

Participant Information Sheet for Bowel Cancer New Zealand's Never too young survey

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<p>Study Coordinator and first contact</p>	<p>Name. Victoria Thompson Bowel Cancer New Zealand Position. Clinical nurse specialist</p>	<p>here4you@bowelcancernz.org.nz Phone: 0800 226968 Text: 021 367968</p>

Kia ora, Kia orāna, Tālofa lava, mālō e lelei, fakaalofa lahi atu, Mālō nī, Ni sa bula vinaka, Talofa, Mauri, Noa'ia and hello.

Thank you for your time and interest in taking part in this survey for Bowel Cancer New Zealand, in collaboration with the University of Otago - Christchurch, Department of Surgery.

Thank you for showing an interest in this project. Please read this information sheet carefully. Take time to consider and, if you wish, talk with relatives or friends, before deciding whether or not to participate.

If you decide to participate, we thank you. If you decide not to take part, there will be no disadvantage to you, and we thank you for considering our request.

Background and aims

Aotearoa, New Zealand, continues to have some of the highest rates of bowel cancer internationally. Around 3300 people are diagnosed **each year** with this disease, and more than 1200 people die from it, making bowel cancer our second biggest cause of cancer deaths.

In Aotearoa and around the world, the number of those aged under 50 being diagnosed with bowel cancer is rising, there is often a delay for younger people getting a diagnosis, and this delay means many bowel cancers are found when it has already spread to other parts of the body and system.

We would like to know why there are delays and how having bowel cancer impacts younger New Zealanders. Is it due to not knowing what symptoms and issues to look for? Or that there weren't

any symptoms? Is it because healthcare professionals feel unable to refer young people for investigations? Or maybe it is a combination of things which lead to not just a delay, but also finding out about it when admitted to hospital.

For a younger person there are different impacts on their lives, their ability to continue working, raising children, socializing and changes to body image and fertility. While many of these can have an impact on those over 50 years old, there are times these may not be fully talked about and followed up.

This survey aims to help us better understand the journeys of patients diagnosed with bowel cancer to help us reduce delays to diagnosis and improve support available for those who are diagnosed with bowel cancer.

Who is funding this project?

This survey is being run by Bowel Cancer New Zealand with the University of Otago, Christchurch, Department of Surgery.

Who are we seeking to participate in the project?

Patients who were diagnosed with a bowel cancer under the age of 50 years.

If you participate, what will you be asked to do?

Complete a brief online survey. It should take 10-20 minutes to complete.

Many of the questions use a scale for your answer and will have a comments box should you wish to add a bit more to your answer. There will also be a 'not applicable' response for some which allows you to move on.

The answers you supply will help us to help you and ensure the support we offer is tailored to your needs. It will also help us advocate for what is important, for example a lowered bowel screening age, access to medications to improve quality and extend your life.

You will also receive an email thanking you for your participation along with the chance to go in the draw for a grocery voucher. Please keep an eye out for this once you have submitted.

Is there any risk of discomfort or harm from participation?

By answering questions and thinking about your own journey, we understand this may be distressing, and you are welcome to stop at any point. There is also support available to you, should you become distressed, triggered, or upset. You can contact any of the below organizations:

- Bowel Cancer NZ: here4you@bowelcancernz.org.nz or phone 0800 226968 txt 021 367968
- Lifeline: ph. 0800 543354 (0800 LIFELINE) or www.lifeline.org.nz/services/lifeline-helpline

Once you have completed the survey, links for support will be shown to you again.

What data or information will be collected, and how will they be used? What about anonymity and confidentiality?

We will ask your year of birth and gender, and then a range of questions investigating your journey to your bowel cancer diagnosis and through treatment. The results we gather from this survey will be published on the Bowel Cancer NZ website and via our social media platforms. The data may also be published in scientific journals and presented at conferences. Rest assured your anonymity will be maintained. No personal identifiers will be recorded. The data collected from this survey will be stored securely for 10 years and then safely removed.

There will be an option to leave your contact details if you consent to be contacted for a furthermore in-depth interview. This is completely optional and does not commit you to anything. This information will not be linked to your answers and will not be used for any other purpose.

If you agree to participate, can you withdraw later?

As your responses are non-identifiable, once you have submitted the survey, you will not be able to withdraw later.

Any questions?

If you have any questions now or in the future, please feel free to contact either:

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This study has been approved by the University of Otago Human Ethics Committee (Health). If you have any concerns about the ethical conduct of the research, you may contact the Committee through the Human Ethics Committee Administrator (phone +64 3 479 8256 or email: humanethics@otago.c.nz). Any issues you raise will be treated in confidence and investigated, and you will be informed of the outcome.

Ngā mihi, Meitaki, Fa'afetai lava, Mālō 'Aupito, Fakaauae Lahi, Fakafetai lahi lele, Vinaka, Fajākse'ea and thank you.

Many thanks for your valuable input into this survey.