

# Crohn's & Colitis New Zealand Charitable Trust

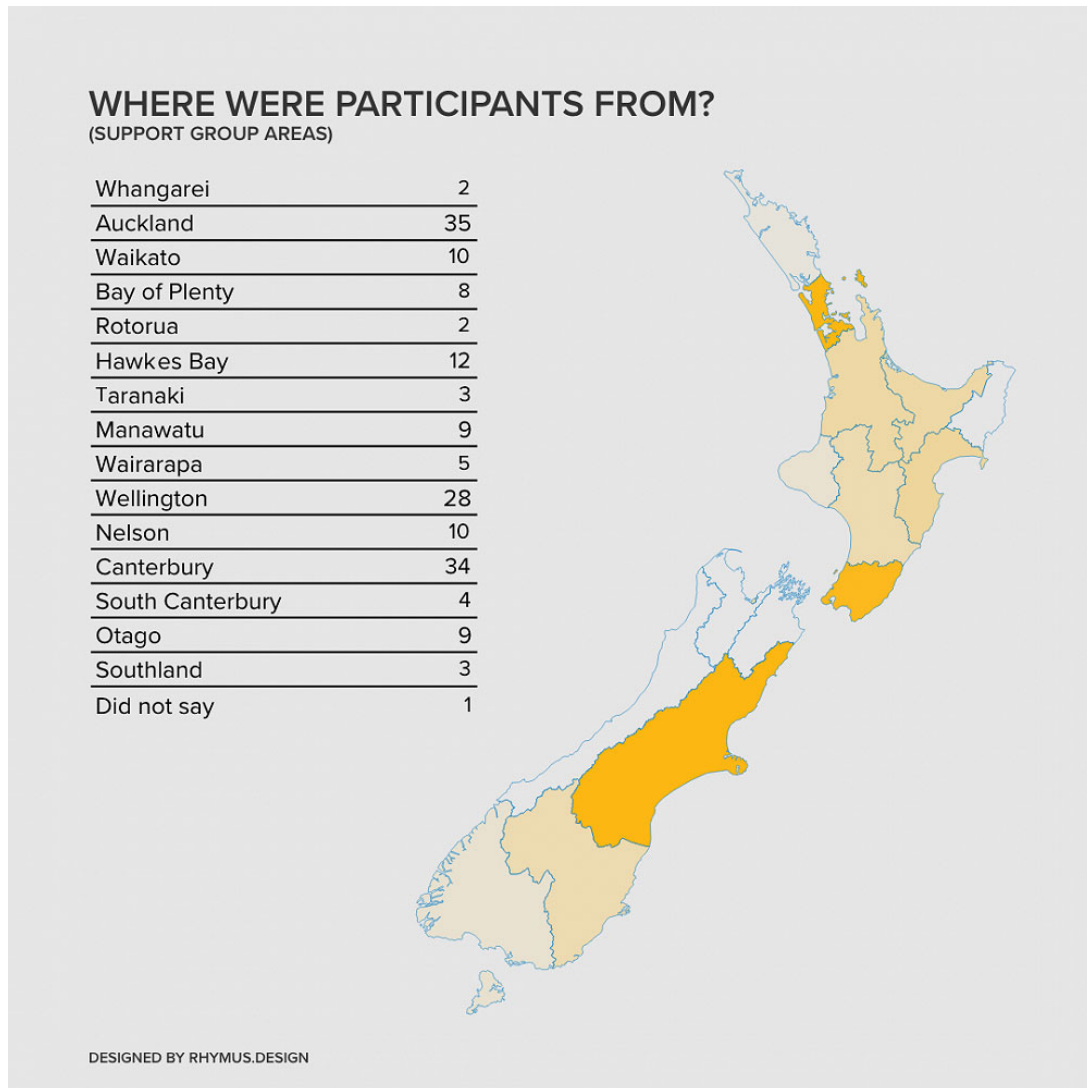


Photo by Rhys Rigione-Pisone

## 2020 Crohn's and Colitis Support Group Survey results.

Anna Scanlen — December 17th, 2020

A bit over a year ago, I wrote about how Crohn's and Colitis New Zealand is working on ways to better support the Crohn's and Colitis Support Groups (CCSGs)[A1] . Over the past year, CCNZ has been meeting with our volunteer support group coordinators to find out what they need in order to better support their communities. Because of the COVID-19 lockdown the support groups had stalled their activities to keep their communities safe. One of the things support groups needed was more information from the community! So, we decided to do an online survey to hear from you.

The survey was designed by Belinda Brown and myself, and shared on social media in June. It had 10 questions, which included whether people had been to a support group event and what they thought about it, and what they would like to see from their support group in future. There were also some demographic

questions regarding people's age and whereabouts in New Zealand they lived, and a space for their email address in case they wanted to volunteer or keep in contact with their support group.

175 people across New Zealand took part, most of whom were IBD patients (144), and parents of patients (26). Three people were parents of an IBD patient, and a patient themselves.

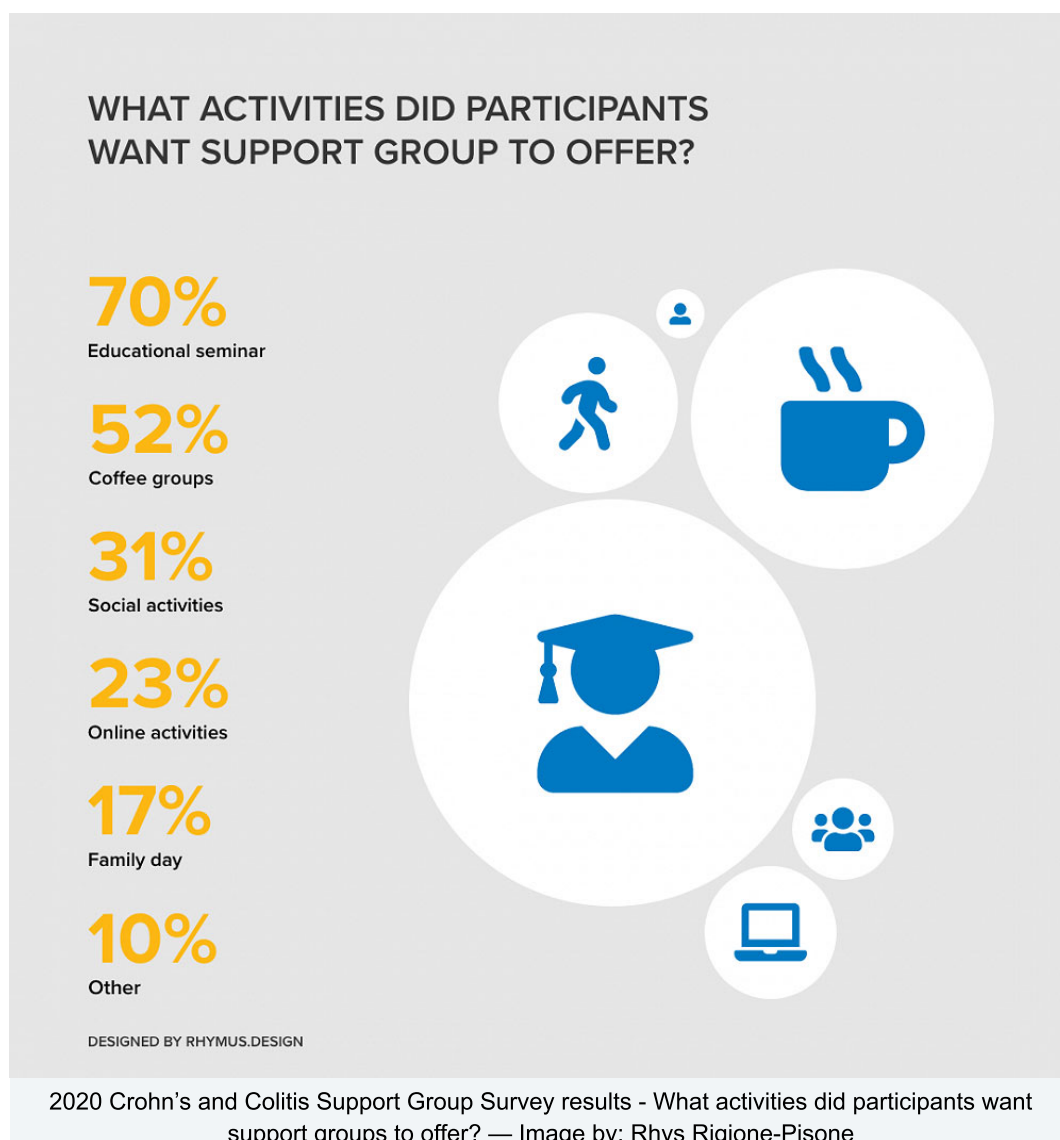
### Some key results:

We found it really interesting that most of the participants (116) had never been to a support group event before! Many said that they did not know about the support groups or they had only recently found out about them. A number of people wanted to participate in a support group event but had not been informed or had tried to make contact with a support group and had no luck.

Of the 59 people who had been to a support group event, it was mostly a really positive experience, and a lot of people specifically highlighted that they liked meeting other people and learning new things during educational seminars.

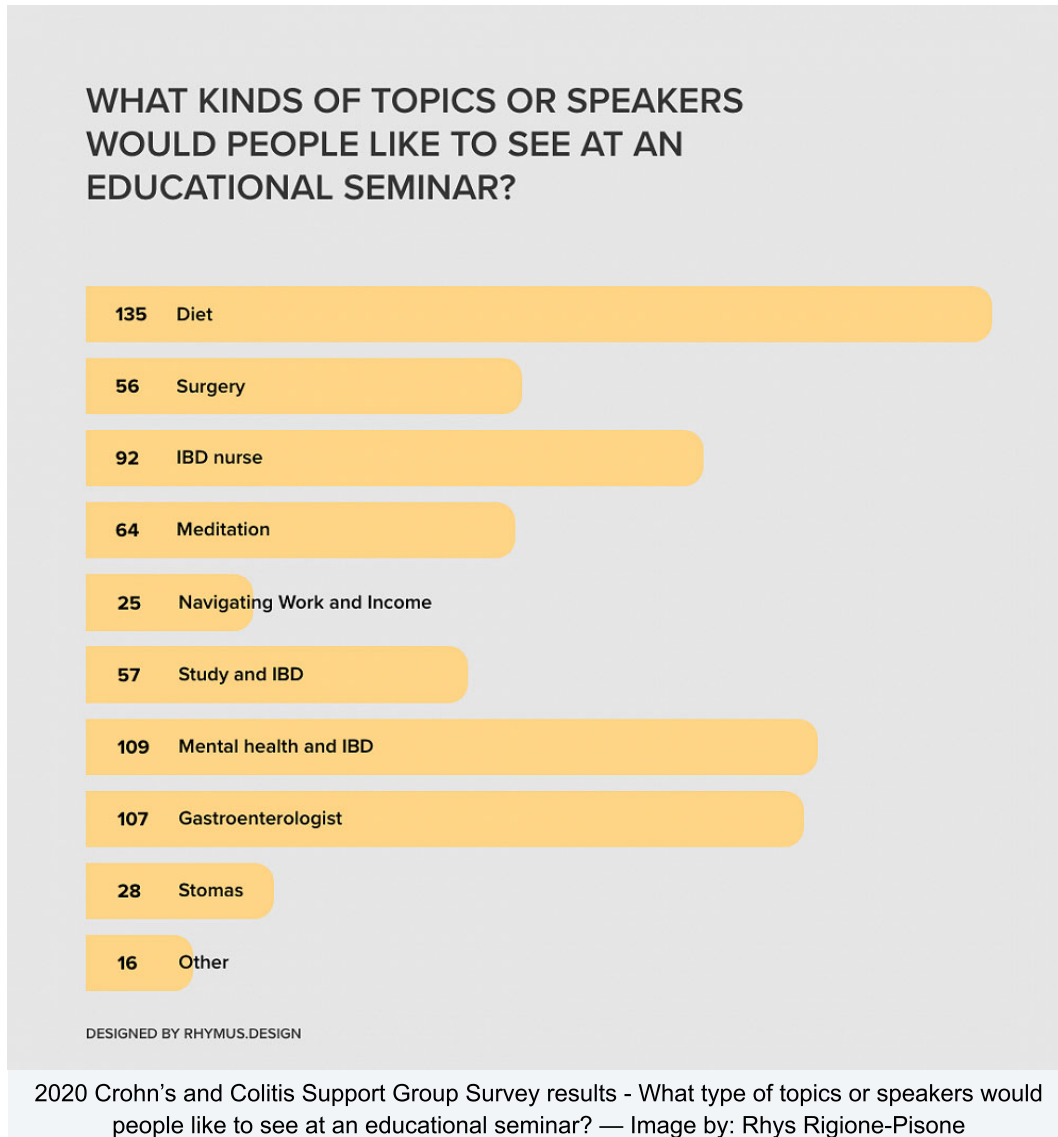
Survey participants were asked what they wanted their support group to offer, and they could select more than one option:

- 70% wanted educational seminars,
- 52% wanted coffee groups, and
- 31% wanted social activities.



Participants were also asked what they would like to learn about at educational seminars. Again, they could select more than one option:

- 77% wanted to learn about diet and IBD,
- 62% wanted to learn about mental health and IBD,
- 61% wanted to learn about gastroenterologists, and
- 53% wanted to learn about IBD nurses.



#### How the information is being used:

We've put together all the information from the survey into a report, which is attached to this article for you to read. We also put together special reports just for the support group coordinators with all the information from the survey specific to their support group areas. If participants shared their email address, this was also shared with coordinators so they can get in touch with people who want to help out, or even if they just want to be added to the mailing list. This is so the support groups have the information they need to best support their community.

#### How you can help the support groups:

CCNZ are working hard to ensure that the support groups are all getting active and supporting their communities. If you are feeling up to it, please head along to an event, your community would love to meet you!

If you would like to get in touch with your local support group, the email addresses for each support group are below:

Whangarei CCSG

Jo Field

[whangarei@crohnsandcolitis.org.nz](mailto:whangarei@crohnsandcolitis.org.nz)

Auckland CCSG

Helen Miller / Bobbi Laing

[auckland@crohnsandcolitis.org.nz](mailto:auckland@crohnsandcolitis.org.nz)

Waikato CCSG

Danielle Le Heron

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Taranaki CCSG

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BOP CCSG

Kerry Styles

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Rotorua CCSG

Susan / Janine / Cameron

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Hawkes Bay CCSG

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Manawatu CCSG

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Wellington CCSG

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Nelson CCSG

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Canterbury CCSG

Kirsty Kelly

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Otago CCSG

Rachel O'Boyle / Danielle Wilson

[otago@crohnsandcolitis.org.nz](mailto:otago@crohnsandcolitis.org.nz)

Southland CCSG

Christina Sandford

[southland@crohnsandcolitis.org.nz](mailto:southland@crohnsandcolitis.org.nz)

West Coast CCSG

Looking for a volunteer!

If you have any comments about the survey report, please contact Belinda at [info@crohnsandcolitis.org.nz](mailto:info@crohnsandcolitis.org.nz).

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## **Attachments**

[2020 CCNZ Support Group Survey Report](#)

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