State of the Nation in Inflammatory Bowel Disease in Australia: Summary Report

February 2025

Crohn's & Colitis Australia

Insight Economics
Public Policy Corporate Strategy

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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 Current estimates are outdated and there is a need to establish new evidence from which to plan the next important steps to improve quality of life for people living fearlessly with IBD.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.

L.K. Raven.

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Acknowledgements

Insight Economics would like to acknowledge the community of people living with IBD and the incredible work of Crohn’s & Colitis Australia and its partners to support the development of this report.

The strong engagement of people with lived experience, governments and thought leaders from the IBD clinical and research community have made it possible to gather the evidence and identify the priorities for action. Without their insights and ideas, this report would not be possible.

Thank you to the more than 567 people living with IBD from across Australia participated in the survey of people and carers living with IBD. We are grateful for your time and help to better understand the impacts and costs of IBD for you and your families.

Thank you to the stakeholders that participated in the many one-on-one interviews, focus groups and workshops to inform our understanding of progress to date, opportunities for improvement and priorities for change. We appreciate your time, energy and ideas to help improve outcomes for people living with IBD everywhere.

Key stakeholders supporting the development of this report included:

Sheridan Rodda	Advanced Pharmacy Australia
Dr Emma Halmos	Alfred Health, Dietitians Crohn's Colitis Australian Network
A/Prof Jakob Begun	Australia and New Zealand IBD Consortium
Prof Paul Pavli	Australian National University
Prof Jane Andrews	Crohn’s Colitis Cure, The Royal Adelaide Hospital, University of Adelaide
Bill Petch	Crohn’s Colitis Cure
Joseph Pipicella	Crohn’s Colitis Cure
Dr Wai Kin Su	Crohn’s Colitis Cure
Dr Hugh Giddings	Colorectal Surgical Society of Australia and New Zealand
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Julie Weldon	Consumer
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Ruth Malcolm	St Vincent's Hospital Melbourne
Dr Lauren White	Sunshine Coast University Private Hospital
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Sally Badcock	Tasmanian Department of Health
A/Prof Rob Bryant	The Queen Elizabeth Hospital, SA
Prof Michael Kidd	University of NSW
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Summary Report

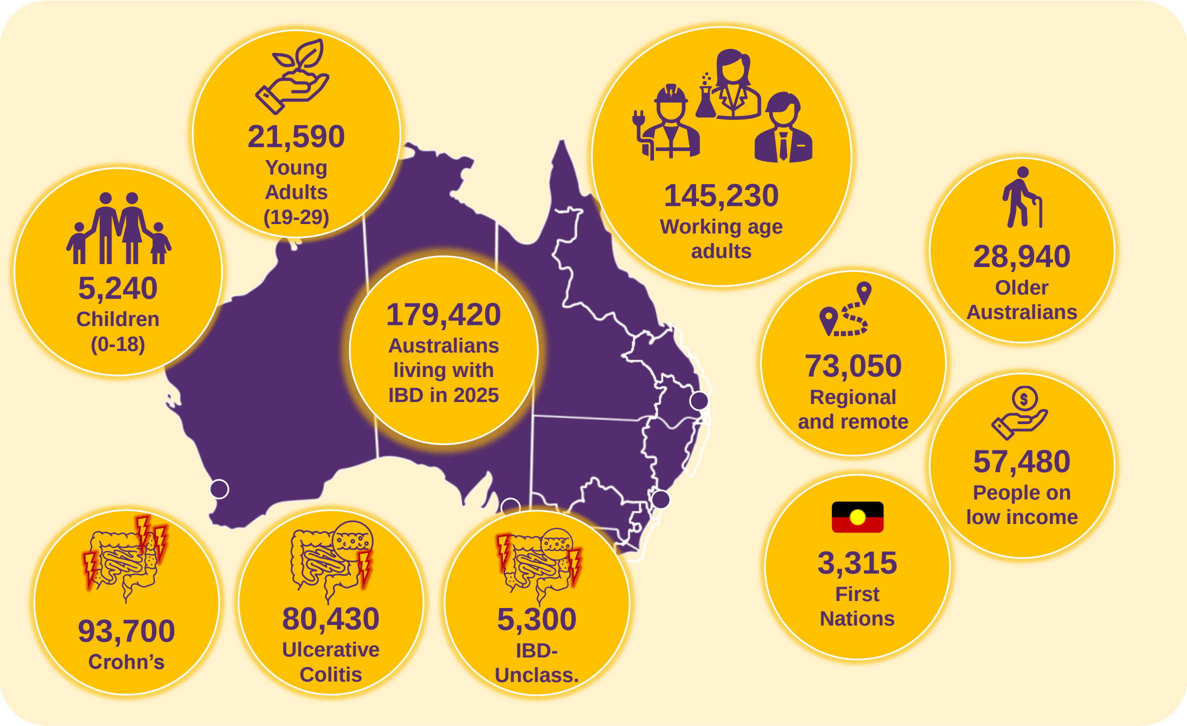
Understanding inflammatory bowel disease

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

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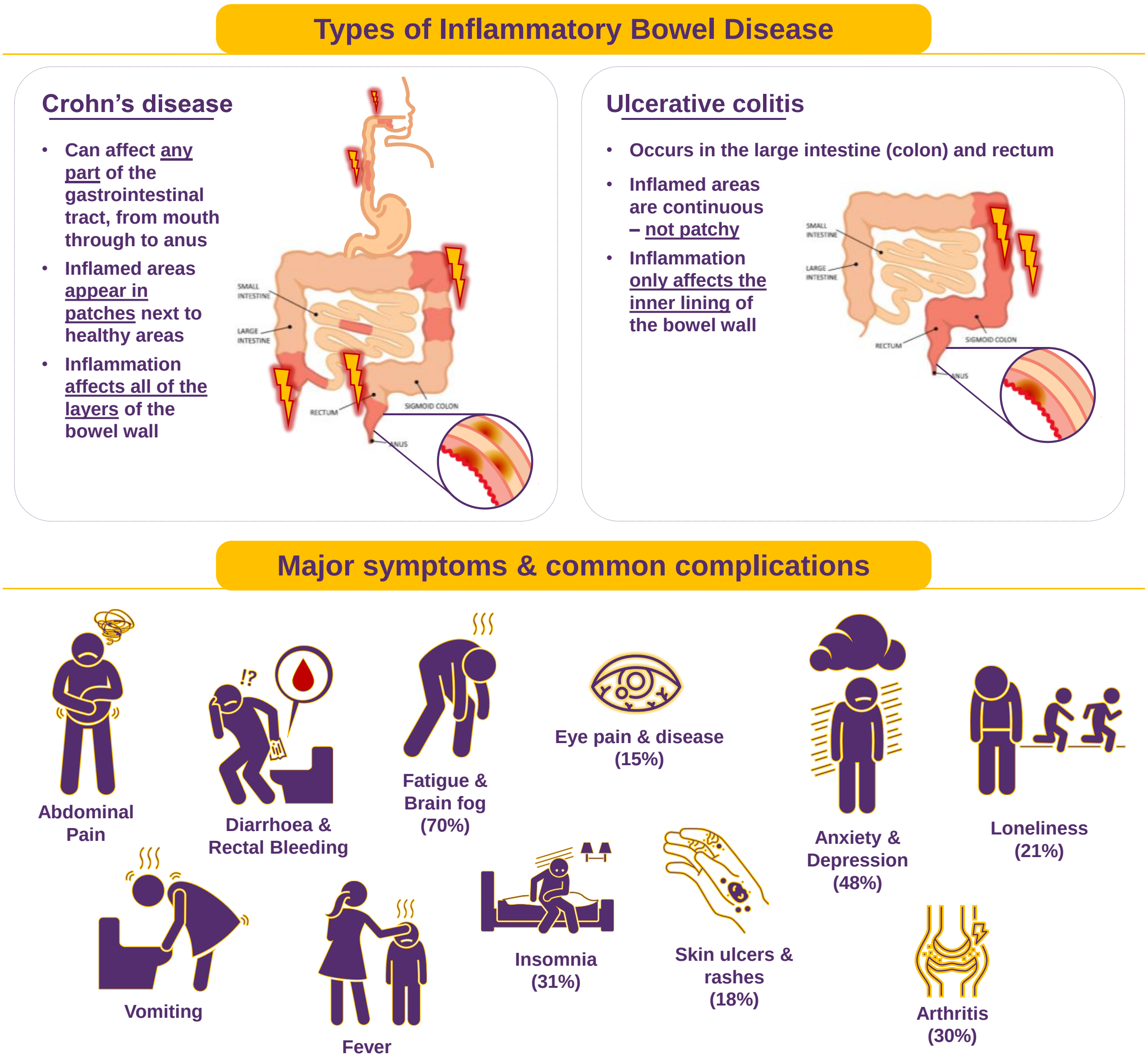
[1] Gastroenterological Society of Australia, editor. 2018. *Clinical update for general practitioners and physicians : Inflammatory Bowel Disease* Gastroenterological Society of Australia, [Melbourne, Vic.] viewed 9 May 2024 http://nla.gov.au/nla.obj-2712116930.

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



Types of Inflammatory Bowel Disease

Crohn's disease

- Can affect any part of the gastrointestinal tract, from mouth through to anus
- Inflamed areas appear in patches next to healthy areas
- Inflammation affects all of the layers of the bowel wall

Ulcerative colitis

- Occurs in the large intestine (colon) and rectum
- Inflamed areas are continuous – not patchy
- Inflammation only affects the inner lining of the bowel wall

Major symptoms & common 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

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[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.

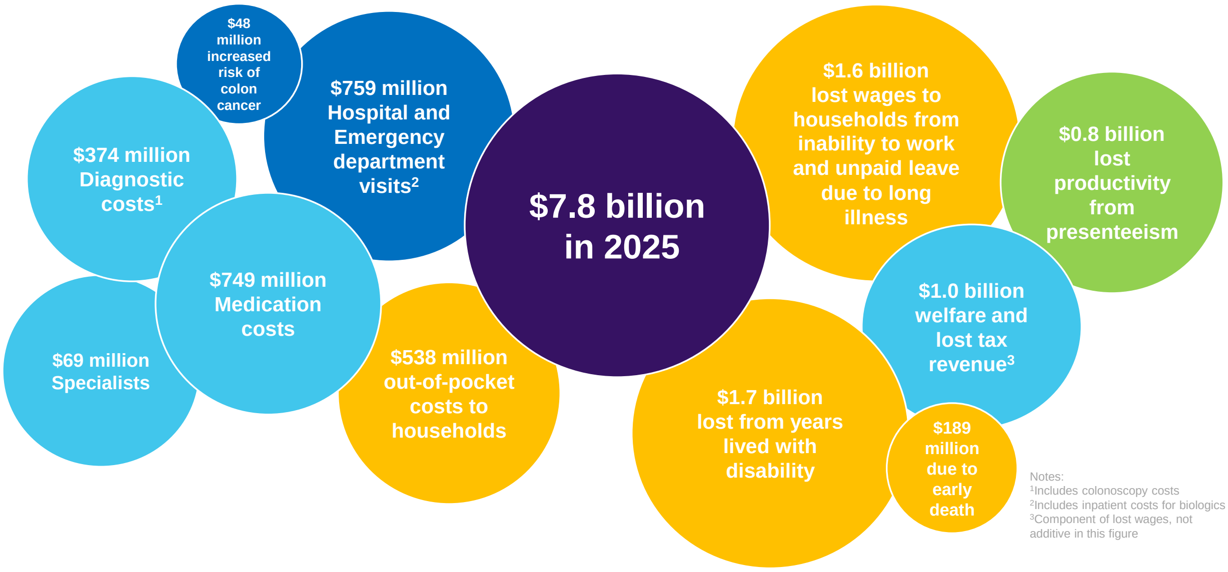
A similar pattern was observed for children with their parents reporting that their IBD created serious challenges for having an active social life, including their ability to participate in sports, their ability to sleep well at night, their ability to go to school and their ability to have friends.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



Notes:
[1] Includes colonoscopy costs
[2] Includes inpatient costs for biologics
[3] Component of lost wages, not additive in this figure

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

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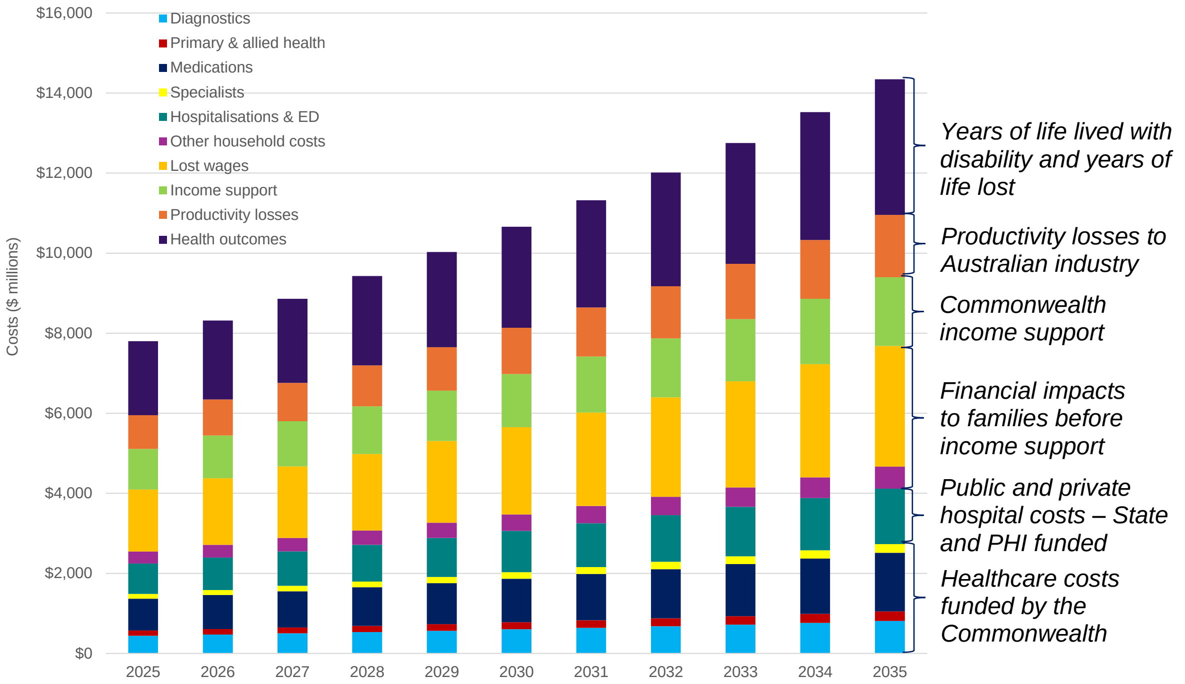
[3] Mattar, M. C., Lough, D., Pishvaian, M. J., & Charabaty, A. (2011). Current management of inflammatory bowel disease and colorectal cancer. Gastrointestinal cancer research : GCR, 4(2), 53–61; and Carchman E. (2019). Crohn's Disease and the Risk of Cancer. Clinics in colon and rectal surgery, 32(4), 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 $77.9 billion in net present value (NPV) terms, discounted at a social discount rate of 7 per cent ($\text{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

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[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.

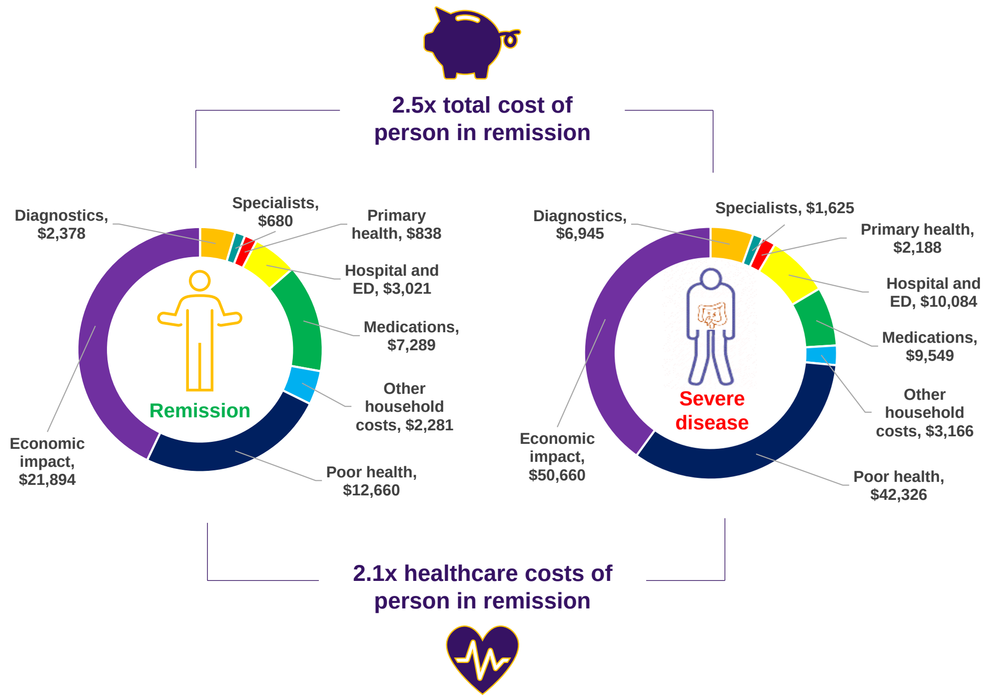
High-quality care for IBD should prioritise sustaining long-term remission through comprehensive, patient-centred management plans that include regular monitoring, early proactive treatments and personalised treatment adjustments.[5]

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.

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[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

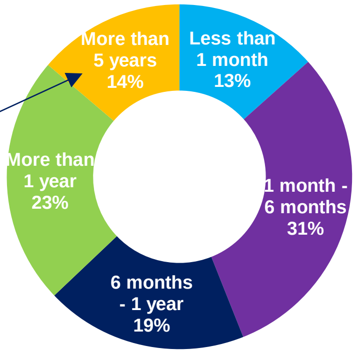
In spite of these high health and economic costs associated with poor disease management, there is evidence to suggest that Australian IBD patients are falling through the cracks.

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.

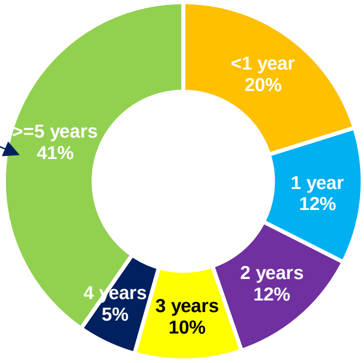


Source: State of the Nation Survey of People Living with Inflammatory Bowel Disease (See Appendix B).

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

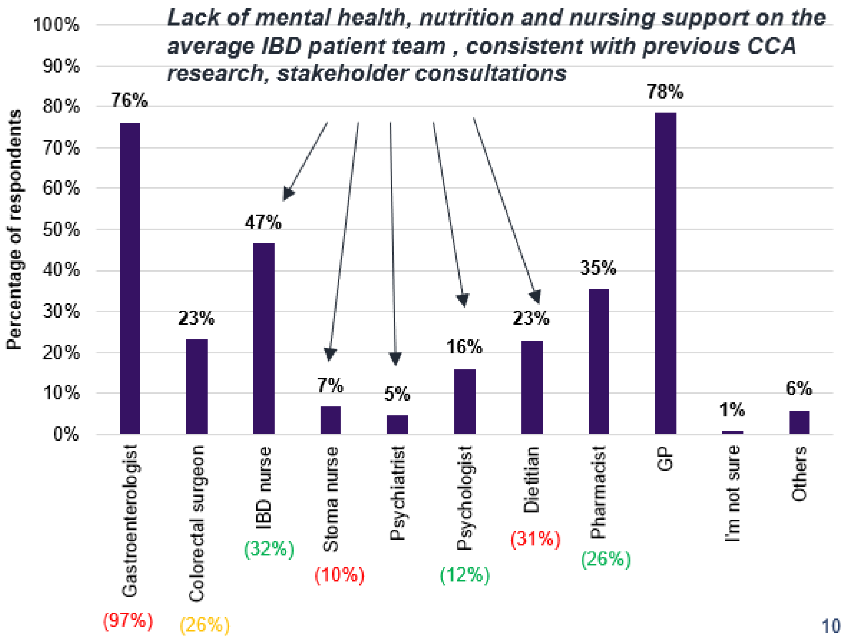
41% of patients reported it took more than 5 years before their IBD symptoms were under control (in remission)



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.

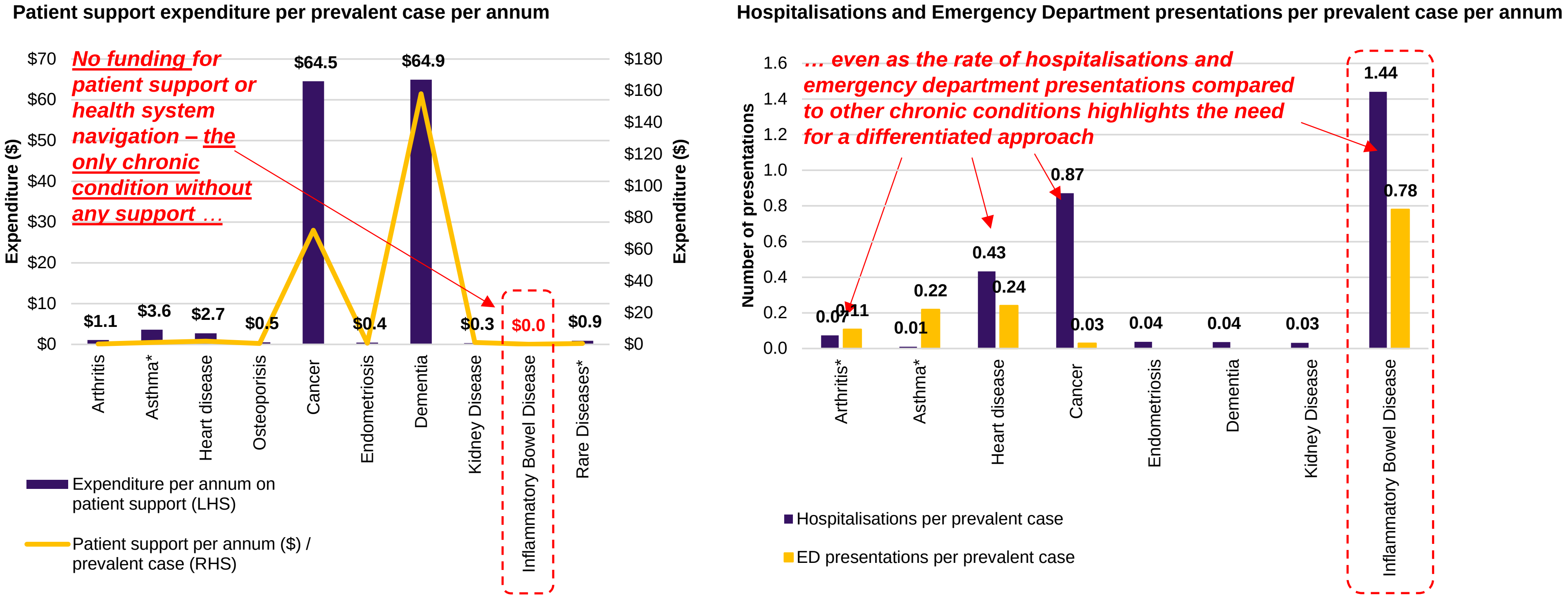
And yet, it is the only condition for which there has been no funding for patient support over the past 10 years, even as key items in the National Action Plan for IBD, launched in 2019, recommended improved access to multi-disciplinary care (Figure ES.9).

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



Patient support expenditure per prevalent case per annum

Hospitalisations and Emergency Department presentations per prevalent case per annum

No funding for patient support or health system navigation – the only chronic condition without any support …

… even as the rate of hospitalisations and emergency department presentations compared to other chronic conditions highlights the need for a differentiated approach

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

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[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

All Australians living with IBD are diagnosed in a timely way and empowered to equitably access best practice, integrated care so that they can live fearlessly and to their full potential

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.

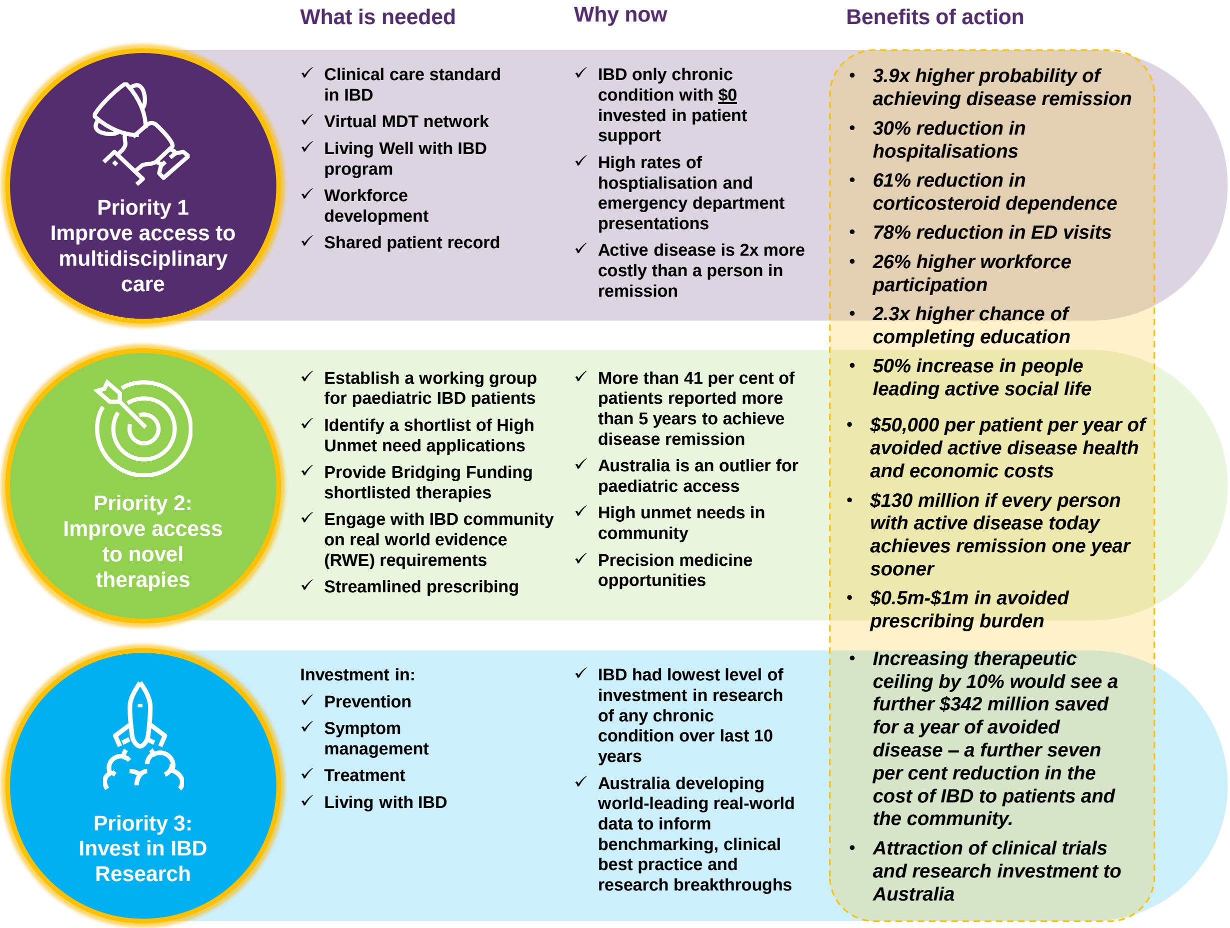
For every person who avoids one year of active disease, $50,000 is saved – through avoided healthcare utilisation, avoided income support, avoided out-of-pocket costs to households, increased workforce participation, increased workforce productivity and avoided suffering for the person living with IBD.

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



	What is needed	Why now	Benefits of action
Priority 1 Improve access to multidisciplinary care	✓ Clinical care standard in IBD ✓ Virtual MDT network ✓ Living Well with IBD program ✓ Workforce development ✓ Shared patient record	✓ IBD only chronic condition with <u>$0</u> invested in patient support ✓ High rates of hosptialisation and emergency department presentations ✓ Active disease is 2x more costly than a person in remission	• *3.9x higher probability of achieving disease remission* • *30% reduction in hospitalisations* • *61% reduction in corticosteroid dependence* • *78% reduction in ED visits* • *26% higher workforce participation* • *2.3x higher chance of completing education*
Priority 2: Improve access to novel therapies	✓ Establish a working group for paediatric IBD patients ✓ Identify a shortlist of High Unmet need applications ✓ Provide Bridging Funding shortlisted therapies ✓ Engage with IBD community on real world evidence (RWE) requirements ✓ Streamlined prescribing	✓ More than 41 per cent of patients reported more than 5 years to achieve disease remission ✓ Australia is an outlier for paediatric access ✓ High unmet needs in community ✓ Precision medicine opportunities	• *50% increase in people leading active social life* • *$50,000 per patient per year of avoided active disease health and economic costs* • *$130 million if every person with active disease today achieves remission one year sooner* • *$0.5m-$1m in avoided prescribing burden*
Priority 3: Invest in IBD Research	Investment in: ✓ Prevention ✓ Symptom management ✓ Treatment ✓ Living with IBD	✓ IBD had lowest level of investment in research of any chronic condition over last 10 years ✓ Australia developing world-leading real-world data to inform benchmarking, clinical best practice and research breakthroughs	• *Increasing therapeutic ceiling by 10% would see a further $342 million saved for a year of avoided disease – a further seven per cent reduction in the cost of IBD to patients and the community.* • *Attraction of clinical trials and research investment to Australia*

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.

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