

Australian IBD Research Priorities Survey

Have Your Say on Crohn's & Colitis Australia Research

What are the most important questions for future research on inflammatory bowel disease (IBD) to answer?

What is this survey for?

We recently ran a survey that asked people with IBD, carers, healthcare professionals and clinical researchers to tell us their questions about the prevention, treatment, symptoms, diagnosis and living with IBD. These questions will help us find important areas to research in order to improve the healthcare and wellbeing of Australians affected by IBD. Thank you to over 200 Australians who took part in the survey. We have taken all of these questions into account and checked the evidence to see if any had already been answered. The questions that have not been answered by research are summarised and listed in this new survey. This survey seeks to find which questions are the most important to you.

You can see more about the project here

<https://www.crohnsandcolitis.com.au/ibdqoc/research-priorities/>

Please take part in this survey if you are:

- Aged 16 years and over living with IBD
- A carer or family member of someone living with IBD
- A healthcare professional (clinician with experience caring for people with IBD)

This survey is open to people living in Australia.

What are we asking you to do?

We have made a list of questions where people with IBD, carers, healthcare professionals and clinical researchers have suggested that more research on IBD is needed.

1. Please read the list and tick the questions that you think it is most important for researchers to answer based on your own experiences and opinions
2. From your selection, please choose up to 10.

Please ask others to complete this survey too. We want to make researchers aware of the issues that matter to many people.

What will happen next?

After this survey has closed, we will use the survey responses to work out which are the most pressing questions. We will then hold a meeting via Zoom for people with experience of IBD, carers and healthcare professionals. At the meeting they will discuss the most pressing questions and agree a final top 10 that patients, carers and healthcare professionals jointly want research to answer.

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

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

2. Which of the following categories **best** describes you?
 - 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
 - Healthcare professional* (clinician with experience caring for people with IBD). Please list your profession below.

*Please note healthcare professionals include clinicians or clinician researchers who *have experience caring for people with IBD*. If you are a non-clinician researcher, you are ineligible to complete this survey. Non-clinician researchers have been involved and helpful in other aspects of the process so far.

Section 1

We would like you to read through the questions on this list and tick the ones that you think are the most important for researchers to answer. Please do this based on your own experience. You do not need to know about research, and we do not need you to try to answer them. That's for researchers to do later.

3. Please tick the questions that you think are important for future research to answer (you can tick as many as you like, but try not to choose all of them, as at the next stage you will be asked to narrow your selection down to 10):

List questions here

Section 2

4. From your selection, please now tick the questions that you think are most important for research to answer – you can choose up to 10:

Selected questions to appear here

Section 3

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?

We will ask for some information about you. This is so we can understand what groups are completing the survey and whether we are hearing from a wide range of people. You do not have to tell us your name and you will not be identified in any of the survey results.

5. Which state or 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. What is your postcode?

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?

- English
- Please list any other languages you speak at home
- Prefer not to say

What is next?

We will be looking for people with lived experience and professional expertise to participate in Zoom workshop that will discuss the most pressing questions and agree on the final top

10 research questions. Please let us know if you would be interested in taking part. Numbers will be limited so we cannot guarantee a place to everyone. We are aiming to involve people with a range of different experiences and backgrounds.

If you would like to be involved, please provide your name, email address and tell us why you would be interested in participating. By doing that, you are providing Crohn's & Colitis Australia with information about yourself and your health. 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 express interest in participating in the discussion workshop

- Yes
- No

12. Please provide your details to participate in the discussion workshop

- Name
- Email address
- Confirm email address

13. Briefly tell us why you are interested in taking part in the discussion workshop to agree on the final top 10 research questions for IBD.

If you would like more information about this project, please contact the team at:

info@crohnsandcolitis.com.au

CCA thanks you for completing our survey!