



Te Rēhita Mate Ūtaetae
Breast Cancer Foundation
National Register



**Information for
breast cancer
patients**

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 all pre-invasive and invasive breast cancer patients in Aotearoa New Zealand to help improve breast cancer care and outcomes for all.

“The register helps improve the care of current and future breast cancer patients.”

– Dr Alison Foster, Chair of the Clinical Advisory Group

The register has been operating for over 20 years. It is a confidential collection of information, vital for doctors, researchers and health planners to understand breast cancer better. Learnings from research studies and analysis of the data have led to steady improvements in breast cancer care.

The register is a taonga | treasure benefiting future generations of Aotearoa New Zealand.



For more information on what we

What can I do to help?

Please allow your information to be included.

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.

Your information is securely collected, entered and stored in the register. We use your National Health Index (NHI) number to accurately and safely link to your health records and other health sources to collect your data. Only authorised staff can access your information.

The Privacy Act 2020, Health Information Privacy Code and Health and Disability Ethics Committee approval apply to the breast cancer register. 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. You are helping to improve breast cancer outcomes.

How my data is used

A governance group is responsible for managing the information we hold and approving use of the data. The group includes breast cancer doctors as well as Māori, Pacific, researcher and patient representatives. They ensure the appropriate approvals are in place prior to data use.

Your information is used by doctors and hospitals to improve care and in health planning and research. This helps us to:

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

So that doctors and hospitals can improve care, your information may be securely linked and combined with information from other organisations; e.g. Manatū Hauora - Ministry of Health, Te Whatu Ora - Health NZ and other breast care health providers, and used in audits such as BreastSurgANZ Quality Audit. For more information go to **breastcancerregister.org.nz/latest-research/audits**.

Research helps improve treatment and care. Researchers are provided coded data only (your details are not identifiable). There is a secure coded process to link data for research. Research data is stored securely and destroyed after use.



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 visit the Office of the Privacy Commission website privacy.org.nz.

How do I access my information?

You have the right to request and correct your information. Contact your doctor, or us directly, to request your breast cancer register information. Once we receive the request your information will be provided via your doctor within 10 working days.

What if I want to opt out?

You can opt out at any time by emailing or calling us. Opting out will not affect your breast cancer care in any way.

To opt out or contact us:

Call 0800 005 849

Or email admin@breastcancerregister.org.nz



Te Rēhita Mate Ūtaetae
Breast Cancer Foundation
National Register



How we help improve breast cancer outcomes

Go to breastcancerregister.org.nz/latest-research to read research and reports that are helping improve equity, care and outcomes;

- Over 30 New Zealand research studies.
- 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.



Te Rēhita Mate Ūtaetae
Breast Cancer Foundation
National Register

Call 0800 005 849

Visit breastcancerregister.org.nz