



Consumer-Driven Research for Crohn's Disease and Ulcerative Colitis

Australia's Top 10 Priorities

May 2022



Executive Summary

Inflammatory bowel disease (IBD) is a term to describe a group of serious intestinal diseases, the most common of which are Crohn's disease and ulcerative colitis. An estimated 100,000 Australians live with IBD, one of the highest prevalence in the world. There is no cure for IBD and the cause is unknown.

The need for more IBD research is clear. Commonly the direction of research is influenced by scientists, industry, government, peak bodies, academia, grant and philanthropy funding. High quality and meaningful contributions should be sought from consumers, healthcare professionals and clinical researchers who can ensure relevance through direct experience and insight.

CCA partnered with the James Lind Alliance (JLA), of the UK to determine the top 10 research priorities for IBD, as identified by people with IBD in Australia and IBD clinicians. Research into cause and cure are accepted as a high priority but were excluded from this project, which sought to address medium-term achievable goals. The process involved:

1. **Gathering uncertainties survey:** 240 people living with IBD, carers, healthcare professionals and clinical researchers submitted 890 questions about IBD they would like researched.
2. **Evidence checking:** 117 summary questions were formed and checked against the evidence to determine whether the question was answered (20%), partially answered (40%) or unanswered (40%) by current research.
3. **Prioritisation survey:** 538 people with IBD, carers and healthcare professionals completed a survey to rank the remaining 56 unanswered research questions.
4. **Discussion workshops:** 2 workshops were held with 10 people living with IBD, 2 carers and 11 healthcare professionals to rank the top 17 questions and decide on the final top 10 list of research priorities for IBD in Australia.

"The whole exercise was superbly well organised and facilitated. Perhaps the best example of the many such consensus gatherings I have attended!"

- Discussion workshop participant

The final top 10 research priorities for IBD in Australia:

1. What are the risk factors for developing IBD (e.g. environmental factors, stress, insecticides, vaccines, antibiotics, glandular fever, removed appendix, susceptibility genes)?
2. How can microbiome (bacteria and other organisms) be modified to prevent IBD?
3. How can IBD be prevented (including those with a family history of IBD or genetic risk, and lifestyle factors, such as food and exercise)?
4. How can quality of life be improved for people with IBD (e.g. reduced visits to the toilet, coping with illness and psychological support)?
5. How can an individual's response to specific IBD medications be predicted?
6. How can food cause or prevent IBD symptoms and/or improve IBD disease severity?
7. What are the potential short- and long-term health effects from taking different IBD medications?
8. What is the most effective treatment for maintaining remission in IBD?
9. What is the link between IBD and mental health and are people with IBD adequately screened for mental health conditions?
10. What is the cause of IBD flares and how can they be recognised and avoided?

All of the prioritised questions fall into four broad themes that share a common purpose:

1. preventing IBD;
2. IBD symptom management;
3. IBD treatment; and
4. living with IBD.

CCA are working towards promoting the top 10 list and advocating for IBD research to answer these questions. We would appreciate your help to share the top 10 research priorities, this report, research opportunities and your experiences of the issues discussed in this report through your social media networks. Your help to like, comment and share our posts help us to spread the word about IBD and current research opportunities.



Contents

Executive Summary	2
Foreword	5
Why do we need research priorities for IBD?	6
How did we get to the top 10?	8
What are the top 10 questions for IBD research prioritised by the IBD community?	9
What other questions for IBD research were prioritised by the IBD community?	16
What are the next steps?	17
How can you help?	18
Acknowledgements	19
References	20



Foreword

There are so many unanswered questions about inflammatory bowel disease. I ask myself every day some of them, and my doctors at every visit. The question was how do we prioritise all those questions for future research in an objective, inclusive and respected manner?



Crohn's and Colitis Australia (CCA) sought the advice and support of the James Lind Alliance to help us identify the top 10 research priorities in a methodology that included a broad reach of engagement. This included the stretch from medical and allied medical professionals, carers, family members and most importantly people living with inflammatory bowel disease - what questions do those living with the disease want answered?

Living with IBD is difficult. It is an unseen disability, one not often spoken about and one that sits below the belly button. I mean, who likes talking about their poo. Importantly, the ten priorities recognised four main segments: prevention, symptom management, treatment and living with IBD providing a scope that is both comprehensive and yet focused.

Whilst the research specifically excluded cause and cure, I am sure everyone in the inflammatory bowel community still dreams of the day we have a known cause/s and cure for this disease.

If we can achieve answers to the top 10, then we will have meaningful impact on the lives of those living with IBD, the answers will change their lives and allow them to live fearlessly. If we can improve prevention of flares, enhance the impact and outcome of symptom management, reduce the negatives of treatment and improve its efficacy, and help people living with IBD live a better quality of life, then the research value will be immeasurable.

The next step is obvious – let's get on with it and find the answers! We need support and commitment to change the lives of over 100,000 people and their family and friends all of whom also live with the disease in some way.

Let me thank the hundreds of people with IBD, their carers and health professionals that contributed their thoughts to this project. We now know what matters to you. Thanks also to the leadership of Prof Paul Pavli AM, the wonderful team of 14 people on the Steering group from across such a broad base that helped build these priorities and let us fulfil their work and the needs of the 100,000 by answering these questions.

We are grateful to the JLA advisors for their hard work in guiding this process. This project was funded by Janssen Australia, Takeda Pharmaceuticals Australia and a generous anonymous philanthropic organisation and we are incredibly thankful for their support.

A handwritten signature in black ink, appearing to read 'Bruce', with a long, sweeping horizontal line extending to the right.

Bruce Rosengarten
Chairman, Crohn's & Colitis Australia

Why do we need research priorities for IBD?

Inflammatory bowel disease (IBD) is a term to describe a group of serious intestinal diseases, the most common of which are Crohn's disease and ulcerative colitis. There is no cure for IBD and the cause is unknown. In Australia, we have one of the highest prevalence of IBD in the world.¹ Estimated to be 330 per 100,000 Australians in 2013, a study published in 2021 estimated that the prevalence was 653 per 100,000 in a large general practice population.^{2,3}

*100,000
Australians live
with Crohn's
disease and
ulcerative
colitis*

For people living with these debilitating conditions the quality of care varies and often does not meet the recommended standards.^{2,4}

The need for more research is clear: while the direction of research is currently influenced by scientists, industry, government, peak bodies, academia, grant and philanthropy funding, high quality and meaningful contributions should be sought from consumers, healthcare professionals and clinical researchers. The benefits of this include:

- relevance to the community,
- direct lived experience, and
- insights on missing evidence.⁵

CCA is the peak consumer body representing the needs of people living with IBD. For this project, we have collaborated with people living with IBD, their carers and health professionals (gastroenterologists, nurses, psychologists, dietitians, pharmacists, and surgeons) to identify the top 10 research priorities for IBD in Australia.

The methodology that we used was developed by the James Lind Alliance (JLA) to ensure a fair and equitable balance of all participating voices.⁶ For a project to be considered a JLA Priority Setting Partnership (PSP), it must exclude funding from organisations that may have a commercial interest in the results. Our project was partly funded by grants from pharmaceutical organisations, so it was therefore conducted as a JLA Lab activity rather than as a PSP, to test the independence of the process from funding influence.

"It was quite fun and engaging and a great opportunity to contribute to research for the IBD community"

- Discussion workshop participant

Whilst we acknowledge the importance of cause and cure of IBD, this project aligns with the JLA methodology and seeks to achieve reachable goals in the short to medium term.

The project was defined, and the following areas were excluded:

- cause of IBD,
- cure of IBD,
- information-seeking questions which do not require a research response, and
- microscopic colitis and other forms of inflammatory enteritis.

What is Inflammatory Bowel Disease (IBD)?

Crohn's disease and ulcerative colitis are conditions in which there is inflammation of the bowel. Inflammation causes redness, swelling and pain, and is the body's response to infection, injury or irritation. They are chronic, long-term conditions.

Crohn's disease can involve any part of the gastrointestinal tract from the mouth to the anus but most commonly affects the small intestine. Crohn's disease can affect the full thickness of the bowel and this can result in narrowing (strictures) which can block the bowel (obstruction) or small holes through the bowel (fistulas) to the skin, other loops of bowel or other organs, sometimes causing a collection of pus called an abscess.

Ulcerative colitis is a type of IBD that can cause inflammation and ulceration in the large intestine (colon and rectum). Ulcers (sores) develop on the surface of the inner lining of the intestine, which may bleed.

Both these inflammatory bowel diseases lead to symptoms such as pain, diarrhoea, urgency to use the bowels, fatigue and fever. The acute symptoms may be extremely distressing and can result in significant social stigma and isolation. Their chronic, relapsing nature has broader effects on an individual's emotional, physical and social well-being. Often the conditions are diagnosed in young people disrupting the time they are establishing their careers and relationships.

Who are the James Lind Alliance?

The JLA is a United Kingdom-based initiative that exists to support patients, carers and clinicians to work together to agree which are the most important unanswered questions affecting their particular interest, in order to influence the prioritisation of future research in that area. It has completed over 100 research prioritising processes around the world. The JLA method, described in the JLA Guidebook, is designed to change the way research funding is granted, and to raise awareness of research questions which are of direct relevance and potential benefit to patients and the clinicians who treat them.



About Crohn's & Colitis Australia

Crohn's & Colitis Australia's primary purpose is to provide support services, advice and encouragement to people with inflammatory bowel disease (IBD). At CCA we dream of a future free Crohn's and colitis and we empower people to live fearlessly whilst we help search for a cure.

While we invest in research to build capacity, we continue to advocate for world best treatments and health services for those living with IBD. Through our programs we offer education and support for Australia's growing Crohn's and colitis community and raise awareness of the disease.



How did we get to the top 10?

Gathering uncertainties survey
Dec 2020 – Jan 2021

- **890** IBD research uncertainties were identified in a national online survey completed by **224** participants.
- **170** participants were people living with IBD, **22** carers, **44** healthcare professionals and **13** clinical researchers.

Survey topics

Topic	Percentage
IBD treatment	27%
Living with IBD	24%
IBD prevention	14%
IBD symptoms	12%
IBD diagnosis	10%
Out of scope	13%

Summary questions formed and evidence checking
Feb 2021 – Oct 2021

- **117** summary questions were formed and checked against evidence to determine whether the question was answered, partially answered or unanswered by current research.
- After removing **23** answered questions and those only asked by one person, questions were regrouped. **56** unanswered questions remained.

Evidence check results

Result	Percentage
Answered	20%
Partially answered	40%
Unanswered	40%

Prioritisation survey
Nov 2021 – Dec 2021

- **538** participants completed a second survey to rank the remaining **56** questions and prioritise their own top 10 list.
- **446** participants were people living with IBD, **35** carers and **57** healthcare professionals.
- The top **17** ranked questions from people with IBD, carers and healthcare professionals were shortlisted for the discussion workshops.

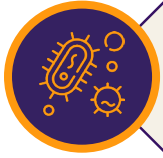
Discussion workshops
Feb 2022

- **2** discussion workshops were held online with **10** people living with IBD, **2** carers and **11** healthcare professionals to challenge and rank the top 17 questions and decide on the final top 10 list.

What are the top 10 questions for IBD research prioritised by the IBD community?



1. What are the risk factors for developing IBD (e.g. environmental factors, stress, insecticides, vaccines, antibiotics, glandular fever, removed appendix, susceptibility genes)?



2. How can microbiome (bacteria and other organisms) be modified to prevent IBD?



3. How can IBD be prevented (including those with a family history of IBD or genetic risk, and lifestyle factors, such as food and exercise)?



4. How can quality of life be improved for people with IBD (e.g. reduced visits to the toilet, coping with illness and psychological support)?



5. How can an individual's response to specific IBD medications be predicted?



6. How can food cause or prevent IBD symptoms and/or improve IBD disease severity?



7. What are the potential short- and long-term health effects from taking different IBD medications?



8. What is the most effective treatment for maintaining remission in IBD?



9. What is the link between IBD and mental health and are people with IBD adequately screened for mental health conditions?



10. What is the cause of IBD flares and how can they be recognised and avoided?



"The top 10 reflect a fair spread of questions that were important to all stakeholders, including different nuanced areas of healthcare" - Discussion workshop participant

"The final decisions were very collaborative and reflect thoughts of the entire group"

"Listening to the views of other patients, carers and healthcare professionals was very insightful and often influenced the groups views positively"

"The whole exercise was superbly well organised and facilitated. Perhaps the best example of the many such consensus gatherings I have attended!"

- Discussion workshop participants



The top 10 priorities fall into four broad themes that share a common purpose. Furthermore, all 17 important priorities discussed at the workshops fit into these themes (see Table 1):

1. preventing IBD;
2. IBD symptom management;
3. IBD treatment; and
4. living with IBD.

Table 1. The top 17 priorities ranked in discussion workshops

Priorities	Prevention	Symptom management	Treatment	Living with IBD
1. What are the risk factors for developing IBD (e.g. environmental factors, stress, insecticides, vaccines, antibiotics, glandular fever, removed appendix, susceptibility genes)?	✓			
2. How can microbiome (bacteria and other organisms) be modified to prevent IBD?	✓			
3. How can IBD be prevented (including those with a family history of IBD or genetic risk, and lifestyle factors, such as food and exercise)?	✓			
4. How can quality of life be improved for people with IBD (e.g. reduced visits to the toilet, coping with illness and psychological support)?				✓
5. How can an individual's response to specific IBD medications be predicted?			✓	
6. How can food cause or prevent IBD symptoms and/or improve IBD disease severity?		✓		
7. What are the potential short- and long-term health effects from taking different IBD medications?			✓	✓
8. What is the most effective treatment for maintaining remission in IBD?			✓	
9. What is the link between IBD and mental health and are people with IBD adequately screened for mental health conditions?				✓
10. What is the cause of IBD flares and how can they be recognised and avoided?		✓		
11. Why do people with IBD feel fatigued and how can it be managed?				✓
12. What lifestyle factors can improve IBD severity?				✓
13. How can childhood experiences (e.g. mental health status and adverse life events) and illness (e.g. asthma, and pneumonia) influence the development of IBD?	✓			
14. What effect does IBD have on aging (e.g. life expectancy, severity and other health conditions)?				✓
15. What is the cause of joint pain for people with IBD?				✓
16. Can food additives lead to IBD diagnosis or IBD flares?		✓		
17. What is the role of stem cell treatment in the treatment of IBD?			✓	

Theme 1: Prevention

Rationale

There is currently no cause known or cure for IBD. Research suggests that it is related to genetics and how the environment affects the immune system. A systematic review found that smoking, appendectomy, and tonsillectomy increased the risk of developing Crohn's disease, while consumption of soft drinks increased the risk of ulcerative colitis.⁷ Urban living, antibiotic exposure, oral contraceptive use, vitamin D deficiency and some bacteria increase the risk of IBD.⁷

Physical activity, bed sharing in childhood, and high levels of vitamin D appear to reduce the risk of Crohn's disease, while tea consumption and appendectomy are likely to reduce the risk of ulcerative colitis.^{7,8} Breastfeeding, high folate levels and some bacteria are likely to reduce the risk of developing IBD overall.⁷

An additional 11 risk factors were identified and 16 preventative factors, however the supporting evidence is weak.⁷

The microbiome is a hot topic for researchers of gut health and its understanding is important for finding new ways of preventing and managing IBD. Research is emerging that shows links between the microbiome and IBD.

Further research is required to identify and provide stronger evidence for the risk factors associated with developing IBD and the factors that are likely to reduce the risk of developing IBD. As the prevalence of IBD is increasing, this will help CCA provide education to consumers and clinicians about ways of preventing the development of IBD.

Potential research question examples

- How can the microbiome be improved to prevent IBD?
- What lifestyle factors can prevent IBD?
- How does the environment increase the risk of developing IBD?
- How does a family history of IBD increase the risk of developing IBD?
- How do genetics increase the risk of developing IBD?

"It was evident that how IBD can be prevented was the greatest concern and it only makes sense that this is in the top 10"

- Discussion workshop participant



Theme 2: Symptom management



Rationale

Symptoms of IBD can be different for each person: they can range from mild to severe. People with IBD experience flares, and are likely to develop abdominal pain, diarrhoea, constipation, tiredness, and weight loss.⁹ Some people may also experience fever, mouth ulcers or nausea and vomiting; symptoms will depend on where inflammation appears in the gut.⁹

The goal of IBD treatment is for people with IBD to maintain remission and be completely free of symptoms or flares.⁹

Current evidence and guidelines make recommendations about what people with IBD should do and whom they should contact when they are experiencing a flare. There is limited evidence about what causes a flare, how to recognise one and what strategies could be used to avoid one.

The role of diet in IBD has become an increasingly popular topic for people with IBD, healthcare professionals and researchers. Dietary factors that prevent IBD are not necessarily the same as treating a flare or symptoms. With the exception of some dietary therapies for specific IBD problems, it is recommended that patients with IBD follow the Australian Guide to Healthy Eating.¹⁰

There is some evidence that suggests eating high fibre and including fish a few times per week has a protective effect for Crohn's disease, whilst consuming less red and processed meats may have a protective effect in ulcerative colitis.¹⁰ We also know that there are diets that can treat active Crohn's disease in specific target populations, including the Exclusive Enteral Nutrition diet and Crohn's Disease Exclusion Diet.¹⁰ Current evidence and information available online is conflicting and further research is required to identify which specific diets or foods improve IBD symptoms. We know from this project that the IBD community is interested in research into high protein, vegetarian, gluten free, lactose free, low sugar and organic food diets.

Identifying how to improve symptom management for IBD is an important research area to help improve the quality of life for people living with IBD while we search for a cause and cure.

Potential research question examples

- What is the cause of IBD flares?
- How can IBD flares be recognised?
- What interventions can help to avoid IBD flares?
- How can food cause IBD symptoms?
- What foods or dietary supplements can improve IBD symptoms?
- How can food additives impact IBD?

Theme 3: Treatment

Rationale

There are many different treatments to manage IBD. Some of them are used to control inflammation while others help people with IBD stay in remission. Each person will find that some treatments work better than others, so it is important that people with IBD work with their healthcare team to find the right treatment.

As the IBD treatment response is different for each person, it is difficult to predict the best treatment plan for an individual. There is limited evidence to predict the best model of treatment for a patient.¹¹ Further research into predicting an individual's response to medication will assist healthcare professionals to be more confident in the course of treatment they are prescribing for their patients.

There has been limited research to address the potential short- and long-term effects of some IBD medications.¹²⁻¹⁵ Many people with IBD view complementary therapies or natural remedies (usually treatments without a sound evidence base) as less likely to cause harm. More research is needed to measure the safety of medication and complementary therapy to build consumer confidence that treatments are efficacious and safe in the short- and long-term. This project identified that consumers and healthcare professionals are interested in further research into the side effects of biologics, thiopurines, infliximab, anti-fibrosis therapy and prednisone. This will inform evidence-based treatment decisions between consumers and health professionals.

Potential research question examples

- How can clinicians best determine which medication to prescribe a person living with IBD?
- How can a person with IBD's response to different medications be predicted?
- What are the potential short-term health effects from taking different IBD medications?
- What are the potential long-term health effects from taking different IBD medications?
- What is the most effective treatment for maintaining remission in IBD?



Theme 4: Living with IBD

Rationale

IBD can have a major impact on an individual's daily living. The quality of life for people with IBD can be poorer than healthy individuals.¹⁷⁻¹⁸ Focusing on physical symptoms is very normal and important. However, coping well with a long-term condition requires a person with IBD to take care of more than their physical condition, to live a full and productive life. People with IBD commonly face day-to-day challenges with exercise, fatigue, fertility and pregnancy, sexual health, mental health, social events and sometimes struggle to leave the house. There is limited evidence explaining how people with IBD can improve their quality of life. Research into this topic would provide information for people to take steps to reduce the impact of the IBD on their life and improve quality of life.



We know that people with IBD are more likely to experience significant mental health problems, such as depression and anxiety.¹⁹⁻²⁴ Up to 50% of people with IBD experience psychological distress that's related to their illness.²⁵ The gut and brain are closely connected, so it is important people with IBD take care of both the mind and body to manage IBD well. Further research is required to assess whether mental health conditions are adequately screened for by healthcare professionals, and explain what support and treatments are effective to manage mental health and gut disease.

Potential research question examples

- How can quality of life be improved for people with IBD?
- How can people with IBD have reduced visits to the toilet?
- In what ways can people with IBD receive psychological support?
- How can psychological support services be improved?
- What impact does IBD have on mental health?
- Can mental health conditions lead to the development of IBD?
- How often are people with IBD screened for mental health conditions?
- How can fatigue be better managed for people with IBD?

What other questions for IBD research were prioritised by the IBD community?

An additional 7 research priorities ranked highly in the prioritisation survey, but just outside the top 10. These priorities are still important to address by funders and researchers and are consistent with the four themes identified. Through feedback from the discussion workshops, people living with IBD were disappointed that priority 11 just missed out on being prioritised into the top 10 list.

"Fatigue seemed like a very important concern that remains unanswered by research. People living with IBD were passionate about including it in the top 10"

"Fatigue is very important as there currently is no cure and how to manage IBD should be a priority at the moment"

- Discussion workshop participants

To view the complete list of summary research questions, please visit <https://crohnsandcolitis.org.au/research-priorities/>.



What are the next steps?

This IBD research priorities process has identified novel and important information. The value of the project will be in how this information can shape further research to benefit people living with IBD.

The rigorous approach and national participation in this study should compel these stakeholders to act through research directions, funding and awareness:

- Governments and Health Departments
- National Health and Medical Research Council, Medical Research Future Fund and Australian Research Council
- Philanthropy and scholarship funds
- Scientists and researchers
- Consumers and representative groups

CCA will also contribute to these goals by working to ensure people with IBD are engaged in research study planning to promote relevance of outcomes. Scholarships offered by CCA in the future will focus on areas that are prioritised in this report.

CCA supporting current research

CCA fundraises for, and invests in, research into IBD primarily through scholarships and research partnerships. In the future CCA will direct these research opportunities toward the top priority questions identified in this report. We are pleased that many of the current research studies align:

- The role of microbiome throughout course of IBD (priority 2)
- Does removing emulsifiers from the diet of people with Crohn's disease induces disease remission (priority 6 and 16)
- Does a whole diet approach using a 4-SURE (4-strategies for a Sulphide-Reducing) diet supplied to people with mildly flaring ulcerative colitis or pouchitis can: improve symptoms; reduce inflammation in the large bowel/pouch; effectively reduce bacterial sulphur gas production and be well tolerated compared to a control diet (priority 6)
- The role of cell death in IBD through studies of similar phenomena in Crohn's disease and ulcerative colitis (priority 3)
- How to accurately predict IBD activity in pregnancy and subsequently any changes to the foetal/neonatal immune system and brain development (priority 5)
- What is the mechanism by which the immune system of patients with IBD turns on its host. It will then utilise this understanding to inform developing a treatment that uses the patients' own immune system to turn off the inflammation and regenerate the damage that has been caused (priority 8)

CCA also supports research through encouraging consumers to participate in research, advertised in our eNews, member magazine, social media channels and website.

For further information on research grants and awards, please visit:

<https://crohnsandcolitis.org.au/research-grants-awards/>

How can you help?

Although CCA have identified the top 10 list of research priorities for IBD in Australia, we are still working towards promoting the list and advocating for IBD research to answer these questions. We would appreciate your help to work with us to encourage future IBD research.



Funders and researchers

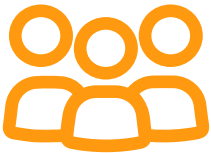
You can help us and partnering organisations to fund research into the top 10 priorities identified, so that we can maximise the scale and quality of IBD research in Australia.

If you are a researcher, funder or organisation working with people with IBD, please use this list to assist you in prioritising funding for IBD research. Knowing that your research is targeting the most urgent needs for consumers will provide a great impact to people with IBD.



Healthcare professionals

Help us to share the list of top 10 priorities with researchers in your organisation or other collaborators.



Consumers

Researchers are continually looking for people with IBD and their families to participate in IBD research. Research ranges from clinical trials in drug therapy and dietary investigations, to population surveys to discover information and cause, prevention, treatment and quality of life. Your involvement is entirely up to you!

CCA support and advertise research opportunities for you to take part in through our eNews, member magazine and on the CCA website here: <https://crohnsandcolitis.org.au/current-research/>

CCA would appreciate your help to share the top 10 research priorities, this report, research opportunities and your experiences of the issues discussed in this report through your social media networks. Your help to like, comment and share our posts help us to spread the word about IBD and current research opportunities.

You can donate to CCA to help us fund scholarships for research here: <https://crohnsandcolitis.org.au/donate/>

To join our mailing list, request updates or let us know how you are using these questions, please contact info@crohnsandcolitis.org.au.

Acknowledgements

CCA would like to thank everyone living with inflammatory bowel disease, their carers and healthcare professionals who participated in the surveys and workshops to identify the top 10 research priorities for inflammatory bowel disease in Australia.

We are also grateful to supporting organisations who assisted CCA to promote the project, surveys and workshops:

- Gastroenterological Society of Australia
- Australian General Practice Accreditation Limited
- Australian Psychological Society
- Colorectal Surgical Society of Australia and New Zealand
- Dietitian Crohn's Colitis Australian Network
- Gastroenterological Nurses College of Australia
- Hospital Pharmacists Association
- IBD Support Australia
- National Rural Health Alliance
- Pharmaceutical Society of Australia
- Primary Health Networks
- The Limbic

This project was made possible with funding from Janssen Australia, Takeda Pharmaceuticals Australia and a generous anonymous philanthropic organisation. We are incredibly thankful for their support.

Steering group

We are grateful to the steering group and JLA advisors for their hard work, dedication and expertise in guiding this process.

Member	Role	Professional organisation
Prof Paul Pavli	CCA Board Member and Co-chair (Gastroenterologist)	Canberra Hospital, Australian National University
Katherine Cowan	Co-chair	James Lind Alliance
Dr Rimma Goldberg	Information Specialist (Gastroenterologist)	Monash University, Monash Health
Wayne Massuger	Lead	Crohn's & Colitis Australia
Hailey Fisher	Coordinator	Crohn's & Colitis Australia
Cassandra Anslow	Consumer Member	
Marnie O'Brien	Consumer Member	
Blake Tierney	Consumer Member	
Leanne Raven	Member	Crohn's & Colitis Australia
Prof Susan Connor	Gastroenterologist Member	Liverpool Hospital, University of New South Wales, Ingham Institute of Applied Medical Research
Dr Emma Halmos	Dietitian Member	Monash University, Alfred Health
Dr Ed Giles	Paediatric Gastroenterologist Member	Monash University, Hudson Institute of Medical Research
Prof Antonina Mikocka-Walus	Psychology Member	Deakin University
Claire Reilly	Nurse Member	Queensland Children's Hospital

References

1. Wilson J, Hair C, Knight R, Catto-Smith A, Bell S, Kamm M, Desmond P, McNeil J, Connell W. High incidence of inflammatory bowel disease in Australia: a prospective population-based Australian incidence study. *Inflamm Bowel Dis*. 2010 Sep;16(9):1550-6. doi: 10.1002/ibd.21209.
2. PricewaterhouseCoopers Australia (PwC). Improving inflammatory bowel disease care across Australia. March 2013. Available at: <https://crohnsandcolitis.org.au/wp-content/uploads/2022/02/PwC-report-2013.pdf>.
3. Busingye D, Pollack A, Chidwick K. Prevalence of inflammatory bowel disease in the Australian general practice population: A cross-sectional study. *PLoS One*. 2021 May 27;16(5):e0252458. doi: 10.1371/journal.pone.0252458.
4. Massuger W, Moore GTC, Andrews JM, Kilkenny MF, Reyneke M, Knowles S, Purcell L, Alex G, Buckton S, Page AT, Stocks N, Cameron D, Manglaviti F, Pavli P. Crohn's & Colitis Australia inflammatory bowel disease audit: measuring the quality of care in Australia. *Intern Med J*. 2019 Jul;49(7):859-866. doi: 10.1111/imj.14187.
5. National Health and Medical Research Council. Statement on Consumer and Community Involvement in Health and Medical Research. September 2016. Available at: www.nhmrc.gov.au/guidelines/publications/s01.
6. National Institute for Health Research. The James Lind Alliance Guidebook. Version 10 March 2021. Available at: <https://www.jla.nihr.ac.uk/jla-guidebook/>
7. Piovani D, Danese S, Peyrin-Biroulet L, Nikolopoulos GK, Lytras T, Bonovas S. Environmental Risk Factors for Inflammatory Bowel Diseases: An Umbrella Review of Meta-analyses. *Gastroenterology*. 2019 Sep;157(3):647-659.e4. doi: 10.1053/j.gastro.2019.04.016.
8. Rasmussen T, Fonnes S, Rosenberg J. Long-Term Complications of Appendectomy: A Systematic Review. *Scand J Surg*. 2018 Sep;107(3):189-196. doi: 10.1177/1457496918772379.
9. Gastroenterological Society of Australia. Inflammatory Bowel Disease (IBD) Crohn's Disease & Ulcerative Colitis. 2021. Available at: https://www.gesa.org.au/public/13/files/Education%20%26%20Resources/Patient%20Resources/IBD/16_%20IBD-Crohns-Colitis_Fact-Sheet.pdf.
10. Gastroenterological Society of Australia. Diet and IBD. 2021. Available at: https://www.gesa.org.au/public/13/files/Education%20%26%20Resources/Patient%20Resources/IBD/Diet%20and%20IBD_v1.pdf.
11. Stevens TW, Matheeuwsen M, Lönnkvist MH, Parker CE, Wildenberg ME, Gecse KB, D'Haens GR. Systematic review: predictive biomarkers of therapeutic response in inflammatory bowel disease-personalised medicine in its infancy. *Aliment Pharmacol Ther*. 2018 Dec;48(11-12):1213-1231. doi: 10.1111/apt.15033.
12. Mattoo VY, Basnayake C, Connell WR, Ding N, Kamm MA, Lust M, Niewiadomski O, Thompson A, Wright EK. Systematic review: efficacy of escalated maintenance anti-tumour necrosis factor therapy in Crohn's disease. *Aliment Pharmacol Ther*. 2021 Aug;54(3):249-266. doi: 10.1111/apt.16479.

13. Schreiber S, Dignass A, Peyrin-Biroulet L, Hather G, Demuth D, Mosli M, Curtis R, Khalid JM, Loftus EV Jr. Systematic review with meta-analysis: real-world effectiveness and safety of vedolizumab in patients with inflammatory bowel disease. *J Gastroenterol.* 2018 Sep;53(9):1048-1064. doi: 10.1007/s00535-018-1480-0.
14. Saag, KG, Furst, DE. Major side effects of systemic glucocorticoids. Uptodate. 2021. Available at: <https://www.uptodate.com/contents/major-side-effects-of-systemic-glucocorticoids>.
15. Kremer, JM. Major side effects of low-dose methotrexate. 2020. Uptodate. Available at: <https://www.uptodate.com/contents/major-side-effects-of-low-dose-methotrexate>.
16. Gastroenterological Society of Australia. Complementary and Alternative Therapies in IBD. 2021. Available at: https://www.gesa.org.au/public/13/files/Education%20%26%20Resources/Patient%20Resources/IBD/Complementary%20and%20Alternative%20therapies%20in%20IBD_v1.pdf.
17. Knowles SR, Graff LA, Wilding H, Hewitt C, Keefer L, Mikocka-Walus A. Quality of Life in Inflammatory Bowel Disease: A Systematic Review and Meta-analyses-Part I. *Inflamm Bowel Dis.* 2018 Mar 19;24(4):742-751. doi: 10.1093/ibd/izx100.
18. Knowles SR, Keefer L, Wilding H, Hewitt C, Graff LA, Mikocka-Walus A. Quality of Life in Inflammatory Bowel Disease: A Systematic Review and Meta-analyses-Part II. *Inflamm Bowel Dis.* 2018 Apr 23;24(5):966-976. doi: 10.1093/ibd/izy015.
19. Barberio B, Zamani M, Black CJ, Savarino EV, Ford AC. Prevalence of symptoms of anxiety and depression in patients with inflammatory bowel disease: a systematic review and meta-analysis. *Lancet Gastroenterol Hepatol.* 2021 May;6(5):359-370. doi: 10.1016/S2468-1253(21)00014-5.
20. Neuendorf R, Harding A, Stello N, Hanes D, Wahbeh H. Depression and anxiety in patients with Inflammatory Bowel Disease: A systematic review. *J Psychosom Res.* 2016 Aug;87:70-80. doi: 10.1016/j.jpsychores.2016.06.001.
21. Mikocka-Walus A, Knowles SR, Keefer L, Graff L. Controversies Revisited: A Systematic Review of the Comorbidity of Depression and Anxiety with Inflammatory Bowel Diseases. *Inflamm Bowel Dis.* 2016 Mar;22(3):752-62. doi: 10.1097/MIB.0000000000000620.
22. Schoultz M, Beattie M, Gorely T, Leung J. Assessment of causal link between psychological factors and symptom exacerbation in inflammatory bowel disease: a systematic review utilising Bradford Hill criteria and meta-analysis of prospective cohort studies. *Syst Rev.* 2020 Aug 1;9(1):169. doi: 10.1186/s13643-020-01426-2.
23. Häuser W, Moser G, Klose P, Mikocka-Walus A. Psychosocial issues in evidence-based guidelines on inflammatory bowel diseases: a review. *World J Gastroenterol.* 2014 Apr 7;20(13):3663-71. doi: 10.3748/wjg.v20.i13.3663.
24. Alexakis C, Kumar S, Saxena S, Pollok R. Systematic review with meta-analysis: the impact of a depressive state on disease course in adult inflammatory bowel disease. *Aliment Pharmacol Ther.* 2017 Aug;46(3):225-235. doi: 10.1111/apt.14171.
25. Gastroenterological Society of Australia. Mental Health and IBD. 2021. Available at: https://www.gesa.org.au/public/13/files/Education%20%26%20Resources/Patient%20Resources/IBD/Mental%20Health%20and%20IBD_v1%201.pdf.

Follow updates on this project:

<https://crohnsandcolitis.org.au/research-priorities/>

Learn more about our JLA partnership:

<https://www.jla.nihr.ac.uk/jla-lab/inflammatory-bowel-disease-australia/>

How to reference this report:

Crohn's & Colitis Australia. Consumer-Driven Research for the Crohn's Disease and Ulcerative Colitis – Australia's Top 10 Priorities. May 2022. Available at:

<https://crohnsandcolitis.org.au/advocacy/our-projects/research-priorities/>.

Stay in touch with Crohn's & Colitis Australia:



@CrohnsAndColitis



@CrohnsColitisAu



@CrohnsAndColitisAU



@CrohnsAndColitisAustraliaCCA

For information please contact:

Leanne Raven
CEO, Crohn's & Colitis Australia
P: +61 3 9815 1266
E: ceo@crohnsandcolitis.org.au
W: www.crohnsandcolitis.org.au

Mail: PO Box 777
Camberwell South. VIC 3124
Visit: Level 1. Suite 4.
363 Camberwell Road. Camberwell. VIC 3124



Crohn's
& Colitis
Australia