

Australian IBD Research Priorities – Communication Material Priority Setting Survey

CCA mailing list and professional organisations

Dear [xxxx],

Crohn's & Colitis Australia is working in collaboration with the James Lind Alliance to identify the Top 10 research priorities of people with IBD, carers and healthcare professionals.

The first stage of this project involves an opportunity for you to participate in a survey to collect questions or concerns you have about IBD that will help identify the most common unanswered research questions. 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.

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. The first stage will be followed by a second survey to prioritise the questions. The final list of Top 10 unanswered research questions will be published with the aim to encourage researchers and research funders to focus on the most urgent and relevant needs of people living with IBD.

The survey is open to people 16 years or older with IBD, carers and healthcare professionals. Please complete the survey by 28/02/2021 using this link https://www.crohnsandcolitis.com.au/ibdqoc/research-priorities/.

Thank you for your participation.

Professor Paul Pavli Chair, IBD Research Priorities Steering Group

Leanne Raven

CEO, Crohn's & Colitis Australia

Member e-News, Facebook, Instagram, LinkedIn

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<mark>Twitter</mark>

Have your say on Crohn's and colitis research. We want to hear what questions or concerns you have about IBD. If you are 16 years or older with IBD, a carer or healthcare professional please click here to take part in our survey. <u>https://www.crohnsandcolitis.com.au/ibdqoc/research-priorities/</u>

Professional organisations

Dear [xxxx],

Crohn's & Colitis Australia (CCA) is working in collaboration with the James Lind Alliance of the UK to identify the "Top 10 research priorities of people with IBD, carers and healthcare professionals".

We want our stakeholders to have a louder voice in research and are seeking ideas and thoughts from people with different experiences and backgrounds.

The first stage of this project involves a web-based survey to identify their most important research questions. The survey is open to people 16 years or older who suffer from IBD, their carers and healthcare professionals and will be available online until 28/02/2021.

The responses from the first stage will be checked against published research to identify those that remain unanswered.

A second survey will prioritise the questions and formulate a final list of the top 10 unanswered research questions. These will be shared with researchers and funders to encourage them to focus on the most urgent and relevant needs of people living with IBD.

We would be grateful if your organisation would promote the survey to healthcare professionals and clinical researchers within your membership and network. In recognition of your support and if you agree, your organisational logo will be displayed on the CCA Research Priorities webpage and final report.

We have attached some example text that you can circulate to members. Further information is also available at https://www.crohnsandcolitis.com.au/ibdqoc/research-priorities/.



If you have any queries about how your organisation can support this project in this and in other ways, please contact <u>info@crohnsandcolitis.com.au</u>.

CCA appreciate your support in promoting the survey and thank you in anticipation.

Professor Paul Pavli Chair, IBD Research Priorities Steering Group

Leanne Raven CEO, Crohn's & Colitis Australia