

Frequently asked questions (FAQs)

Disabled People and Cancer in Aotearoa New Zealand

Why has the Te Aho o Te Kahu | Cancer Control Agency (the Agency) focused on disabled people?

In 2021, the Agency identified a lack of research on cancer incidence and cancer outcomes for disabled people in Aotearoa New Zealand. These new reports aim to highlight issues or attitudes that can make it harder for disabled people to access timely, high-quality cancer diagnosis and care. Health planners, workers and organisations can use these resources to develop evidenced-based health policies and deliver appropriate care to remove the barriers many disabled people currently experience.

What are the Disability and Cancer Reports?

The Agency has released two reports focused on understanding how cancer affects disabled people in Aotearoa New Zealand. These reports are called:

- Disabled People and Cancer: Literature Review
Ngā Tāngata Whaikaha me te mate pukupuku: he arotakenga mātātuhi
- The Burden of Cancer Among Disabled People: Diagnosis Insights
He taumaha te mate pukupuku ki ngā tāngata whaikaha: Ngā Kitenga.

17% of New Zealanders identified as disabled in the Stats NZ Household Disability Survey 2023. The disability and cancer reports aim to help us understand the barriers that many disabled people in New Zealand face when they experience cancer diagnosis and treatment.

The disabled people and cancer literature review ('literature review') will help everyone working in health care learn more about the difficulties disabled people face when being diagnosed or treated for cancer. It uses evidence to explain ways to make it easier for disabled people to receive the care they need and points out areas where more research is needed.

The burden of cancer among disabled people: diagnosis insights report

(‘diagnosis insights report’) looks at how many disabled adults in New Zealand are diagnosed with cancer compared to all adults. The findings show that disabled people get cancer more often than the general population, including for lung, bowel, and breast cancers. However, the report explains that being disabled does not by itself make someone more likely to get cancer. Instead, this is probably because disabled people are more likely to be exposed to things that increase cancer risk, like not being able to access to healthy foods, housing, exercise or smoking.

How were disabled people with cancer involved in this work?

The Agency ensured that disabled people with experience of cancer were part of the project team. Three fixed-term roles were created for individuals with lived experience of both disability and cancer to contribute to the project. The lived experience advisors represented Māori, migrants and refugees, young people under 25, LGBTQI+ people, older adults over 65, and people who had experience with different types of cancer.

A member of He Ara Tangata, which is the Agency’s consumer advisory group, also supported the project team. This person does not identify as disabled but has personal experience with cancer, and also has experience in supporting disabled people.

How did you identify a disabled population in the cohort study?

The burden of cancer among disabled people: Diagnosis insights report used two data sources to identify disabled people in Aotearoa New Zealand:

- census and other household surveys which use the WGSS to identify people with specific impairments, and
- needs assessment data to also identify people with these same functional impairments.

Using these methods the disabled cohort was compared with rates in the total population. More detail on the methods, including some important limitations, are described in the report.

What are the key findings of The Disability and Cancer Reports?

There isn't much published research about the experiences and outcomes for disabled people, either in New Zealand or in other countries. Most of the research that is published only looks at cancer screening. We don't know much about how disabled people are treated, what their results are, what kind of care and support they get when their cancer cannot be cured, or when they are dying.

Are disabled people more likely to be diagnosed with cancer?

Yes. Disabled people in Aotearoa New Zealand are 22% more likely than the total population to be diagnosed with cancer. The largest disparity occurred in the 45–65-year age group, where disabled people were 34% more likely to be diagnosed with cancer compared to the total population of the same age. Tāngata whaikaha Māori (disabled Māori) had the highest rate of cancer diagnosis within the disabled population. Other subgroups with high rates included males, people living rurally, and those residing in areas of high deprivation.

We also looked at the diagnosis patterns of four specific cancers. Disabled people are more likely to be diagnosed with breast, bowel, and lung cancer when compared to the general population, however, are less likely to be diagnosed with prostate cancer.

Higher rates of cancer, especially lung and colorectal cancers, among disabled people under 75 suggest that some of these cases could potentially be prevented and highlight the crucial role of screening in detecting these cancers early.

While some health conditions that are disabling can increase cancer risk, for example, diabetes, chronic lung disease, these conditions are more common in people who are disabled. In most cases being disabled does not mean you are more likely to get cancer. Instead, disabled people might have a higher risk because they are more exposed to things that cause cancer, like smoking. They may also face challenges like lower income, poor housing, and problems getting to doctors or cancer screening. All these issues can make it harder to stay healthy and get cancer diagnosed early.

These findings show why it is important cancer programmes and services are designed to be inclusive of disabled people, since they are more likely to be diagnosed with cancer compared to non-disabled people, and this is true for all age groups and backgrounds.

What are the main barriers disabled people face in accessing cancer screening?

The main challenges are:

- Medical centres and equipment are sometimes hard to get to or use if you are disabled
- Screening tests can be painful or uncomfortable for some people
- Information about the tests may not be easy to understand, or not given in a way that works for everyone
- Some health care workers do not have enough training about disability and may not treat disabled people respectfully
- It can be hard to afford the tests or travel to appointments
- Some people have experienced trauma or sexual assault, which can make screening even harder.

What is diagnostic overshadowing and how does it affect disabled people?

Diagnostic overshadowing happens when medical professionals mistake signs of cancer for symptoms of a person's disability. Because of this, cancer might

not be found or treated as early as it should be. This can lead to worse health outcomes for disabled people.

Do disabled people receive the same cancer treatment as non-disabled people?

Not always. Studies show that disabled people sometimes do not get the same cancer treatments as people without disabilities. For example, women with learning disabilities are more likely to have their whole breast removed instead of just the part with cancer, and disabled people who have cervical or lung cancer usually get less treatment than those who are not disabled.

How do health care workers' attitudes impact cancer care for disabled people?

When health care workers have negative attitudes about disabled people, don't show understanding, or haven't had enough training, it can cause problems. They might not talk clearly, make things easy, or offer the right help. This can make it harder for disabled people to get the screenings and treatments they need at every step of cancer care.

Are there disparities in cancer screening rates for disabled people?

Yes. Studies from around the world show that disabled people are less likely to get screened for cancer, especially breast and cervical cancer. This means cancer may not be found early, making it harder to treat and leading to worse health.

There are many reasons disabled people face challenges with cancer screening and treatment. These include clinics and appointment times that do not meet their needs, not having enough help to use health services, unclear or hard-to-read information for patients, and health staff who may not have enough training about disabilities.

Prevention interventions (especially smoking cessation), screening programmes (including lung cancer screening) and cancer services all need to be accessible and acceptable to disabled people, with appropriate models of care.

What role does data play in improving cancer care for disabled people?

Collecting good, clear data about disabled people is important for spotting unfair differences and making health services better. If health systems do not keep proper records, disabled people may be overlooked, and their needs may not be met.

In New Zealand, information about disability is not always collected in the same way, which makes it hard to know who is disabled and what they need. This is a big problem for all health data, not just for cancer care.

Other countries also struggle because disability is defined and counted differently, making it hard to compare results and understand the big picture. To make things fair and improve services, it is essential to collect disability data carefully and use the same standards everywhere.

What can be done to improve cancer services for disabled people?

Options include:

- Co-designing services with disabled people
- Making sure that all information about health is easy to understand
- Giving health professionals good quality training about disability
- Making sure that all health centres and equipment are accessible
- Offering longer appointments and help to understand the processes.

Are Māori disabled people (tāngata whaikaha Māori) disproportionately affected?

Yes. Tāngata whaikaha Māori are more likely to be diagnosed with cancer and face extra challenges because of unfair treatment, the effects of colonisation, and discrimination against disabled people. This needs to be fixed urgently.

How can people working in the health system use these reports?

The Agency's disability and cancer reports are for health professionals, people who manage cancer services in hospitals, and government agencies.

These reports give information that can help people talk about, investigate, and improve cancer services at local, regional, and national levels.

For instance, tackling the social factors that affect health among disabled people—especially tāngata whaikaha Māori, Pacific disabled people, and those who become disabled at a young age—is essential for reducing the risk of cancer and other health conditions.

The reports also help us understand how cancer affects disabled people. They provide facts that can be used to make better plans for preventing cancer, finding it early, and improving cancer services for everyone.

What is being done to improve cancer services for disabled people?

Here are some things being done to make health services better for disabled people:

1. A new version of the New Zealand Disability Strategy (for 2026-2030) is being developed. It includes five main actions for health:
 - Looking at and improving ways of doing things so health services are more accessible and welcoming.
 - Helping health workers learn how to better support disabled people.
 - Giving disabled people more chances to learn the skills they need to work in the health system.
 - Making sure disabled people are counted in the country's health data.
 - Setting up systems so disabled people can say what help or support they need in their National Health Index (NHI) record.

2. Health New Zealand Te Whatu Ora is working on a project called the Patient Profile and National Health Index (PPNHI). This will let disabled people tell health services what support they need when they get care.
3. As part of the PPNHI project, work is also being done to make sure disabled people can be identified in national health data. Right now, health records can show details like age, gender, ethnicity, and where someone lives, but they can't show if someone is disabled. This makes it hard to understand and fix health problems that affect disabled people.
4. The Disability Health team at Health NZ has a big work plan to help the organisation give better care to disabled people. This includes teaching staff, changing policies, and making sure services are easier to use and more welcoming.
5. The Ministry of Health is working on ways to improve the health of people with learning (intellectual) disabilities. One idea being looked at is to offer yearly health check-ups. This could help more people with learning (intellectual) disabilities get screened for cancer.
6. The Detailed Business Case for the National Lung Screening Programme (NLSP) is currently being scoped. If it proceeds, this programme will help find and treat lung cancer sooner, manage it more effectively, and lower its impact on families and communities. The new reports about disability and cancer will help inform this programme on how to support disabled people better.

Sharing these reports will give everyone more information about disabled people with cancer. This will help improve health policies, planning, and care throughout the health system.

What are the next steps following the release of this report?

The disability and cancer reports will be published on our website in November 2025. We will also share the main points and next steps with key organisations, people and groups.

The Agency will keep working with health organisations and the disability community to better understand the health needs of disabled people and

their families when it comes to cancer. Together, we will look for ways to make cancer care and outcomes better for disabled people.

What are the next steps for improving cancer outcomes for disabled people?

We need to learn more about how long disabled people live after a cancer diagnosis, what stage their cancer is found at, and what treatment they get. The Agency and others are working with the disability community to collect better information and improve services and results for disabled people.