



Te Rēhita Mate Ūtaetae
Breast Cancer Foundation
National Register



**Information for
breast cancer
patients and
whānau**

breastcancerregister.org.nz

What is the Register and why do we need it?

Te Rēhita Mate Ūtaetae - Breast Cancer Foundation National Register collects information about people with pre-invasive and invasive breast cancer in Aotearoa New Zealand to help improve breast cancer care and outcomes.

"The Register helps improve the care of current and future breast cancer patients."

– Dr Abbey Wrigley, Chair of the Clinical Advisory Group

The Register is a taonga, a treasured resource for improving breast cancer care. For over 25 years, it has helped doctors, researchers and health planners better understand breast cancer leading to steady improvements. Your information is a gift that will help shape better care for future generations. We will honour your trust and protect your privacy. Together, we can make a difference, help others and save lives.



For more information on what we

What can I do to help?

Please gift us your information.

Every breast cancer patient's information is important. The more complete the Register information is, the greater the value. You don't have to do anything. We include your breast cancer patient information in the Register unless you contact us to opt out.

We collect your information from your health records held by hospitals, laboratories and other health providers, rather than directly from you. This ensures your information is accurate and complete. We use your National Health Index (NHI) number to safely link to these records. Only authorised staff can access your information.

Your data is collected and stored securely according to The Privacy Act 2020, Health Information Privacy Code and Health and Disability Ethics Committee. We are guided by Te Tiriti o Waitangi and Māori data sovereignty principles.

We collect the following information:

- your NHI number, name, age, ethnicity, postcode
- your breast symptoms and risk factors
- your diagnostic information
- treatment you received in hospital
- ongoing care and wellness after discharge

Thank you for participating.

Together we can save lives.

How my data is used

Our Clinical Advisory Group is responsible for managing the information we hold, assessing, and approving use of the data. This governance group includes breast cancer doctors as well as researchers, ethics, Māori, Pacific, and patient representatives.

Your information is used by doctors and hospitals, health planners, and researchers in NZ. This helps us to:

- understand more about breast cancer
- improve diagnosis, treatment and services
- identify inequalities in patient care
- monitor and continually improve breast cancer survival

Researchers are only provided de-identified data. Research data is stored securely and destroyed after use.

Doctors and hospitals use identifiable data to help provide and improve care, such as through the BreastSurgANZ Quality Audit. In this case, health information is securely linked using your NHI number.

With information in one place in the Register, we can work together with health organisations to strengthen services and care.

Learn more about privacy, security, data linkage, data use and audit at **breastcancerregister.org.nz**



My privacy rights

The Register complies with New Zealand privacy laws. The doctor treating you can provide more information on your privacy rights, or you can contact us, or view our Privacy Policy.*

What if I want to opt out?

You can opt out at any time. Opting out won't affect your breast cancer care. Once you opt-out from the Register, we only keep minimal information* to respect your choice. Data is removed, excluded from future research and audits, and not visible to doctors. However, please consider sharing your data. When you gift data, we can help others.

How do I access my information?

You have the right to request and correct your information. We'll confirm your request then provide information through your doctor within 10 working days.

Contact us to opt out or request information

Call us: 0800 005 849

Email us: admin@breastcancerregister.org.nz

Or talk to your doctor or nurse

*www.breastcancerregister.org.nz/privacy



How we help improve breast cancer outcomes

Go to **[breastcancerregister.org.nz/latest research](https://breastcancerregister.org.nz/latest-research)** to read research and reports that are helping improve equity, care and outcomes;

- [Over 50 research studies on New Zealanders.](#)
- [30,000 voices: Informing a better future for breast cancer](#) report which shows improved outcomes over the years across all ethnicities and how we can improve further.
- [Advanced Breast Cancer: "I'm still here"](#) report identifying areas for improvement in advanced breast cancer.

For interpreter and translation services:

If you need help to better understand this brochure, please ask your doctor to connect you with your regional hospital interpreter service.



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Email admin@breastcancerregister.org.nz

Visit breastcancerregister.org.nz