



Australian IBD Research Priorities Survey

Have Your Say on Crohn's & Colitis Research

Do you have unanswered questions about your Crohn's disease or ulcerative colitis, also known as inflammatory bowel disease (IBD)? Tell us what you think and help change lives of people living with IBD.

Why we need your help

Crohn's & Colitis Australia (CCA) working with the James Lind Alliance are looking for the Top 10 research priorities of people with IBD, carers and healthcare professionals. Your questions can help us find important areas to research in order to improve the healthcare and wellbeing of Australians affected by IBD. We are interested in giving you a louder voice in research. We want ideas and thoughts from people with different experiences and backgrounds.

This survey is the first step in collecting your questions about IBD, that will be followed by a second survey to prioritise the questions. The final list of Top 10 unanswered research questions will be shared with researchers and research funders to encourage them to focus on the most urgent and relevant needs of people living with IBD.

What do we mean by unanswered questions?

An unanswered question is any uncertainty related to IBD that you think could benefit from research. You do not need to know whether or not the question is actually unanswered. It is enough to write a short sentence about something that is important to you, but for which you haven't been able to find an answer. We will then turn your responses into research questions.

After your questions are collected, we will check them against published research to see if they have been answered. The most important thing is to draw on your personal experience of IBD. Whilst we acknowledge the importance of finding a cause and cure for IBD, we are particularly interested in questions about prevention (limited to lifestyle factors), treatment, symptoms, diagnosis and living with IBD.

1. Do you live in Australia?
 - Yes
 - No (you are ineligible to participate and this survey will end for you)

Section 1

This section is where you get to describe your unanswered research questions. Please put as little or as much detail as you would like in answering Q2, 3 & 4. You may also skip questions. Some examples of research questions include:

- What can I do to prevent passing IBD on to my children?
- How can IBD lead to other health conditions?
- How can my lifestyle affect my IBD symptoms?

Please remember, these are just examples and should not limit you.

2. What questions or concerns about the **prevention or treatment of** IBD would you like to see answered by research?
3. What questions or concerns about the **symptoms or diagnosis** of IBD would you like to see answered by research?
4. What questions or concerns about **living with IBD** would you like to see answered by research?

Section 2

Please tell us a little bit about yourself. We will use this information to make sure we are reaching a wide range of people and to better understand the needs of different groups.

What will happen with my information?

Unanswered research questions will be published, but not linked to you or your organisation (for healthcare professionals). All personal data will remain confidential.

5. Which state/territory do you live in?
 - New South Wales
 - Victoria
 - Queensland
 - South Australia
 - Western Australia
 - Australian Capital Territory
 - Tasmania
 - Northern Territory
 - Prefer not to say
6. Which of these categories describes you (allow more than one response)?
 - Person diagnosed with Crohn's disease
 - Person diagnosed with ulcerative colitis
 - Person diagnosed with IBD unclassified
 - Carer or family member of someone under the age of 16 living with IBD
 - Carer or family member of someone 16 years or older living with IBD
 - Clinical researcher
 - Healthcare professional (please list your profession below. For example, gastroenterologist, dietitian, nurse, psychologist, etc.)

7. Are you:
- Male
 - Female
 - Other (please describe)
 - Prefer not to say
8. What is your age?
- 16-29
 - 30-39
 - 40-49
 - 50-59
 - 60-69
 - 70+
 - Prefer not to say
9. For people with IBD: How long has it been since you were diagnosed with IBD?
- Less than 1 year
 - 1 to less than 5 years
 - 5 to less than 10 years
 - 10+
 - N/A (for carers and healthcare professionals)
 - Prefer not to say
10. What language do you speak at home (allow more than one response)?
- English
 - Please list any other languages you speak at home
 - Prefer not to say

Would you like to help us in the next stage of this project which is to help prioritise the most important questions? If yes, please provide your name and email address. By doing that, you are providing Crohn's & Colitis Australia with information about yourself and health condition. Please only provide details if you consent to Crohn's & Colitis Australia collecting that sensitive personal data for the purposes of this research exercise. Your personal details will not be shared with anyone else or used for any other purpose.

11. I would like to participate in the next round of this project

Yes

- No

12. Please provide your details to participate in the next round of this project

- Name
- Email address
- Confirm email address

If you would like more information about this project or would like help with this survey, please contact the team at: ibdaudit@crohnsandcolitis.com.au

CCA thank you for completing our survey!