicines for people living with IBD include:

- Establishing a working group for paediatric IBD patients to address access gaps for paediatric populations. As part of this, IBD consumers and clinicians could identify key therapies where access gaps exist and develop a plan for evidence development and access, including potentially through a clinician led trials program
- Identify a shortlist of High Unmet Need therapies and engage with government to obtain a case manager to navigate potential pathways for access
- Engage with government on real world evidence data frameworks, data standards, and evidence requirements
- Engage with government in horizon scanning and the development of criteria for identification of areas of therapeutic need.

Engaging with government in these important domains will help to shape access to novel therapies. Unfortunately, it will require continued coordination, advocacy and engagement by the IBD community with government.

Figure 4.8: Recommendations of the HTA Review – key areas of opportunity for people living with IBD



Notes: HTA = Health Technology Assessment; RWE = Real World Evidence (evidence that is collected outside of clinical trials); MEA = Managed Entry Agreement, HUCN = High unmet clinical need; RCT = Randomised Controlled Trial; RWD = Real World Data (data that is collected outside of clinical trials); paed = paediatric.

4.5 Reduce the risks of financial hardship for people living with IBD

As shown in Chapter 2, the financial impacts of IBD on a family can be significant, and can grow exponentially with disease severity, as ever deteriorating health leads not only to escalating costs but also a reducing ability to work. For people from low socioeconomic status (SES) backgrounds the risks that patients being to forgo treatments and care, leading to poorer health outcomes, are very real.

There are three key opportunities to reduce the financial burden and risk of financial hardship for people living with IBD. These include:

- Expanding MBS listing for key tests, such as expanding subsidy support for faecal calprotectin tests to include funding for ongoing disease monitoring
- Targeting the elimination of out-of-pocket costs for consumers through funding model reforms
- Reform to income support for people who are unable to work due to long term illness.

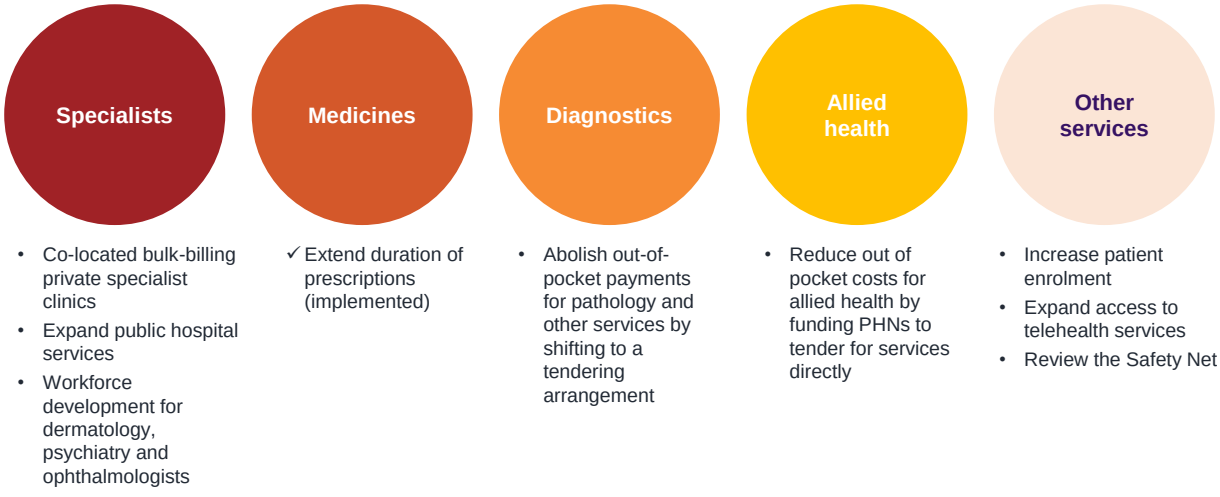
The latter two require more significant systems reform but significant opportunities in the context of wider cost-of-living challenges.

Targeting the elimination of out-of-pocket costs

In 2022, the Grattan Institute undertook a major study focused on reducing out-of-pocket costs.[76] It identified a range of opportunities, including one reform that has already been implemented: extending the duration of prescriptions. Other important opportunities highlighted by that study with relevance to IBD included:

- Eliminating OOP costs for selected diagnostics through alternative tendering models
- Expanding access to co-located public & private bulk-billed clinics and services
- Expanding access to public hospital services
- Expanding access to telehealth services
- Funding PHNs to tender for allied health services directly.

Figure 4.9: Reducing out-of-pocket costs for key health services – Grattan Institute



Source: Duckett, S., Stobart, A., and Lin, L. (2022). Not so universal: How to reduce out-of-pocket healthcare payments. Grattan Institute.

[76] Duckett, S., Stobart, A., and Lin, L. (2022). Not so universal: How to reduce out-of-pocket healthcare payments. Grattan Institute.

Additionally, stakeholders similarly raised concerns for out pocket costs to access GP services and encouraged a review of policies contributing to the growth in out-of-pocket costs for GPs.

In the context of increasing cost of living all of these represent important system-wide reforms with the potential to improve outcomes for a number of chronic conditions, including people living with IBD.

Improving income support safety nets for people with severe disease

Similarly, more support is needed to supplement income for people requiring long term leave from the workforce due to their IBD.

Currently, IBD patients requiring extended leave can access a Disability Support Payment if they expect to be out of the workforce for more than 2 years or JobSeeker if they expect to be out of the workforce for an extended period but less than two years. Given the age profile of IBD patients, most people requiring income support seek JobSeeker support.

As shown in Chapter 2, JobSeeker is structured to encourage people to seek employment, the levels of support are low. The maximum fortnightly payment is $833.20 as of September 2024, which translates into income support of around $21,658 per annum. This is substantially less than the average wage and less than the implied average household running costs of around $34,000 per annum.[77] Taking into consideration average out-of-pocket costs of $5,900 per annum it paints a picture of serious financial challenges for people at their most vulnerable.

At a minimum, there is an opportunity to reform the eligibility criteria for the Disability Support Pension to allow for selected conditions to access support at the disability pension rate, which could provide for a 40 per cent increase in support (to $29,754),[78] noting that this support would still not cover average household running costs.

4.6 Invest in IBD research

Following access to medicines, consumers also put investment in research as amongst the highest priorities for government over the next three to five years.

Research in IBD is advancing rapidly with the integration of cutting-edge technologies in genomics, microbiomics, immunology, and clinical care. Key trends include the focus on precision medicine, improving patient quality of life, developing targeted therapies, understanding the role of the gut microbiome, and exploring novel treatment modalities. These efforts have the potential to significantly enhance the ability to diagnose, treat, and manage IBD in ways that are more personalised, effective, and less invasive.

- *Advances in Precision Medicine* — Research has focused on identifying genetic risk factors associated with Crohn's and ulcerative colitis.[79] Epigenetic factors are being explored for their role in regulating gene expression in immune cells and gut tissues[80] and there is ongoing work to identify biomarkers for predicting disease onset, flare-ups, and treatment responses.[81] The goal is to identify biomarkers that could allow for earlier diagnosis, more personalised treatment regimens, and better monitoring of disease progression.

- *The role of the microbiome* — Studies have continued to explore the role of the gut microbiome in IBD, with recent studies indicating that dysbiosis (an imbalance in gut

[77] Calculated as the difference between average gross household income and average disposable household income.
[78] Services Australia. (2024). DSP Payment rates accessed at: https://www.servicesaustralia.gov.au/payment-rates-for-disability-support-pension?context=22276
[79] Ye, B. D., & McGovern, D. P. (2016). Genetic variation in IBD: progress, clues to pathogenesis and possible clinical utility. *Expert review of clinical immunology*, *12*(10), 1091–1107. https://doi.org/10.1080/1744666X.2016.1184972
[80] Jarmakiewicz-Czaja, S., Zielińska, M., Sokal, A., & Filip, R. (2022). Genetic and Epigenetic Etiology of Inflammatory Bowel Disease: An Update. *Genes*, *13*(12), 2388. https://doi.org/10.3390/genes13122388
[81] Plaza, J., Mínguez, A., Bastida, G., Marqués, R., Nos, P., Poveda, J. L., & Moret-Tatay, I. (2024). Genetic Variants Associated with Biological Treatment Response in Inflammatory Bowel Disease: A Systematic Review. International journal of molecular sciences, 25(7), 3717. https://doi.org/10.3390/ijms25073717

bacteria) may contribute to inflammation in IBD.[82] Researchers are investigating ways to modify the microbiome through probiotics, prebiotics, or fecal microbiota transplants (FMT) to reduce inflammation and promote remission.[83]

- *The role of the gut barrier* — Advances in understanding the role of gut barrier dysfunction in IBD is another important area of research, with some studies showing that a 'leaky gut' may allow bacteria and toxins to trigger inflammation.[84] The aim is that by better understanding the causes of IBD, interventions can be developed focused on strategies to restore the intestinal barrier.

- *The interaction between gut bacteria and the white blood cells that fight infections* — Genetic studies suggest that IBD susceptibility genes affect the ability of white blood cells to detect and respond to bacteria and other triggers of inflammation.

- *Immunomodulatory therapies* — The development of new biologic therapies targeting specific immune pathways has been advanced considerably and remains an active area of research. Looking forward, combining biologics with other immunomodulatory agents is being investigated to enhance therapeutic responses, particularly in patients who do not respond to single agents.[85] Researchers are also investigating other ways to regulate the immune response through targeting regulatory T cells (Tregs), as well as stem cells and stem cell derivatives, which help suppress inappropriate immune responses .[86]

- *Regenerative medicine and stem cell therapies* — Researchers are also investigating the use of stem cell therapies to repair damaged gut tissues and regenerate healthy mucosa.[87] Research using organoids (3D cultures derived from patient tissues) are being developed to study disease mechanisms, test new drugs, and understand individual responses to treatments.[88]

- *The role of diet and lifestyle factors* — There has also increasing interest in understanding the role of diet in managing IBD.[89] Research has shown that specific diets, such as the low FODMAP diet or exclusive enteral nutrition (EEN), may help reduce inflammation and induce remission in some patients.[90] Ongoing studies are examining how diet interacts with the microbiome and immune system to influence disease outcomes. Other studies have explored how lifestyle factors like stress, smoking, and exercise impact disease progression, with findings suggesting that smoking cessation and regular exercise can improve outcomes for IBD.

---

[82] Santana, P. T., Rosas, S. L. B., Ribeiro, B. E., Marinho, Y., & de Souza, H. S. P. (2022). Dysbiosis in Inflammatory Bowel Disease: Pathogenic Role and Potential Therapeutic Targets. *International journal of molecular sciences*, *23*(7), 3464. https://doi.org/10.3390/ijms23073464

[83] Noguera-Fernández, N., Candela-González, J., & Orenes-Piñero, E. (2024). Probiotics, Prebiotics, Fecal Microbiota Transplantation, and Dietary Patterns in Inflammatory Bowel Disease. *Molecular nutrition & food research*, *68*(18), e2400429. https://doi.org/10.1002/mnfr.202400429

84 Yu, S., Sun, Y., Shao, X., Zhou, Y., Yu, Y., Kuai, X., & Zhou, C. (2022). Leaky Gut in IBD: Intestinal Barrier-Gut Microbiota Interaction. Journal of microbiology and biotechnology, 32(7), 825–834. https://doi.org/10.4014/jmb.2203.03022

[85] Hirten, R.P. et al. (2018). Combining Biologics in Inflammatory Bowel Disease and Other Immune Mediated Inflammatory Disorders, Clinical Gastroenterology and Hepatology, Volume 16, Issue 9, 2018, https://doi.org/10.1016/j.cgh.2018.02.024.

[86] Laukova, M., & Glatman Zaretsky, A. (2023). Regulatory T cells as a therapeutic approach for inflammatory bowel disease. *European journal of immunology*, *53*(2), e2250007. https://doi.org/10.1002/eji.202250007

[87]Wang, M., Shi, J., Yu, C., Zhang, X., Xu, G., Xu, Z., & Ma, Y. (2023). Emerging strategy towards mucosal healing in inflammatory bowel disease: what the future holds?. *Frontiers in immunology*, *14*, 1298186. https://doi.org/10.3389/fimmu.2023.1298186

[88] Poling, H.M. et al. (2024). Human pluripotent stem cell-derived organoids repair damaged bowel in vivo, Cell Stem Cell, Volume 31, Issue 10, 1513 - 1523.e7

[89] Wark, G., Samocha-Bonet, D., Ghaly, S., & Danta, M. (2020). The Role of Diet in the Pathogenesis and Management of Inflammatory Bowel Disease: A Review. *Nutrients*, *13*(1), 135. https://doi.org/10.3390/nu13010135

[90] Mitrev N., et al. (2021). Review of exclusive enteral therapy in adult Crohn's disease,*BMJ Open Gastroenterology* 2021;**8:**e000745. doi: 10.1136/bmjgast-2021-000745; Więcek, M., Panufnik, P., Kaniewska, M., Lewandowski, K., & Rydzewska, G. (2022). Low-FODMAP Diet for the Management of Irritable Bowel Syndrome in Remission of IBD. *Nutrients*, *14*(21), 4562. https://doi.org/10.3390/nu14214562.

- *Advanced imaging techniques* — Advances in imaging technologies like MRI and ultrasound[91] are improving the ability to monitor IBD disease progression without the need for invasive procedures like colonoscopy (See Box 4.4 on the next page). These imaging modalities are also being explored for their potential in assessing treatment responses in real-time, particularly in cases of strictures or fistulas. The application of AI to imaging also offers an exciting frontier of research to improve diagnosis and monitoring of IBD reducing risk of variation.[92]

Box 4.4: Emerging opportunities in IBD diagnosis and monitoring – intestinal ultrasound

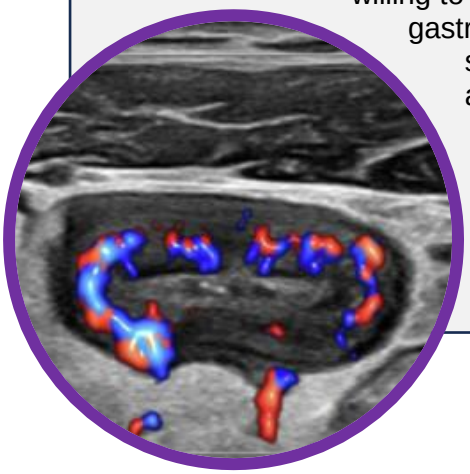
Intestinal ultrasound has emerged as a valuable tool for assessing and monitoring IBD activity. Ultrasound offers a non-invasive, radiation-free alternative to endoscopies and biomarkers through real-time, high-resolution examination of the bowel wall, mesentery, and adjacent structures. Ultrasound has been used to guide IBD care for over a decade in Europe and its adoption in the US is growing significantly.

Ultrasonography is operator-dependent, but studies in IUS show moderate to excellent inter-observer reliability and the application of AI to support assessments holds significant opportunity to further reduce the risk of error. MRE and IUS demonstrated similar accuracy for assessing disease activity in the terminal ileum in newly diagnosed or clinically active patients with CD in a multi-center randomised trial.

There are multiple clinical roles for intestinal ultrasound. First, ultrasound can be used as a screening tool, akin to faecal calprotectin, to rule out IBD in the appropriate clinical context. Further, positive ultrasound findings can help expedite colonoscopy for IBD diagnosis confirmation.

IUS is especially valuable in special IBD populations, such as pregnant patients, patients with serious comorbidities, and obese patients. Several studies have demonstrated that treatment response indicated by improvement or resolution of ultrasound findings can be identified within 3 months of biologic therapy initiation in CD. Further, treatment failure can be predicted in patients with CD who have a higher baseline bladder wall thickening, as these patients were 42 per cent less likely to achieve transmural healing 1 year after treatment initiation independent of the type of therapy.

Ultrasound provides a patient-centered approach to care. Although patients with IBD are willing to undergo invasive testing with colonoscopy when their gastroenterologist requires it, qualitative research data has also shown that they prefer noninvasive monitoring options, such as ultrasound.



Although ultrasound still has some limitations, it is strongly patient centred and has the potential to transform current approaches to diagnosis and monitoring of patients with IBD.

Source: Selected excerpts from Chavannes, Mallory et al. (2024). AGA Clinical Practice Update on the Role of Intestinal Ultrasound in Inflammatory Bowel Disease: Commentary, Clinical Gastroenterology and Hepatology, Volume 22, Issue 9, 1790 - 1795.e1

[91] Merrill, C. et al. (2024). Ultrasound of the bowel with a focus on IBD: the new best practice. *Abdom Radiol* (2024). https://doi.org/10.1007/s00261-024-04496-1

[92] Gu, P. et al. (2024). AI-luminating Artificial Intelligence in Inflammatory Bowel Diseases: A Narrative Review on the Role of AI in Endoscopy, Histology, and Imaging for IBD, *Inflammatory Bowel Diseases*, 2024;, izae030, https://doi.org/10.1093/ibd/izae030; Shaban N, Hoad CL, Naim I, et al. (2022). Imaging in inflammatory bowel disease: current and future perspectivesFrontline Gastroenterology 2022;13:e28-e34.

- *The role of psychological interventions* — Research also continues to demonstrate the high mental health burden for people living with IBD,[93] and to explore the role of psychological therapies in treatment.[94] The effectiveness of 'third wave' psychological therapies are an emerging major area of research,[95] with some benefits relative to cognitive behavioral therapy (CBT) demonstrated to date, while other research has been investigating the impact of psychological interventions can have an impact on disease biomarkers.[96]

- *Artificial intelligence and data integration* — The use of artificial intelligence (AI) and machine learning algorithms to analyse large datasets (e.g., from electronic health records, genetic data, and imaging) is emerging as a powerful tool in IBD. AI can help identify patterns in disease progression, predict flare-ups, and assist in personalised treatment planning.[97] For Australia, the development of world-leading real-world datasets through a clinical quality registry in IBD, could open up additional investment in AI research projects in IBD.

While significant breakthroughs have been made in the treatment of IBD in the last decade, further research is needed to achieve higher levels of population remission.[98] To break through prevalent therapeutic thresholds and improve outcomes for all people diagnosed with IBD, investment in research is needed. Crohn's & Colitis Australia, in partnership with the IBD community, developed consumer driven research priorities for IBD (Figure 4.10). Research priorities were identified for four major domains:

- Prevention, including understanding risk factors for IBD, the role of the microbiome, the influence of lifestyle factors and childhood experience on the risk of IBD

- Symptom management, including better understanding of food triggers and protective factors, risks for disease flares and the impact of food additives on IBD activity

- Treatment, including the development of more personalised medicine, a reduction in therapy side effects, remission maintenance and the potential of stem cell treatments

- Living with IBD, including improved understanding of interventions for quality-of-life improvements, managing medication side effects, the role of mental health and mental health interventions, the management of fatigue and joint pain, as well as the role of lifestyle factors and ageing on lived experience and quality of life.

[93] Mikocka-Walus, A., Massuger, W., Knowles, S. R., Moore, G. T., Buckton, S., Connell, W., Pavli, P., Raven, L., & Andrews, J. M. (2019). Psychological distress is highly prevalent in inflammatory bowel disease: A survey of psychological needs and attitudes. *JGH open : an open access journal of gastroenterology hepatology*, *4*(2), 166–171. https://doi.org/10.1002/jgh3.12236; Knowles, S. R., Apputhurai, P., Palsson, O. S., Bangdiwala, S., Sperber, A. D., & Mikocka-Walus, A. (2023). The epidemiology and psychological comorbidity of disorders of gut-brain interaction in Australia: Results from the Rome Foundation Global Epidemiology Study. *Neurogastroenterology and motility*, *35*(6), e14594. https://doi.org/10.1111/nmo.14594

[94] Riggot, C. et al. (2023). Efficacy of psychological therapies in people with inflammatory bowel disease: a systematic review and meta-analysis, Lancet Gastroenterol Hepatol 2023; 8: 919–31.

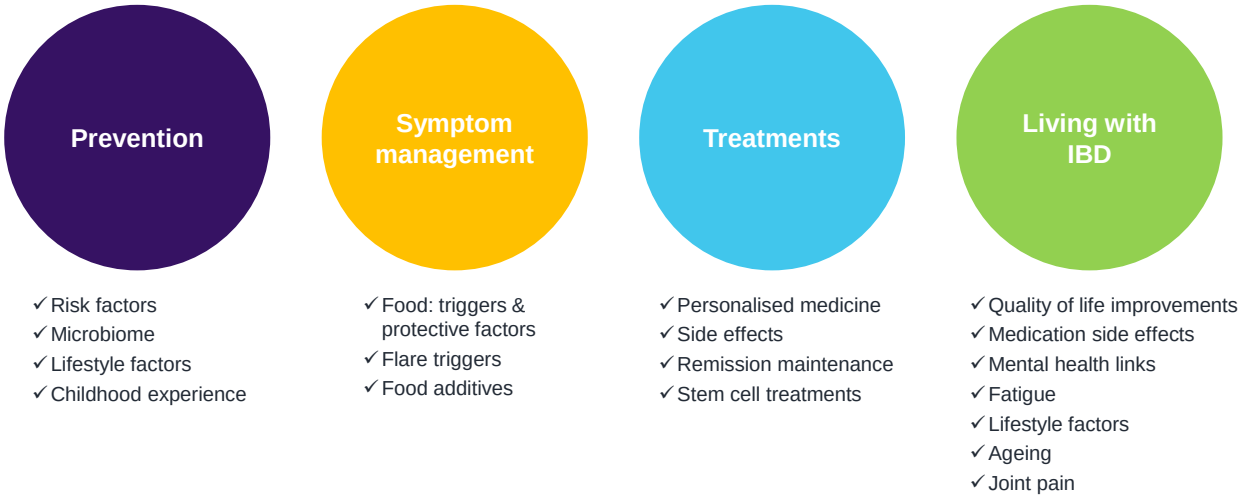
[95] Naude, C., Skvarc, D., Maunick, B., Evans, S., Romano, D., Chesterman, S., Russell, L., Dober, M., Fuller-Tyszkiewicz, M., Gearry, R., Gibson, P. R., Knowles, S., McCombie, A., O, E., Raven, L., Van Niekerk, L., & Mikocka-Walus, A. (2024). Acceptance and Commitment Therapy for Adults Living With Inflammatory Bowel Disease and Distress: A Randomized Controlled Trial. *The American journal of gastroenterology*, 10.14309/ajg.0000000000003032. Advance online publication. https://doi.org/10.14309/ajg.0000000000003032; Riggot, C. et al. (2023). Efficacy of psychological therapies in people with inflammatory bowel disease: a systematic review and meta-analysis, Lancet Gastroenterol Hepatol 2023; 8: 919–31.

[96] Seaton, N., Hudson, J., Harding, S., Norton, S., Mondelli, V., Jones, A. S. K., & Moss-Morris, R. (2024). Do interventions for mood improve inflammatory biomarkers in inflammatory bowel disease?: a systematic review and meta-analysis. *EBioMedicine*, *100*, 104910. https://doi.org/10.1016/j.ebiom.2023.104910

[97] Stidham, R.W. et al. (2022). Artificial Intelligence for Disease Assessment in Inflammatory Bowel Disease: How Will it Change Our Practice? Gastroenterology, Volume 162, Issue 5, 1493 - 1506

[98] Raine, T. et al., (2022). Breaking Through the Therapeutic Ceiling: What Will It Take?, Gastroenterology, Volume 162, Issue 5, 1507 – 1511 10.1053/j.gastro.2021.09.078; Feng, Z., et al. (2022) Breaking through the therapeutic ceiling of inflammatory bowel disease: Dual-targeted therapies, Biomedicine & Pharmacotherapy,https://doi.org/10.1016/j.biopha.2022.114174.

Figure 4.10: Consumer driven research priorities



Source: Summary of Crohn's & Colitis Australia. (2022). Consumer-Driven Research for Crohn's and Ulcerative Colitis: Australia's Top 10 Priorities.

To realise breakthroughs in these domains, investment is needed in at all phases of research from basic research to clinical trials and health implementation science. Investment in basic science is needed to better understand the role of the microbiome, the gut barrier, regenerative medicine and stem cell therapy, and the inflammatory response, which can then identify new avenues of therapy that could be developed to treat those who have not attained remission in spite of significant recent advances in therapy. Investment in clinical trials is needed to expand treatment options available and opportunities for personalised medicine, while health implementation science can identify system reforms to reduce variation in care and improve patient experiences and health outcomes.

4.7 Conclusions

The analysis shows that while there are many challenges for people living with IBD today (Chapter 3) there are also a range of evidence-based solutions available to governments to address these barriers, and frameworks for collaboration available to support action.

The following chapter identifies, from this longer list of opportunities, the top three priorities for the next implementation horizon.

Chapter 5

Priorities for government for the next implementation horizon

Five years on from the launch of the National Action Plan for IBD, it is clear that while important investments have been made, important work remains to be done. This chapter presents a refreshed vision for people living with IBD and key priorities for reform and investment over the next implementation horizon.

5.1 Vision for IBD in Australia

Crohn's & Colitis Australia, in partnership with patients, clinicians and consumers, are calling on Australian governments to address the barriers for people living with IBD by implementing the evidence-based solutions identified in this report.

Implementing these reforms and investing in research will work through time to support the realisation of a new vision for people living with IBD.

Figure 5.1: A refreshed vision for IBD in 2030

Source: Policy prioritisation workshop with IBD consumers and clinicians October 2024.

This vision, developed with the IBD community, emphasises the need for:

- Improved *timeliness* of diagnosis
- Improved *equity* of access – including for children and people living in regional areas
- The *empowerment* of consumers through information and support
- Delivery of *best practice, integrated* care so that no one living with IBD suffers unnecessarily.

In line with the *Measuring What Matters* framework, this will help Australians to live fearlessly and *to their full potential*.

With action, this vision can be realised by 2030.

But without leadership by Australian governments, the complexity of Australia's health system, the barriers to stakeholder coordination, misalignment of benefits and costs, and smaller patient numbers compared to other chronic conditions will continue to see IBD patients fall through the cracks. These patients will suffer unnecessarily and at great cost to themselves and the wider community.

5.2 Top 3 priorities for the next horizon

The National Action Plan included a long list of actions for implementation, and important, foundational progress was made by government. Five years on, it is timely to look to the next five years and identify the priorities for change.

In light of the progress that has been made and the gaps that remain, the following three major priorities have been identified for implementation within the next five years (Figure 5.2). These top three priorities are:

- *Priority 1: Improve access to multi-disciplinary care* — Together with the IBD community, Australian governments should work together to progressively increase access to multi-disciplinary team care. Because of the proven benefits that can be realised from such an approach in the short term, the goal would be to see action on this priority within the next three years. Ideally, a robust package of reforms could be implemented to build the foundations for quality, safe and coordinated care, including the implementation of a clinical care standard, support for the development of a national network of multi-disciplinary teams, a Living Well with IBD program, delivered through the Primary Healthcare Networks, and national access to a shared patient record, with reporting into a clinical quality registry for IBD.
- *Priority 2: Improve access to novel therapies* — Following on from the release of the Health Technology Assessment (HTA) review, the IBD community could engage with the Department of Health and Aged Care, HTA Implementation Committee and regulators to progress improved access for novel therapies, including in particular for paediatric patients.
- *Priority 3: Invest in IBD research* — In light of the low levels of funding for IBD research compared to other chronic conditions and high unmet needs of the community, a competitive call for Medical Research Future Fund research for IBD could be issued, similar to other areas of research priority. This would include investment in basic science and clinical research to improve the potential for disease prevention, new treatment options, better symptom management and understanding of the lived experience and outcomes of people living with IBD. Australia has the potential to develop a strategic, structured data asset in IBD if it were to support access to a shared patient record linked to a clinical quality registry. While the data asset could deliver improvements in patient care in its own right, it could also see the attraction of additional private sector investment in research.

These priorities, like the vision for people living with IBD by 2030, were developed in partnership with the IBD community. The IBD community is seeking to partner with Australian governments in the delivery of these priorities over the next 3-5 years.

The benefits of working together to deliver action against these priority areas are significant.

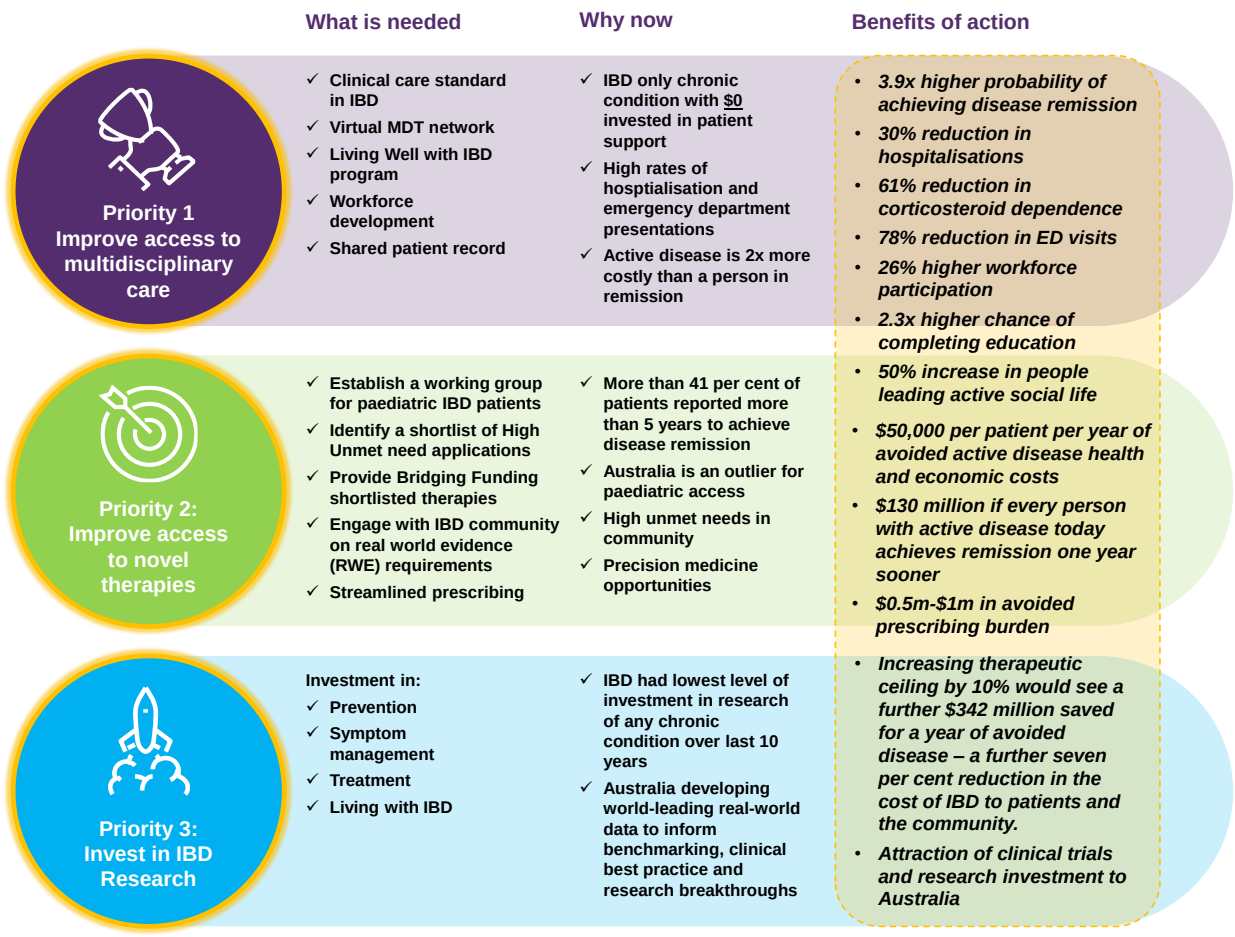
For example, improving access to multi-disciplinary care today would deliver a rapid, step change improvement in outcomes in the short term. Research has shown that access to multi-disciplinary team care is associated with a 3.9 times higher probability of achieving remission. Because the cost of active disease is so great, preventing even one year of disease, for even a small number of people, would be expected to yield considerable health, economic and social benefits:

- For every person who avoids one year of active disease, $50,000 is saved – through avoided healthcare utilisation, avoided income support, avoided out-of-pocket costs to households, increased workforce participation, increased workforce productivity and avoided suffering for the person living with IBD.
- The value of an avoided year of disease increases to $75,000 for people experiencing severely active disease. Preventing a year of severely active disease nearly doubles the probability of a person being able to work and triples the chance of a person – often at an important phase of life – completing their education. It also doubles their probability of having an active social life and restores their life satisfaction to be in line with their age matched peers.

In aggregate, more than $130 million in savings could be realised if people experiencing active disease today had been able to achieve remission *only one year sooner* – this creates a substantial willingness-to-pay funding envelope for governments to invest and bring about change.

Similarly, access to medicines and research can add to this benefit potential, by improving treatment options for patients and lifting the therapeutic ceiling through time, as well as increasing investment in research in Australia.

Figure 5.2: Priorities for the next five years



Source: Policy prioritisation workshop with IBD consumers and clinicians October 2024. Benefits based on active disease (all severity) are relative to a person in remission or having rarely active disease.

These benefits can be realised – but only if Australian communities and governments come together to make IBD a priority and to act.

Appendix A: Bibliography

Abegunde, A. T., Muhammad, B. H., Bhatti, O., & Ali, T. (2016). Environmental risk factors for inflammatory bowel diseases: Evidence based literature review. World journal of gastroenterology, 22(27), 6296–6317. https://doi.org/10.3748/wjg.v22.i27.6296

Abreu M. T. (2019). Combining Biologic Agents in Inflammatory Bowel Disease. *Gastroenterology & hepatology*, *15*(10), 549–551.

Ahmed, S., Alam, S., & Alsabri, M. (2022). Health-Related Quality of Life in Pediatric Inflammatory Bowel Disease Patients: A Narrative Review. *Cureus*, *14*(9), e29282. https://doi.org/10.7759/cureus.29282

AMA. (2022). General practice facts, accessed at: https://www.ama.com.au/articles/general-practice-facts-0#:~:text=In%202020%20-%202021%3A%20%5B1%5D%201%20there%20were,aged%20groups%207%2041.4%25%20of%20GPs%20trained%20overseas

Amaro, F., & Chiarelli, F. (2020). Growth and Puberty in Children with Inflammatory Bowel Diseases. *Biomedicines*, *8*(11), 458. https://doi.org/10.3390/biomedicines8110458.

AMII. (2020). Roche Canada Launches National Artificial Intelligence Centre of Excellence, accessed at: https://www.amii.ca/latest-from-amii/roche-ai-centre-of-excellence/

Australia Government Office of Impact Analysis, Reserve Bank of Australia, Statement on Monetary Policy - August 2024 (rba.gov.au), Table 3.1

Australia Government Office of Impact Analysis, Reserve Bank of Australia, Statement on Monetary Policy - August 2024 (rba.gov.au), Table 3.1

Australian Commission for Quality and Safety in Healthcare. (2024). About the Clinical Care Standards, accessed at: https://www.safetyandquality.gov.au/standards/clinical-care-standards/about-clinical-care-standards.

Australian Indigenous Health*Info*net. (2024). https://healthinfonet.ecu.edu.au/learn/health-facts/latest-information-and-statistics/hospitalisation/

Australian Institute of Health and Welfare. (2024). Rural and Remote Health, https://www.aihw.gov.au/reports/rural-remote-australians/rural-and-remote-health.

Australian Research Council. (2023). Selection Report: ARC Centres of Excellence for Funding Commencing in 2023, accessed at: https://www.arc.gov.au/funding-research/funding-outcome/selection-outcome-reports/Selection-Report%3A-ARC-Centres-of-Excellence-for-Funding-Commencing-in-2023#leverage-of-arc-funding

Australian Treasury. (2023). *Measuring What Matters*, accessed at: https://treasury.gov.au/policy-topics/measuring-what-matters.

Bakry, M., Hoffmann, P., Prematunga, R., Keightley, P., & Subramaniam, K. (2024). The Transitioning From Pediatric to Adult Inflammatory Bowel Disease Services: A Qualitative Study of Adolescents and Their Parents. *Gastroenterology research*, *17*(3), 146–149. https://doi.org/10.14740/gr1724

Bhatia, R., Yeoh, S.W., Vaz, K., Studd, C., Wilson, J., Bell, S., Otáhal, P., & Venn, A.J. (2019). Inflammatory bowel disease incidence, prevalence and 12-month initial disease course in Tasmania, Australia. *Internal Medicine Journal, 49*.

Blumenstein, I. & Sonnenburg, E. (2023). Sex- and gender-related differences in inflammatory bowel diseases, Frontiers in Gastroenterology,

https://www.frontiersin.org/journals/gastroenterology/articles/10.3389/fgstr.2023.1199687.

Bowel Cancer Australia. (2024). A Colonoscopy Wait Time and Performance Guarantee, data accessed from AIHW 2023. https://www.bowelcanceraustralia.org/a-colonoscopy-wait-time-and-performance-guarantee.

Bowel Disease Nursing Service, Inflammatory Bowel Diseases, Volume 30, Issue 6, June 2024, Pages 960–969, https://doi.org/10.1093/ibd/izad145

Busingye D, Pollack A, & Chidwick K. (2021). Prevalence of inflammatory bowel disease in the Australian general practice population: A cross-sectional study. PLoS One. May 27;16(5):e0252458. doi: 10.1371/journal.pone.0252458

Carchman E. (2019). Crohn's Disease and the Risk of Cancer. Clinics in colon and rectal surgery, 32(4), 305–313. https://doi.org/10.1055/s-0039-1683923.

CCA. (2024). Patient Stories, https://crohnsandcolitis.org.au/stories

CCCure, (2024). About Crohn's and Colitis Care, https://c-c-cure.org/cccare/#:~:text=CCCare%20is%20used%20to%20directly%20document%20routine%20care,share%20important%20information%20directly%20with%20the%20clinical%20teams

Chavannes, M. Dolinger, M.T., Cohen, S. & Abraham, B. (2024). AGA Clinical Practice Update on the Role of Intestinal Ultrasound in Inflammatory Bowel Disease: Commentary, Clinical Gastroenterology and Hepatology, Volume 22, Issue 9, 1790 - 1795.e1

Colino, S. (2024). *Why Gut Health Issues Are More Common in Women*, https://time.com/7020911/women-gut-health-ibs-ibd/;

Colombel, J. F., Panaccione, R., Bossuyt, P., Lukas, M., Baert, F., Vaňásek, T., Danalioglu, A., Novacek, G., Armuzzi, A., Hébuterne, X., Travis, S., Danese, S., Reinisch, W., Sandborn, W. J., Rutgeerts, P., Hommes, D., Schreiber, S., Neimark, E., Huang, B., Zhou, Q., … D'Haens, G. (2017). Effect of tight control management on Crohn's disease (CALM): a multicentre, randomised, controlled phase 3 trial. *Lancet (London, England)*, *390*(10114), 2779–2789. https://doi.org/10.1016/S0140-6736(17)32641-7

Crohn's & Colitis Australia. (2018). Inflammatory Bowel Disease National Action Plan: Literature Review.

Crohn's & Colitis Australia. (2018). My IBD Experience: Australian Inflammatory Bowel Disease Patient Experience of Health Care, Research report 2018.

Crohn's & Colitis Australia. (2024). Framework for Integrated Care in Inflammatory Bowel Disease.

Crohn's & Colitis Australia. (2024). Gut Smart Courses: see https://gutsmart.com.au/all-courses/

Crohn's and Colitis Canada. (2023). Impact of Inflammatory Bowel Disease in Canada.

Crohn's and Colitis Foundation. (2020). Managing Inflammatory Bowel Diseases in the Elderly Populationhttps://www.crohnscolitisfoundation.org/sites/default/files/2020-08/IBD%20and%20elderly%20tip_FINAL_Aug.%202020.pdf

Duckett, S., Stobart, A., & Lin, L. (2022). Not so universal: How to reduce out-of-pocket healthcare payments. Grattan Institute.

Economist Impact. (2023). Inflammatory Bowel Disease: Addressing the hidden disease with innovative, multi-disciplinary and patient-centric care.

El Hadad, J., Schreiner, P., Vavricka, S. R., & Greuter, T. (2024). The Genetics of Inflammatory Bowel Disease. Molecular diagnosis & therapy, 28(1), 27–35. https://doi.org/10.1007/s40291-023-00678-7

EMJ. (2022). Perspectives on Treatment of Inflammatory Bowel Disease in Older Patients: Applying Gut-Feeling in an Evidence-Based Era?, DOI/10.33590/emj/21-00262. https://doi.org/10.33590/emj/21-00262.

Feng, Z., Kang, G., Wang, J., Gao, X., Wang, X., Ye, Y., Liu, L., Zhao, J., Liu, X., Huang, H., & Cao, X. (2023). Breaking through the therapeutic ceiling of inflammatory bowel disease: Dual-targeted therapies. *Biomedicine & pharmacotherapy = Biomedecine & pharmacotherapie*, *158*, 114174. https://doi.org/10.1016/j.biopha.2022.114174.

Ferman, M., Lim, A.H., Hossain, M., Siow, G.W. & Andrews, J.M. (2018), Multidisciplinary team meetings appear to be effective in inflammatory bowel disease management: an audit of process and outcomes. Intern Med J, 48: 1102-1108. https://doi.org/10.1111/imj.13965

Forbes, A. J., Frampton, C. M. A., Day, A. S., Kaplan, G. G., & Gearry, R. B. (2024). The Epidemiology of Inflammatory Bowel Disease in Oceania: A Systematic Review and Meta-Analysis of Incidence and Prevalence. *Inflammatory bowel diseases*, *30*(11), 2076–2086. https://doi.org/10.1093/ibd/izad295.

Gastro Girl. (2024). The Emotional Impact of IBD: Doctor and Patient Perspectives - Gastro Girl, Meghan, accessed at: https://gastrogirl.com/the-emotional-impact-of-ibd-doctor-and-patient-perspectives/#:~:text=78%20YEAR%20OLD%20WOMAN%20WITH%20ULCERATIVE%20COLITIS

Gastroenterological Society of Australia, editor. (2018). Clinical update for general practitioners and physicians: Inflammatory Bowel Disease Gastroenterological Society of Australia, http://nla.gov.au/nla.obj-2712116930

Gearry, R. B., Richardson, A. K., Frampton, C. M., Dodgshun, A. J., & Barclay, M. L. (2010). Population-based cases control study of inflammatory bowel disease risk factors. *Journal of gastroenterology and hepatology*, *25*(2), 325–333. https://doi.org/10.1111/j.1440-1746.2009.06140.x.

Gearry, R. B., Richardson, A., Frampton, C. M., Collett, J. A., Burt, M. J., Chapman, B. A., & Barclay, M. L. (2006). High incidence of Crohn's disease in Canterbury, New Zealand: results of an epidemiologic study. *Inflammatory bowel diseases*, *12*(10), 936–943. https://doi.org/10.1097/01.mib.0000231572.88806.b9

Giles, E. (2023). Access to advanced therapies for paediatric inflammatory bowel disease (IBD) patients in Australia, submission to the Health Technology Assessment Review

Glasziou, P., (2013). Common general practice presentations and publication frequency, https://www.racgp.org.au/afp/2013/january-february/common-general-practice-presentations

Goren, I., Barkan, R., Biron, I. A., Leibovitzh, H., Golan, M. A., Eran, H. B., Snir, Y., Broitman, Y., Konikoff, T., Amir-Barak, H., Yafee, H., Adani, E., Shiber, S., Steiner, H., Drescher, M. J., Dotan, I., Yanai, H., & Israeli IBD Research Nucleus (IIRN) (2022). Specialized Emergency Department Assessment and Multi-disciplinary Intervention After Discharge Improve Management of Patients With Inflammatory Bowel Diseases. *Journal of clinical gastroenterology*, *56*(2), 148–153. https://doi.org/10.1097/MCG.0000000000001490

Gu, P., Mendonca, O., Carter, D., Dube, S., Wang, P., Huang, X., Li, D., Moore, J. H., & McGovern, D. P. B. (2024). AI-luminating Artificial Intelligence in Inflammatory Bowel Diseases: A Narrative Review on the Role of AI in Endoscopy, Histology, and Imaging

for IBD. *Inflammatory bowel diseases*, *30*(12), 2467–2485. https://doi.org/10.1093/ibd/izae030

Gumidyala, A. P., Greenley, R. N., Plevinsky, J. M., Poulopoulos, N., Cabrera, J., Lerner, D., Noe, J. D., Walkiewicz, D., Werlin, S., & Kahn, S. A. (2018). Moving On: Transition Readiness in Adolescents and Young Adults With IBD. *Inflammatory bowel diseases*, *24*(3), 482–489. https://doi.org/10.1093/ibd/izx051

Hasan, N., & Yang, H. (2019). Factors affecting the composition of the gut microbiota, and its modulation. *PeerJ*, *7*, e7502. https://doi.org/10.7717/peerj.7502

Hong S.J. & Katz S. (2021). The elderly IBD patient in the modern era: changing paradigms in risk stratification and therapeutic management. Therap Adv Gastroenterol. 2021 Jul 3;14:17562848211023399. doi: 10.1177/17562848211023399.

Ironmonger, L. (2024). 'I knew what sex looked like for me': Love and dating with Crohn's", Sydney Morning Herald, accessed at: https://www.smh.com.au/lifestyle/life-and-relationships/i-knew-what-sex-looked-like-for-me-love-and-dating-with-crohn-s-20241015-p5kidf.html.

Jarmakiewicz-Czaja, S., Zielińska, M., Sokal, A., & Filip, R. (2022). Genetic and Epigenetic Etiology of Inflammatory Bowel Disease: An Update. *Genes*, *13*(12), 2388. https://doi.org/10.3390/genes13122388

Kaplan, G. G., & Ng, S. C. (2017). Understanding and Preventing the Global Increase of Inflammatory Bowel Disease,mGastroenterology, Volume 152, Issue 2, 2017, https://doi.org/10.1053/j.gastro.2016.10.020.

Kaplan, G.G. & Windsor, J.W., (2021). The four epidemiological stages in the global evolution of inflammatory bowel disease. *Nature reviews Gastroenterology & hepatology*, *18*(1), pp.56-66

Kaplan, G.G. (2015). The global burden of IBD: from 2015 to 2025. Nature reviews Gastroenterology & hepatology, 12(12), pp.720-727.

Karnon, J. & Partington, A., (2024). Ambulance ramping is getting worse in Australia. Here's why – and what we can do about it, published July 5. (2024). accessed at: https://theconversation.com/ambulance-ramping-is-getting-worse-in-australia-heres-why-and-what-we-can-do-about-it-232720

Khor, B., Gardet, A. and Xavier, R. Genetics and pathogenesis of inflammatory bowel disease. Nature 474, 307–317 (2011). https://doi.org/10.1038/nature10209

Knowles, S. R., Apputhurai, P., Palsson, O. S., Bangdiwala, S., Sperber, A. D., & Mikocka-Walus, A. (2023). The epidemiology and psychological comorbidity of disorders of gut-brain interaction in Australia: Results from the Rome Foundation Global Epidemiology Study. *Neurogastroenterology and motility*, *35*(6), e14594. https://doi.org/10.1111/nmo.14594

Lamb. S., & Ho, S. (2017). Counting the costs of lost opportunity in Australian education https://content.vu.edu.au/sites/default/files/media/counting-the-costs-of-lost-opportunity-in-aus-education-mitchell-institute.pdf

Laukova, M., & Glatman Zaretsky, A. (2023). Regulatory T cells as a therapeutic approach for inflammatory bowel disease. *European journal of immunology*, *53*(2), e2250007. https://doi.org/10.1002/eji.202250007

Leach, S. T., Day, A. S., Moore, D., & Lemberg, D. A. (2014). Low rate of inflammatory bowel disease in the Australian indigenous paediatric population. *Journal of paediatrics and child health*, *50*(4), 328–329. https://doi.org/10.1111/jpc.12535.

Lees, C. (2022). Improving outcomes for IBD in 2022, Atomic IBD, https://charlielees.substack.com/p/improving-outcomes-for-ibd-in-2022.

Litwin, P. and Andrews, J. (2025). Benchmarking in inflammatory bowel disease: lessons from Australia and New Zealand, Journal of the Canadian Association of Gastroenterology, 2025;, gwae046, https://doi.org/10.1093/jcag/gwae046

Lungaro, L., Costanzini, A., Manza, F., Barbalinardo, M., Gentili, D., Guarino, M., Caputo, F., Zoli, G., De Giorgio, R., and Caio, G. (2023). Impact of Female Gender in Inflammatory Bowel Diseases: A Narrative Review. *Journal of personalized medicine*, *13*(2), 165. https://doi.org/10.3390/jpm13020165.

Mackner, L. M. & Crandall, W. V. (2013). "Health-related Quality of Life in Pediatric Inflammatory Bowel Disease." *Inflammatory Bowel Diseases*, 19(6), 1213-1222. DOI: 10.1097/MIB.0b013e31828c5e91.

Mackner, L.M. & Crandall, W.V. (2013). Psychological Aspects of IBD in Children and Adolescents. In: Mamula, P., Markowitz, J., Baldassano, R. (eds) Pediatric Inflammatory Bowel Disease. Springer, New York, NY. https://doi.org/10.1007/978-1-4614-5061-0_44

Mattar, M. C., Lough, D., Pishvaian, M. J., & Charabaty, A. (2011). Current management of inflammatory bowel disease and colorectal cancer. Gastrointestinal cancer research : GCR, 4(2), 53–61.

McNamara, J., Su, W., Pipicella, J., Wilson, W., Ghaly, S., Cabaero, A., Walker, G., Forbes, A., Su, H., Brett, L., Dutt, S., An, Y., Lawrance, I., Lynch, K., Andrews, J., and Connor, S. (2024). Documented Variation in Inflammatory Bowel, Disease Care in Australasia – Crohn's Colitis Cure Data, Insights Program, Gastroenterology, Volume 166, Issue 5, S-839, also available at: https://c-c-cure.org/wpcontent/uploads/2024/03/P286_McNamara_CCC_KPI_v2_2024.02.08.pdf.

Mehta, F. (2016). Report: economic implications of inflammatory bowel disease and its management. *The American journal of managed care*, *22*(3 Suppl), pp.s51-60

Merrill, C., & Wilson, S. R. (2024). Ultrasound of the bowel with a focus on IBD: the new best practice. *Abdominal radiology (New York)*, 10.1007/s00261-024-04496-1. Advance online publication. https://doi.org/10.1007/s00261-024-04496-1

Mikocka-Walus, A., Massuger, W., Knowles, S. R., Moore, G. T., Buckton, S., Connell, W., Pavli, P., Raven, L., & Andrews, J. M. (2019). Psychological distress is highly prevalent in inflammatory bowel disease: A survey of psychological needs and attitudes. *JGH open : an open access journal of gastroenterology hepatology*, *4*(2), 166–171. https://doi.org/10.1002/jgh3.12236

Mikocka-Walus, A., Massuger, W., Knowles, S.R., Moore, G.T., Buckton, S., Connell, W., Pavli, P., Raven, L. & Andrews, J.M. (2020). Quality of care in inflammatory bowel disease: actual health service experiences fall short of the standards. Intern Med J, 50: 1216-1225. https://doi.org/10.1111/imj.14683

Mitrev, N., Huang, H., Hannah, B., & Kariyawasam, V. C. (2021). Review of exclusive enteral therapy in adult Crohn's disease. *BMJ open gastroenterology*, *8*(1), e000745. https://doi.org/10.1136/bmjgast-2021-000745

Molander, P., Jussila, A., Toivonen, T., Mäkkeli, P., Alho, A., & Kolho, K. L. (2018). The impacts of an inflammatory bowel disease nurse specialist on the quality of care and costs in Finland. *Scandinavian journal of gastroenterology*, *53*(12), 1463–1468. https://doi.org/10.1080/00365521.2018.1541477

Musculoskeletal Australia and Arthritis Australia. (2022). Delays in receiving scripts and biologic medication – A national survey.

Naude, C., Skvarc, D., Maunick, B., Evans, S., Romano, D., Chesterman, S., Russell, L., Dober, M., Fuller-Tyszkiewicz, M., Gearry, R., Gibson, P. R., Knowles, S., McCombie, A., O, E., Raven, L., Van Niekerk, L., & Mikocka-Walus, A. (2024). Acceptance and

Commitment Therapy for Adults Living With Inflammatory Bowel Disease and Distress: A Randomized Controlled Trial. *The American journal of gastroenterology*, 10.14309/ajg.0000000000003032. Advance online publication. https://doi.org/10.14309/ajg.0000000000003032

Nicholas, D. B., Otley, A., Smith, C., Avolio, J., Munk, M., & Griffiths, A. M. (2007). Challenges and strategies of children and adolescents with inflammatory bowel disease: a qualitative examination. *Health and quality of life outcomes*, *5*, 28. https://doi.org/10.1186/1477-7525-5-28

Noguera-Fernández, N., Candela-González, J., & Orenes-Piñero, E. (2024). Probiotics, Prebiotics, Fecal Microbiota Transplantation, and Dietary Patterns in Inflammatory Bowel Disease. *Molecular nutrition & food research*, *68*(18), e2400429. https://doi.org/10.1002/mnfr.202400429

Novo Nordisk Foundation's Center for Protein Research. (2019). Study: Across Diseases, Women Are Diagnosed Later Than Men, accessed at: https://www.cpr.ku.dk/cpr-news/2019/study-across-diseases-women-are-diagnosed-later-than-men/

Peña-Sánchez, J. N., Lix, L. M., Teare, G. F., Li, W., Fowler, S. A., & Jones, J. L. (2017). Impact of an Integrated Model of Care on Outcomes of Patients With Inflammatory Bowel Diseases: Evidence From a Population-Based Study. *Journal of Crohn's & colitis*, *11*(12), 1471–1479. https://doi.org/10.1093/ecco-jcc/jjx106

Pipicella, J.L., Gu, B., McNamara, J., Wilson, W., Palmer, L.J., Connor, S.J. and Andrews, J.M. (2025), Proposal and exploration of a novel score to quantify patient-perceived burden of inflammatory bowel disease under routine care. Intern Med J. https://doi.org/10.1111/imj.16634

Plaza, J., Mínguez, A., Bastida, G., Marqués, R., Nos, P., Poveda, J. L., & Moret-Tatay, I. (2024). Genetic Variants Associated with Biological Treatment Response in Inflammatory Bowel Disease: A Systematic Review. International journal of molecular sciences, 25(7), 3717. https://doi.org/10.3390/ijms25073717

Poling, H. M., Sundaram, N., Fisher, G. W., Singh, A., Shiley, J. R., Nattamai, K., Govindarajah, V., Cortez, A. R., Krutko, M. O., Ménoret, S., Anegon, I., Kasendra, M., Wells, J. M., Mayhew, C. N., Takebe, T., Mahe, M. M., & Helmrath, M. A. (2024). Human pluripotent stem cell-derived organoids repair damaged bowel in vivo. *Cell stem cell*, *31*(10), 1513–1523.e7. https://doi.org/10.1016/j.stem.2024.08.009

Pudipeddi, A., Liu, J., Kariyawasam, V., Borody, T. J., Cowlishaw, J. L., McDonald, C., Katelaris, P., Chapman, G., Corte, C., Lemberg, D. A., Lee, C. H., Keshava, A., Napoli, J., Clancy, R., Chan, W., Paramsothy, S., & Leong, R. (2021). High prevalence of Crohn disease and ulcerative colitis among older people in Sydney. *The Medical journal of Australia*, *214*(8), 365–370. https://doi.org/10.5694/mja2.50910

Qualter, P., Rouncefield-Swales, A., Bray, L., Blake, L., Allen, S., Probert, C., Crook, K., & Carter, B. (2021). Depression, anxiety, and loneliness among adolescents and young adults with IBD in the UK: the role of disease severity, age of onset, and embarrassment of the condition. *Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation*, *30*(2), 497–506. https://doi.org/10.1007/s11136-020-02653-9

Raine, T., & Danese, S. (2022). Breaking Through the Therapeutic Ceiling: What Will It Take?. *Gastroenterology*, *162*(5), 1507–1511. https://doi.org/10.1053/j.gastro.2021.09.078

Riggott, C., Mikocka-Walus, A., Gracie, D. J., & Ford, A. C. (2023). Efficacy of psychological therapies in people with inflammatory bowel disease: a systematic review and meta-

analysis. *The lancet. Gastroenterology & hepatology*, *8*(10), 919–931. https://doi.org/10.1016/S2468-1253(23)00186-3.

Sack, C., Phan, V. A., Grafton, R., Holtmann, G., van Langenberg, D. R., Brett, K., Clark, M., & Andrews, J. M. (2012). A chronic care model significantly decreases costs and healthcare utilisation in patients with inflammatory bowel disease. *Journal of Crohn's & colitis*, *6*(3), 302–310. https://doi.org/10.1016/j.crohns.2011.08.019

Santana, P. T., Rosas, S. L. B., Ribeiro, B. E., Marinho, Y., & de Souza, H. S. P. (2022). Dysbiosis in Inflammatory Bowel Disease: Pathogenic Role and Potential Therapeutic Targets. *International journal of molecular sciences*, *23*(7), 3464. https://doi.org/10.3390/ijms23073464

Seaton, N., Hudson, J., Harding, S., Norton, S., Mondelli, V., Jones, A. S. K., & Moss-Morris, R. (2024). Do interventions for mood improve inflammatory biomarkers in inflammatory bowel disease?: a systematic review and meta-analysis. *EBioMedicine*, *100*, 104910. https://doi.org/10.1016/j.ebiom.2023.104910

Selinger, C. P., Andrews, J. M., Titman, A., Norton, I., Jones, D. B., McDonald, C., Barr, G., Selby, W., Leong, R. W., & Sydney IBD Cohort Study Group (2014). Long-term follow-up reveals low incidence of colorectal cancer, but frequent need for resection, among Australian patients with inflammatory bowel disease. *Clinical gastroenterology and hepatology : the official clinical practice journal of the American Gastroenterological Association*, *12*(4), 644–650. https://doi.org/10.1016/j.cgh.2013.05.017

Services Australia. (2024). DSP Payment rates accessed at: https://www.servicesaustralia.gov.au/payment-rates-for-disability-support-pension?context=22276

Spagnuolo, R., Corea, A., Napolitano, D., Nisticò, E., Pagnotta, R., Pagliuso, C., Schiavoni, E., Turchini, L., Fiorino, G., Radice, S., Armuzzi, A., & Doldo, P. (2021). Nursing-sensitive outcomes in adult inflammatory bowel disease: A systematic review. *Journal of advanced nursing*, *77*(5), 2248–2266. https://doi.org/10.1111/jan.14744

Stidham, R. W., & Takenaka, K. (2022). Artificial Intelligence for Disease Assessment in Inflammatory Bowel Disease: How Will it Change Our Practice?. *Gastroenterology*, *162*(5), 1493–1506. https://doi.org/10.1053/j.gastro.2021.12.238

Studd, C., Cameron, G., Beswick, L., Knight, R., Hair, C., McNeil, J., Desmond, P., Wilson, J., Connell, W., & Bell, S. (2016). Never underestimate inflammatory bowel disease: High prevalence rates and confirmation of high incidence rates in Australia. *Journal of gastroenterology and hepatology*, *31*(1), 81–86. https://doi.org/10.1111/jgh.13050

Targownik, L. E., Bollegala, N., Huang, V. H., Windsor, J. W., Kuenzig, M. E., Benchimol, E. I., Kaplan, G. G., Murthy, S. K., Bitton, A., Bernstein, C. N., Jones, J. L., Lee, K., Peña-Sánchez, J. N., Rohatinsky, N., Ghandeharian, S., Davis, T., Weinstein, J., Im, J. H. B., Jannati, N., Khan, R., … Seow, C. H. (2023). The 2023 Impact of Inflammatory Bowel Disease in Canada: The Influence of Sex and Gender on Canadians Living With Inflammatory Bowel Disease. *Journal of the Canadian Association of Gastroenterology*, *6*(Suppl 2), S55–S63. https://doi.org/10.1093/jcag/gwad011

Taylor, C, 2017, Economic Evaluation, https://australianprescriber.tg.org.au/articles/economic-evaluation-of-medicines.html#r7

Thapwong, P., Norton, C., Rowland, E., Farah, N., & Czuber-Dochan, W. (2023). A systematic review of the impact of inflammatory bowel disease (IBD) on family members. *Journal of Clinical Nursing*, 32, 2228–2238. https://doi.org/10.1111/jocn.16446

Tsai, L., Ma, C., Dulai, P. S., Prokop, L. J., Eisenstein, S., Ramamoorthy, S. L., Feagan, B. G., Jairath, V., Sandborn, W. J., & Singh, S. (2021). Contemporary Risk of Surgery in Patients With Ulcerative Colitis and Crohn's Disease: A Meta-Analysis of Population-Based Cohorts. Clinical gastroenterology and hepatology : the official clinical practice journal of the American Gastroenterological Association, 19(10), 2031–2045.e11. https://doi.org/10.1016/j.cgh.2020.10.039

Veerisetty, S, Eschete, S.O., Uhlhorn, A, & De Felice, K.M. (2018). Women's Health in Inflammatory Bowel Disease, The American Journal of the Medical Sciences,

Vernon-Roberts, A., Chan, P., Christensen, B., Day, A. S., Havrlant, R., Giles, E., & Williams, A. J. (2024). Transitional care of adolescents with inflammatory bowel disease to adult services varies widely across Australia and New Zealand. JGH open : an open access journal of gastroenterology and hepatology, 8(1), e13032. https://doi.org/10.1002/jgh3.13032

Victorian Government. (2024). Inquiry into Women's Pain, accessed at: https://www.health.vic.gov.au/inquiry-into-womens-pain.

Wang, M., Shi, J., Yu, C., Zhang, X., Xu, G., Xu, Z., & Ma, Y. (2023). Emerging strategy towards mucosal healing in inflammatory bowel disease: what the future holds?. *Frontiers in immunology*, *14*, 1298186. https://doi.org/10.3389/fimmu.2023.1298186

Wark, G., Samocha-Bonet, D., Ghaly, S., & Danta, M. (2020). The Role of Diet in the Pathogenesis and Management of Inflammatory Bowel Disease: A Review. *Nutrients*, *13*(1), 135. https://doi.org/10.3390/nu13010135.

Więcek, M., Panufnik, P., Kaniewska, M., Lewandowski, K., & Rydzewska, G. (2022). Low-FODMAP Diet for the Management of Irritable Bowel Syndrome in Remission of IBD. *Nutrients*, *14*(21), 4562. https://doi.org/10.3390/nu14214562

Ye, B. D., & McGovern, D. P. (2016). Genetic variation in IBD: progress, clues to pathogenesis and possible clinical utility. *Expert review of clinical immunology*, *12*(10), 1091–1107. https://doi.org/10.1080/1744666X.2016.1184972

Yu, N., Wu, K., Samyue, T., Fry, S., Stanley, A., Ross, A., Malcolm, R., Connell, W., Wright, E., Ding, N. S., Niewiadomski, O., Lust, M., Schulberg, J., Flanagan, E., Kamm, M. A., & Basnayake, C. (2024). Outcomes of a Comprehensive Specialist Inflammatory Bowel Disease Nursing Service. *Inflammatory bowel diseases*, *30*(6), 960–969. https://doi.org/10.1093/ibd/izad145

Yu, S., Sun, Y., Shao, X., Zhou, Y., Yu, Y., Kuai, X., & Zhou, C. (2022). Leaky Gut in IBD: Intestinal Barrier-Gut Microbiota Interaction. *Journal of microbiology and biotechnology*, *32*(7), 825–834. https://doi.org/10.4014/jmb.2203.03022

Appendix B: State of the Nation Survey of People Living with Inflammatory Bowel Disease

This appendix summarises the approach and key outcomes from the State of the Nation Survey of People Living with Inflammatory Bowel Disease.

B.1 Survey method: overview

The State of Nation in Inflammatory Bowel Disease Survey was conducted from August 13, 2024, to September 30, 2024. A total of 632 individuals participated in the survey; however, 65 responses were excluded due to incomplete data. Consequently, the analysis is based on 567 valid responses, which delivers a statistically significant sample of the IBD population in Australia, with 95 per cent confidence within a five per cent margin of error.

There was also good distribution of responses by:

- Age, IBD subtype and relationship to IBD (Figures B.1-B.3)
- Public and private patients (Figures B.4-B.5)
- Income and socioeconomic status (Figures B.6-B.9)
- Geography (Figures B.10-B.11)
- Culturally and Linguistically Diverse (CALD) backgrounds, sexual orientation and Aboriginal and Torres Strait Islander status (Figures B.12-B.14)
- Duration of living with IBD (Figure B.15)
- Varying levels of IBD severity (Figure B.16-B.17)

5.3 Survey: who responded?

Figure B.1: Age

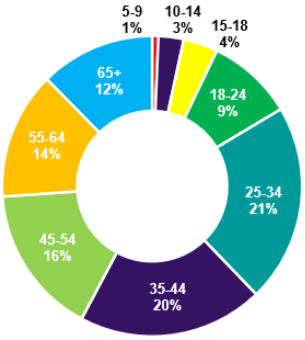


Figure B.2: Subtype

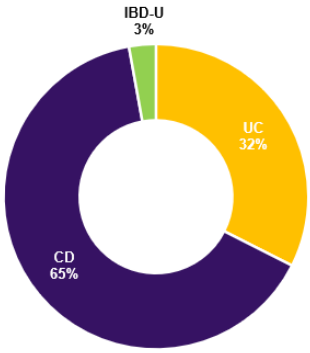


Figure B.3: Relationship to IBD

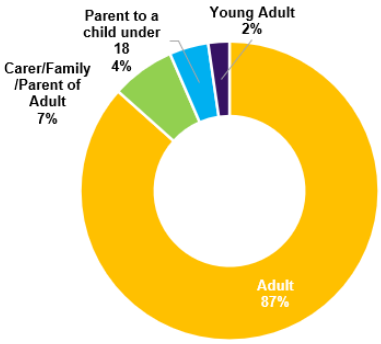


Figure B.4: Private insurance

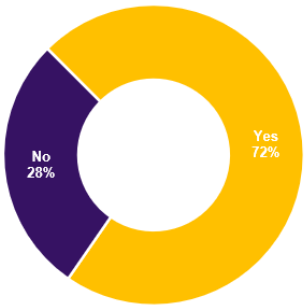


Figure B.5: Private or public service

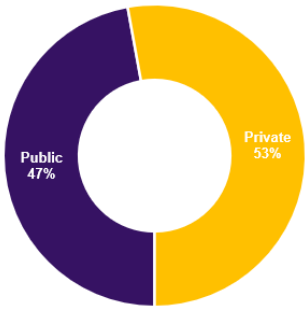


Figure B.6: Index of relative socio-economic disadvantage

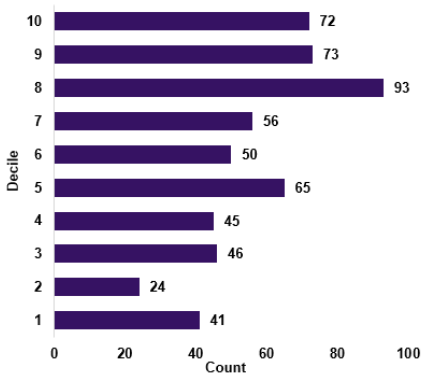


Figure B.7: Income levels of Adult IBD Patients

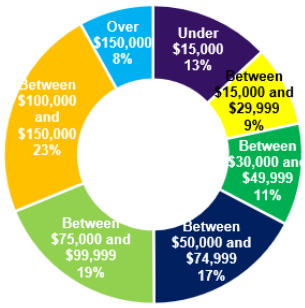


Figure B.8: Income levels of parents with children diagnosed with IBD

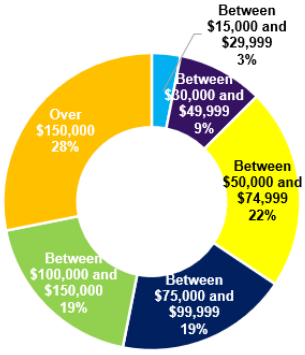


Figure B.9: Income Levels of Carers for Adults Diagnosed with IBD

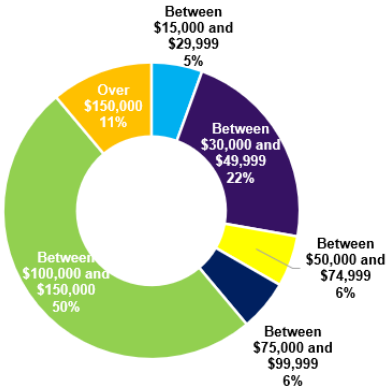


Figure B.10: State and Territories

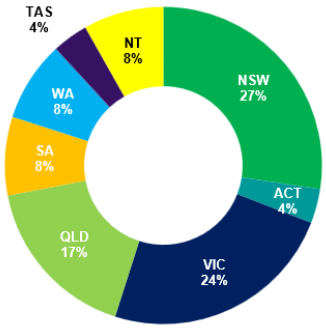


Figure B.11: Remoteness

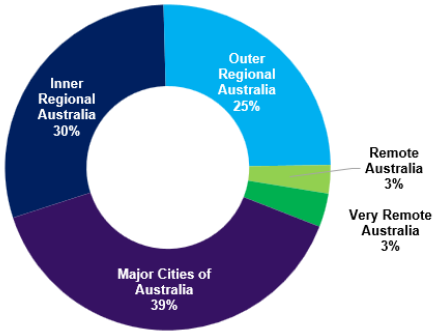


Figure B.12: CALD backgrounds

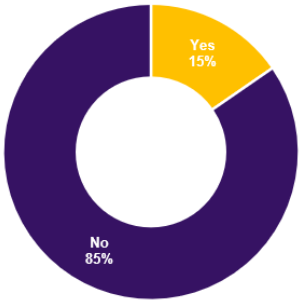


Figure B.13: Sexual Orientation

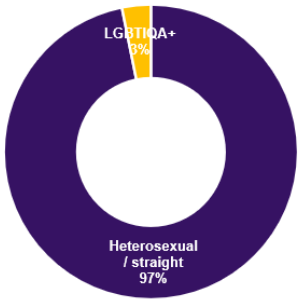


Figure B.14: Aboriginal and Torres Strait Islander status

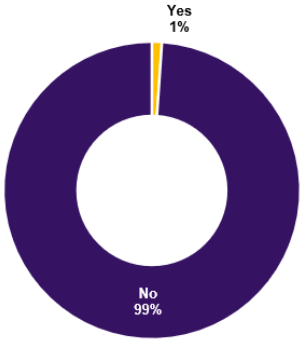


Figure B.15: Years lived with IBD

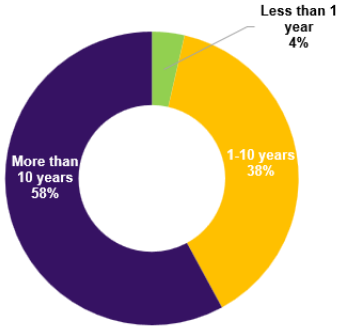


Figure B.16: Adult IBD Severity

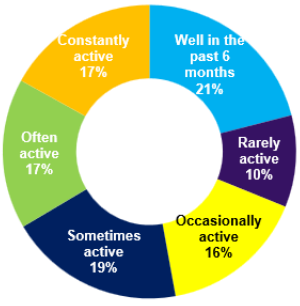
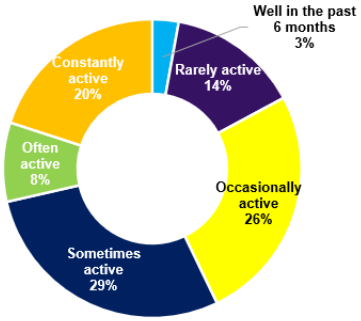


Figure B.17: Children IBD Severity



Appendix C: Epidemiological and economic impact modelling

This appendix outlines the method, key data sources and assumptions for the epidemiological and economic impact modelling.

Epidemiological modelling and economic impact assumptions

Final Report

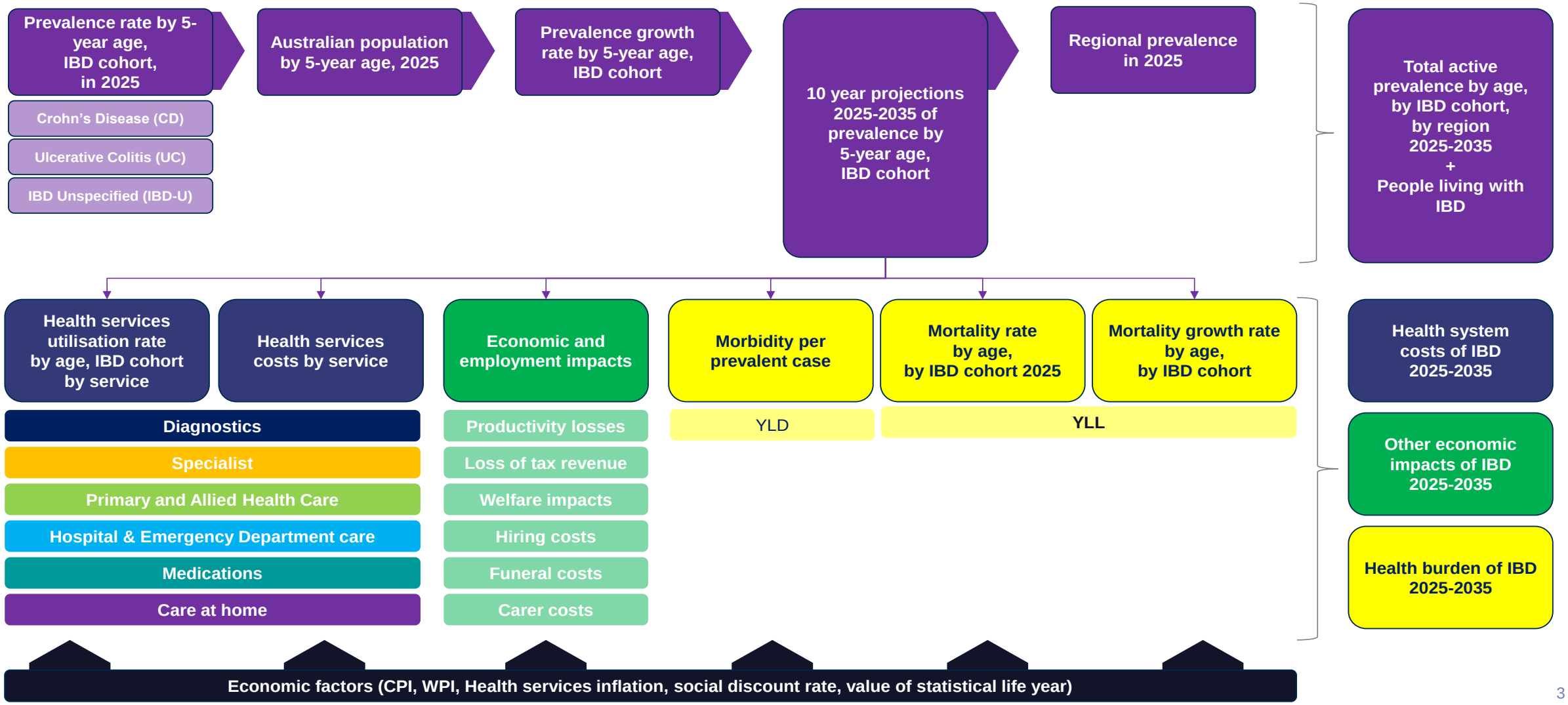
December 2024

Insight Economics
Public Policy Corporate Strategy

Section 1: Model Overview

Model schematic

Figure 1: Model schematic



Economic factor assumptions

Table 1: General principles and assumptions

Variable	Assumption	Source
Real discount rate	5%	Social discount rate
Value of Statistical Life Year	$50,000 (2017), with sensitivity of $235,000 (Australian Government)	Taylor, C, 2017, Economic Evaluation https://australianprescriber.tg.org.au/articles/economic-evaluation-of-medicines.html#r7 Australia Government Office of Impact Analysis
Inflation and price adjustment	CPI series	Reserve Bank of Australia, Statement on Monetary Policy - August 2024 (rba.gov.au), Table 3.1
Modelling period	2025-2035	CCA and Insight Economics assumptions

Section 2: Epidemiological assumptions

Prevalence assumptions

Updated literature and data

We conducted a follow-up literature review to identify new Australian studies on trends in prevalence in inflammatory bowel disease (IBD).

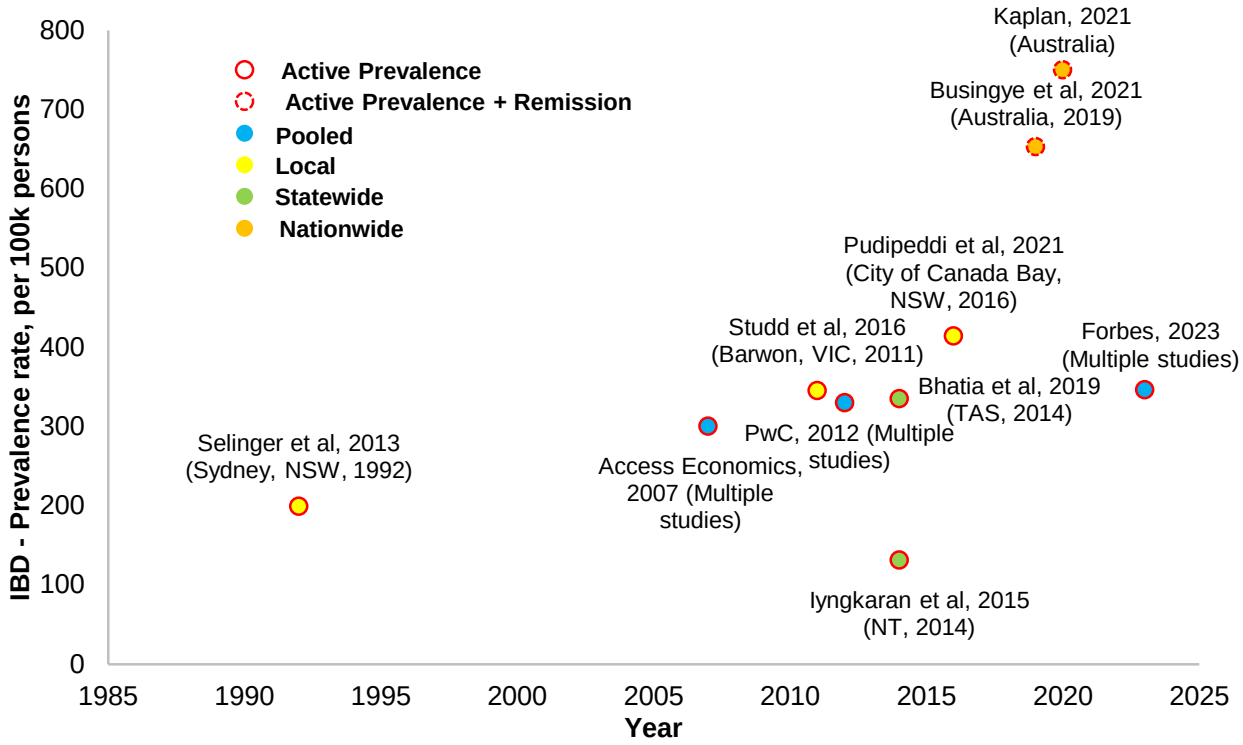
In 2023, Forbes conducted a comprehensive meta-analysis to assess the prevalence of Crohn's disease (CD) and ulcerative colitis (UC) in Oceania. This analysis incorporated data from six Australian studies covering both conditions, spanning years from 1992 to 2019. The age-standardised prevalence rates observed in these studies varied from 83 to 306 cases per 100,000 people for CD and from 107 to 304 cases per 100,000 people for UC. These studies included local, statewide, and nationwide design and provided estimates of both active prevalence and active prevalence combined with remission. The six studies are:

- Busingye et al., 2021
- Pudipeddi et al., 2021
- Studd et al., 2016
- Selinger et al., 2013
- Iyngkaran et al., 2015
- Bhatia et al., 2016.

Kaplan et.al (2021) and Busingye et.al (2021) are distinguished from the other cohort studies in that these studies included estimates of prevalence that is under active management as well as people in remission based on electronic medical record data.

The cohort studies were determined to estimate prevalence that is under active management with a treating team, which was a subset of lifetime prevalence.

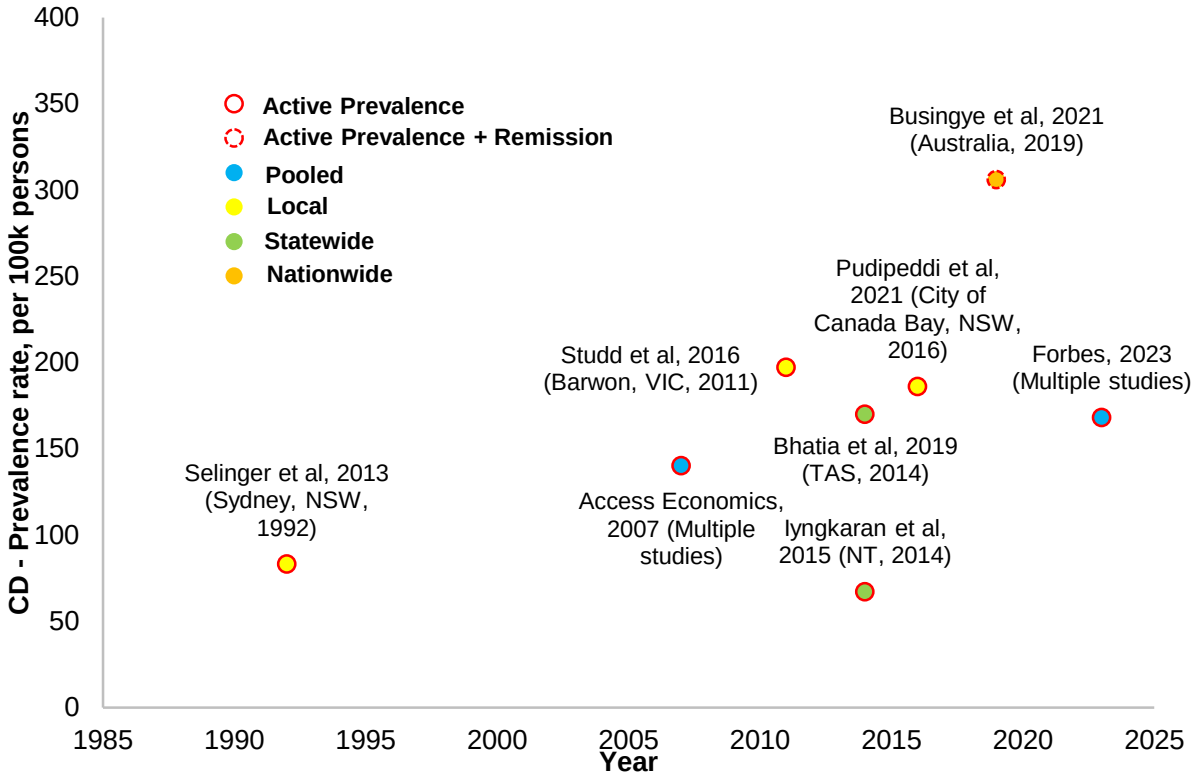
Figure 4: Comparison of age-standardised prevalence rates of IBD per 100,000 persons in Australian studies



Source: Literature review of Australian IBD prevalence studies as of the date of publication

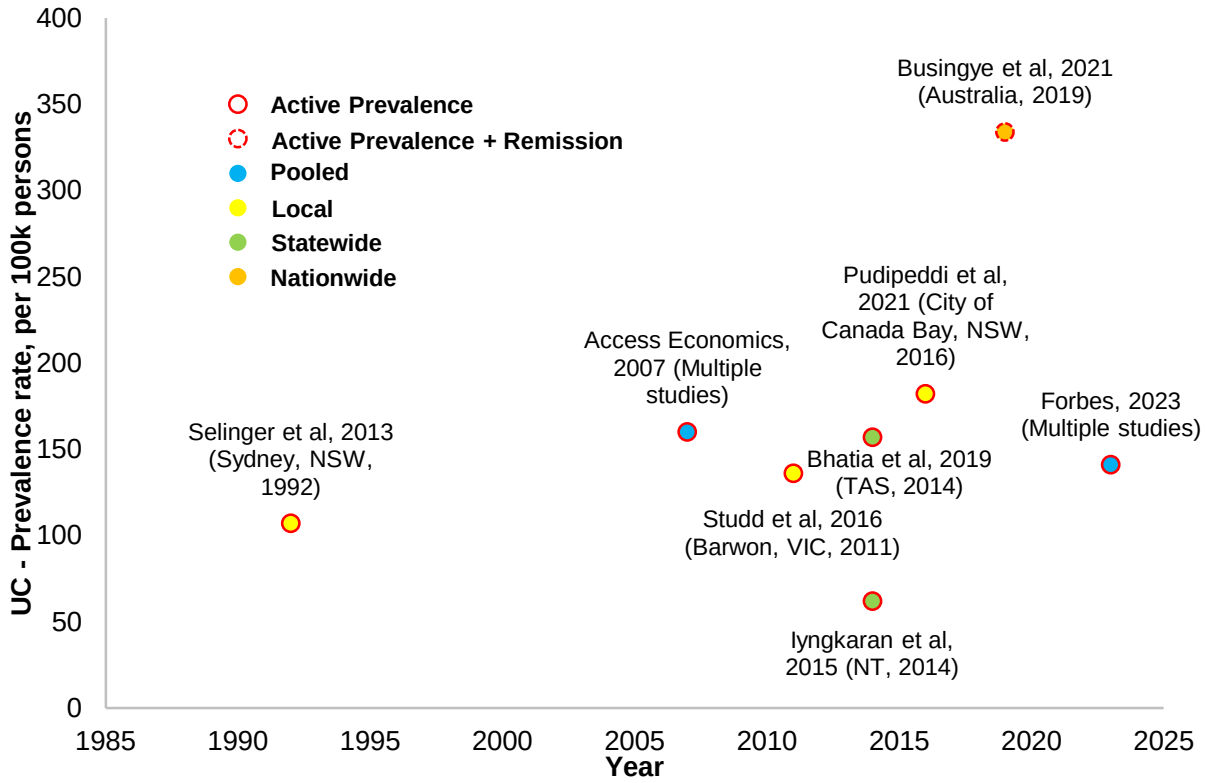
Prevalence by IBD subtypes

Figure 5: Comparison of age-standardised prevalence rates of CD per 100,000 persons in Australian studies



Source: Literature review of Australian UC prevalence studies as of the date of publication

Figure 6: Comparison of age-standardised prevalence rates of UC per 100,000 persons in Australian studies



Source: Literature review of Australian CD prevalence studies as of the date of publication

Updated literature and data

Forbes et al. (2023) estimated the IBD prevalence in Australia to be 319 cases per 100,000 persons, while Kaplan et al. (2021) and Busingye et al. (2021) estimated it to be 750 and 653 cases per 100,000 persons, respectively. The large difference between Forbes et al. (2023) and the other two studies is due to the different types of prevalence estimates: Forbes reported active prevalence only, whereas Kaplan and Busingye included both active prevalence and remission.

Table 2: Age-standardised prevalence rates of IBD subtypes per 100,000 persons in Australian studies

Author, Publication Year	Study Location, Date	IBD prevalence rate, per 100k persons	CD prevalence, per 100k persons	UC prevalence, per 100k persons	IBD-U prevalence, per 100k persons	Prevalence estimate type
Pooled						
Access Economics, 2007	Multiple studies	300	140	160	N/A	Active prevalence
PwC, 2012	Multiple studies	330	N/A	N/A	N/A	Active prevalence
Forbes, 2023	Multiple studies	319	168	141	10	Active prevalence
Kaplan, 2021	Multiple studies	750	N/A	N/A	N/A	Active prevalence + remission
Local						
Selinger et al., 2013	Sydney, NSW, 1992	199	83	107	9	Active prevalence
Studd et al., 2016	Barwon, VIC, 2011	345	197	136	9	Active prevalence
Pudipeddi et al., 2021	City of Canada Bay, NSW, 2016	414	186	182	45	Active prevalence
Statewide						
Bhatia et al., 2019	Tasmania, 2014	335	170	157	8	Active prevalence
Iyngkaran et al., 2015	Northern Territory, 2014	131	67	62	2	Active prevalence
Nationwide						
Busingye et al., 2021	Australia, 2019	653	306	334	12	Active prevalence + remission

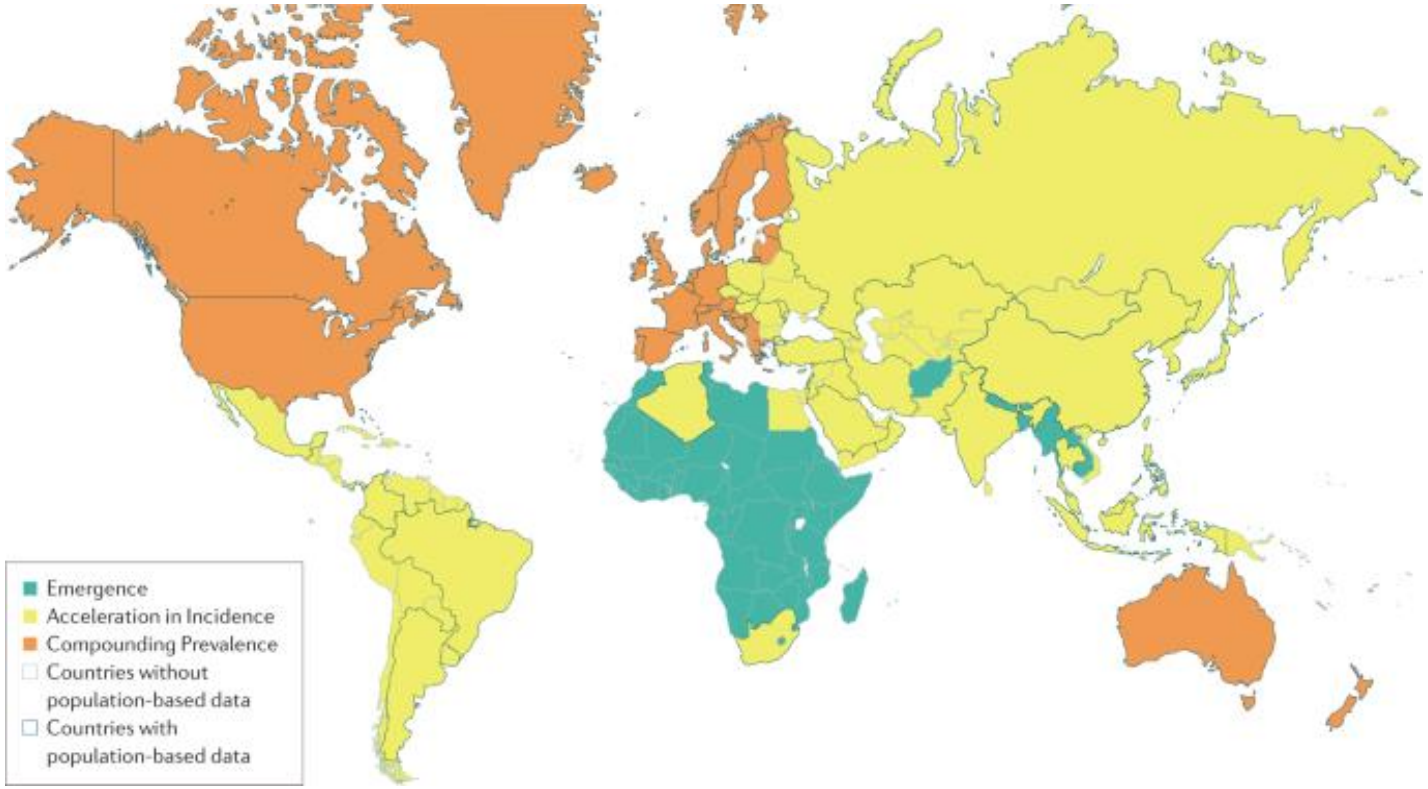
Source: Literature review of Australian IBD prevalence studies as of the date of publication

Growth in prevalence rates

Kaplan et al. (2021) characterised the global evolution of inflammatory bowel disease by four epidemiological stages: Emergence, Acceleration in Incidence, Compounding Prevalence, and Prevalence Equilibrium. In 2020, developing nations are at the Emergence stage, characterised by a low but increasing incidence of the disease. Newly industrialised countries are experiencing the Acceleration in Incidence stage, characterised by a rapid rise in incidence as urbanisation and lifestyle changes contribute to higher disease rates. Meanwhile, Western countries, including Australia, are in the Compounding Prevalence stage. In this stage, the incidence of the disease has stabilised with incidence still outpacing mortality rates. Although the prevalence continues to rise, the rate of increase has slowed and remains steady. All nations will eventually reach the final Prevalence Equilibrium stage in which the incidence of IBD approximates mortality, causing prevalence to stabilise, or even decline in some regions.

Coward et al. (2024) analysed historical trends of Canadian IBD incidence and prevalence using data from 2002 to 2014 and forecasted trends up to 2035. Their findings supported Kaplan et al. (2021), confirming that the compounding prevalence of IBD was consistently observed. The Canadian forecasted annual average percentage change (AAPC) in prevalence is used to project our estimated prevalence rate from 2023 through to 2035.

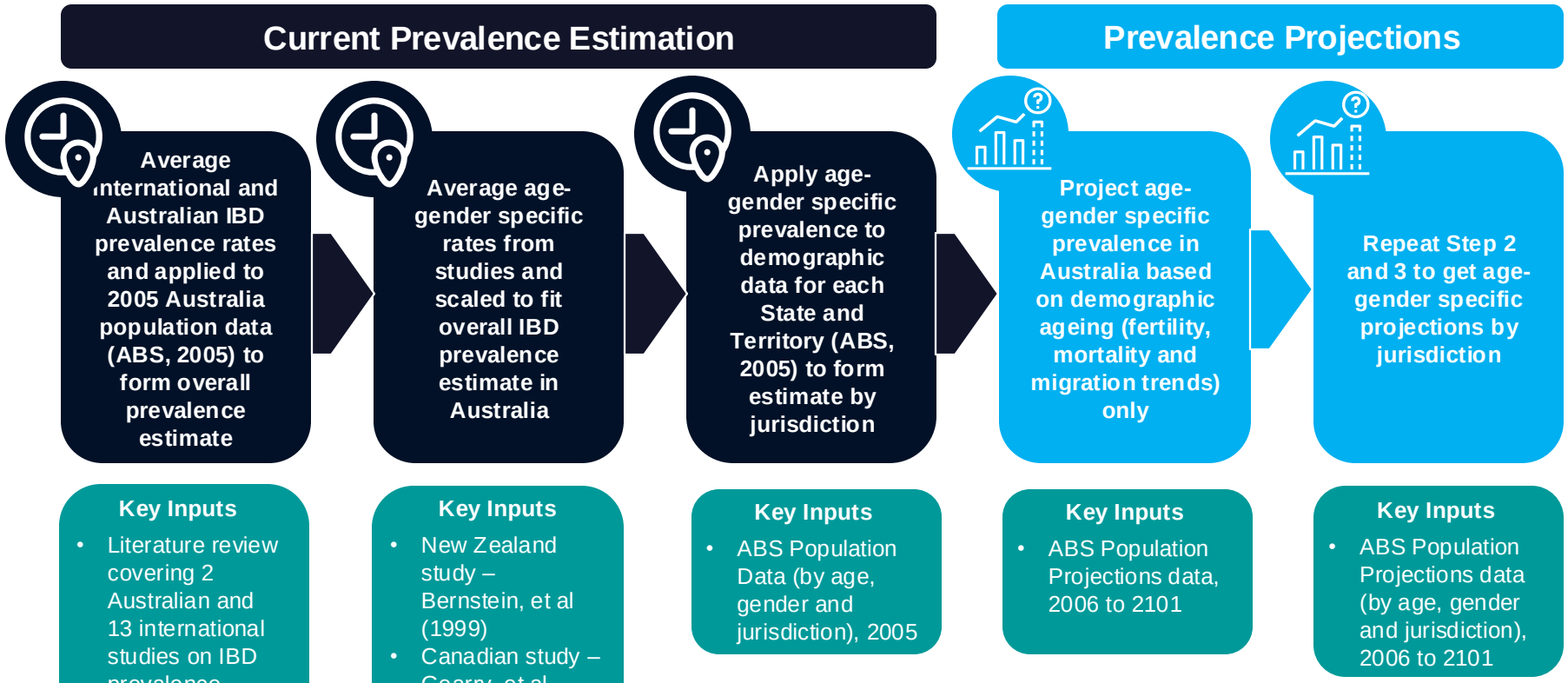
Figure 7: Australia in a compounding prevalence phase of IBD prevalence, similar to other developed nation peers



Source: Kaplan and Windsor, 2021, The four epidemiological stages in the global evolution of inflammatory bowel disease - PubMed (nih.gov)

Review of previous methodology and estimates

Figure 2: Access Economics (2007) prevalence assumptions



Challenges

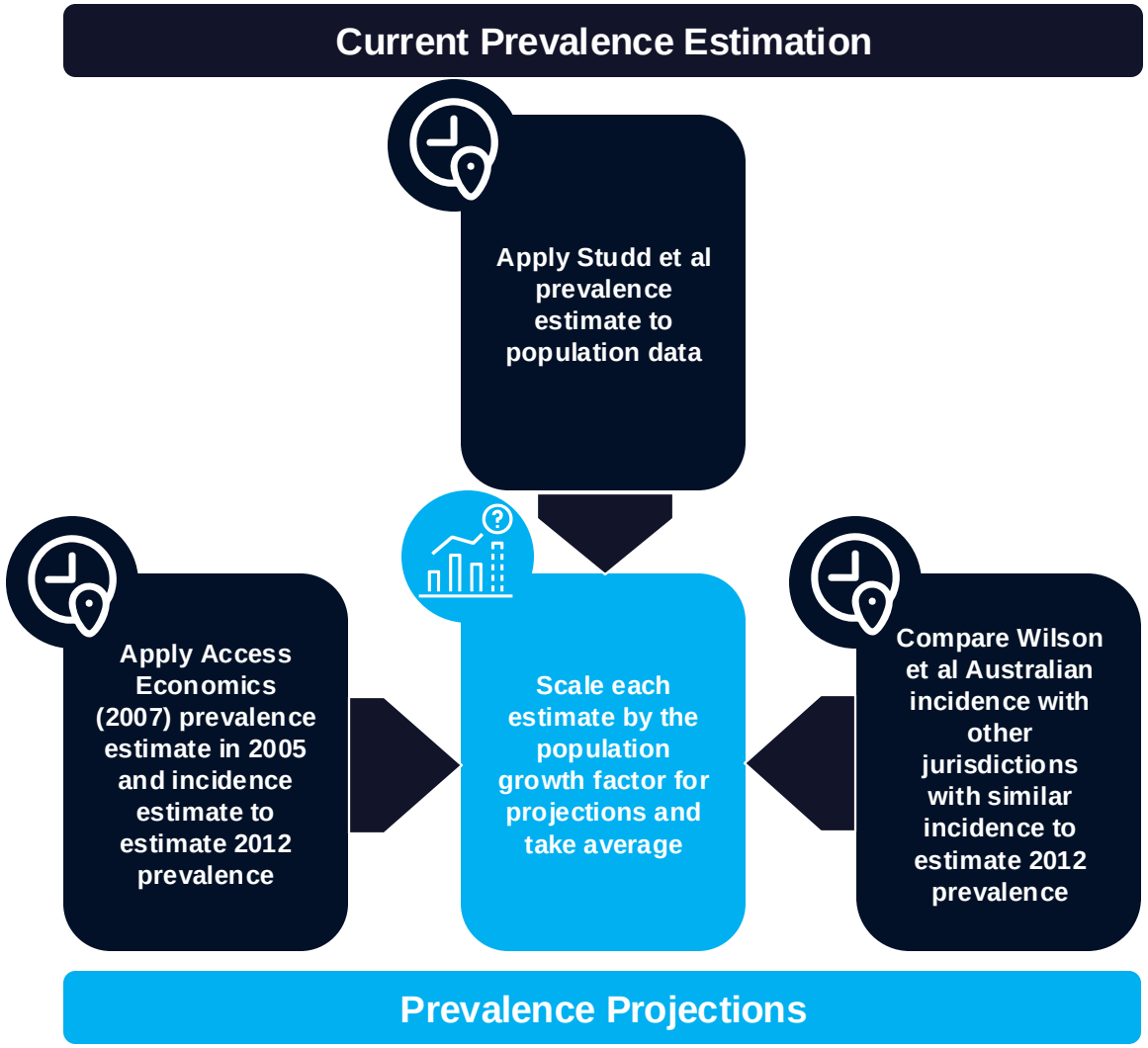
- No Australian prevalence data for UC and CD
- ABS NHS only source to provide prevalence by disease type
- No Australian studies with age-specific prevalence data

Limitations

- Projections does not consider potential changes in risk factors or treatment that may influence age-gender prevalence rates such as change in disease specific incidence and mortality

Review of previous methodology and estimates (cont'd)

Figure 3: PwC (2013) prevalence assumptions



Key Inputs

- ABS Population Projections data (by jurisdiction), 2012 to 2101
- ABS Population data, 2011
- Literature review covering international studies on IBD prevalence
- Access Economics IBD Costs Report, 2007
- Studd et al, 'High incidence and prevalence of inflammatory bowel disease in Victoria; a prospective, observational, population-based Australian epidemiology study', St Vincent's Hospital, Melbourne, VIC, Australia.
- Wilson et al. 'High incidence of inflammatory bowel disease in Australia: A prospective population-based Australian incidence study', Inflammatory Bowel Diseases, Vol. 16, Issue 9, 2010

Challenges

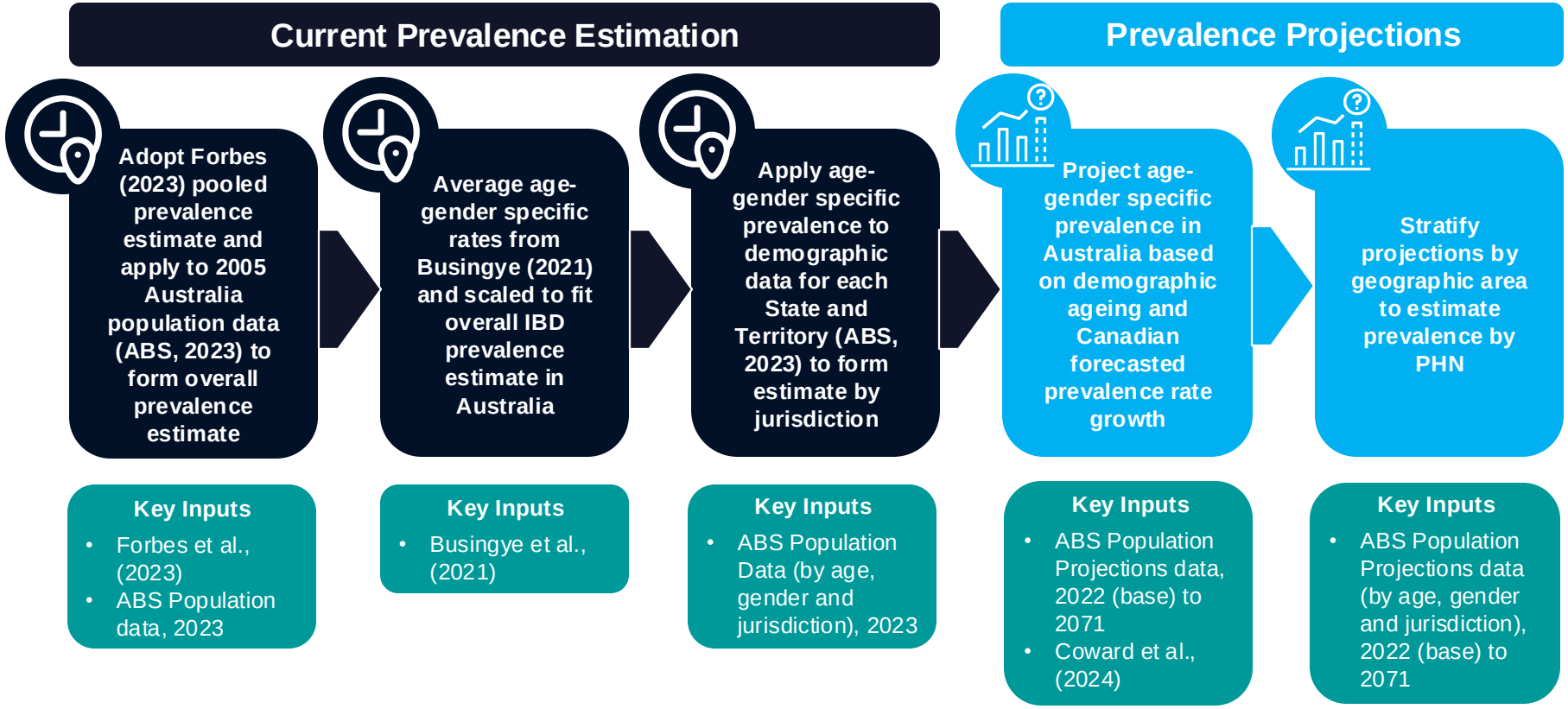
- **Limited Australian prevalence data for UC and CD**

Limitations

- **Projections does not consider potential changes in risk factors or treatment that may influence prevalence**
- **No disease and age-gender specific prevalence reported**
- **Unclear methodology**

Proposed prevalence modelling approach

Figure 8: Proposed prevalence modelling approach



Alternative Method explored

If historical data of Australian prevalence in UC and CD was available, it would be possible to use the ARIMA model to estimate the prevalence for 2023 and project trends for the next 10 years. This approach has been used in recent studies, such as Coward et al. (2024) in Canada and Kim et al. (2024) in South Korea.

Challenges

- Limited Australian prevalence data for UC and CD
- Only one Australian study with age-specific prevalence data (Busingye)

Limitations

- Projections does not consider potential changes in risk factors or treatment that may influence age-gender prevalence rates such as change in disease specific incidence and mortality

Expected prevalence under active management

Table 3: Forecasted Australian prevalence of IBD by subtype for adults and children, 2023 – 2035

Year	2023	2024	2025	2026	2027	2028	2029	2030	2031	2032	2033	2034	2035
Crohn's disease													
Adults >18													
Population	20,511,881	20,882,714	21,256,756	21,636,673	22,010,634	22,373,669	22,728,603	23,067,771	23,396,992	23,714,086	24,022,060	24,323,933	24,624,154
Prevalence rate (per 100,000 persons)	210	215	219	224	228	233	237	242	247	252	257	262	268
Implied CAGR	2.02%												
Crude prevalence	43,169	44,858	46,601	48,397	50,209	52,052	53,930	55,837	57,765	59,718	61,720	63,782	65,913
Ulcerative colitis													
Adults >18													
Population	20,511,881	20,882,714	21,256,756	21,636,673	22,010,634	22,373,669	22,728,603	23,067,771	23,396,992	23,714,086	24,022,060	24,323,933	24,624,154
Prevalence rate (per 100,000 persons)	179	184	188	193	197	202	207	212	218	223	228	234	240
Implied CAGR	2.46%												
Crude prevalence	36,752	38,351	40,004	41,712	43,461	45,247	47,082	48,964	50,891	52,849	54,852	56,914	59,039
Indeterminate IBD													
Adults >18													
Population	20,511,881	20,882,714	21,256,756	21,636,673	22,010,634	22,373,669	22,728,603	23,067,771	23,396,992	23,714,086	24,022,060	24,323,933	24,624,154
Prevalence rate (per 100,000 persons)	12	12	12	13	13	13	14	14	14	14	15	15	15
Implied CAGR	2.21%												
Crude prevalence	2,433	2,532	2,634	2,740	2,848	2,957	3,069	3,184	3,300	3,419	3,541	3,666	3,796

Cont'd next page

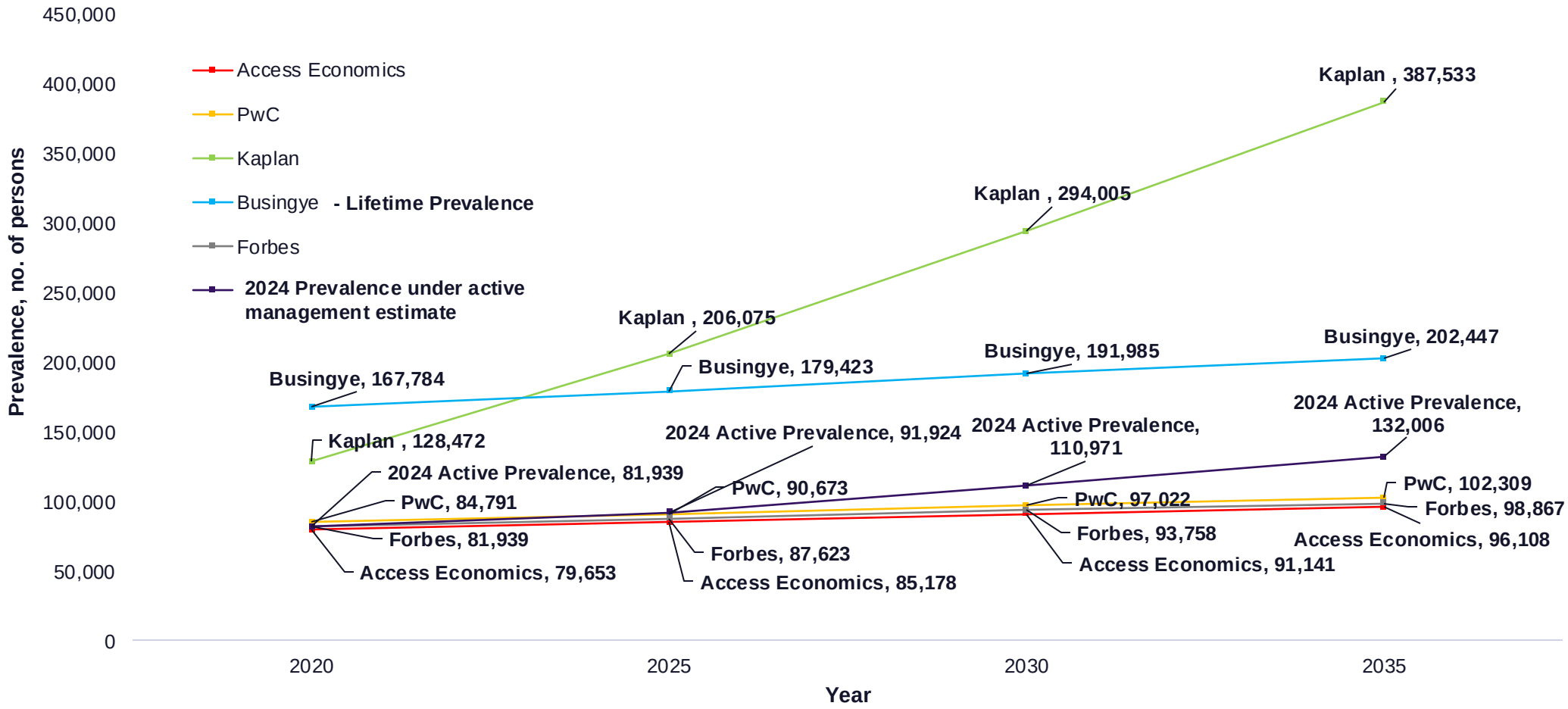
Expected prevalence under active management (cont'd)

Year	2023	2024	2025	2026	2027	2028	2029	2030	2031	2032	2033	2034	2035
Paediatric IBD													
Children <18													
Population	6,100,259	6,168,083	6,219,953	6,254,506	6,280,542	6,302,444	6,317,634	6,332,700	6,342,136	6,347,696	6,356,449	6,368,664	6,378,508
Prevalence rate (per 100,000 persons)	41	42	43	44	45	46	46	47	48	49	50	50	51
Implied CAGR	1.81%												
Crude prevalence	2,513	2,604	2,685	2,758	2,821	2,879	2,934	2,987	3,040	3,096	3,149	3,205	3,258
All subtypes													
All ages													
Population	26,612,140	27,050,797	27,476,709	27,891,179	28,291,176	28,676,113	29,046,237	29,400,471	29,739,128	30,061,782	30,378,509	30,692,597	31,002,662
Prevalence rate (per 100,000 persons)	319	327	335	343	351	360	368	377	387	396	406	416	426
Implied CAGR	2.44%												
Crude prevalence	84,866	88,345	91,924	95,606	99,338	103,135	107,016	110,971	114,996	119,083	123,262	127,567	132,006

Source: ABS Population data, 2023, ABS Population Projections data, 2022 (base) to 2071 and literature review. Detailed methodology on p16.

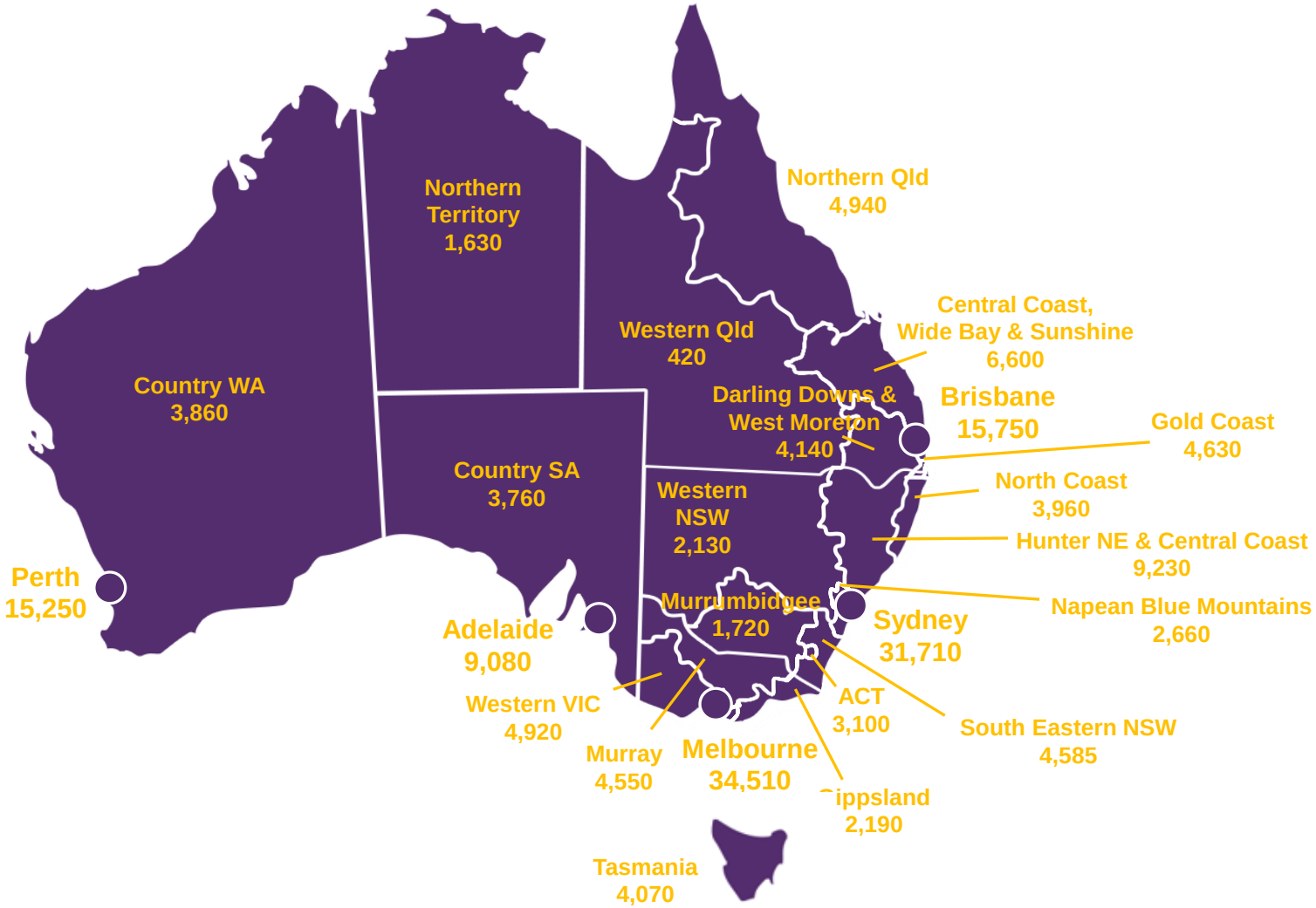
Benchmarking prevalence projections (potential sensitivities)

Figure 9: Benchmarking prevalence projections



Source: Access Economics (2007), PwC (2012), Kaplan et al. (2021), Businge et al. (2021), Forbes et al. (2024), and ABS Population Projections data, 2022 (base) to 2071

Lifetime prevalence by State and PHN in 2025

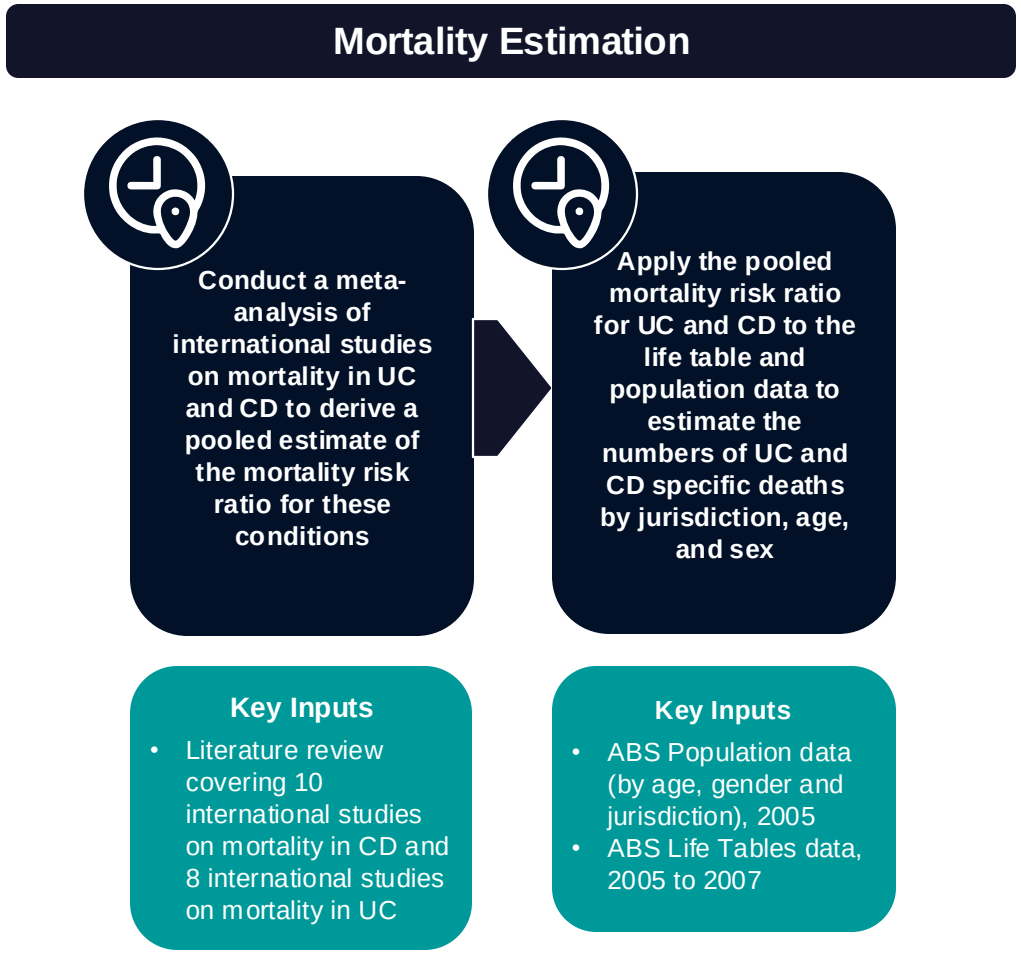


State	Lifetime Prevalence
New South Wales	56,003
Victoria	46,173
Queensland	36,486
South Australia	12,845
Western Australia	19,115
Tasmania	4,072
Northern Territory	1,630
Australian Capital Territory	3,100
Australia	**179,423**

Mortality

Review of previous methodology and estimates

Figure 10: Access Economics (2007) mortality assumptions



Challenges

- No Australian studies available in mortality on UC and CD
- Most international studies do not have age-sex specific mortality for UC and CD

Limitations

- Studies included in span a wide range of time periods and may not accurately represent the Australian population
- Uniform mortality rate for UC and CD assumed across all ages, sex and jurisdictions

Figure 11: PwC (2007) mortality assumptions

No mortality estimates were provided

Updated literature and data

The review of mortality data includes information from two primary sources:

- **Global Burden of Disease Study 2021 (GBD 2021):**
  - **Coverage:** Data spans from 1980 to 2021.
  - **Source:** WHO Mortality Database, based on ICD-10 codes.
  - **Details:** Mortality rates are reported in 5-year age intervals, from 0-4 years up to 80+ years.
- **Australian Bureau of Statistics (ABS):**
  - **Coverage:** Data is available from 2013 to 2021.
  - **Source:** Cause of Death by ICD-10 codes.
  - **Details:** Provides aggregated death counts across all ages.

There are notable discrepancies between the GBD study (WHO) and ABS data:

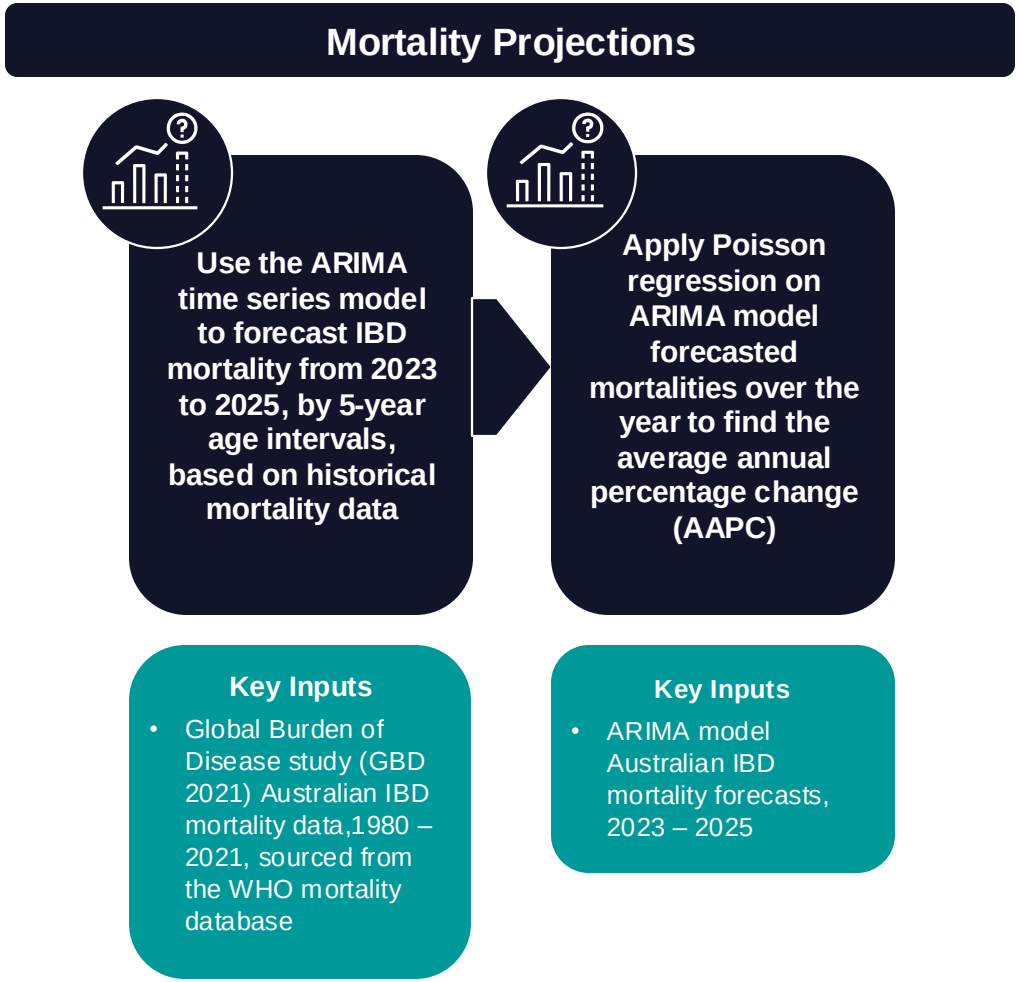
- WHO reported a total of 419.69 IBD deaths in 2021 across Australia while ABS reported 100 IBD deaths.
- WHO reported an age-standardised IBD mortality rate of 1.63 per 100,000 persons while ABS reported a rate of 0.39 per 100,000 persons.

Some international age-standardised mortality rates reported by WHO are 1.09, 1.86 and 0.57 per 100,000 persons for Canada, United States, and New Zealand, respectively.

Finally, the data provided by the GBD study is preferred for it offers extensive data from 1980 to 2021, which allows for detailed time series analysis and age-specific morality forecasting (more details are provided in the following slide) that is essential for estimating health impacts and burden of disease, including calculations for Years of Life Lost (YLL), Years Lived with Disability (YLD), and Disability-Adjusted Life Years (DALY).

Proposed mortality modelling approach

Figure 12: Proposed mortality modelling approach



Challenges

- **Discrepancies between WHO reported Australian IBD mortality and ABS reported Australian IBD mortality**

Limitations

- **Projections does not consider potential changes in risk factors or treatment that may influence age-gender prevalence rates such as change in disease specific incidence and mortality**

Expected mortality

Table 4: Forecasted Australian mortality of IBD by age, both sexes, 2023 – 2035

Year	2023	2024	2025	2026	2027	2028	2029	2030	2031	2032	2033	2034	2035
Age groups													
<5 years													
Population	1,526,317	1,535,540	1,548,901	1,557,302	1,557,213	1,564,766	1,570,882	1,576,615	1,582,493	1,588,942	1,596,561	1,605,229	1,615,199
Mortality rate (per 100,000 persons)	0.010	0.010	0.010	0.010	0.010	0.010	0.010	0.010	0.010	0.010	0.010	0.010	0.010
Regression AAPC (%)	0.00%												
Crude mortality	0.15	0.15	0.15	0.16	0.16	0.16	0.16	0.16	0.16	0.16	0.16	0.16	0.16
5-9 years													
Population	1,616,275	1,616,776	1,613,817	1,610,103	1,620,022	1,625,084	1,630,568	1,640,124	1,644,712	1,640,760	1,645,177	1,648,940	1,653,170
Mortality rate (per 100,000 persons)	0.011	0.012	0.012	0.012	0.013	0.013	0.013	0.013	0.014	0.014	0.014	0.014	0.014
Regression AAPC (%)	1.91%												
Crude mortality	0.18	0.19	0.20	0.20	0.21	0.21	0.22	0.22	0.22	0.22	0.23	0.23	0.23
10-14 years													
Population	1,662,506	1,678,317	1,687,029	1,701,506	1,704,660	1,700,986	1,698,305	1,692,105	1,685,148	1,691,757	1,694,110	1,697,490	1,705,635
Mortality rate (per 100,000 persons)	0.003	0.004	0.005	0.006	0.006	0.006	0.006	0.007	0.007	0.007	0.007	0.007	0.007
Regression AAPC (%)	5.5%												
Crude mortality	0.06	0.08	0.09	0.10	0.10	0.11	0.11	0.11	0.11	0.11	0.12	0.12	0.12

Cont'd next page

Expected mortality (cont'd)

Year	2023	2024	2025	2026	2027	2028	2029	2030	2031	2032	2033	2034	2035
Age groups													
15-19 years													
Population	1,617,105	1,672,913	1,720,009	1,750,668	1,769,814	1,784,704	1,795,782	1,799,612	1,809,259	1,807,467	1,800,557	1,795,771	1,788,271
Mortality rate (per 100,000 persons)	0.020	0.020	0.020	0.020	0.020	0.020	0.020	0.020	0.020	0.020	0.020	0.020	0.020
Regression AAPC (%)	0.00%												
Crude mortality	0.32	0.33	0.34	0.35	0.35	0.36	0.36	0.36	0.36	0.36	0.36	0.36	0.36
20-24 years													
Population	1,678,605	1,714,024	1,746,622	1,789,245	1,851,175	1,909,794	1,954,413	1,990,128	2,009,407	2,017,007	2,022,539	2,026,726	2,026,232
Mortality rate (per 100,000 persons)	0.040	0.040	0.040	0.040	0.040	0.040	0.040	0.040	0.040	0.040	0.040	0.040	0.040
Regression AAPC (%)	0.00%												
Crude mortality	0.67	0.69	0.70	0.72	0.74	0.76	0.78	0.80	0.80	0.81	0.81	0.81	0.81
25-29 years													
Population	1,830,642	1,828,709	1,835,183	1,848,273	1,858,861	1,879,355	1,907,148	1,932,029	1,966,900	2,020,902	2,072,642	2,111,614	2,143,428
Mortality rate (per 100,000 persons)	0.060	0.060	0.060	0.060	0.060	0.060	0.060	0.060	0.060	0.060	0.060	0.060	0.060
Regression AAPC (%)	0.00%												
Crude mortality	1.10	1.10	1.10	1.11	1.12	1.13	1.14	1.16	1.18	1.21	1.24	1.27	1.29

Cont'd next page

Expected mortality (cont'd)

Year	2023	2024	2025	2026	2027	2028	2029	2030	2031	2032	2033	2034	2035
Age groups													
30-34 years													
Population	1,944,702	1,962,866	1,974,737	1,976,312	1,975,021	1,966,381	1,959,240	1,960,395	1,968,131	1,973,266	1,989,264	2,013,567	2,036,141
Mortality rate (per 100,000 persons)	0.100	0.100	0.100	0.100	0.100	0.100	0.100	0.100	0.100	0.100	0.100	0.100	0.100
Regression AAPC (%)	0.00%												
Crude mortality	1.94	1.96	1.97	1.98	1.98	1.97	1.96	1.96	1.97	1.97	1.99	2.01	2.04
35-39 years													
Population	1,925,207	1,953,562	1,983,890	2,011,403	2,033,140	2,051,979	2,065,905	2,073,472	2,070,764	2,065,124	2,052,890	2,042,954	2,042,238
Mortality rate (per 100,000 persons)	0.110	0.110	0.110	0.110	0.110	0.110	0.110	0.110	0.110	0.110	0.110	0.110	0.110
Regression AAPC (%)	0.00%												
Crude mortality	2.12	2.15	2.18	2.21	2.24	2.26	2.27	2.28	2.28	2.27	2.26	2.25	2.25
40-44 years													
Population	1,775,438	1,836,719	1,895,283	1,939,761	1,973,536	1,996,554	2,021,894	2,049,148	2,073,577	2,092,194	2,108,394	2,120,227	2,126,378
Mortality rate (per 100,000 persons)	0.150	0.150	0.150	0.150	0.150	0.150	0.150	0.150	0.150	0.150	0.150	0.150	0.150
Regression AAPC (%)	0.00%												
Crude mortality	2.66	2.76	2.84	2.91	2.96	2.99	3.03	3.07	3.11	3.14	3.16	3.18	3.19

Cont'd next page

Expected mortality (cont'd)

Year	2023	2024	2025	2026	2027	2028	2029	2030	2031	2032	2033	2034	2035
Age groups													
45-49 years													
Population	1,616,136	1,625,050	1,647,330	1,690,650	1,745,173	1,810,784	1,869,969	1,926,423	1,968,869	2,000,657	2,022,046	2,046,047	2,072,342
Mortality rate (per 100,000 persons)	0.200	0.200	0.200	0.200	0.200	0.200	0.200	0.200	0.200	0.200	0.200	0.200	0.200
Regression AAPC (%)	0.00%												
Crude mortality	3.23	3.25	3.29	3.38	3.49	3.62	3.74	3.85	3.94	4.00	4.04	4.09	4.14
50-54 years													
Population	1,683,718	1,691,764	1,690,330	1,663,566	1,639,944	1,630,988	1,638,806	1,659,829	1,701,651	1,754,523	1,818,576	1,876,458	1,931,869
Mortality rate (per 100,000 persons)	0.320	0.320	0.320	0.320	0.320	0.320	0.320	0.320	0.320	0.320	0.320	0.320	0.320
Regression AAPC (%)	0.00%												
Crude mortality	5.39	5.41	5.41	5.32	5.25	5.22	5.24	5.31	5.45	5.61	5.82	6.00	6.18
55-59 years													
Population	1,534,430	1,547,450	1,572,502	1,623,143	1,668,724	1,695,534	1,702,173	1,699,425	1,671,783	1,647,211	1,637,414	1,644,456	1,664,793
Mortality rate (per 100,000 persons)	0.570	0.570	0.570	0.570	0.570	0.570	0.570	0.570	0.570	0.570	0.570	0.570	0.570
Regression AAPC (%)	0.00%												
Crude mortality	8.75	8.82	8.96	9.25	9.51	9.66	9.70	9.69	9.53	9.39	9.33	9.37	9.49

Cont'd next page

Expected mortality (cont'd)

Year	2023	2024	2025	2026	2027	2028	2029	2030	2031	2032	2033	2034	2035
Age groups													
60-64 years													
Population	1,532,930	1,558,742	1,569,432	1,564,617	1,557,325	1,553,100	1,564,220	1,586,970	1,634,717	1,677,390	1,702,064	1,707,428	1,704,028
Mortality rate (per 100,000 persons)	0.730	0.730	0.730	0.730	0.730	0.730	0.730	0.730	0.730	0.730	0.730	0.730	0.730
Regression AAPC (%)	0.00%												
Crude mortality	11.19	11.38	11.46	11.42	11.37	11.34	11.42	11.58	11.93	12.24	12.43	12.46	12.44
65-69 years													
Population	1,340,540	1,380,977	1,420,307	1,462,940	1,502,693	1,537,200	1,560,440	1,568,959	1,562,456	1,553,540	1,548,009	1,557,741	1,579,108
Mortality rate (per 100,000 persons)	1.410	1.410	1.410	1.410	1.410	1.410	1.410	1.410	1.410	1.410	1.410	1.410	1.410
Regression AAPC (%)	0.00%												
Crude mortality	18.90	19.47	20.03	20.63	21.19	21.67	22.00	22.12	22.03	21.90	21.83	21.96	22.27
70-74 years													
Population	1,164,955	1,187,817	1,211,951	1,240,701	1,272,892	1,305,986	1,343,711	1,380,310	1,420,001	1,456,815	1,488,789	1,510,224	1,517,842
Mortality rate (per 100,000 persons)	2.550	2.550	2.550	2.550	2.550	2.550	2.550	2.550	2.550	2.550	2.550	2.550	2.550
Regression AAPC (%)	0.00%												
Crude mortality	29.71	30.29	30.90	31.64	32.46	33.30	34.26	35.20	36.21	37.15	37.96	38.51	38.70

Cont'd next page

Expected mortality (cont'd)

Year	2023	2024	2025	2026	2027	2028	2029	2030	2031	2032	2033	2034	2035
Age groups													
75-80 years													
Population	934,716	979,433	1,020,971	1,058,256	1,064,650	1,082,608	1,103,992	1,126,541	1,153,168	1,182,813	1,213,372	1,248,134	1,281,950
Mortality rate (per 100,000 persons)	5.600	5.600	5.600	5.600	5.600	5.600	5.600	5.600	5.600	5.600	5.600	5.600	5.600
Regression AAPC (%)	0.00%												
Crude mortality	52.34	54.85	57.17	59.26	59.62	60.63	61.82	63.09	64.58	66.24	67.95	69.90	71.79
80+ years													
Population	1,151,145	1,201,107	1,256,717	1,317,238	1,406,251	1,485,469	1,558,869	1,632,885	1,705,105	1,773,771	1,842,678	1,908,208	1,974,191
Mortality rate (per 100,000 persons)	27.363	27.864	28.366	28.867	29.369	29.870	30.372	30.873	31.375	31.876	32.378	32.879	33.380
Regression AAPC (%)	1.68%												
Crude mortality	314.99	334.68	356.48	380.25	413.00	443.71	473.46	504.12	534.97	565.41	596.61	627.40	658.99
All ages													
Population	1,164,955	1,187,817	1,211,951	1,240,701	1,272,892	1,305,986	1,343,711	1,380,310	1,420,001	1,456,815	1,488,789	1,510,224	1,517,842
Mortality rate (per 100,000 persons)	1.662	1.710	1.771	1.837	1.909	2.006	2.096	2.182	2.270	2.359	2.445	2.533	2.618
Regression AAPC (%)	3.96%												
Crude mortality	453.71	477.56	503.29	530.88	565.73	599.10	631.68	665.09	698.83	732.21	766.30	800.09	834.45

Source: ABS Population data, 2023, ABS Population Projections data, 2022 (base) to 2071 and literature review. Detailed methodology on p16.

Section 3: Economic impact assumptions

Types of costs

Diagnostics

- Blood tests
- Stool tests
- Biopsy
- Barium enema
- Imaging
- Colonoscopy / sigmoidoscopy
- Gastroscopy / endoscopy

Specialist

- Dermatologist
- Rheumatologist
- Hepatologist
- Psychiatrist
- Ophthalmologist
- Gastroenterologist

Primary and Allied Health Care

- GP
- Counselling support
- Dietitian
- Psychologist

Other household costs

- Medical and nutritional aids
- Increased risk of colon cancer
- Travel costs
- PHI premia

Hospital and Emergency care

- Hospital admissions
- Emergency Department presentations

Medications

- 5-Aminosalicytates (5-ASA)
- Corticosteriods
- S1P receptor modulators
- Biologics
- Janus kinase (JAK) inhibitors
- Other immunomodulators

Health impacts / Burden of Disease

- Years of life lost (YLL)
- Years lived with disability (YLD)

Economic and employment impacts

- Productivity losses
- Loss of tax revenue
- Welfare impacts
- Hiring costs
- Funeral costs
- Carer costs
- Travel costs

Diagnostic costs

Types of costs

- **Diagnostics**
  - Blood tests
  - Stool tests
  - Biopsy
  - Barium enema
  - Imaging
  - Colonoscopy / sigmoidoscopy
  - Gastroscopy / endoscopy
- **Specialist**
  - Dermatologist
  - Rheumatologist
  - Hepatologist
  - Psychiatrist
  - Ophthalmologist
  - Gastroenterologist
- **Primary and Allied Health Care**
  - GP
  - Counselling support
  - Dietitian
  - Psychologist
- **Other household costs**
  - Medical and nutritional aids
  - Increased risk of colon cancer
  - Travel costs
  - PHI premia
- **Hospital and Emergency care**
  - Hospital admissions
  - Emergency Department presentations
  - OOP costs
- **Medications**
  - 5-Aminosalicytates (5-ASA)
  - Corticosteriods
  - S1P receptor modulators
  - Biologics
  - Janus kinase (JAK) inhibitors
  - Other immunomodulators
- **Health impacts / Burden of Disease**
  - Years of life lost (YLL)
  - Years lived with disability (YLD)
- **Economic and employment impacts**
  - Productivity losses
  - Loss of tax revenue
  - Welfare impacts
  - Hiring costs
  - Funeral costs
  - Carer costs
  - Travel costs

Diagnostics: Utilisation data from survey

Table 5: Utilisation rates for adults (>18 yo) with Crohn's Disease (CD), n=317

Frequency of tests	Blood tests - diagnosis	Blood tests - drug monitoring	Stool testing - diagnosis (faecal calprotectin)	Stool testing - monitoring (faecal calprotectin)	Biopsy	Barium enema	Imaging - x ray	Imaging - ultrasound	Imaging - CT scan	Imaging - MRI / MRE	Imaging - other	Colonoscopy / sigmoidoscopy	Gastroscopy / endoscopy	Other
Once in the last six months	19%	31%	18%	31%	25%	1%	14%	18%	16%	24%	3%	38%	20%	3%
Twice in the last six months	20%	21%	8%	13%	4%	0%	3%	5%	3%	4%	1%	2%	3%	1%
Three times in the last six months	11%	7%	2%	5%	1%	0%	1%	1%	2%	2%	0%	2%	1%	0%
Four times in the last six months	7%	5%	1%	2%	0%	0%	1%	1%	0%	0%	0%	0%	0%	1%
Every month	9%	9%	2%	3%	0%	0%	1%	0%	0%	0%	0%	0%	0%	1%
Not applicable / did not access	31%	20%	58%	39%	59%	83%	67%	62%	67%	58%	75%	50%	64%	65%

Table 6: Utilisation rates for adults (>18 yo) with Ulcerative Colitis (UC), n=159

Frequency of tests	Blood tests - diagnosis	Blood tests - drug monitoring	Stool testing - diagnosis (faecal calprotectin)	Stool testing - monitoring (faecal calprotectin)	Biopsy	Barium enema	Imaging - x ray	Imaging - ultrasound	Imaging - CT scan	Imaging - MRI / MRE	Imaging - other	Colonoscopy / sigmoidoscopy	Gastroscopy / endoscopy	Other
Once in the last six months	28%	29%	20%	32%	32%	3%	9%	11%	12%	14%	3%	42%	14%	2%
Twice in the last six months	17%	20%	7%	13%	4%	1%	4%	7%	2%	0%	0%	4%	0%	0%
Three times in the last six months	9%	7%	2%	7%	1%	0%	1%	1%	0%	0%	1%	3%	1%	1%
Four times in the last six months	4%	3%	1%	3%	0%	0%	1%	1%	0%	0%	0%	0%	0%	0%
Every month	7%	10%	1%	3%	0%	0%	1%	0%	0%	0%	0%	0%	0%	0%
Not applicable / did not access	33%	25%	62%	38%	54%	84%	70%	67%	74%	73%	83%	43%	75%	75%

Source: CCA Consumer Survey 2024

Diagnostics: Utilisation data from survey

Table 7: Utilisation rates for adults (>18 yo) with Indeterminate IBD (Ind), n=14

Frequency of tests	Blood tests - diagnosis	Blood tests - drug monitoring	Stool testing - diagnosis (faecal calprotectin)	Stool testing - monitoring (faecal calprotectin)	Biopsy	Barium enema	Imaging - x ray	Imaging - ultrasound	Imaging - CT scan	Imaging - MRI / MRE	Imaging - other	Colonoscopy / sigmoidoscopy	Gastroscopy / endoscopy	Other
Once in the last six months	19%	31%	18%	31%	25%	1%	14%	18%	16%	24%	3%	38%	20%	3%
Twice in the last six months	20%	21%	8%	13%	4%	0%	3%	5%	3%	4%	1%	2%	3%	1%
Three times in the last six months	11%	7%	2%	5%	1%	0%	1%	1%	2%	2%	0%	2%	1%	0%
Four times in the last six months	7%	5%	1%	2%	0%	0%	1%	1%	0%	0%	0%	0%	0%	1%
Every month	9%	9%	2%	3%	0%	0%	1%	0%	0%	0%	0%	0%	0%	1%
Not applicable / did not access	31%	20%	58%	39%	59%	83%	67%	62%	67%	58%	75%	50%	64%	65%

Table 8: Utilisation rates for people with Paediatric patients (Paed), n=35

Frequency of tests	Blood tests - diagnosis	Blood tests - drug monitoring	Stool testing - diagnosis (faecal calprotectin)	Stool testing - monitoring (faecal calprotectin)	Biopsy	Barium enema	Imaging - x ray	Imaging - ultrasound	Imaging - CT scan	Imaging - MRI / MRE	Imaging - other	Colonoscopy / sigmoidoscopy	Gastroscopy / endoscopy	Other
Once in the last six months	28%	29%	20%	32%	32%	3%	9%	11%	12%	14%	3%	42%	14%	2%
Twice in the last six months	17%	20%	7%	13%	4%	1%	4%	7%	2%	0%	0%	4%	0%	0%
Three times in the last six months	9%	7%	2%	7%	1%	0%	1%	1%	0%	0%	1%	3%	1%	1%
Four times in the last six months	4%	3%	1%	3%	0%	0%	1%	1%	0%	0%	0%	0%	0%	0%
Every month	7%	10%	1%	3%	0%	0%	1%	0%	0%	0%	0%	0%	0%	0%
Not applicable / did not access	33%	25%	62%	38%	54%	84%	70%	67%	74%	73%	83%	43%	75%	75%

Source: CCA Consumer Survey 2024

Diagnostics: Utilisation assumptions

CCCure generously provided data confidentially reported higher rates of selected service utilisation than reported in the survey. This likely reflects the CCCure data may have a higher proportion of active disease whereas the survey included people with disease in remission.

Table 9: Assumed rate of diagnostic service utilisation per annum (e.g., number of tests per annum)

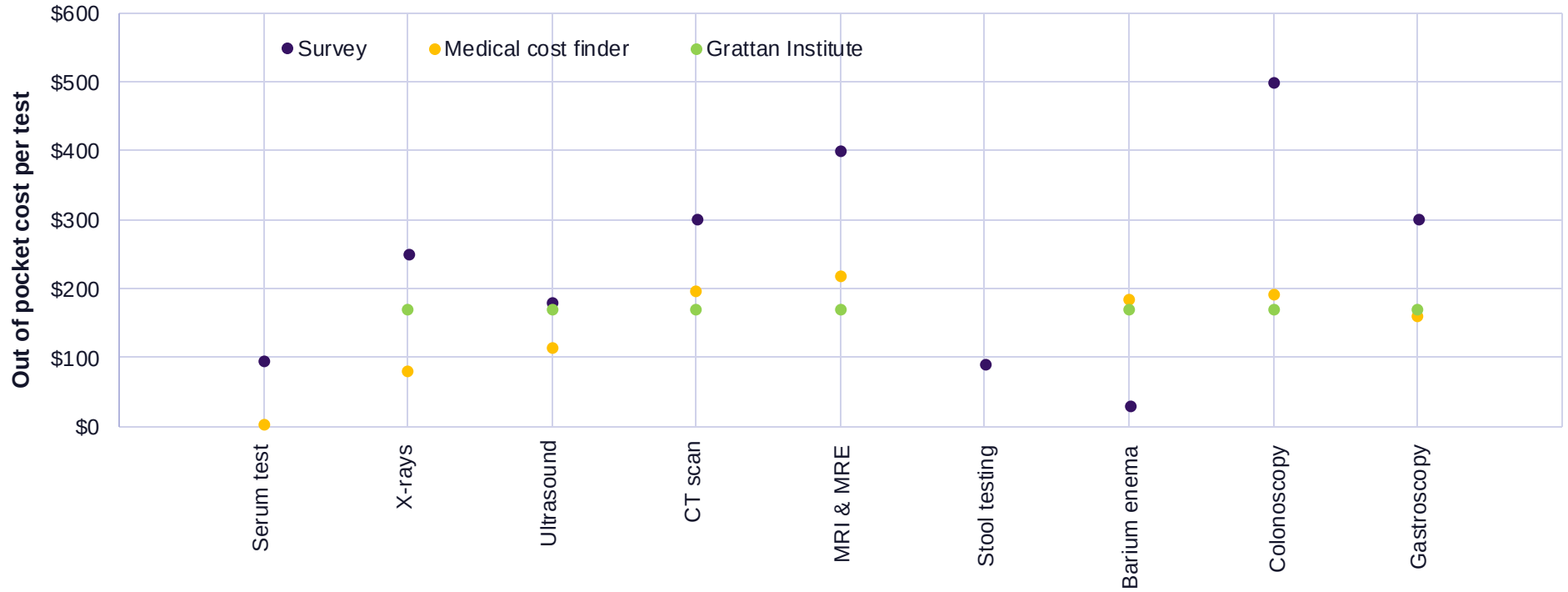
Subtype	Age cohort	Blood tests - diagnosis	Blood tests - drug monitoring	Stool testing - diagnosis (faecal calprotectin)	Stool testing - monitoring (faecal calprotectin)	Biopsy	Barium enema	Imaging - x ray	Imaging - ultrasound	Imaging - CT scan	Imaging - MRI / MRE	Imaging - other	Colonoscopy / sigmoidoscopy	Gastroscopy / endoscopy
CD	**Adults >18**	3.6	3.4	1.2	1.9	0.8	0.1	0.7	0.7	0.6	0.7	0.2	1.0	0.6
UC	**Adults >18**	3.1	3.4	1.2	2.3	0.9	0.1	0.7	0.6	0.4	0.3	0.1	1.2	0.3
IBD-Ind	**Adults >18**	3.3	3.1	1.2	2.1	0.9	0.0	0.6	0.7	0.4	0.5	0.2	0.9	0.5
Paed	**Children <18**	3.8	4.5	2.8	4.8	1.6	0.1	0.9	1.5	0.4	1.2	0.0	1.9	1.4

Source: CCA Consumer Survey 2024. *Note due to small response numbers for IBD-Ind, average of CD and UC was applied for some of the assumptions. .

Diagnostics cost benchmarking

The survey overall reported consistently higher out of pocket costs per test than reported in the Australian government's Medical Cost finder, AIHW data and Grattan Institute data (all adjusted for inflation). For tests involving hospitalisations (colonoscopy and gastroscopy) this is likely due to inclusions of other hospital fees. Overall, the survey results were used unless there were very low rates of response (e.g., barium enema). The expected proportion of patients facing costs and other costs to governments and PHI were based on estimates reported in the Australian Government medical cost finder.

Figure 13: Benchmarking survey cost estimates against Australian Department of Health Medical Cost Finder and Grattan Institute data (indexed to $2024)*



* Health services inflation over the FY23 to FY24 period assumed to be 5.7 per cent (source: ABS) and 2.5% for the preceding years, reflecting a conservative estimate.

Source: CCA Consumer Survey, AIHW data and Australian Government Medical Cost Finder, accessed at: Medical Costs Finder | Australian Government Department of Health

Diagnostics: Cost assumptions

Table 10: Diagnostics services costs assumptions

Key variable	Stakeholder	Cost per test	Source	Notes
Serum test				
	Australian government	$20.54	Average of MBS Item 65060, MBS Item 66500, MBS Item 71153, MBS Item 66823)	ESR, haemoglobin, C-Reactive protein, PR-3 ANCA test 25-hydroxyvitamin D
	State governments	$0.00		
	PHI	$0.00		
	% experiencing OOP costs	73%	Survey	Proportion with PHI
	Households (out of pocket cost)	$95.00	Survey	n=36
Imaging – x ray				Plain x ray
	Australian government	$53.40	MBS Item 58903	Abdomen x ray
	State governments	$0.00		
	PHI	$0.00		
	% experiencing OOP costs	7%	Medical cost finder	
	Households (out of pocket cost)	$250.00	Survey	n=13
Imaging – ultrasound				
	Australian government	$124.70	MBS Item 55036	Intestinal ultrasound
	State governments	$0.00		
	PHI	$0.00		
	% experiencing OOP costs	16%	Medical cost finder	
	Households (out of pocket cost)	$180.00	Survey	n=21

Diagnostics: Cost assumptions

Key variable	Stakeholder	Cost per test	Source	Notes
Imaging – CT scan				
	Australian government	$583.05	MBS Item 56553	Abdomen CT scanning
	State governments	$0.00		
	PHI	$0.00		
	% experiencing OOP costs	8%	Medical cost finder	
	Households (out of pocket cost)	$300.00	Survey	n=16
Imaging – MRI / MRE				
	Australian government	$419.80	Average of MBS Item 63740 / 63741 / 63743	CD MRI
	State governments	$0.00		
	PHI	$0.00		
	% experiencing OOP costs	20%	Medical cost finder	
	Households (out of pocket cost)	$400.00	Survey	n=44
Stool testing				
	Australian government	$75.00	MBS Item 66522 / 66523	Faecal calprotectin test (66523 after if 66522 were inconclusive)
	State governments	$0.00		
	PHI	$0.00		
	% experiencing OOP costs	51%	Survey	Proportion monitoring vs diagnosis
	Households (out of pocket cost)	$90.00	Survey	n=91

Diagnostics: Cost assumptions

Key variable	Stakeholder	Cost per test	Source	Notes
Barium enema				
	Australian government	$117.08	Average of MBS Item 58906, MBS Item 58912, MBS Item 58915, MBS Item 58916)	
	State governments	$0.00		
	PHI	$0.00		
	% experiencing OOP costs	51%	Medical cost finder	
	Households (out of pocket cost)	$140	Medical cost finder, average of MBS out of pocket costs for MBS item numbers 58909, 58921, 58921	Due to the limited number of survey responses (n=4), we are utilising data from Medical cost finder
Colonoscopy / sigmoidoscopy	Total cost			
	Australian government	$580.00	Medical cost finder, colonoscopy average cost	
	State governments	$710.00	Medical cost finder, colonoscopy average cost	Hospital fees
	PHI	$470.00 – for public patients $1,180.00 – for private patients	Medical cost finder, colonoscopy average cost	Hospital fees
	% experiencing OOP costs	73%	Survey	Proportion with PHI
	Households (out of pocket cost)	$500.00	Survey	Survey out of pocket costs (n=97) likely to include out of pocket costs associated with hospitalisation which is excluded in Medical Cost Finder results

Diagnostics: Cost assumptions

Key variable	Stakeholder	Cost per test	Source	Notes
Gastroscopy / endoscopy				
	Australian government	$430	Medical cost finder, gastroscopy average cost	
	State governments	$500.00	Medical cost finder, gastroscopy average cost	Hospital fees
	PHI	$370 – for public patients $870 – for private patients	Medical cost finder, gastroscopy average cost	Service and hospital fees
	% experiencing OOP costs	73%	Survey	Proportion with PHI
	Households (out of pocket cost)	$300.00		Survey out of pocket costs (n=31) likely to include out of pocket costs associated with hospitalisation which is excluded in Medical Cost Finder results
Biopsy				
	Australian government	$59.50	MBS Item 30071	
	State governments	$0.00		
	PHI	$0.00		
	% experiencing OOP costs	95%	Medical cost finder	
	Households (out of pocket cost)	$105.00	Medical cost finder	

Specialist costs

Types of costs

- **Diagnostics**
  - Blood tests
  - Stool tests
  - Biopsy
  - Barium enema
  - Imaging
  - Colonoscopy / sigmoidoscopy
  - Gastroscopy / endoscopy
- **Specialist**
  - Dermatologist
  - Rheumatologist
  - Hepatologist
  - Psychiatrist
  - Ophthalmologist
  - Gastroenterologist
- **Primary and Allied Health Care**
  - GP
  - Counselling support
  - Dietitian
  - Psychologist
- **Other household costs**
  - Medical and nutritional aids
  - Increased risk of colon cancer
  - Travel costs
  - PHI premia
- **Hospital and Emergency care**
  - Hospital admissions
  - Emergency Department presentations
  - OOP costs
- **Medications**
  - 5-Aminosalicytates (5-ASA)
  - Corticosteriods
  - S1P receptor modulators
  - Biologics
  - Janus kinase (JAK) inhibitors
  - Other immunomodulators
- **Health impacts / Burden of Disease**
  - Years of life lost (YLL)
  - Years lived with disability (YLD)
- **Economic and employment impacts**
  - Productivity losses
  - Loss of tax revenue
  - Welfare impacts
  - Hiring costs
  - Funeral costs
  - Carer costs
  - Travel costs

Specialist

Specialists: Utilisation data from survey

Table 11: Utilisation rates for adults (>18 yo) with Crohn's Disease (CD), n=253

Frequency of tests	Gastroenterology clinic	Paediatric gastroenterologist	Pregnancy / fertility clinic	Youth transition / young adults clinic visit	Outpatient visit - other	GP support	Dietitian / nutritional support services	Psychiatrist services	Psychologist services	Counselling support	Dermatologist (Skin specialist) services	Rheumatologist (Arthritis and inflammation specialist) services	Hepatologist (Liver specialist) services	Ophthalmologist (Eye care specialist) services	Optometrist (Eye care specialist) services	Other allied health support	Other
Weekly	0%	-	0%	0%	1%	1%	1%	0%	1%	0%	0%	0%	0%	0%	0%	2%	1%
Fortnightly	0%	-	1%	0%	0%	5%	1%	0%	4%	0%	0%	0%	0%	0%	0%	1%	0%
Monthly	6%	-	2%	0%	0%	21%	3%	1%	6%	2%	0%	1%	0%	0%	1%	5%	3%
Every two months	13%	-	0%	0%	5%	18%	2%	1%	3%	0%	0%	2%	0%	0%	0%	3%	1%
Every four months	15%	-	0%	0%	4%	13%	5%	2%	1%	0%	2%	2%	1%	1%	0%	1%	0%
Every six months	39%	-	2%	0%	5%	19%	5%	0%	2%	1%	14%	8%	2%	5%	21%	6%	2%
N/A	22%	-	76%	79%	63%	16%	67%	76%	64%	77%	68%	70%	77%	73%	59%	65%	67%

Source: CCA Consumer Survey 2024

Specialist

Specialists: Utilisation data from survey

Table 12: Utilisation rates for adults (>18 yo) with Ulcerative Colitis (UC), n=142

Frequency of tests	Gastroenterology clinic	Paediatric gastroenterologist	Pregnancy / fertility clinic	Youth transition / young adults clinic visit	Outpatient visit - other	GP support	Dietitian / nutritional support services	Psychiatrist services	Psychologist services	Counselling support	Dermatologist (Skin specialist) services	Rheumatologist (Arthritis and inflammation specialist) services	Hepatologist (Liver specialist) services	Ophthalmologist (Eye care specialist) services	Optometrist (Eye care specialist) services	Other allied health support	Other
Weekly	0%	-	0%	0%	1%	1%	0%	1%	0%	1%	0%	0%	0%	0%	1%	2%	1%
Fortnightly	1%	-	0%	0%	1%	3%	0%	1%	7%	0%	0%	0%	0%	0%	0%	2%	0%
Monthly	8%	-	1%	2%	3%	12%	2%	2%	6%	2%	1%	0%	0%	0%	0%	5%	1%
Every two months	10%	-	0%	0%	6%	16%	3%	1%	2%	1%	1%	2%	0%	0%	0%	1%	0%
Every four months	10%	-	0%	0%	4%	15%	4%	0%	1%	0%	1%	0%	2%	2%	1%	2%	2%
Every six months	41%	-	1%	0%	9%	21%	8%	2%	5%	0%	11%	7%	1%	7%	16%	4%	2%
N/A	23%	-	73%	74%	55%	22%	63%	71%	60%	75%	66%	71%	75%	70%	62%	63%	65%

Source: CCA Consumer Survey 2024

Specialist

Specialists: Utilisation data from survey

Table 13: Utilisation rates for adults (>18 yo) with Indeterminate IBD (Ind), n=14

Frequency of tests	Gastroenterology clinic	Paediatric gastroenterologist	Pregnancy / fertility clinic	Youth transition / young adults clinic visit	Outpatient visit - other	GP support	Dietitian / nutritional support services	Psychiatrist services	Psychologist services	Counselling support	Dermatologist (Skin specialist) services	Rheumatologist (Arthritis and inflammation specialist) services	Hepatologist (Liver specialist) services	Ophthalmologist (Eye care specialist) services	Optometrist (Eye care specialist) services	Other allied health support	Other
Weekly	0%	-	0%	0%	0%	0%	0%	0%	0%	9%	0%	0%	0%	0%	0%	0%	0%
Fortnightly	0%	-	0%	0%	0%	0%	0%	18%	9%	0%	0%	0%	0%	0%	0%	0%	0%
Monthly	9%	-	0%	0%	9%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
Every two months	18%	-	0%	18%	18%	0%	0%	0%	0%	0%	9%	0%	0%	0%	0%	0%	0%
Every four months	9%	-	0%	0%	9%	0%	0%	0%	0%	0%	0%	0%	0%	0%	9%	0%	0%
Every six months	55%	-	0%	0%	36%	9%	18%	0%	0%	0%	0%	0%	0%	18%	9%	0%	0%
N/A	9%	-	82%	64%	27%	73%	73%	73%	73%	73%	73%	82%	82%	64%	82%	82%	82%

Source: CCA Consumer Survey 2024

Specialist

Specialists: Utilisation data from survey

Table 14: Utilisation rates for people with Paediatric patients (Paed), n=31

Frequency of tests	Gastroenterology clinic	Paediatric gastroenterologist	Pregnancy / fertility clinic	Youth transition / young adults clinic visit	Outpatient visit - other	GP support	Dietitian / nutritional support services	Psychiatrist services	Psychologist services	Counselling support	Dermatologist (Skin specialist) services	Rheumatologist (Arthritis and inflammation specialist) services	Hepatologist (Liver specialist) services	Ophthalmologist (Eye care specialist) services	Optometrist (Eye care specialist) services	Other allied health support	Other
Weekly	0%	0%	-	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
Fortnightly	0%	0%	-	0%	0%	0%	0%	0%	7%	0%	0%	0%	0%	0%	0%	0%	0%
Monthly	0%	7%	-	0%	3%	24%	0%	0%	10%	0%	0%	0%	0%	0%	0%	0%	0%
Every two months	7%	28%	-	0%	10%	24%	17%	0%	7%	0%	0%	3%	0%	0%	3%	0%	0%
Every four months	3%	10%	-	0%	7%	10%	7%	0%	3%	3%	0%	0%	3%	0%	0%	0%	0%
Every six months	7%	21%	-	0%	7%	17%	7%	0%	0%	7%	7%	0%	10%	0%	0%	0%	0%
N/A	66%	24%	-	62%	41%	14%	52%	59%	48%	66%	69%	69%	62%	66%	62%	0%	0%

Source: CCA Consumer Survey 2024

Specialist: Utilisation assumptions

Table 15: Assumed rate of specialist services utilisation per annum (e.g., number of visits per annum)

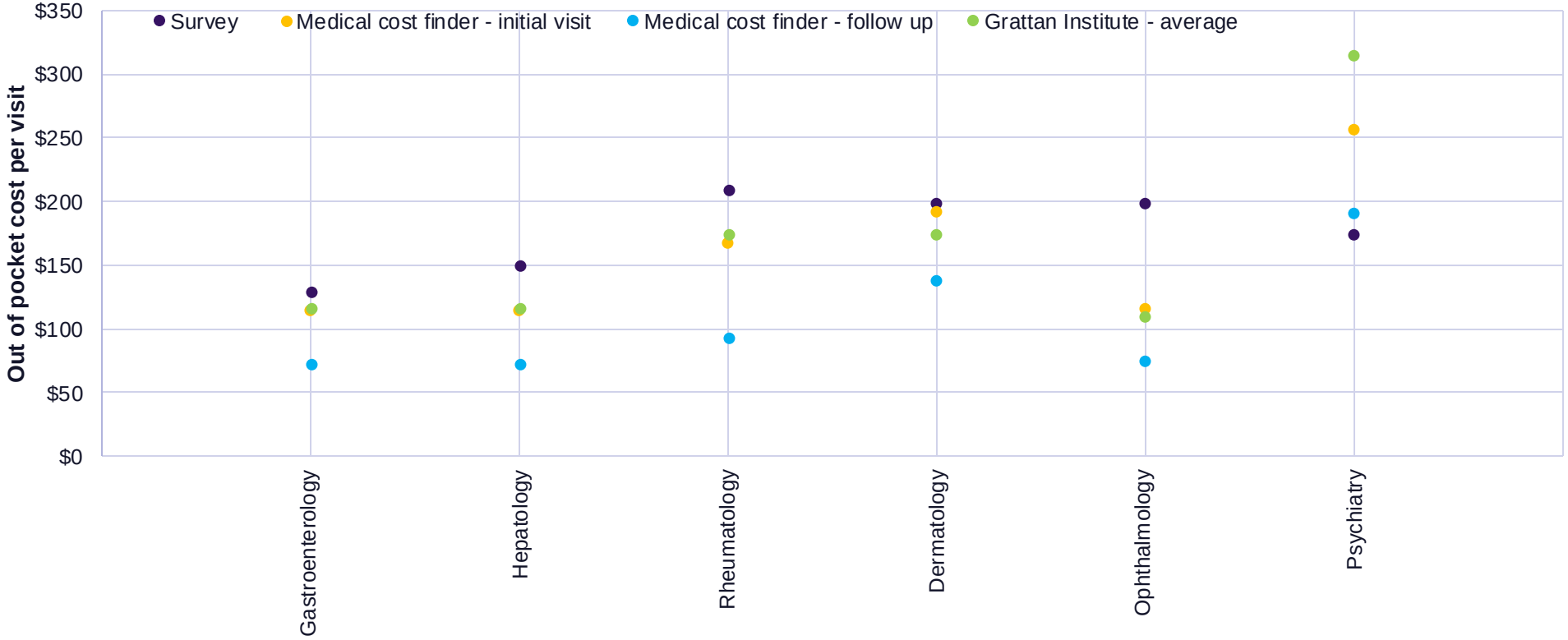
Subtype	Age cohort	Gastroenterology clinic	Paediatric gastroenterologist	Pregnancy / fertility clinic	Youth transition / young adults clinic visit (e.g., paed to adult care)	Outpatient visit - other	GP support	Dietitian / nutritional support services	Physiotherapist / Exercise physiologist	Psychiatrist services	Psychologist services	Counselling support	Dermatologist (Skin specialist) services	Rheumatologist (Arthritis and inflammation specialist) services	Hepatologist (Liver specialist) services	Ophthalmologist (Eye care specialist) services	Optometrist (Eye care specialist) services	Other allied health support	Other
CD	**Adults >18**	3.1	-	0.4	0.0	1.1	6.3	1.4	1.4	0.3	2.7	0.5	0.4	0.4	0.1	0.2	0.6	1.9	0.9
UC	**Adults >18**	3.1	-	0.1	0.2	1.9	5.1	0.9	0.9	0.9	2.7	0.7	0.4	0.4	0.1	0.2	0.8	2.0	0.6
IBD-Ind	**Adults >18**	3.3	-	0.2	0.0	1.0	5.7	1.2	1.2	0.3	2.7	0.7	0.4	0.5	0.1	0.2	0.5	2.0	0.7
Paed	**Children <18**	0.7	3.4	-	0.0	1.4	5.1	1.4	1.4	0.0	3.5	0.3	0.1	0.2	0.4	0.0	0.2	0.0	0.0

Source: CCA Consumer Survey 2024. *Note due to small response numbers for IBD-Ind, average of CD and UC was applied for some of the assumptions.

Specialist cost benchmarking

The survey overall reported almost consistently higher out of pocket costs per specialist visit than reported in the Australian government's Medical Cost finder and report by Grattan Institute (adjusted for inflation). The difference was less for gastroenterology, dermatology and psychiatry visits than other specialist visits.

Figure 14: Benchmarking survey cost estimates ($2024) against Australian Department of Health Medical Cost Finder and Grattan Institute data (indexed to $2024)*



* Health services inflation over the FY23 to FY24 period assumed to be 5.7 per cent (source: ABS) and 2.5% for the preceding years, reflecting a conservative estimate.

Source: CCA Consumer Survey 2024, Australian Medical Cost Finder.

Specialist: Cost assumptions

Table 16: Specialist services costs assumptions

Key variable	Stakeholder	Cost per visit	Source	Notes
Gastroenterologist				
	Australian government	$174.50 / $49.75 $305.15 / $152.80	MBS Item 00110 / 00111 MBS Item 00132 / 00133	Initial / follow up specialist Initial / follow up specialist complex disorder
	State governments	$0.00		
	PHI	$0.00		
	% experiencing OOP costs	73%	Survey	Proportion with PHI
	Households (out of pocket cost)	$130.00	Survey	n=167
Hepatologist				
	Australian government	$174.50 / $49.75 $305.15 / $152.80	MBS Item 00110 / 00111 MBS Item 00132 / 00133	Initial / follow up specialist Initial / follow up specialist complex
	State governments	$0.00		
	PHI	$0.00		
	% experiencing OOP costs	73%	Survey	Proportion with PHI
	Households (out of pocket cost)	$150.00	Survey	n=4

Specialist

Specialist: Cost assumptions

Key variable	Stakeholder	Cost per annum	Source	Notes
Dermatologist				
	Australian government	$98.95 / $49.75	MBS Item 00104 / 00105	Initial / follow up specialist appointment
	State governments	$0.00		
	PHI	$0.00		
	% experiencing OOP costs	92%	Medical Cost Finder	
	Households (out of pocket cost)	$200.00	Survey	n=25
Ophthalmologist				
	Australian government	$98.95 / $49.75	MBS Item 00104 / 00105	Initial / follow up specialist
	State governments	$0.00		
	PHI	$0.00		
	% experiencing OOP costs	87%	Medical Cost Finder	
	Households (out of pocket cost)	$200.00	Survey	n=11

Specialist

Specialist: Cost assumptions

Key variable	Stakeholder	Cost per visit	Source	Notes
Rheumatologist				
	Australian government	$305.15 / $152.80	MBS Item 00132 / 00133	Initial / follow up complex
	State governments	$0.00		
	PHI	$0.00		
	% experiencing OOP costs	80%	Medical Cost Finder	
	Households (out of pocket cost)	$210.00	Survey	n=25
Psychiatrist				
	Australian government	$301.05 / $212.40	MBS Item 00296 / 00306	First long apt in consulting room / long apt in consulting room
	State governments	$0.00		
	PHI	$0.00		
	% experiencing OOP costs	75%	Medical Cost Finder	
	Households (out of pocket cost)	$175.00	Survey	n=15

Costs in primary and community care settings

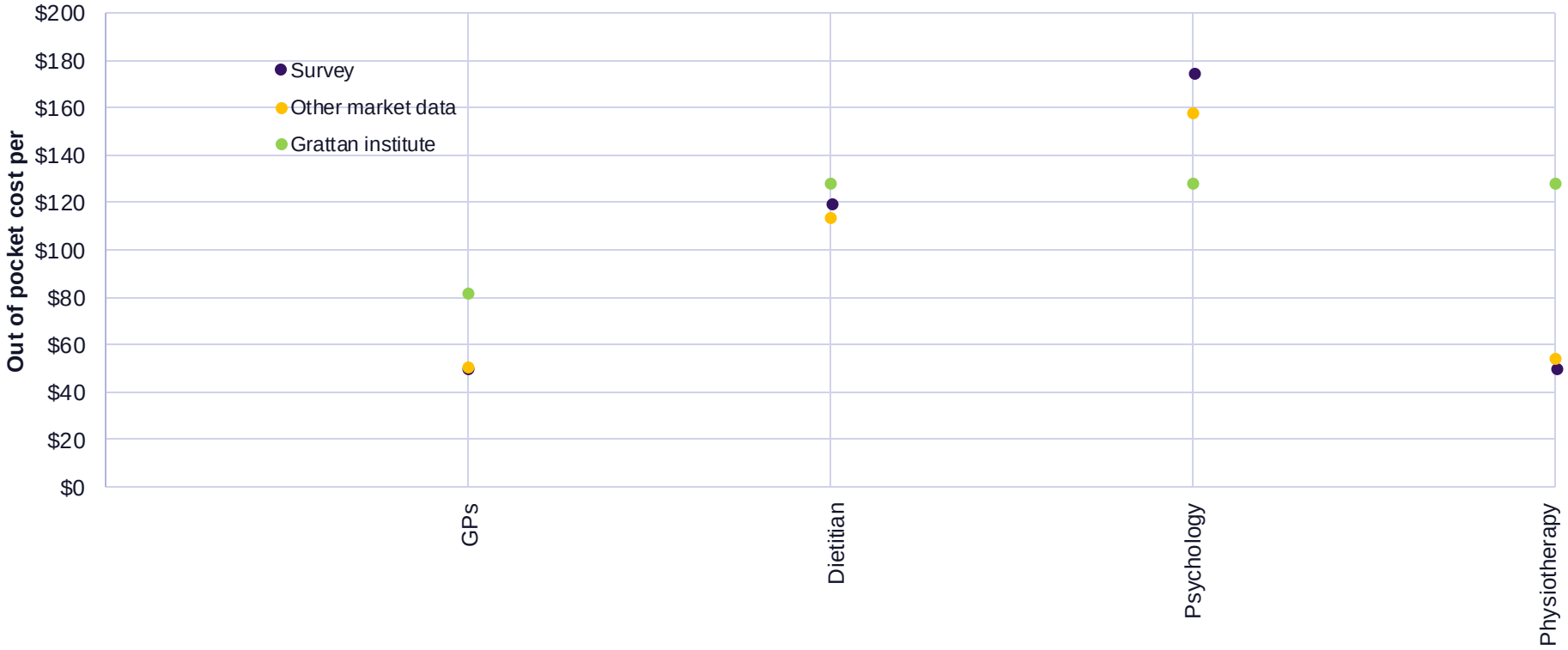
Types of costs

- **Diagnostics**
  - Blood tests
  - Stool tests
  - Biopsy
  - Barium enema
  - Imaging
  - Colonoscopy / sigmoidoscopy
  - Gastroscopy / endoscopy
- **Specialist**
  - Dermatologist
  - Rheumatologist
  - Hepatologist
  - Psychiatrist
  - Ophthalmologist
  - Gastroenterologist
- **Primary and Allied Health Care**
  - GP
  - Counselling support
  - Dietitian
  - Psychologist
- **Other household costs**
  - Medical and nutritional aids
  - Increased risk of colon cancer
  - Travel costs
  - PHI premia
- **Hospital and Emergency care**
  - Hospital admissions
  - Emergency Department presentations
  - OOP costs
- **Medications**
  - 5-Aminosalicytates (5-ASA)
  - Corticosteriods
  - S1P receptor modulators
  - Biologics
  - Janus kinase (JAK) inhibitors
  - Other immunomodulators
- **Health impacts / Burden of Disease**
  - Years of life lost (YLL)
  - Years lived with disability (YLD)
- **Economic and employment impacts**
  - Productivity losses
  - Loss of tax revenue
  - Welfare impacts
  - Hiring costs
  - Funeral costs
  - Carer costs
  - Travel costs

Primary care & Allied health: Cost assumptions

The survey out of pocket costs were closely aligned to other available market data.

Figure 15: Benchmarking survey cost estimates ($2024) against Australian Department of Health Medical Cost Finder, Dieticians Australia, Australian Psychology Association, and Grattan Institute data (indexed to $2024)*



* Health services inflation over the FY23 to FY24 period assumed to be 5.7 per cent (source: ABS) and 2.5% for the preceding years, reflecting a conservative estimate.

Source: CCA Consumer Survey 2024, Department of Health Medical Cost Finder, Dieticians Australia, Australian Psychology Association

Primary care & Allied health: Cost assumptions

Table 17: Primary care and allied health services costs assumptions

Key variable	Stakeholder	Cost per annum	Source	Notes
General Practitioner				
	Australian government	$42.85	MBS Item 00023	Short consult (room)
	State governments	$0.00		
	PHI	$0.00		
	% experiencing OOP costs	25%	AIHW, Medicare funding of GP services over time	
	Households (out of pocket cost)	$50.00	Survey	n=168
Dietitian				
	Australian government	$70.95	MBS Item 10954	
	State governments	$0.00		
	PHI	$22	Teacher's Health Fund, Mid-extras	Extras cover | Teachers Health
	% experiencing OOP costs	73%	Survey	Proportion with PHI
	Households (out of pocket cost)	$120.00	Survey	n=34
Physiotherapist				
	Australian government	$70.95	MBS Item 10956	
	State governments	$0.00		
	PHI	$22	Teacher's Health Fund, Mid-extras	Extras cover | Teachers Health
	% experiencing OOP costs	73%	Survey	Proportion with PHI
	Households (out of pocket cost)	$60.00	Australian Health Professionals	

Primary care & Allied health: Cost assumptions

Key variable	Stakeholder	Cost per annum	Source	Notes
Counselling services				
	Australian government	$0.00		
	State governments	$0.00		
	PHI	$45.00	Teacher's Health Fund, Mid-extras	
	% experiencing OOP costs	100%		
	Households (out of pocket cost)	$100.00	Survey	n=32 (Other allied health professionals, counselling services OOP costs data not collected)
Psychologist				
	Australian government	$113.65 / $142.75	MBS Item 80110 / 80116	Apt in / not in consulting room
	State governments	$0.00		
	PHI	$40	Teacher's Health Fund, Mid-extras	
	% experiencing OOP costs	75%	Medical Cost Finder psychiatric OOP rate	Australian Psychological Society fee $311 in FY25 How much does seeing a psychologist cost? | APS (psychology.org.au)
	Households (out of pocket cost)	$175.00	Survey	n=53

Medical & nutritional aids: Utilisation & cost assumptions

Table 18: Medical and nutritional aids utilisation and costs assumptions

Variable	Proportion of patients accessing supports	Monthly cost ($2024)	Annual cost ($2024)	Source
Enteral nutrition – adults	23%	$125	$1,500	Survey
Enteral nutrition – children	14%	$320	$3,720	Survey
Nutritional supplements – adults	58%	$85	$1,020	Survey
Nutritional supplements – children	44%	$65	$540	Survey
Ostomy bags – adults	5%	$75	$840	Survey
Ostomy bags – children	3%	$90	$1,080	Survey
Over the counter medications – adults	62%	$50	$600	Survey
Over the counter medications – children	67%	$45	$540	Survey
Skin care medications – adults	18%	$50	$600	Survey
Skin care medications – children	15%	$55	$660	Survey
Continence aids – adults	14%	$130	$1,554	Survey, DAE Economic Cost of Incontinence Report
Continence aids – children	14%	$130	$1,554	Survey, DAE Economic Cost of Incontinence Report
Continence aids – government	14%	$58	$695	Services Australia
Travel costs	42%	$100	$1,200	Survey

Source: CCA Consumer Survey 2024, Services Australia, DAE Economic Cost of Incontinence Report

Other household costs: Cost assumptions

Table 19: Other household costs assumptions

Variable	Average monthly cost ($2024)	Average annual cost ($2024)	Source	Notes
Increased risk of colon cancer	$42	$505	Daffodil Centre, Mattar, et al. (2011)	Costs averaged over IBD population over a 10-year horizon
Additional PHI	$43	$519	Canstar, APRA	73% of survey respondents reported having a private health insurance, 18% higher than the Australian average of 55% for general treatment memberships
Higher coverage	$24	$288	Canstar, APRA	73% of survey respondents reported having a private health insurance, 28% higher than the Australian average of 45% for hospital treatment memberships
Funeral costs		$9,067*	The Cost of Funerals in Australia 2024 Update - Mornington Green Legacy Gardens Australian funeral costs soaring: How to plan and save | The Senior | Senior	*Funeral costs are one off costs and discounted by weighted average years of life lost at social discount rate 5% to deal with impact of bringing funeral cost forward in time

Hospital costs

Types of costs

Diagnostics

- Blood tests
- Stool tests
- Biopsy
- Barium enema
- Imaging
- Colonoscopy / sigmoidoscopy
- Gastroscopy / endoscopy

Specialist

- Dermatologist
- Rheumatologist
- Hepatologist
- Psychiatrist
- Ophthalmologist
- Gastroenterologist

Primary and Allied Health Care

- GP
- Counselling support
- Dietitian
- Psychologist

Other household costs

- Medical and nutritional aids
- Increased risk of colon cancer
- Travel costs
- PHI premia

Hospital and Emergency care

- Hospital admissions
- Emergency Department presentations
- OOP costs

Medications

- 5-Aminosalicytates (5-ASA)
- Corticosteriods
- S1P receptor modulators
- Biologics
- Janus kinase (JAK) inhibitors
- Other immunomodulators

Health impacts / Burden of Disease

- Years of life lost (YLL)
- Years lived with disability (YLD)

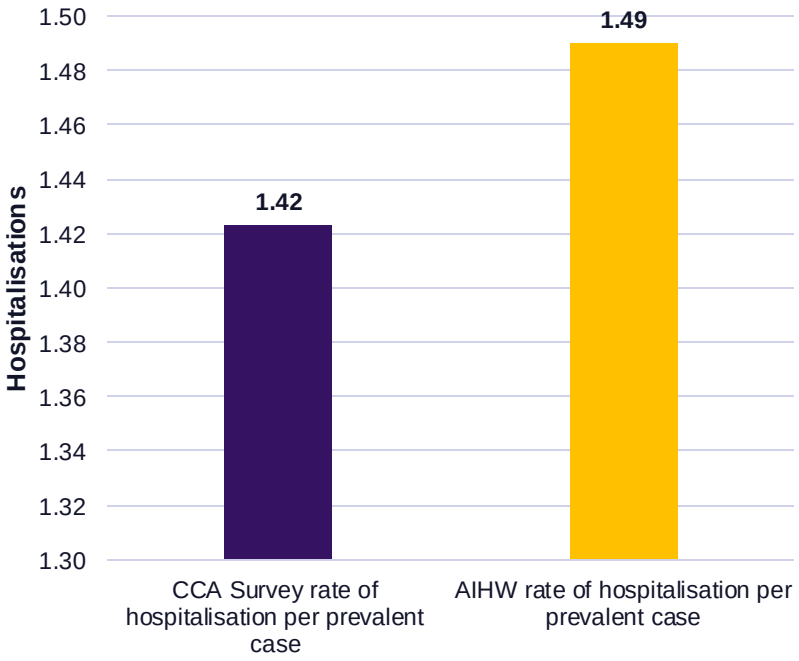
Economic and employment impacts

- Productivity losses
- Loss of tax revenue
- Welfare impacts
- Hiring costs
- Funeral costs
- Carer costs
- Travel costs

Hospital and emergency department utilisation

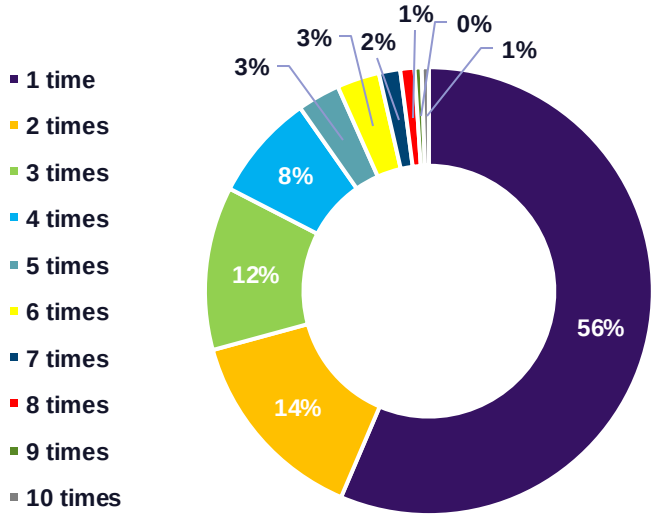
The survey enjoyed strong consistency with AIHW for hospitalisation rate per prevalent case. Additional data has been requested than is publicly reported in AIHW, Emergency department care 2022–23: Australian hospital statistics, Table 4.6, Table 4.6: Emergency department presentations(a) by principal diagnosis in ICD-10-AM(b) chapters and triage category, 2022–23 to facilitate further benchmarking of emergency department data.

Figure 16: Benchmarking hospitalisations per prevalent case per annum



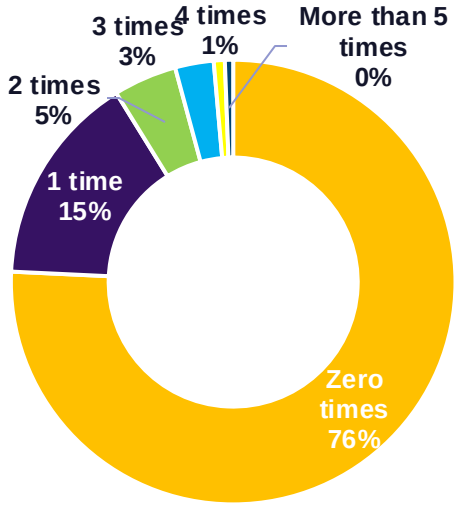
Source: CCA Consumer Survey 2024 and AIHW data

Figure 17: Number of times respondents had been hospitalised in last six months



Source: CCA Consumer Survey 2024

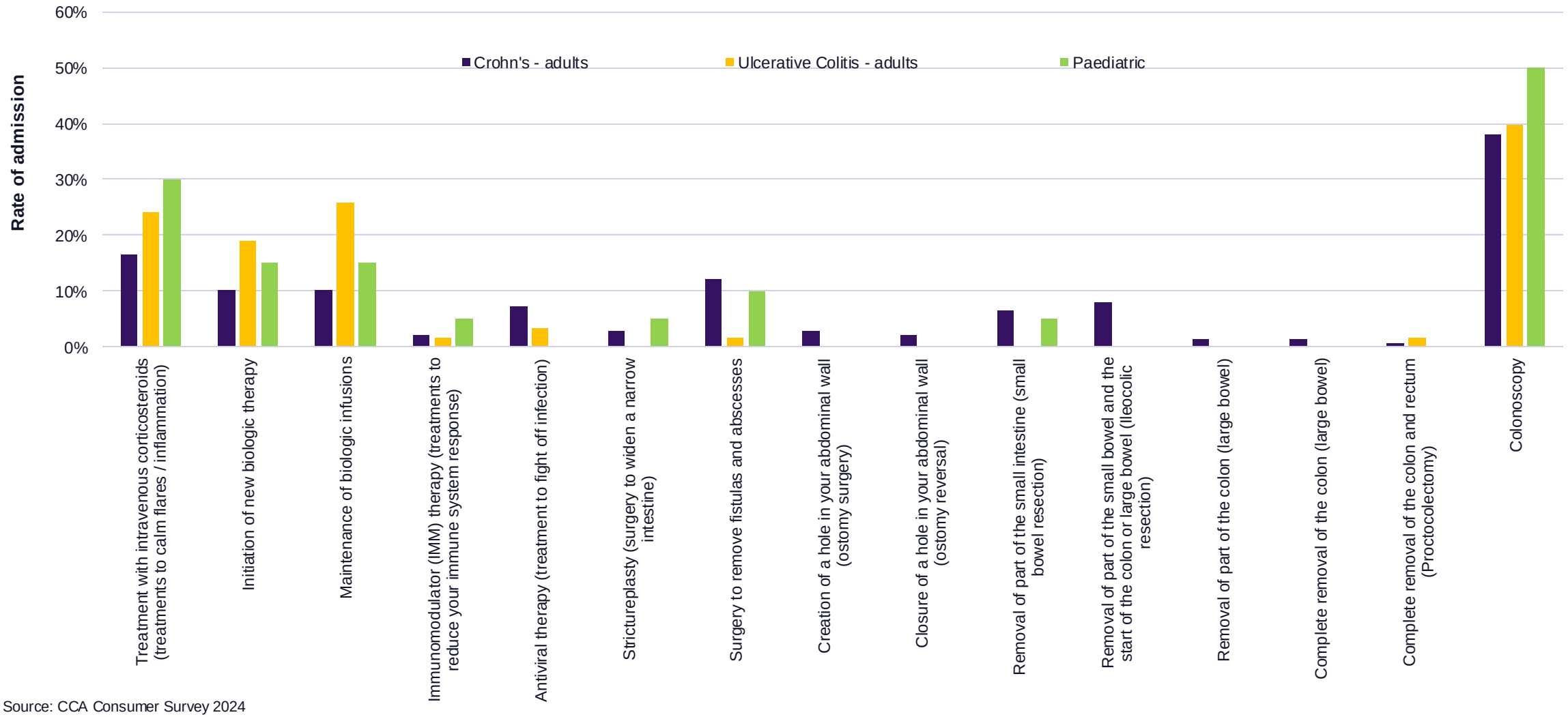
Figure 18: Number of times respondents presented to emergency department



Source: CCA Consumer Survey 2024

Hospital and emergency department utilisation and costs

Figure 19: Distribution of procedures by hospital admissions



Source: CCA Consumer Survey 2024

Hospital and emergency department utilisation and costs

Table 20: Hospital procedures (surgeries and IV) utilisation assumptions

Subtype	Age cohort	Strictureplasty (surgery to widen a narrow intestine)	Surgery to remove fistulas and abscesses	Creation of a hole in your abdominal wall (ostomy surgery)	Closure of a hole in your abdominal wall (ostomy reversal)	Removal of part of the small intestine (small bowel resection)	Removal of part of the small bowel and the start of the colon or large bowel (ileocolic resection)	Removal of part of the colon (large bowel)	Complete removal of the colon (large bowel)	Complete removal of the colon and rectum (Proctocolectomy)	IV
CD	**Adults >18**	2%	9%	2%	2%	5%	6%	2%	1%	1%	21%
UC	**Adults >18**	0%	7%	2%	1%	2%	2%	0%	1%	0%	38%
IBD-Ind	**Adults >18**	1%	8%	2%	1%	4%	4%	1%	1%	0%	27%
Paed	**Children <18**	1%	8%	2%	1%	4%	4%	1%	1%	0%	59%

Source: CCA Consumer Survey 2024. *Note due to small response numbers for IBD-Ind and Paed, average of CD and UC was applied for some of the assumptions.

Hospital and emergency department utilisation and costs

Table 21: Hospital preocedures and emergency department presentation costs assumptions

Variable	Cost ($2024)	Source
Strictureplasty (surgery to widen a narrow intestine)	$20,178.80	NHCDC 2020-21 Appendix 8, national average
Surgery to remove fistulas and abscesses	$5,806.25	NHCDC 2020-21 Appendix 8, national average
Creation of a hole in your abdominal wall (ostomy surgery)	$5,806.25	NHCDC 2020-21 Appendix 8, national average
Closure of a hole in your abdominal wall (ostomy reversal)	$5,806.25	NHCDC 2020-21 Appendix 8, national average
Removal of part of the small intestine (small bowel resection)	$47,182.56	NHCDC 2020-21 Appendix 8, national average
Removal of part of the small bowel and the start of the colon or large bowel (Ileocolic resection)	$47,182.56	NHCDC 2020-21 Appendix 8, national average
Removal of part of the colon (large bowel)	$47,182.56	NHCDC 2020-21 Appendix 8, national average
Complete removal of the colon (large bowel)	$47,182.56	NHCDC 2020-21 Appendix 8, national average
Complete removal of the colon and rectum (Proctocolectomy)	$47,182.56	NHCDC 2020-21 Appendix 8, national average
IV	$2,068.62	NHCDC 2020-21 Appendix 8, national average
Emergency department presentation	$993.91	NHCDC 2020-21 Appendix 8, national average

Source: NHCDC 2020-21 Appendix 8, national average

Hospital out of pocket cost assumptions

Table 22: Hospital services out of pocket cost assumptions

Subtype	Age cohort	Accommodation	Operating theatre fees	Specialist fees	Surgeon costs	Assistant surgeon costs	Anaesthetist fees	Pharmaceutical costs	After care costs (e.g., dressings)	Travel costs - accommodation	Travel costs - parking	Private health insurance excess
CD	**Adults >18**	$251	$616	$223	$869	$128	$316	$54	$96	$114	$35	$190
UC	**Adults >18**	$184	$282	$87	-	-	$49	$50	-	$137	$43	$132
IBD-Ind	**Adults >18**	$218	$449	$155	$869	$128	$183	$52	$96	$126	$39	$161
Paed	**Children <18**	$184	$282	$87	-	-	$49	$50	-	$137	$43	$132

Source: CCA Consumer Survey 2024. *Note due to small response numbers for IBD-Ind, average of CD and UC was applied for some of the assumptions.

Hospital out of pocket cost assumptions

Table 23: Type of costs incurred by hospital procedures

Procedure	Accommodation	Operating theatre fees	Specialist fees	Surgeon costs	Assistant surgeon costs	Anaesthetist fees	Pharmaceutical costs	After care costs (e.g., dressings)	Travel costs - accommodation	Travel costs - parking	Private health insurance excess
IV or infusion – Private hospital	-	-	✓	-	-	-	✓	-	✓	✓	✓
Surgery (any) – Private hospital	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
IV or infusion – Public hospital	-	-	-	-	-	-	-	-	-	✓	-
Surgery (any) – Public hospital	-	-	-	-	-	-	-	-	✓	✓	-

Source: Insight Economics assumptions

Medication costs

Types of costs

Diagnostics

- Blood tests
- Stool tests
- Biopsy
- Barium enema
- Imaging
- Colonoscopy / sigmoidoscopy
- Gastroscopy / endoscopy

Specialist

- Dermatologist
- Rheumatologist
- Hepatologist
- Psychiatrist
- Ophthalmologist
- Gastroenterologist

Primary and Allied Health Care

- GP
- Counselling support
- Dietitian
- Psychologist

Other household costs

- Medical and nutritional aids
- Increased risk of colon cancer
- Travel costs
- PHI premia

Hospital and Emergency care

- Hospital admissions
- Emergency Department presentations
- OOP costs

Medications

- 5-Aminosalicytates (5-ASA)
- Corticosteriods
- S1P receptor modulators
- Biologics
- Janus kinase (JAK) inhibitors
- Other immunomodulators

Health impacts / Burden of Disease

- Years of life lost (YLL)
- Years lived with disability (YLD)

Economic and employment impacts

- Productivity losses
- Loss of tax revenue
- Welfare impacts
- Hiring costs
- Funeral costs
- Carer costs
- Travel costs

List of medications

Medications

5-Aminosalicylates (5-ASA)

- Mesalazine
- Sulfasalazine
- Olsalazine
- Balsalazide

Corticosteroids

- Predinisone / Prednisolone
- Budesonide

S1P receptor modulators

- Etrasimod
- Ozanimod

Biologics

- Adalimumab
- Golimumab
- Infliximab
- Mirikizumab
- Risankizumab
- Ustekinumab
- Vedolizumab

Janus kinase (JAK) inhibitors

- Tofactinib
- Upadactinib

Other immunomodulators

- Cyclosporine
- Azathioprine
- Methotrexate
- Mercaptopurine

Medications: Prescription information

Table 24: Medication prescription information

Key variable	Dosage / Prescription course	Source
5-Aminosalicylates		
Mesalazine – oral or rectal route	**Oral route:** For induction: 4.8 g once a day for 6 weeks (>50kg), 3.6 g once a day for 6 weeks (35-50kg), 2.4 g once a day for 6 weeks (24-35kg). For maintenance: Adults – 1.6 g once a day. Children – dose to be determined. **Rectal route:** For induction: Adults – 4 g every night for 6 weeks. Children – dose to be determined.	Mayo Clinic
Sulfasalazine	For treatment: Adults – 500 to 1000 mg every 6 to 8 hours per day for 4 weeks. Children (>= 6 years) – 40 to 60 mg per kg of body weight per day for 4 weeks. Children (<6 years) – dose to be determined. For maintenance: Adults – 2000 mg per day. Children (>=6 years) – 30 mg per kg of body weight per day. Children (<6 years) – dose to be determined.	Mayo Clinic
Olsalazine	For induction: Adults – 2g per day for 4 weeks. Children – dose to be determined. For maintenance: Adults – 500 mg 2 times a day, Children – dose to be determined.	Mayo Clinic
Balsalazide	For induction: Adults and Children (>= 5 years) – 2.25 g three times a day for 8 weeks. Children (<5 years) – Dose to be determined. For maintenance: Adults – 750 mg twice daily. Children – dose to be determined.	Mayo Clinic Literature review
Corticosteroids		
Prednisone – oral or rectal	**Oral route:** For induction: Adults – 5 to 60 mg per day for 4 weeks. Children – dose to be determined. For maintenance: Typically, not used for maintenance long term therapy. **Rectal route:** For induction: Same as oral route.	Mayo Clinic Literature review
Budesonide – oral	For induction: Adults – 9 mg once a day for up to 8 weeks. Children (8-17 years and >25 kg) – 9 mg once a day for 8 weeks, 6 mg once a day after for 2 weeks. Children (<8 years and <25 kg) – dose to be determined. For maintenance: Adults – 6mg once daily for up to 12 weeks. Children – dose to be determined.	Mayo Clinic Literature review

Medications: Prescription information

Key variable	Dosage / Prescription course	Source
Budesonide – rectal	For induction: Adults – 2 mg twice daily for 2 weeks. Then, 2mg once daily for 4 weeks. Children – dose to be determined.	Mayo Clinic Literature review
Janus kinase (JAK) inhibitors		
Tofactinib	For induction: 10 mg twice daily for 8 weeks and reassess. For maintenance: 5 mg twice daily. Continue for another 16 weeks max.	XELJANZ® full prescribing information
Upadactinib	For induction: 45 mg once daily for 8 weeks. For maintenance: 15-30 mg once daily.	RINVOQ® full prescribing information
Other immunomodulators		
Cyclosporine – oral or injection	**Oral route:** For induction: Adults – 2 mg per kg of body weight per day for 4 weeks. Children – dose to be determined. For maintenance: Cyclosporine is an effective 'rescue therapy' which may serve as a rapidly acting "bridge" to maintenance. **Injection route:** For induction and maintenance: Same as oral route.	NHS UK Literature review
Azathioprine	For induction: Adults – 2 mg per kg of body weight per day for 3 months. Children – dose to be determined. For maintenance: Adults – 1.5 mg per kg of body weight per day. Children – dose to be determined.	NHS UK Literature review
Mercaptopurine	For induction: Adults – 1.5 mg per kg of body weight per day for 4 weeks. Children – dose to be determined. For maintenance: Adults – 1 mg per kg of body weight per day. Children – dose to be determined.	Literature review
Methotrexate – oral or injection	**Oral route:** For induction: Adults – 25 mg per week for 16 weeks. Children – dose to be determined. For maintenance: Adults – 15 mg per week. Children – dose to be determined. **Injection route:** For induction and maintenance: Same as oral route.	NHS UK

Medications: Prescription information

Key variable	Dosage / Prescription course	Source
S1P receptor modulators		
Etrasimod	For induction: Adults – 2 mg once a day for 12 weeks. Children – dose to be determined. For maintenance: Adults – 2 mg once a day. Children – dose to be determined.	Mayo Clinic Literature review
Ozanimod	For induction: Adults – On Days 1 to 4, 0.23 g once a day. Then, on Days 5 to 7, 0.46 g once a day. And on Day 8-70, 0.92 g once a day. Children – dose to be determined. For maintenance: Adults – 0.92 g once a day. Children – dose to be determined.	Mayo Clinic Literature review
Biologics		
Adalimumab	For induction: Adults and children (>= 6 years) (>40kg) – 160 mg in Week 0-1, 80 mg in Week 2-3. Children (>= 6 years) (17-40kg) – 80mg in Week 0-1, 40 mg in Week 2-3. Children (others) – dose to be determined. For maintenance: Adults and children (>= 6 years) (>40kg) – 40 mg at Week 4 and every other week thereafter. Children (>= 6 years) (17-40kg) – 20 mg at Week 4 and every other week thereafter. Children (others) – dose to be determined.	HUMIRA® full prescribing information
Golimumab	For induction: Adults – 200 mg dose at Week 0, 100 mg dose given at Week 2. Children – dose to be determined. For maintenance: Adults – 100 mg at Week 6 and every 4 weeks thereafter. Children – dose to be determined.	SIMPONI® full prescribing information
Infliximab	For induction: Adults – 5 mg dose for every kg of body weight at Week 0, 2 and 6. Children – same as adult. For maintenance: Adults – 5 mg dose for every kg of body weight every 8 weeks thereafter. Children – same as adult.	INFLECTRA® full prescribing information
Mirikizumab	For induction: Adults – 300 mg administered at Week 0, 4, 8. Children – dose to be determined. For maintenance: Adults – 200 mg administered at Week 12, and every 4 weeks thereafter. Children – dose to be determined.	OMVOH® full prescribing information
Risankizumab	For induction: Adults CD – 600 mg at Week 0, 4, 8. Adults UC – 1200 mg at Week 0, 4, 8. Children – dose to be determined. For maintenance: Adults – 180 mg or 360 mg at Week 12, and every 8 weeks thereafter. Children – dose to be determined.	SKYRIZI® full prescribing information
Ustekinumab	For induction: Adults – 0-55 kg – 260 mg, 55-85 kg – 390 mg, >85 kg – 520 mg at Week 0. Children – dose to be determined. For maintenance: Adults – 90 mg at Week 8, and every 8 weeks thereafter. Children – dose to be determined.	STELARA® full prescribing information
Vedolizumab	For induction: 300 mg at Week 0, 2, 6. Children – dose to be determined. For maintenance: 300 mg at Week 14, and every 8 weeks thereafter. Children – dose to be determined.	ENTYVIO® full prescribing information

Medications: Utilisation assumptions

Table 25: Proportion of patients on medications in last six months

IBD type	Cohorts	Mesalazine - oral	Mesalazine - rectal	Sulfasalazine - oral	Balsalazide	Olsalazine	Prednisone/prednisolone - oral	Prednisolone - rectal	Corticosteroids - injection	Budesonide- oral	Budesonide- rectal	Azathioprine	Mercaptopurine	Methotrexate - oral	Methotrexate - injection	Cyclosporine - oral	Cyclosporine - injection	Adalimumab	Golimumab	Infliximab	Mirikizumab	Risankizumab	Tofacitinib	Upadacitinib	Ustekinumab	Vedolizumab	Etrasimod	Ozanimod	Other
CD	Adults >18	14%	3%	7%	0%	0%	18%	2%	5%	13%	2%	25%	10%	6%	0%	1%	0%	17%	0%	25%	0%	0%	0%	3%	26%	5%	0%	0%	11%
UC	Adults >18	62%	26%	5%	4%	0%	23%	7%	5%	8%	5%	16%	9%	6%	1%	0%	0%	2%	0%	18%	0%	0%	2%	8%	8%	19%	0%	0%	7%
IBD-Ind	Adults >18	55%	18%	9%	0%	0%	18%	0%	0%	27%	0%	9%	0%	9%	0%	0%	0%	0%	0%	0%	0%	0%	0%	9%	9%	27%	0%	0%	27%
Paed	Child <18	44%	13%	0%	0%	0%	28%	3%	0%	9%	3%	44%	13%	22%	6%	0%	0%	19%	0%	53%	0%	0%	0%	3%	0%	3%	0%	0%	13%

Source: CCA Consumer Survey 2024

Medications: Utilisation assumptions

According to the National Health Survey 2022, the average weight of an Australian adult is 80 kg. Based on the average age of diagnosis of paediatric IBD and using height/weight charts, it's assumed that the average weight of a pediatric IBD patient in Australia is 33 kg.

These weight figures are important for determining the dosages for various medications used in treating IBD. Treatment typically involves:

- **Induction Therapy**: This phase lasts between 4 to 12 weeks, aimed at quickly reducing inflammation and managing symptoms.
- **Maintenance Therapy**: Following the induction phase, maintenance therapy generally continues for 40-48 weeks to sustain remission and prevent relapse. During this phase, patients are prescribed medication with dosages categorised as **under** standard, **standard**, or **over** standard. It is generally accepted, based on literature review, and hence assumed, that 'under standard' dosage refers to half the standard dosage, while 'over standard' dosage refers to twice the standard dosage.

Total dosage for the entire course of induction and maintenance therapy with the different medications are provided. When dosage information is not available for children, it is assumed that their dosage will be scaled down from the average dosage based on weight ratios.

Medications: Government costs

Table 26: Government costs for adult patients, per annum

	Mesalazine - oral	Mesalazine - rectal	Sulfasalazine - oral	Balsalazide	Olsalazine	Budesonide- oral	Budesonide- rectal	Azathioprine	Mercaptopurine	Methotrexate - oral	Methotrexate - injection	Cyclosporine - oral	Cyclosporine - injection
Government contribution per script	**$106**	**$184**	**$61**	**$88**	**$13**	**$383**	**$120**	**$0**	**$138**	**$0**	**$59**	**$145**	**$23**
No. of subsidised scripts per year	2	6	1	2	3	9	4	-	1	-	14	2	9
No. of subsidised scripts per year	3	-	2	2	7	5	-	-	3	-	9	-	-
No. of subsidised scripts per year	5	-	4	3	14	9	-	-	6	-	18	-	-
No. of subsidised scripts per year	9	-	7	5	27	17	-	-	11	-	36	-	-
Cost per annum - induction	$212	$1,102	$61	$176	$40	$3,450	$481	-	$138	-	$830	$290	$203
Cost per annum - under-standard dose	$318	-	$121	$176	$94	$1,916	-	-	$413	-	$533	-	-
Cost per annum - standard dose	$531	-	$242	$264	$188	$3,450	-	-	$826	-	$1,067	-	-
Cost per annum - over-standard dose	$955	-	$424	$440	$363	$6,516	-	-	$1,514	-	$2,134	-	-

Cont'd next page

Medications: Government costs (cont'd)

	Adalimumab	Golimumab	Infliximab	Mirikizumab	Risankizumab	Tofacitinib	Upadacitinib	Ustekinumab	Vedolizumab	Etrasimod	Ozanimod
Government contribution per script	**$1,983**	**$1,130**	**$945**	**$0**	**$0**	**$1,181**	**$1,181**	**$3,940**	**$2,918**	**$0**	**$2,189**
No. of subsidised scripts per year	2	6	3	-	-	4	6	5	3	-	2
No. of subsidised scripts per year	2	12	3	-	-	2	6	3	3	-	5
No. of subsidised scripts per year	4	24	5	-	-	4	11	6	6	-	9
No. of subsidised scripts per year	8	48	10	-	-	8	22	12	12	-	18
Cost per annum - induction	$3,967	$6,782	$2,835	-	-	$4,723	$7,087	$19,700	$8,755	-	$4,379
Cost per annum - under-standard dose	$3,967	$13,564	$2,835	-	-	$2,362	$7,087	$11,820	$8,755	-	$10,946
Cost per annum - standard dose	$7,933	$27,129	$4,726	-	-	$4,723	$12,993	$23,640	$17,510	-	$19,704
Cost per annum - over-standard dose	$15,866	$54,257	$9,451	-	-	$9,446	$25,986	$47,281	$35,020	-	$39,407

Source: Insight Economics calculations based on cost per mg and expected dose for adult at average weight (80Kg) and child (33kg) where required.

Medications: Government costs (cont'd)

Table 27: Government costs for paediatric patients, per annum

	Mesalazine - oral	Mesalazine - rectal	Sulfasalazine - oral	Balsalazide	Olsalazine	Budesonide- oral	Budesonide- rectal	Azathioprine	Mercaptopurine	Methotrexate - oral	Methotrexate - injection	Cyclosporine - oral	Cyclosporine - injection
Government contribution per script	**$106**	**$184**	**$61**	**$88**	**$13**	**$383**	**$120**	**$0**	**$138**	**$0**	**$59**	**$145**	**$23**
No. of subsidised scripts per year	1	3	1	2	1	9	4	-	1	-	6	1	4
No. of subsidised scripts per year	1	-	1	2	3	2	-	-	2	-	4	-	-
No. of subsidised scripts per year	2	-	2	3	6	4	-	-	3	-	8	-	-
No. of subsidised scripts per year	4	-	4	5	12	7	-	-	5	-	15	-	-
Cost per annum - induction	$106	$551	$61	$176	$13	$3,450	$481	-	$138	-	$356	$145	$90
Cost per annum - under-standard dose	$106	-	$61	$176	$40	$767	$0	-	$275	-	$237	-	-
Cost per annum - standard dose	$212	-	$121	$264	$81	$1,533	-	-	$413	-	$474	-	-
Cost per annum - over-standard dose	$425	-	$242	$440	$161	$2,683	-	-	$688	-	$889	-	-

Cont'd next page

Medications: Government costs (cont'd)

	Adalimumab	Golimumab	Infliximab	Mirikizumab	Risankizumab	Tofacitinib	Upadacitinib	Ustekinumab	Vedolizumab	Etrasimod	Ozanimod
Government contribution per script	**$1,983**	**$1,130**	**$945**	**$0**	**$5,370**	**$1,181**	**$1,181**	**$3,940**	**$2,918**	**$0**	**$2,189**
No. of subsidised scripts per year	1	3	1	-	10	2	3	2	2	-	1
No. of subsidised scripts per year	1	5	1	-	3	1	3	2	2	-	2
No. of subsidised scripts per year	2	5	2	-	6	2	5	3	3	-	4
No. of subsidised scripts per year	4	10	4	-	12	4	10	5	5	-	8
Cost per annum - induction	$1,983	$3,391	$945	-	$53,703	$2,362	$3,544	$7,880	$5,837	-	$2,189
Cost per annum - under-standard dose	$1,983	$5,652	$945	-	$16,111	$1,181	$3,544	$7,880	$5,837	-	$4,379
Cost per annum - standard dose	$3,967	$5,652	$1,890	-	$32,222	$2,362	$5,906	$11,820	$8,755	-	$8,757
Cost per annum - over-standard dose	$7,933	$11,304	$3,780	-	$64,443	$4,723	$11,812	$19,700	$14,592	-	$17,514

Source: Insight Economics calculations based on cost per mg and expected dose for adult at average weight (80Kg) and child (33kg) where required.

Medications: Out of pocket costs

Table 28: Out of pocket costs to patients (co-payment plus brand premia)

IBD type	Cohorts	Mesalazine - oral	Mesalazine - rectal	Sulfasalazine - oral	Balsalazide	Olsalazine	Prednisone/prednisolone - oral	Prednisolone - rectal	Budesonide- oral	Budesonide- rectal	Azathioprine	Mercaptopurine	Methotrexate - oral	Methotrexate - injection	Cyclosporine - oral	Cyclosporine - injection	Adalimumab	Golimumab	Infliximab	Mirikizumab	Risankizumab	Tofacitinib	Upadacitinib	Ustekinumab	Vedolizumab	Etrasimod	Ozanimod	Other
CD	Adults >18	$36	$38	$41	-	-	$28	$65	$84	$98	$59	$47	$43	$39	$7	-	$99	$30	$69	-	-	-	$56	$47	$43	-	-	$227
UC	Adults > 18	$61	$40	$61	$30	-	$25	$34	$117	$30	$48	$74	$27	$30	-	-	$35	-	$125	-	-	$39	$43	$42	$125	-	-	$58
IBD-Ind	Adults >18	$31	$53	$150	-	-	$14	-	$70	-	$31	-	$35	-	-	-	-	-	-	-	-	-	$180	$31	-	-	-	$53
Paed	Child <18	$34	$31	-	-	-	$21	-	$23	$65	$24	$41	$34	$7	-	-	$17	-	$26	-	-	-	-	-	-	-	-	$8

Source: CCA Consumer Survey 2024

Health outcomes

Types of costs

Diagnostics

- Blood tests
- Stool tests
- Biopsy
- Barium enema
- Imaging
- Colonoscopy / sigmoidoscopy
- Gastroscopy / endoscopy

Specialist

- Dermatologist
- Rheumatologist
- Hepatologist
- Psychiatrist
- Ophthalmologist
- Gastroenterologist

Primary and Allied Health Care

- GP
- Counselling support
- Dietitian
- Psychologist

Other household costs

- Medical and nutritional aids
- Increased risk of colon cancer
- Travel costs
- PHI premia

Hospital and Emergency care

- Hospital admissions
- Emergency Department presentations
- OOP costs

Medications

- 5-Aminosalicytates (5-ASA)
- Corticosteriods
- S1P receptor modulators
- Biologics
- Janus kinase (JAK) inhibitors
- Other immunomodulators

Health impacts / Burden of Disease

- Years of life lost (YLL)
- Years lived with disability (YLD)

Economic and employment impacts

- Productivity losses
- Loss of tax revenue
- Welfare impacts
- Hiring costs
- Funeral costs
- Carer costs
- Travel costs

Health impacts / Burden of Disease

Health and safety impact assumptions

To value the cost of early death, the model calculated years of life lost as the difference between the expected age at death and life expectancy. Disability weightings are adopted to account for reduced quality of life (1 is life lost, 0 is perfect health). For co-morbidities, we constructed a weighted disability score. This was developed using disability weights from the Institute for Health Metrics and Evaluation and Global Burden of Disease Study 2019 (GBD 2019) Disability Weights. Where multi-morbidity was observed, the maximum disability weight was applied (e.g., weights were not added).

Table 29: Disability weights for IBD and associated comorbidities

Sequela	Health state name	Health state lay description	Disability Weight
Ulcerative colitis with mild anemia	Crohn disease or ulcerative colitis	has cramping abdominal pain, has diarrhea several times a day, and feels very tired for two months every year. When the person does not have symptoms, there is anxiety about them returning.	0.231
Ulcerative colitis with moderate anemia	Crohn disease or ulcerative colitis	has cramping abdominal pain, has diarrhea several times a day, and feels very tired for two months every year. When the person does not have symptoms, there is anxiety about them returning.	0.231
Ulcerative colitis with severe anemia	Crohn disease or ulcerative colitis	has cramping abdominal pain, has diarrhea several times a day, and feels very tired for two months every year. When the person does not have symptoms, there is anxiety about them returning.	0.231
Ulcerative colitis without anemia	Crohn disease or ulcerative colitis	has cramping abdominal pain, has diarrhea several times a day, and feels very tired for two months every year. When the person does not have symptoms, there is anxiety about them returning.	0.231
Asymptomatic ulcerative colitis	Asymptomatic		0
Crohn's disease with mild anemia	Crohn disease or ulcerative colitis	has cramping abdominal pain, has diarrhea several times a day, and feels very tired for two months every year. When the person does not have symptoms, there is anxiety about them returning.	0.231
Crohn's disease with moderate anemia	Crohn disease or ulcerative colitis	has cramping abdominal pain, has diarrhea several times a day, and feels very tired for two months every year. When the person does not have symptoms, there is anxiety about them returning.	0.231
Crohn's disease with severe anemia	Crohn disease or ulcerative colitis	has cramping abdominal pain, has diarrhea several times a day, and feels very tired for two months every year. When the person does not have symptoms, there is anxiety about them returning.	0.231
Crohn's disease without anemia	Crohn disease or ulcerative colitis	has cramping abdominal pain, has diarrhea several times a day, and feels very tired for two months every year. When the person does not have symptoms, there is anxiety about them returning.	0.231
Asymptomatic Crohn's disease	Asymptomatic		0

Health impacts / Burden of Disease

Health and safety impact assumptions

Sequela	Health state name	Health state lay description	Disability Weight
Mild anxiety disorders	Anxiety disorders, mild	feels mildly anxious and worried, which makes it slightly difficult to concentrate, remember things, and sleep. The person tires easily but is able to perform daily activities.	0.03
Moderate anxiety disorders	Anxiety disorders, moderate	feels anxious and worried, which makes it difficult to concentrate, remember things, and sleep. The person tires easily and finds it difficult to perform daily activities.	0.133
Severe anxiety disorders	Anxiety disorders, severe	constantly feels very anxious and worried, which makes it difficult to concentrate, remember things and sleep. The person has lost pleasure in life and thinks about suicide.	0.523
Anxiety disorders, currently without symptoms	Asymptomatic		0
Mild major depressive disorder	Major depressive disorder, mild episode	feels persistent sadness and has lost interest in usual activities. The person sometimes sleeps badly, feels tired, or has trouble concentrating but still manages to function in daily life with extra effort.	0.145
Moderate major depressive disorder	Major depressive disorder, moderate episode	has constant sadness and has lost interest in usual activities. The person has some difficulty in daily life, sleeps badly, has trouble concentrating, and sometimes thinks about harming himself (or herself).	0.396
Severe major depressive disorder	Major depressive disorder, severe episode	has overwhelming, constant sadness and cannot function in daily life. The person sometimes loses touch with reality and wants to harm or kill himself (or herself).	0.658
Major depressive disorder, currently without symptoms	Asymptomatic		0
Anorexia nervosa	Anorexia nervosa	feels an overwhelming need to starve and exercises excessively to lose weight. The person is very thin, weak and anxious.	0.224
Intestinal perforation ~~due to typhoid~~	Abdominopelvic problem, severe	has severe pain in the belly and feels nauseous. The person is anxious and unable to carry out daily activities.	0.324
Stoma from colon and rectum cancers, beyond 10 years	Stoma	has a pouch attached to an opening in the belly to collect and empty stools.	0.095

Health impacts / Burden of Disease

Health and safety impact assumptions

Sequela	Health state name	Health state lay description	Disability Weight
Severe decubitus ulcer*	Disfigurement, level 3, with itch/pain	has an obvious physical deformity that is very painful and itchy. The physical deformity makes others uncomfortable, which causes the person to avoid social contact, feel worried, sleep poorly, and think about suicide.	0.576
Mild rheumatoid arthritis**	Musculoskeletal problems, upper limbs, moderate	has moderate pain and stiffness in the arms and hands, which causes difficulty lifting, carrying, and holding things, and trouble sleeping because of the pain.	0.117
Rectovaginal fistula	Rectovaginal fistula	has an abnormal opening between her vagina and rectum causing flatulence and feces to escape through the vagina. The person gets infections in her vagina, and has pain when urinating.	0.501
Chronic abdominal pain due to congenital atresia and/or stenosis of the digestive tract	Abdominopelvic problem, moderate	has pain in the belly and feels nauseous. The person has difficulties with daily activities.	0.114
Cirrhosis and other chronic liver diseases due to other, decompensated, with no anemia	Decompensated cirrhosis of the liver	has a swollen belly and swollen legs. The person feels weakness, fatigue and loss of appetite.	0.178
Cirrhosis and other chronic liver diseases due to other, decompensated, with moderate anemia	Decompensated cirrhosis of the liver and moderate anemia	(combined DW)	0.22
Cirrhosis and other chronic liver diseases due to other, decompensated, with severe anemia	Decompensated cirrhosis of the liver and severe anemia	(combined DW)	0.3
Mild psoriasis	Disfigurement, level 1 with itch/pain	has a slight, visible physical deformity that is sometimes sore or itchy. Others notice the deformity, which causes some worry and discomfort.	0.027
Moderate psoriasis	Disfigurement, level 2, with itch/pain	has a visible physical deformity that is sore and itchy. Other people stare and comment, which causes the person to worry. The person has trouble sleeping and concentrating.	0.188
Severe psoriasis	Disfigurement, level 3, with itch/pain	has an obvious physical deformity that is very painful and itchy. The physical deformity makes others uncomfortable, which causes the person to avoid social contact, feel worried, sleep poorly, and think about suicide.	0.576

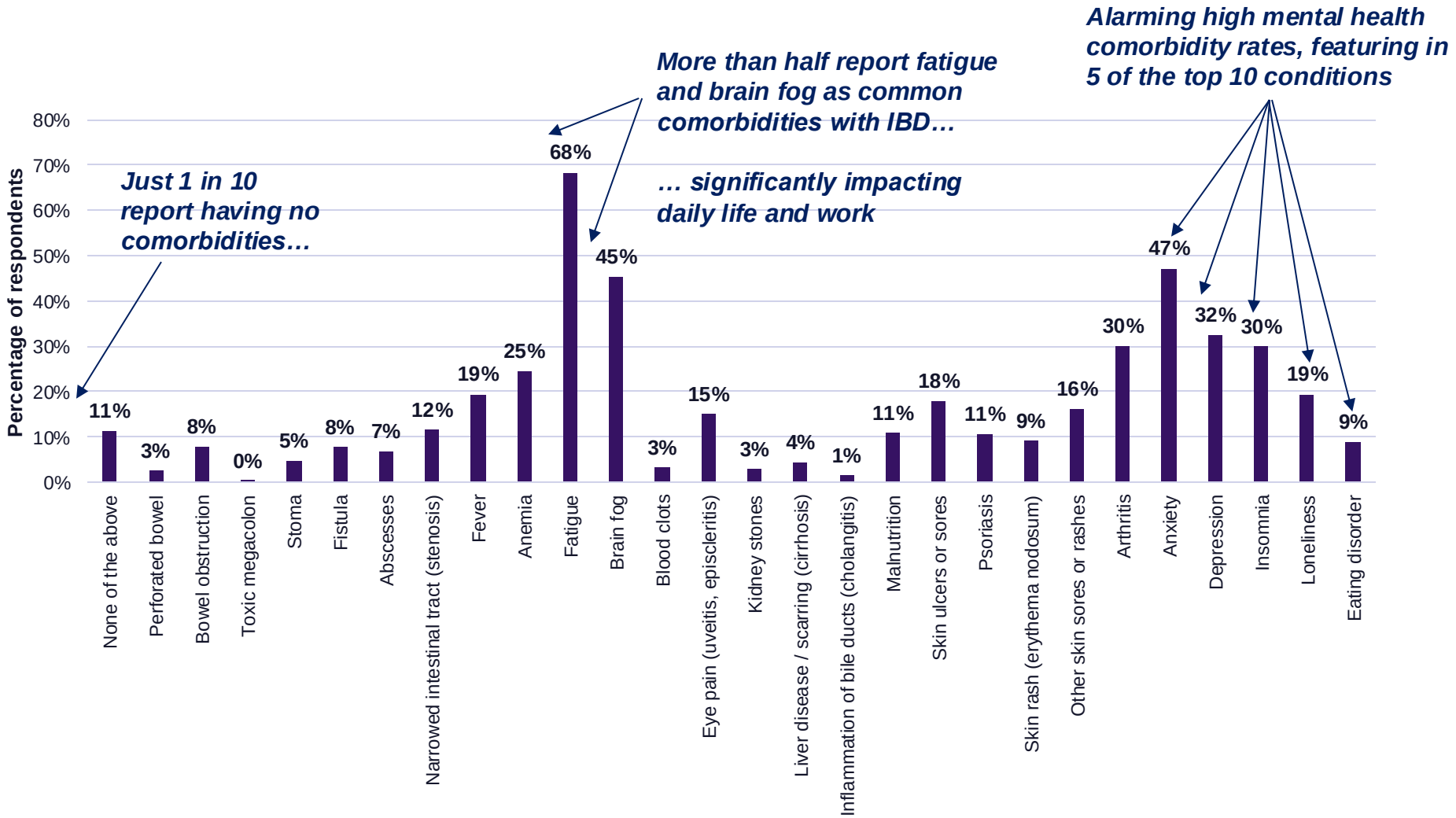
*Ulcers developed by IBD patients are termed pyoderma gangrenosum and a severe extra-intestinal manifestation of IBD with lesions having significant pain and scarring and patients often requiring hospitalization.

**Crohn's' and Colitis Foundation fact sheets reported the arthritis that complicates IBD is not as severe as rheumatoid arthritis. The joints do not ordinarily undergo destructive changes, and joint involvement is not symmetric (affecting the same joints on both sides of the body).

Source: Global Burden of Disease 2019

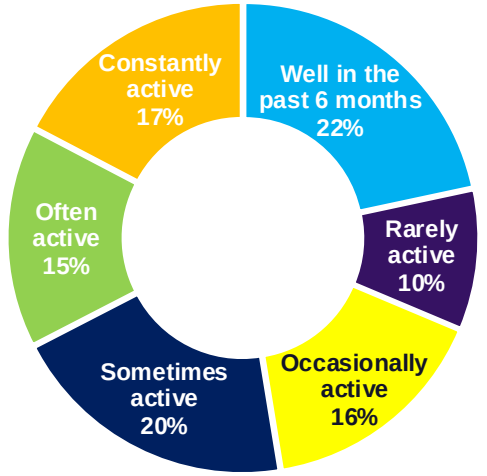
Rate of co-morbidities and disease severity for adults

Figure 20: Reported comorbidities - adults



Source: CCA Consumer Survey 2024

Figure 21: Reported severity - adults

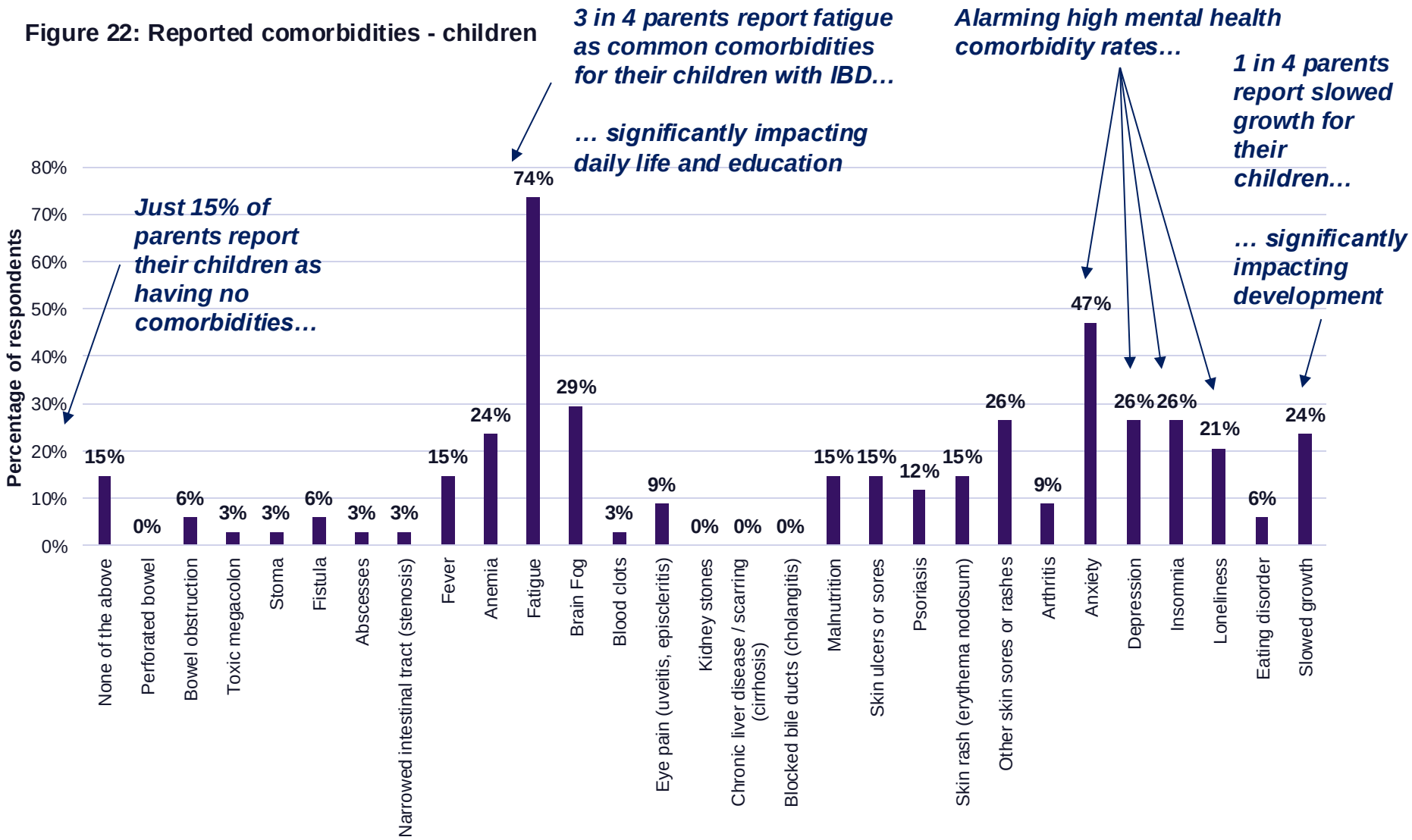


68% report active IBD exhibiting symptoms in the past 6 months – nearly 1 in 5 experience them every single day

Source: CCA Consumer Survey 2024

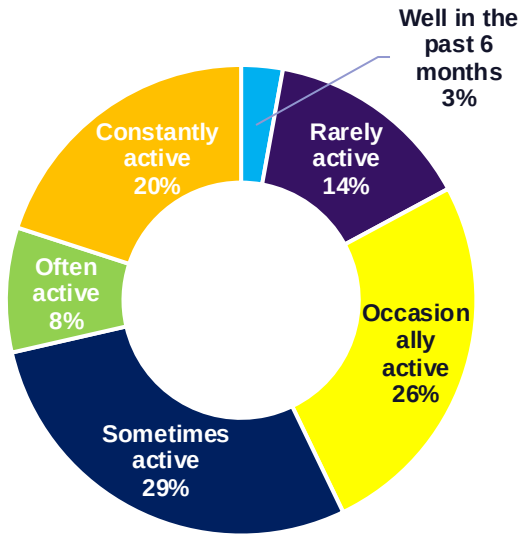
Rate of co-morbidities and disease severity for children

Figure 22: Reported comorbidities - children



Source: CCA Consumer Survey 2024

Figure 23: Reported severity - children



4 in 5 parents say their children have shown symptoms in the past 6 months – and 1 in 5 face them every single day

Source: CCA Consumer Survey 2024

Health and safety impact assumptions

Table 30: Disability weights for IBD health burdens

Health burden	Disability weight	Adults	Children
Ulcer + Fistula + Depression + Anxiety	0.658	1.4%	1.4%
Depression + Anxiety + Fistula	0.658	1.4%	0.0%
Ulcer + Fistula + Anxiety	0.576	1.2%	0.0%
Ulcer + Depression	0.658	6.5%	0.0%
Ulcer + Anxiety	0.576	1.9%	0.0%
Ulcer	0.576	3.7%	0.0%
Fistula + Depression + Anxiety (Severe)	0.658	1.2%	8.3%
Fistula + Depression + Anxiety (Moderate)	0.396	1.0%	0.0%
Fistula + Anxiety (Severe)	0.523	0.0%	20.8%
Fistula	0.501	0.0%	0.0%
Anxiety + Depression (Severe)	0.658	9.5%	4.2%
Anxiety + Depression (Moderate)	0.523	8.3%	0.0%
Depression (Severe)	0.658	0.7%	33.3%
Depression (Moderate)	0.396	0.6%	0.0%
Anxiety (Severe)	0.523	4.0%	0.0%
Anxiety (Moderate)	0.133	3.5%	0.0%

Health burden	Disability weight	Adults	Children
Asymptomatic IBD, but arthritis	0.117	4.6%	0.0%
Asymptomatic IBD, but psoriasis	0.118	0.9%	0.0%
Asymptomatic IBD, but anorexia	0.224	0.4%	0.0%
Asymptomatic IBD, but cirrohisis	0.3	0.4%	0.0%
Symptomatic IBD	0.231	39.1%	15.2%
Asymptomatic and no co-morbidities	0	9.7%	16.7%

Source: CCA Consumer Survey 2024 and Global Burden of Disease 2019

Economic and employment impacts

Employment costs

Diagnostics

- Blood tests
- Stool tests
- Biopsy
- Barium enema
- Imaging
- Colonoscopy / sigmoidoscopy
- Gastroscopy / endoscopy

Specialist

- Dermatologist
- Rheumatologist
- Hepatologist
- Psychiatrist
- Ophthalmologist
- Gastroenterologist

Primary and Allied Health Care

- GP
- Counselling support
- Dietitian
- Psychologist

Care at home

- Nutritional supplements
- Ostomy bags

Inpatients/ Hospital care

- Medications
- Accommodation
- Operating theatre fees
- Specialist fees
- Surgeon costs
- Assistant surgeon costs
- Anaesthetist fees
- Pharmaceutical costs
- After care costs
- PHI excess

Medications

- 5-Aminosalicytates (5-ASA)
- Corticosteriods
- S1P receptor modulators
- Biologics
- Janus kinase (JAK) inhibitors
- Other immunomodulators

Health impacts / Burden of Disease

- Years of life lost (YLL)
- Years lived with disability (YLD)

Economic and employment impacts

- Productivity losses
- Loss of tax revenue
- Welfare impacts
- Hiring costs
- Funeral costs
- Carer costs

Employment and education impacts

Figure 24: Impact on workforce participation

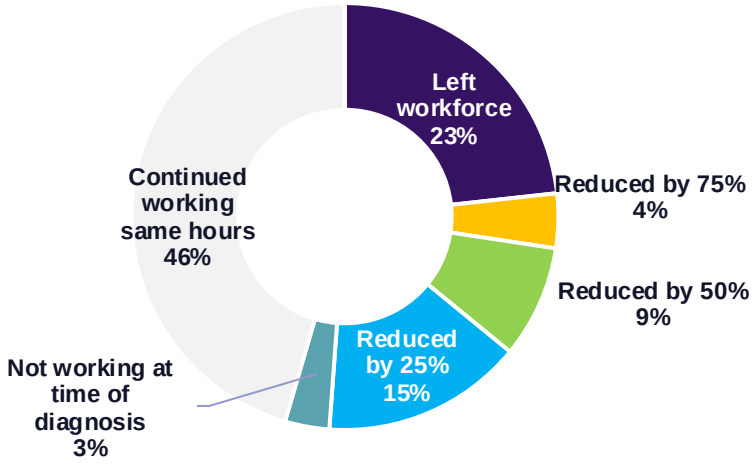
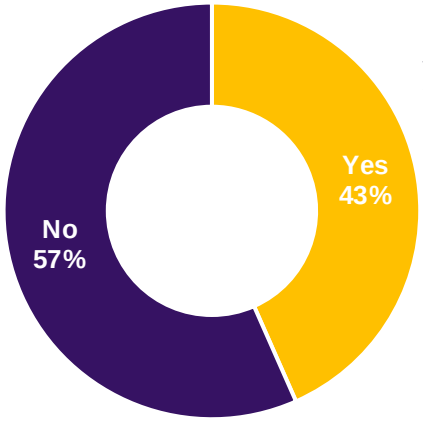


Figure 25: Impact on additional leave



30 days on average (20 days more than the standard 10 days of sick / carer's leave

Figure 26: Presenteeism

Has your IBD impacted your productivity at work?

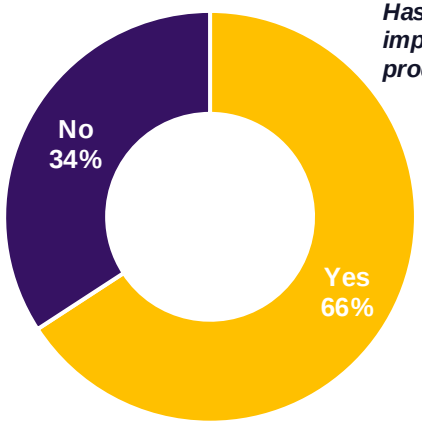


Figure 27: Carer workforce participation

Has your IBD diagnosis influenced the ability of your partner or other family member to work? / (Carers) Has their IBD influenced your ability to work?

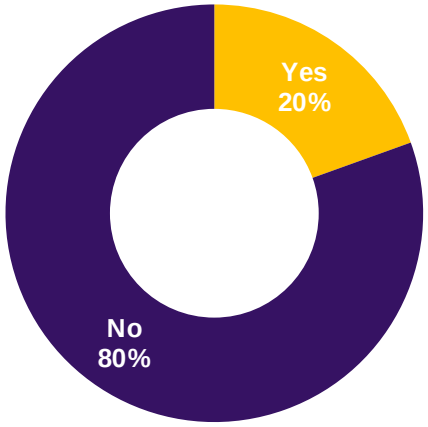


Figure 28: Carer leave

Has your IBD required your partner to take more carers or unpaid leave than would be normally expected?

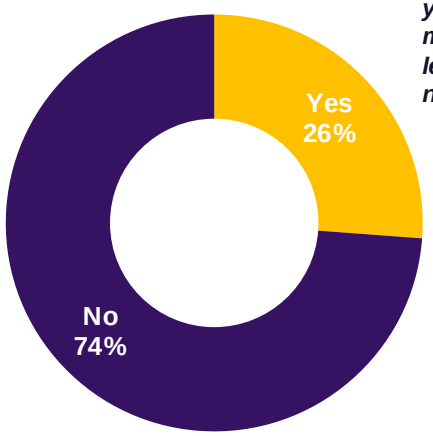
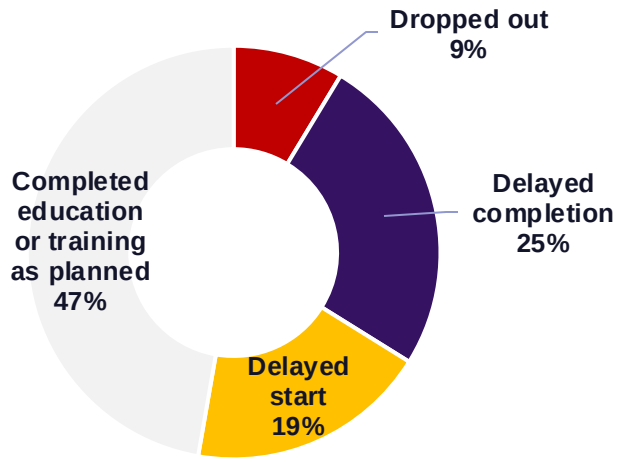


Figure 29: Impact on education and training



Source: CCA Consumer Survey 2024

Employment assumptions

Table 31: Employment assumptions

Cost item	Carers	Patients	Source
Average adult earnings per annum ($2024)	$96,170	$96,170	ABS, Average Weekly Earnings, Australia, May 2024
Average adult weekly earnings ($2024)	$1,923.40	$1,923.40	ABS, Average Weekly Earnings, Australia, May 2024
Average daily earnings ($2024)	$384.68	$384.68	ABS, Average Weekly Earnings, Australia, May 2024
Average hourly earnings ($2024)	$50.62	$50.62	ABS, Average Weekly Earnings, Australia, May 2024

Source: CCA Consumer Survey 2024

Productivity: impact on employment participation

Table 32: IBD impact on employment participation assumptions

	Patients	Carers	Source
Percentage out of the workforce that might otherwise be in	24%	1%	Survey
Reduced hours by 75%	4%	0%	Survey
Reduced hours by 50%	8%	1%	Survey
Reduced hours by 25%	15%	5%	Survey
If left workforce, accessing welfare support?*			
- Jobseeker single payment, no children	5%	0%	Survey
- Jobseeker single payment, dependents	0%	0%	Survey
- Jobseeker single payment, >55	1%	0%	Survey
- Jobseeker single payment, partnered	0%	0%	Survey
- Jobseeker single payment, prin. Carer	0%	0%	Survey
- Single Disability Support Payment	15%	0%	Survey
- Couple Disability Support Payment	1%	0%	Survey

Source: CCA Consumer Survey 2024

* Due to small sample size to this question (n=3), carer assumptions based on adult IBD responses.

Productivity: excess leave and presenteeism

Table 32: IBD impact on employment participation assumptions

	Patients	Carers	Source
Additional days of leave above standard sick / carer's leave allowance per annum	20 days	1 day	Survey
Proportion feeling less productive at work	66%	77%	Survey
How frequently less productive during last six months	26% of the time	35% of the time	Survey
Impact on productivity when feeling less productive	30% less productive than usual	25% less productive than usual	Survey

Source: CCA Consumer Survey 2024

Section 7: Economic impact modelling

Total economic impact

Table 33: Economic impact by cost and payer, through time ($millions)

Cost	Payer	2023	2024	2025	2026	2027	2028	2029	2030	2031	2032	2033	2034	2035
Diagnostics	Aus govt	$145.5	$155.2	$165.5	$176.4	$187.8	$199.8	$212.4	$225.7	$239.6	$254.2	$269.7	$286.0	$303.2
	State govt	$17.3	$18.5	$19.7	$21.0	$22.4	$23.8	$25.4	$26.9	$28.6	$30.4	$32.2	$34.2	$36.3
	PHI	$166.2	$177.4	$189.2	$201.7	$214.8	$228.6	$243.2	$258.5	$274.6	$291.5	$309.3	$328.1	$348.1
	Households	$58.2	$62.1	$66.2	$70.6	$75.1	$80.0	$85.0	$90.4	$96.0	$101.9	$108.1	$114.7	$121.6
	Total	$387.2	$413.1	$440.6	$469.6	$500.1	$532.2	$566.0	$601.5	$638.8	$678.0	$719.3	$763.0	$809.2
Medications	Aus govt	$658.7	$702.7	$749.4	$798.8	$850.7	$905.4	$962.9	$1,023.5	$1,087.1	$1,153.9	$1,224.2	$1,298.6	$1,377.4
	State govt*	$0.9	$1.0	$1.0	$1.1	$1.1	$1.2	$1.2	$1.3	$1.3	$1.4	$1.4	$1.5	$1.6
	PHI*	$12.1	$12.9	$13.8	$14.7	$15.7	$16.7	$17.8	$18.9	$20.1	$21.4	$22.7	$24.1	$25.5
	Households	$41.5	$44.3	$47.3	$50.4	$53.7	$57.2	$60.8	$64.7	$68.7	$72.9	$77.4	$82.1	$87.1
	Total	$700.3	$747.0	$796.6	$849.2	$904.5	$962.5	$1,023.8	$1,088.2	$1,155.8	$1,226.8	$1,301.6	$1,380.8	$1,464.6

Total economic impact

Economic impact by cost and payer, through time ($millions) (cont'd)

Cost	Payer	2023	2024	2025	2026	2027	2028	2029	2030	2031	2032	2033	2034	2035
Hospitalisations & Emergency Dept	Aus govt	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0
	State govt**	$171.7	$183.1	$195.1	$207.9	$221.2	$235.3	$250.1	$265.6	$281.9	$299.0	$317.0	$336.0	$356.2
	PHI**	$464.2	$495.0	$527.6	$562.0	$598.2	$636.1	$676.1	$718.1	$762.1	$808.3	$857.0	$908.5	$963.1
	Households	$32.1	$34.2	$36.5	$38.9	$41.5	$44.1	$46.9	$49.9	$53.0	$56.3	$59.7	$63.3	$67.2
	Total	$668.0	$712.3	$759.2	$808.9	$860.9	$915.5	$973.1	$1,033.6	$1,097.0	$1,163.6	$1,233.7	$1,307.9	$1,386.4
Specialists	Aus govt	$60.6	$64.6	$69.0	$73.5	$78.3	$83.4	$88.7	$94.4	$100.3	$106.5	$113.0	$119.9	$127.2
	State govt	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0
	PHI	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0
	Households	$43.9	$46.8	$50.0	$53.3	$56.8	$60.4	$64.3	$68.4	$72.7	$77.2	$81.9	$86.9	$92.2
	Total	$104.5	$111.5	$118.9	$126.8	$135.1	$143.8	$153.1	$162.7	$172.9	$183.6	$194.9	$206.8	$219.5

Total economic impact

Economic impact by cost and payer, through time ($millions) (cont'd)

Cost	Payer	2023	2024	2025	2026	2027	2028	2029	2030	2031	2032	2033	2034	2035
Primary & allied health	Aus govt	$61.2	$65.3	$69.6	$74.2	$79.0	$84.0	$89.3	$94.9	$100.8	$106.9	$113.4	$120.2	$127.5
	State govt	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0
	PHI	$10.9	$11.6	$12.4	$13.2	$14.0	$14.9	$15.9	$16.9	$17.9	$19.0	$20.1	$21.4	$22.7
	Households	$42.3	$45.1	$48.1	$51.3	$54.6	$58.1	$61.8	$65.6	$69.7	$74.0	$78.5	$83.2	$88.2
	Total	$114.3	$122.0	$130.0	$138.6	$147.6	$157.0	$166.9	$177.4	$188.3	$199.9	$212.0	$224.8	$238.4
Economics & employment	Aus govt	$906.0	$958.0	$1,012.7	$1,070.3	$1,130.4	$1,193.1	$1,258.8	$1,327.3	$1,398.9	$1,473.4	$1,551.5	$1,633.6	$1,720.0
	State govt	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0
	Industry	$740.8	$790.5	$843.3	$899.4	$958.3	$1,020.3	$1,085.7	$1,154.6	$1,227.0	$1,302.9	$1,383.0	$1,467.7	$1,557.5
	Households	$1,346.3	$1,445.6	$1,551.5	$1,664.2	$1,783.1	$1,908.9	$2,042.0	$2,182.6	$2,331.1	$2,487.3	$2,652.6	$2,827.9	$3,014.1
	Total	$2,993.1	$3,194.1	$3,407.5	$3,633.9	$3,871.8	$4,122.2	$4,386.4	$4,664.6	$4,956.9	$5,263.6	$5,587.1	$5,929.2	$6,291.6

Total economic impact

Economic impact by cost and payer, through time ($millions) (cont'd)

Cost	Payer	2023	2024	2025	2026	2027	2028	2029	2030	2031	2032	2033	2034	2035
Health outcomes	Aus govt	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0
	State govt	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0
	PHI	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0
	Households	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0
	Total	$1,611.7	$1,735.6	$1,850.2	$1,971.5	$2,099.5	$2,233.8	$2,374.9	$2,523.2	$2,679.0	$2,842.3	$3,014.1	$3,195.5	$3,387.2
Other household costs	Aus govt	$8.1	$8.6	$9.2	$9.8	$10.4	$11.1	$11.8	$12.5	$13.3	$14.1	$15.0	$15.9	$16.9
	State govt	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0
	PHI	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0
	Households	$254.4	$271.4	$289.4	$308.4	$328.5	$349.5	$371.6	$394.8	$419.2	$444.8	$471.8	$500.3	$530.5
	Total	$262.5	$280.0	$298.6	$318.2	$338.9	$360.5	$383.4	$407.3	$432.5	$459.0	$486.8	$516.2	$547.3

Total economic impact

Economic impact by cost and payer, through time ($millions) (cont'd)

Cost	Payer	2023	2024	2025	2026	2027	2028	2029	2030	2031	2032	2033	2034	2035
Total	Aus gvt	$1,840.1	$1,954.4	$2,075.3	$2,203.0	$2,336.6	$2,476.7	$2,623.9	$2,778.3	$2,940.0	$3,109.0	$3,286.7	$3,474.2	$3,672.3
	State gvt	$189.0	$202.6	$215.9	$230.0	$244.8	$260.3	$276.7	$293.9	$311.9	$330.8	$350.7	$371.8	$394.1
	Industry	$1,382.1	$1,488.0	$1,586.9	$1,691.7	$1,801.8	$1,917.5	$2,039.5	$2,167.9	$2,302.7	$2,444.2	$2,593.3	$2,751.0	$2,918.1
	Hhlds	$1,818.7	$1,949.6	$2,088.9	$2,237.1	$2,393.3	$2,558.1	$2,732.5	$2,916.4	$3,110.4	$3,314.4	$3,530.0	$3,758.5	$4,001.0
	Total	$6,841.6	$7,315.7	$7,801.7	$8,316.8	$8,858.4	$9,427.6	$10,027.5	$10,658.5	$11,321.5	$12,016.8	$12,749.5	$13,524.2	$14,344.2

Economic costs by severity

Table 34: Average costs per patient by disease severity

IBD severity	Total	Commonwealth	States / PHI	Consumers	Productivity losses	Burden of disease
Remission	$51,260.82	$12,495.40	$3,832.27	$17,595.14	$4,678.22	$12,659.79
Moderate	$86,531.96	$18,834.86	$6,433.59	$16,197.86	$4,116.57	$40,949.09
Severe	$126,724.03	$27,853.52	$12,236.90	$32,098.13	$12,209.43	$42,326.06
Average	$101,140.72	$22,422.14	$9,032.11	$24,991.15	$8,562.78	$36,132.54
Additional cost of severe disease	$75,463.21	$15,358.12	$8,404.63	$14,502.99	$7,531.21	$29,666.27
Additional cost average IBD to remission	$49,879.91	$9,926.74	$5,199.84	$7,396.01	$3,884.56	$23,472.76

Appendix D: Policy landscape review

This appendix summarises a rapid review of Australian government policy agendas related to IBD.

D.1 Commonwealth strategies: overview

There are a number initiatives in the policy landscape at both the Federal and State & Territory level that provide relevant context and important lessons for the development and prioritisation of key policy initiatives for improving systems and service delivery in IBD care and improving outcomes for all patients. The following slides address each of these initiatives in turn, including:

- The *National Strategic Framework for Chronic Conditions* established in 2017 and its recent 2023 review
- The *Australian Health Performance Framework* and the AIHW's chronic disease dashboards
- The *Primary Health Network (PHN) Program* established in 2015, and its associated *Performance and Quality Framework*
- The *Australian Cancer Plan*, released in 2023, including the *Australian Cancer Nursing and Navigation Program*
- The *National Nursing Workforce Strategy* which is currently under development, with the draft Strategy released for public consultation in September 2024
- The *Health Technology Assessment Review*, released September 2024
- A minority of State & Territory-based preventative health strategies and associated action plans with relevance for chronic conditions.

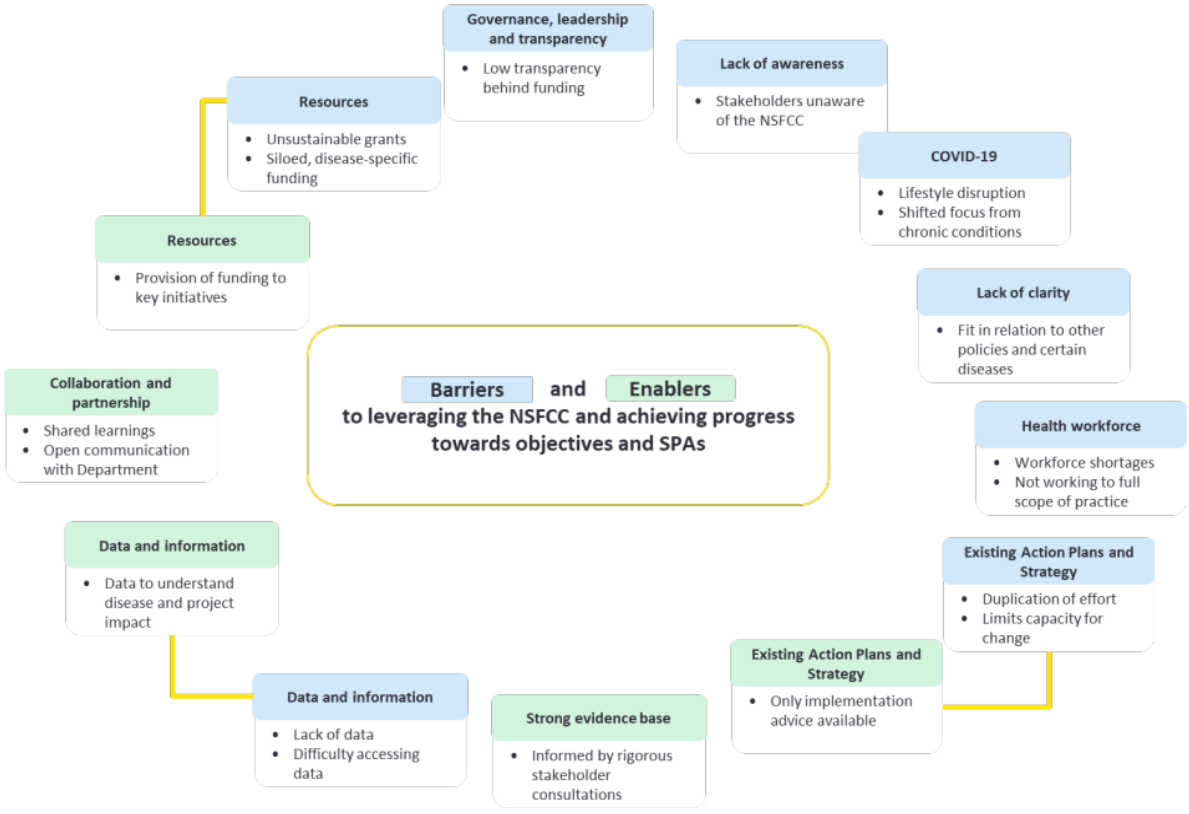
The National Strategic Framework for Chronic Conditions

The National Strategic Framework for Chronic Conditions (NSFCC) was developed by the CoAG Health Council and released in 2017, with the aim of providing strategic guidance with respect to an effective, coordinated, nation-wide response to chronic conditions, recognising that many chronic conditions share similar prevention and management approaches. Since its implementation, 11 National Action Plans and two strategies have been released that are specific to chronic conditions. In 2018, the AIHW was engaged to develop a monitoring and reporting framework for the NSFCC. The reporting framework identifies 45 indicators to measure the impact of the NSFCC and assess national progress against its objectives.

In December 2023, the Australian Government engaged Ernst & Young to undertake a review of the achievements of, and lessons from, the NSFCC to inform its scheduled refresh in 2025 and amplify its impact. The review found that the NSFCC has enabled activities related to its objectives and strategic priority areas to varying degrees, with stakeholders expressing concern that the NSFCC may in fact fuel the unintended outcomes of more siloed

disease-specific activity due to funding competition. It also found that the absence of measurable actions in the NSFCC created challenges in implementation and measurement of progress, and that actions are detailed in disease-specific Action Plans, contributing to fragmentation in implementation at the disease-specific level.

Figure D.1: Barriers and enablers to leveraging the NSFCC &/or achieving its intended outcomes



Australian Health Performance Framework and AIHW chronic disease dashboards

The Australian Health Performance Framework (AHPF) is a tool for reporting on the health of Australians, the performance of health care in Australia and the Australian health system. Data is collected and published by the AIHW against 45 indicators.

While the AHPF provides a robust framework as a foundation for evaluation, indicator metrics focus overwhelmingly on determinants of health (Figure 2), and do not provide data that can comprehensively evaluate health system performance, particularly with respect to efficiency measures and as relevant for chronic conditions including IBD.

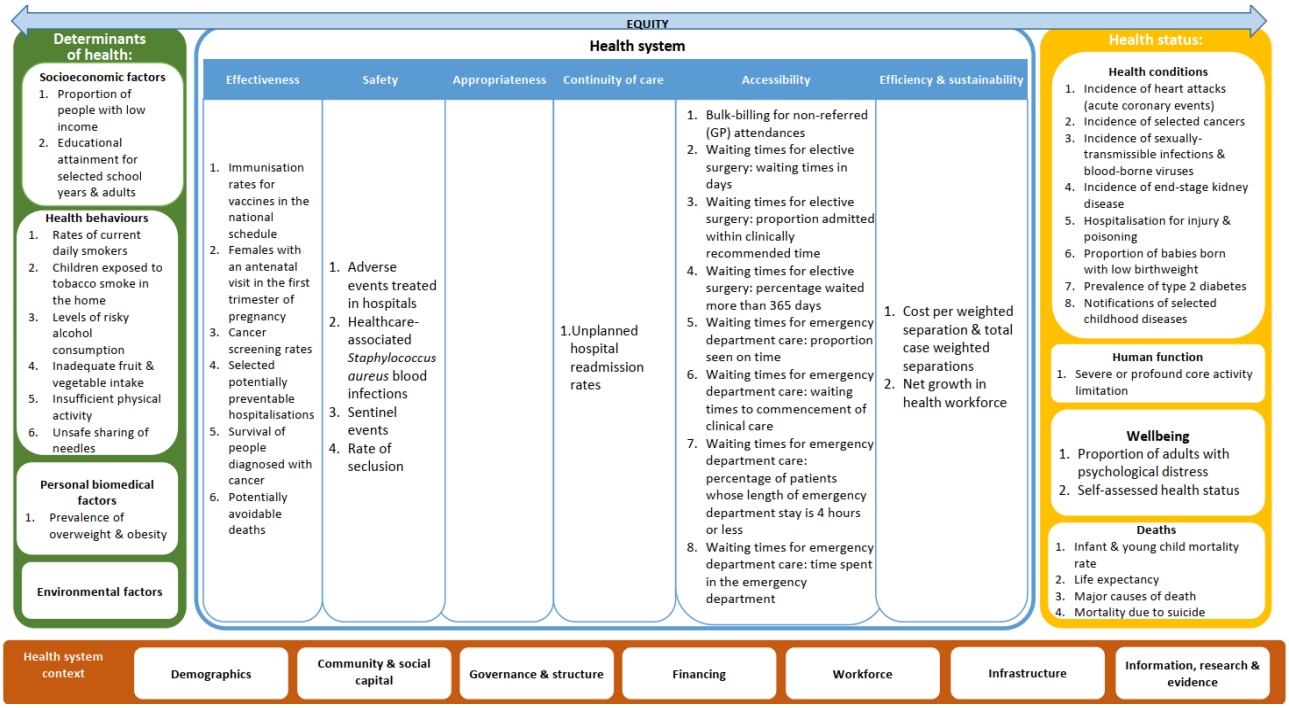
This focus is similarly reflected in the State & Territory Government health strategies on chronic conditions, which largely focus on the common modifiable risk factors such as smoking, diet and nutrition, and mental health (Figure D.2).

In addition, there are currently no indicators under the dimension of appropriateness such as those measuring the patient experience, although the Australian Commission on Safety and Quality in Health Care is currently working to develop indicators for this dimension.

The AIHW's chronic disease dashboards for conditions such as type 2 diabetes, cardiovascular and chronic kidney disease, show distribution of impact including prevalence, hospitalisation and death rates at different geographical levels, alongside profiles of health and selected population characteristics. These dashboards provide important supplementary data to the AHPF that could be similarly collected for IBD, to inform a granular view of

where variation to adherence to best practice treatment is occurring and assist in identifying and addressing unmet need.

Figure D.2: Australian Health Performance Framework – Initial set of core indicators



Primary Health Network Program Performance and Quality Framework

The Primary Health Networks (PHN) Program was established in 2015, when 31 PHNs were established and assigned responsibility in identifying and addressing the areas of primary health needs in their region and improving outcomes through strategic planning, commissioning of services, supporting general practitioners and other healthcare providers, and supporting the integration of local healthcare services.

The PHN Program has two program objectives and seven priority areas (Table 1), with both individual PHNs and the PHN Program overall evaluated on the basis of a Performance and Quality Framework (Figure 3. The Framework identifies five outcome themes linked to the Program objectives, with outcomes identified for each theme. Progress against these outcomes is then monitored and assessed via indicators. These 54 indicators are made up of 39 performance indicators and 15 organisational indicators, with each outcome associated with selected indicators and the source of data for each indicator identified (see Figure D.3).

Figure D.3: PHN Objectives and outcomes

PHN Program Objectives	PHN priority areas for targeted work
Increase the efficiency and effectiveness of medical services, particularly for patients at risk of poor health outcomes. Improve coordination of care to ensure patients receive the right care in the right place at the right time.	Mental Health Aboriginal and Torres Strait Islander Health Population Health Workforce Digital Health Aged Care Alcohol and Other Drugs

Outcomes	Indicators	Data Provision
Addressing Needs: PHN activities and initiatives address local needs	P1 PHN activities address prioritised needs	PHN
	P2 Health system improvement and innovation	PHN
	To be developed: an indicator of health literacy in each PHN region	TBD
Quality Care: PHNs support general practices and other health care providers to provide quality care to patients	P3 Rate of general practice accreditation	PHN
	P4 Support provided to general practices and other health care providers	PHN
	P5 Rate of regular uploads to My Health Record	ADHA

Case study in chronic disease: The Australian Cancer Plan

In 2023, the Commonwealth Government released the *Australian Cancer Plan* (ACP) with the purpose of improving cancer outcomes for all Australians and achieving equity in cancer outcomes, in particular those from priority populations whose health outcomes are currently the poorest. To achieve this, the ACP's conceptual framework (Figure D.4) identifies six Strategic Objectives. The *Enhanced Consumer Experience* Strategic Objective provides lessons for the IBD sector in its focus on the delivery of a personalised model of consumer navigation in cancer care.

Figure D.4: Australian Cancer Plan Conceptual Framework

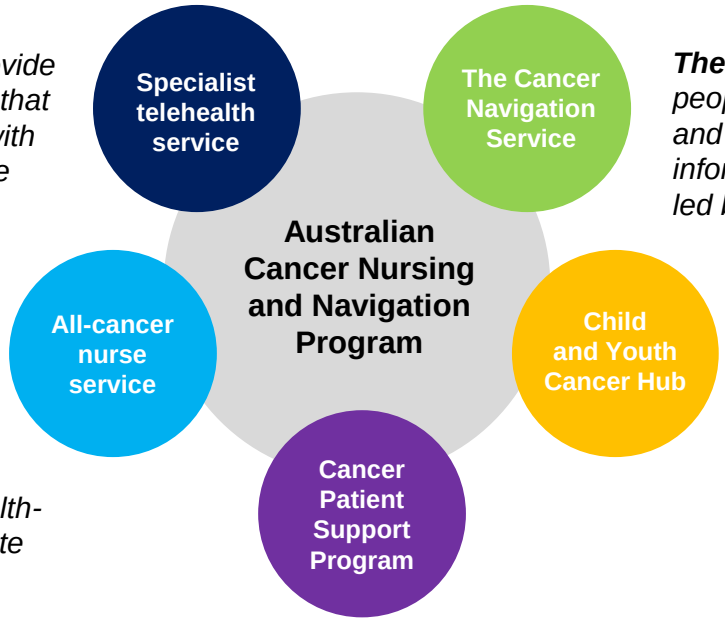
These person-centred, navigation models of care will be nationally defined, co-designed, developed and tested with consumers. These nationally integrated models of cancer care will provide personalised care across the cancer continuum that accommodates consumer cultural and social needs and enables consumer involvement in decision making through the provision of access to appropriate information, clear communication, and the adaptation of community support systems.

The existing workforce will be re-oriented to enable this enhanced consumer experience, including the modification of workforce training programs to prepare workers for personalised models of care and the adoption of strategies to ensure a fair distribution of the cancer health workforce. This includes the *Australian Cancer Nursing and Navigation Program*.

As part of the ACP, $166 million has been invested to establish a new *Australian Cancer Nursing and Navigation Program*. The program will ensure all people with cancer have access to high quality and culturally safe care, irrespective of their cancer type or location. The program includes multiple components, as shown in Figure D.5.

Figure D.5: Australian Cancer Nursing and Navigation Program

The specialist telehealth service *will provide specialist information, support and advice that is tailored to the unique needs of people with particular tumour types. The service will be delivered by the cancer NGO sector.*



The Cancer Navigation Service *will connect people to multidisciplinary telehealth teams and refer people to clinically appropriate information and services. The service will be led by Cancer Council Australia*

The all-cancer nurse service*, led by the McGrath Foundation in partnership with the cancer sector, will deliver around 250 Commonwealth-funded all-cancer nurses in health and hospital services across Australia. This is in addition to the existing Commonwealth-funded prostate cancer nurses that the Prostate Cancer Foundation of Australia deliver.*

The Child and Youth Cancer Hub *will deliver cancer navigation, support and counselling services for children and young people with cancer and their families. Canteen will lead the Hub in collaboration with Camp Quality and Redkite.*

The Cancer Patient Support Program *involves a $16.5 million investment to lead the way to better outcomes for patients in priority populations and focus on increasing equity across tumour types.*

The National Nursing Workforce Strategy (Draft)

The *National Nursing Workforce Strategy* is currently under development, with the draft Strategy released for public consultation in September 2024. The Strategy will establish priorities to guide the current and future nursing workforce, providing a strategic approach to future workforce planning, investment and reform. It is intended to guide long-term reform for workforce sustainability and planning, diversity within the nursing profession, pathways from novice to expert for nurses, and practices for data sharing.

The Strategy's framework and actions will align with areas that are crucial for nursing support of patients living with IBD, including supporting nurses to work at their full scope of practice, enabling nurses to deliver quality, evidence-based, person-centred care, and sustaining a nursing workforce including in regional, rural and remote areas.

Stage 1 of public stakeholder consultation took place between September 2023 and February 2024, with a consultation and research summary report released in May 2024. The report identified that nurses' roles and skills need to be optimised in line with changing community needs, noting that Australians are living longer but doing so with chronic conditions, with stakeholders suggesting that nurses' scope of practice could be optimised to ensure they are able to meet these changing community needs. The report also noted that there is a need to improve planning for future nursing workforce needs and that nurses in regional, rural and remote areas face additional challenges.

These findings align with the nursing needs identified for Australians with chronic conditions, including IBD. A workforce strategy that establishes an approach to plan and invest in growing the capacity of the nursing and other workforce to meet the specific needs of patients with IBD would enable a strategic approach to ensuring high-quality, best practice care is available to all patients with IBD.

The Draft Strategy identified the following actions relevant to IBD:

Value

1.1 Invest in nurse leadership.

1.4 Support internationally qualified nurses to transition into Australia’s health and aged care system.

1.5 Modernise the identity of nursing.

Plan

2.1 Implement nationally coordinated nursing workforce data, modelling and planning.

2.2 Implement strategies that enhance workforce mobility and flexibility.

Design

3.1 Prepare and engage the nursing workforce to drive the innovation and use of emerging technologies.

3.2 Grow nurse leadership and involvement in the design and delivery of innovative models of care.

3.4 Create and embed funding models that drive evolution and enhancement of nursing practice.

3.5 Enable nurses to work to their optimum scope of practice in all settings.

Deliver

4.2 Develop a national professional development framework.

4.4 Develop a national career framework.

4.5 Build and grow nurse clinical-academic/research career pathways.

4.6 Develop a dedicated rural and remote recruitment and retention strategy (inclusive of students).

D.2 State and territory strategies: overview

State & Territory plans focus on common modifiable risk factors, including some established risk factors for IBD—unhealthy eating & poor diet, smoking & tobacco use, and mental health.

Most plans include some focus on priorities and/or actions in improving outcomes related to these modifiable risk factors. For example, improving healthy eating, reducing tobacco and vaping use, and improving emotional well-being & mental health.

However, no plan specifically mentions IBD. Two plans mention bowel cancer, but not in relation to IBD.

The National Strategic Framework for Chronic Conditions and Australian Cancer Plan, along with a minority of State-base plans, identify system-level actions with relevance for improvements in IBD care.

There are the beginnings of action and indicator development with relevance to chronic conditions at local levels. For example, the WA Primary Health Alliance has a new Performance Management Framework and Commissioned Services Reporting Portal, with several indicators that are identified as required reporting for chronic conditions commissioned service providers and include improved health equity, improved patient experience and improved health outcomes domains. However, no clinical reporting systems in line with international best practice are in place.

Table D.1: Overview of state and territory government strategies related to IBD

Jurisdiction & Strategy	Elements related to IBD
Prevention Strategic Framework 2017 to 2026 **(Queensland Health)**	• Includes focus on unhealthy eating/poor diet & smoking (risk factors for IBD). Focus on healthy eating and being smoke-free. • No mention of IBD. • No specific actions.
Health, Well and Thriving – The Northern Territory's prevention and early intervention framework for chronic conditions, 2024-2030	• Includes focus on unhealthy eating/poor diet, smoking & mental health (risk factors for IBD). Focus on healthy eating, reducing tobacco and vaping use, & emotional well-being. • No mention of IBD. • Number of actions focused on reducing tobacco use and increasing healthy eating.
Healthy Canberra ACT Preventative Health Action Plan, 2023-2025	• Includes focus on unhealthy eating/poor nutrition & smoking (risk factors for IBD). Priority areas include increasing healthy eating and reducing risky behaviours, including smoking. • Priority population includes people with mental health conditions.

Jurisdiction & Strategy	Elements related to IBD
	• No mention of IBD. • 10 actions focused on increasing healthy eating (p.26-27). 5 actions focused on reducing smoking (p.32). • Action: Promote participation in screening programs for breast, cervical and bowel cancer in the ACT community.
Western Australian Health Promotion Strategic Framework, 2022-2026	• Includes focus on unhealthy eating/poor diet, tobacco smoking & mental wellbeing (risk factors for IBD). Focus on healthy eating and making smoking history. • No mention of IBD. Bowel cancer mentioned once. Mental health mentioned as chronic disease. • Number of actions focused on reducing tobacco use and increasing healthy eating.
WA Chronic Conditions Outcomes Framework (Consultation Draft as at June 2023)	• Aims to improve program and service planning, coordination and delivery, guide investment through strategic commissioning and procurement, and provide guidance for how community-level programs and services can align with state-level priorities and outcomes. • No mention of IBD. • No specific actions, but suggested strategies for each outcome in Appendix. Suitable indicators and/or measurement approaches to be developed to measure headline outcomes.
State Public Health Plan, 2019-2024 **(SA Health)**	• Includes focus on unhealthy eating/poor diet & smoking (risk factors for IBD). Focus on healthy eating and being smoke-free. • Suggests potential action areas, including healthy eating & reducing tobacco use. Identifies SA Health commitments. • No mention of IBD.
Healthy Tasmania Five-Year Strategic Plan, 2022-2026	• Includes focus on unhealthy eating/poor diet & smoking (risk factors for IBD). Focus areas include mental health & wellbeing, eating well, smoke-free communities. • No mention of IBD. • Number of actions focused on improving mental health, eating well, and reducing smoking.
Victorian Public Health and Wellbeing Plan, 2023-2027	• Includes focus on tobacco use & dietary risks (risk factors for IBD). Priority areas include increasing healthy eating, reducing harm from tobacco & e-cigarette use, improving wellbeing. • No mention of IBD. • Targets & measures in associated Victorian public health and wellbeing outcomes framework on increasing healthy eating, reducing harm from tobacco & e-cigarette use, improving wellbeing.
Future Health – Guiding the next decade of care in NSW, 2022-2032	• Focus on modifiable risk factors including tobacco use & poor diet (risk factors for IBD). Key objectives include mental health & wellbeing, • No mention of IBD.

Appendix E: Stakeholders consulted

This appendix summarises the stakeholders consulted through the course of the research project.

Organisation	Stakeholder name
Advanced Pharmacy Australia	Sheridan Rodda
Alfred Health, Dietitians Crohn's Colitis Australian Network	Dr Emma Halmos
Australia and New Zealand IBD Consortium	A/Prof Jakob Begun
Australian National University	Prof Paul Pavli
Crohn’s Colitis Cure, The Royal Adelaide Hospital, University of Adelaide	Prof Jane Andrews
Crohn’s Colitis Cure	Bill Petch
Crohn’s Colitis Cure	Joseph Pipicella
Crohn’s Colitis Cure	Dr Wai Kin Su
Colorectal Surgical Society of Australia and New Zealand	Dr Hugh Giddings
Consumer	Blake Tierney
Consumer	Rose Mitchell
Consumer	Julie Weldon
Consumer	A/Prof Kelly Lambert
Crohn’s & Colitis Australia	Bruce Goodwin
Crohn’s & Colitis Australia	Dr Eva Jenkins
Crohn’s & Colitis Australia	Leanne Raven
Crohn’s & Colitis Australia	Wayne Massuger
Crohn's and Colitis Canada	Kate Lee
Deakin University	Prof Antonina Mikocka-Walus
Department of Health and Aged Care	Dr Leanne Laajoki
Department of Health and Aged Care	Vanessa Burgess
Department of Health and Aged Care	Chris Carlile

Organisation	Stakeholder name
Department of Health and Aged Care	Charika Herath Mudiyanselage
Department of Health and Aged Care	Frances Rice
Department of Health Victoria	Dr Lance Emerson
Dietitians Crohn's Colitis Australian Network	Jessica Fitzpatrick
Gastroenterological Nurses College of Australia	Daniel Lightowler
Gastroenterologists Society of Australia	Jacquie O'Brien
Gastroenterologists Society of Australia	Dr Ray Boyapati
IBD Nurses Australia	Carly Bramley
Monash University	A/Prof Gregory Moore
Monash University, Monash Health	A/Prof Edward Giles
NSW Health	Alexandra Sechi
Queensland Department of Health	Paul Hassad
Queensland Department of Health	Prof Gerald Holtmann
Queensland Department of Health	Dr Gareth Walker
Queensland Department of Health	Dr Asif Shahzad
Queensland Department of Health	Dr Amanda Whaley
Royal Australian College of General Practitioners	A/Prof Jane Smith
Royal Australasian College of Surgeons	Michael Johnston
Royal Melbourne Hospital	Prof Finlay Macrae
St Vincent's Hospital Melbourne	Ruth Malcolm
Sunshine Coast University Private Hospital	Dr Lauren White
Swinburne University	A/Prof Simon Knowles
Tasmanian Department of Health	Hannah Paal
Tasmanian Department of Health	Michael Parker
Tasmanian Department of Health	Markeeta Matthews
Tasmanian Department of Health	Sally Badcock
The Queen Elizabeth Hospital, SA	A/Prof Rob Bryant
University of NSW	Prof Michael Kidd
Royal Prince Alfred Hospital, University of Sydney	Prof Michael Solomon
Western Australian Department of Health	Dr Simon Towler

Appendix F: Project governance

The project was overseen by Crohn's & Colitis Australia's IBD State of the Nation Project Advisory Committee. Committee members are shown below.

Name	Organisation
A/Prof Gregory Moore (Chair)	Monash University, Monash Health, CCA board
Prof Antonina Mikocka-Walus	Deakin University
Blake Tierney	Living with IBD
Bruce Goodwin	CCA Board
Daniel Lightowler	Royal Prince Alfred Sydney
A/Prof Edward Giles	Monash University, Monash Health
Dr Emma Halmos	Alfred Health (DECCAN)
Dr Eva Jenkins	Crohn's & Colitis Australia
Dr Hugh Giddings	Royal Prince Alfred Sydney
Prof Jane Andrews	Royal Adelaide Hospital/Adelaide University
A/Prof Jane Smith	James Bond University
Julie Weldon	Living with IBD
A/Prof Kelly Lambert	Living with IBD
Leanne Raven	Crohn's & Colitis Australia
Prof Paul Pavli	Australian National University
A/Prof Rob Bryant	The Queen Elizabeth Hospital, SA
Rose Mitchell	Living with IBD
Ruth Malcolm	St Vincent's Melbourne
Sheridan Rodda	Monash Health
A/Prof Simon Knowles	Swinburne University
Wayne Massuger	Crohn's & Colitis Australia