Participate. Shape the future – Cancer Action Plan 2019–29

Overview

66 people are told they have cancer every day.

Most New Zealanders will be impacted by cancer in their lifetime – either directly, or through friends or family members affected by cancer.

Right now, we are finalising the New Zealand Cancer Action Plan 2019–2029.

We want to hear what matters most to you.

New Zealand's Cancer Action Plan

The New Zealand Cancer Control Strategy 2003 first set the direction for managing cancer control activities in New Zealand. The goals and objectives of the Strategy remain relevant.

Since then, we have seen overall improvements in cancer outcomes due to our efforts in preventing and screening for cancer, and in diagnosing, treating and caring for people with cancer. For example, we have invested in a tobacco control programme, which has led to reduced smoking rates.

While we have made good progress, we can do better to address the ongoing challenges in addressing cancer, particularly reducing inequity in cancer outcomes.

This is why we are renewing our commitment and reinvigorating our approach to preventing and managing cancer over the next 10 years.

This survey will provide us with a greater understanding on what's most important to you.

It will take 15–20 minutes to complete. Please note that all responses are optional – you can share as much or as little information as you feel comfortable doing.

Your cancer story

Chances are you or someone you know has been affected by cancer. Maybe you or someone you care about has undergone treatment for cancer. Making cancer care better starts with people and their stories. **What's yours?**

What is your experience with cancer?

Please share your story.

Which of the below best describes you?

Please select all that apply

☐ Person with cancer ☐ Cancer survivor

☐ Whānau/Family/Friend of someone who has been affected by cancer

☐ Caregiver of someone who has been affected by cancer ☐ Member of the general public

☐ Other

If you selected other, please specify

Getting to know you

Please tell us a little more about yourself. This will help us better understand people's responses.

Please note that all responses are optional – you can share as much or as little information as you wish.

What is your ethnicity?

Tick the boxes that apply to you.

Please select all that apply

☐ New Zealand European ☐ Māori ☐ Samoan ☐ Cook Island Māori ☐ Tongan

☐ Niuean ☐ Chinese ☐ Indian ☐ Other

If you selected other, please state

What is your age?

Please select only one item

○ Under 18 ○ 18–24 ○ 25–29 ○ 30–34 ○ 35–39 ○ 40–44 ○ 45–49

○ 50–54 ○ 55–59 ○ 60–64 ○ 65–69 ○ 70–74 ○ 75–79 ○ 80–84

○ 85 plus

What is your gender?

Please select only one item

○ Male ○ Female ○ Gender diverse ○ Prefer not to say

What is your post code?

☐

A lot has changed over the last 16 years…

A lot has changed since New Zealand’s first cancer strategy was created back in 2003.

Cancer care has improved, which is good news.

In some cases, there have been decreases in cancer incidence, such as cervical cancer. This could be linked to our efforts in prevention and our ability to detect it before it turns into cancer through our Cervical Screening Programme.

But, there are growing and new challenges.

New Zealand’s population is getting older and the costs for our health care system keep rising. People aged 65+ are more likely to develop cancer, so more older people equals more cancer cases, more people in treatment and more home and family supports needed.

Some people have longer wait times for cancer care than they should, which adds to their stress and affects their overall health.

Finally, some people in New Zealand have a harder time getting the cancer services they need, like Māori, Pacific people, people who live further away from big cities in remote communities, those who have a mental illness, disabled people and people who are poor.

Cancer journey

People who have had cancer often say it feels like a journey – a long and hard walk without an end in sight. Even with people to help like friends, family and caring health workers, it can feel like a journey they take alone.

Everyone’s cancer journey is different – it doesn’t begin or end at the same place.

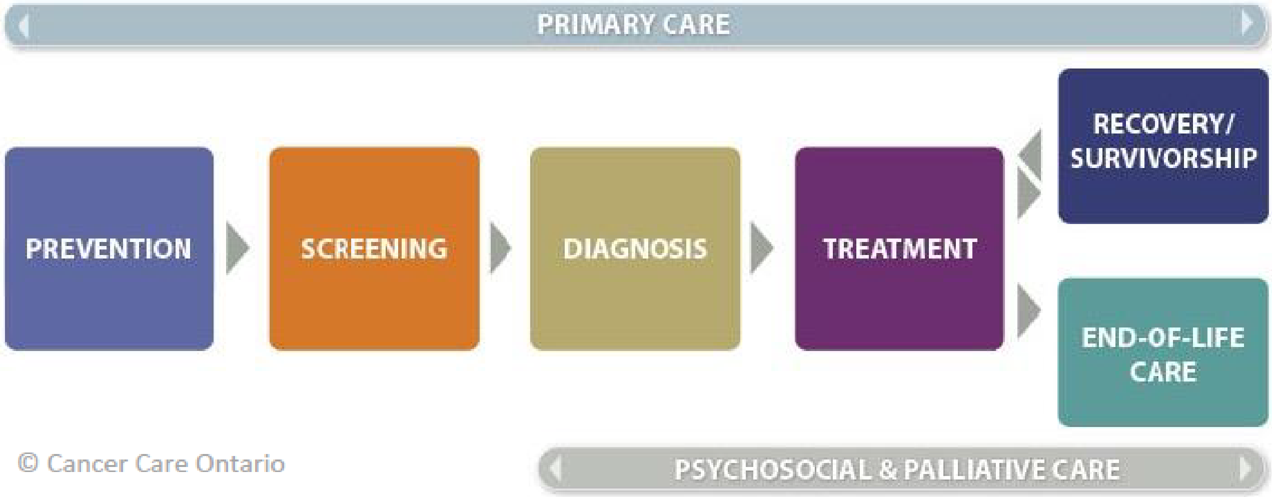
Some live with cancer for a long time as it’s monitored and managed. For others, the cancer returns and they need to undergo new treatments. And some people get rid of one cancer only to be diagnosed with another type of cancer later on.

For others, their cancer journey keeps going into palliative care and, sometimes, they come to the end of their lives.

Possible steps in people’s cancer journey

Here’s a picture that shows some of the possible steps in the cancer journey. It’s important to remember that each journey is different, and does not always head in the direction people expect or as reflected in the picture below.

In the next part of this survey, you’ll learn more about each of these steps and have the opportunity to tell us what you think.



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Improving prevention

Prevention is about lowering a person’s chance of getting cancer in the first place.

For example… Hugh recently heard on the news that about 30% of cancers can be caused by the environment they live in and some of the lifestyle factors they are exposed to. Now he’s trying to eat healthier food and get more exercise. He’s also working with his GP to try and stop smoking because he knows it causes lung cancer.

Some facts to think about

- At least 30% of cancers can be prevented.
- New Zealanders can be better supported to reduce their risk of developing some cancers by eating healthier foods, getting exercise, having a healthy body weight, drinking less alcohol, not getting sunburnt, and not smoking.
- Tobacco use (eg smoking) is responsible for 80% of lung cancer cases in New Zealand.

How important is it to focus on prevention in New Zealand’s cancer plan?

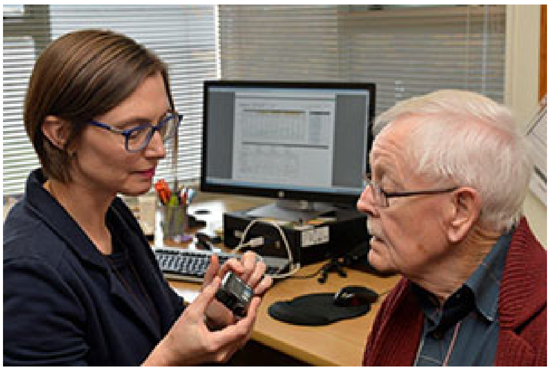
Please select only one item

○ Not important ○ Slightly important ○ Moderately important ○ Important
○ Very important

Comments

Improving early detection of cancer

Diagnosis is the step when people find out whether they have cancer or not; dealing with the news and finding out more about possible treatment options to fight the cancer.



For example… Thomas was consistently getting chest infections and was coughing all the time. Every time Thomas got a chest infection he went to his doctor and he would be prescribed with antibiotics to clear it up. After multiple visits, Thomas’s doctor suggested a chest x-ray. The results came back and did not suggest there was anything wrong. In the meantime, Thomas continued to cough. Later his doctor then suggested he get a CT scan, which detected a small tumour.

Some facts to think about

- Many people have to wait longer than they should for a cancer diagnosis.
- In July 2019, almost 5000 people waited for a colonoscopy (a test to detect bowel cancer) longer than the recommended time.
- Survival (at one and five years) following treatment is much higher if cancer is detected at an early stage. Surviving colorectal cancer if detected early (ie, at stage one) is 98%, but falls to 44% if detected late (ie, at stage four).

How important is it to focus on improving early detection in New Zealand’s Cancer Action Plan?

Please select only one item

○ Not important ○ Slightly important ○ Moderately important ○ Important
○ Very important

Comments

Improving screening

Screening is about getting tested for cancer early *before* a person sees any signs or symptoms.

For example… Anna recently turned 60. Last week, she received a package in the mail with a sample kit and a letter explaining that it is for National Bowel Screening Programme. At first she’s sceptical and uneasy about having to provide the sample and mail it. But then she thinks of her co-worker who died of bowel cancer two years ago because it was diagnosed late. She decides to go ahead and send in the sample and makes a note to discuss it with her family doctor at her next check-up.

Some facts to think about

- 64% of Māori and 72% of non-Māori are being screened for cervical cancer.
- Since introducing the cervical screening programme the incidence of cervical screening has reduced by 50% and deaths has decreased by 60%.

How important is it to focus on improving screening in New Zealand’s Cancer Action Plan?

Please select only one item

○ Not important ○ Slightly important ○ Moderately important ○ Important
○ Very important

Comments

Improving treatment

Treatment is about curing the cancer or at least slowing its growth to reduce symptoms. It can include things like surgery, radiation, or drugs.

For example… Margaret just started treatment for blood cancer. She’s often tired and feeling sick because of the drugs she has to take. She hopes the chemotherapy works, but she’s worried about what other options will be available to her if the chemo drug she’s on doesn’t work.

Some facts to think about

- 1 in 2 people with cancer would benefit from radiation therapy, but only 1 in 3 people receive it.
- Just over 20% of Māori patients receive chemo within eight weeks, compared with more than 40% of non-Māori.
- Relatively little is known around who should be accessing drugs to treat cancer and who are actually accessing it.

How important is it to focus on improving treatment in New Zealand's Cancer Action Plan?

Please select only one item

○ Not important ○ Slightly important ○ Moderately important ○ Important ○ Very important

Comments

Improving palliative care

Palliative care is a special kind of health care that helps patients with the symptoms and stress of a serious illness like cancer.

Provided by health care workers, the goal of palliative care is **not just** end-of-life care – it's to help patients and their families carry on with daily life through their cancer journeys. Palliative care should start early in a person's cancer journey.

For example… Helen has been diagnosed with cervical cancer. She and her family are working with palliative and primary care teams to help them cope and return to normal life. Helen's care plan makes sure she gets help for her pain, a psychologist to help her with her emotions and ability to cope, and a multidisciplinary team to support and coordinate her care.

Some facts to think about

Palliative care can:

- reduce unnecessary pain and discomfort and manage symptoms of treatment
- support patients and their families cope emotionally and practically
- provide care as much as possible, reducing avoidable emergency department visits and minimising days in hospital
- decrease the likelihood of dying in hospital.

How important is it to focus on improving palliative care in New Zealand's Cancer Action Plan?

Please select only one item

○ Not important ○ Slightly important ○ Moderately important ○ Important
○ Very important

Comments

☐

Survivorship

Survivorship focuses on your health and life once your cancer treatment is over.

For example… Kelly finished her treatment 2 months ago and the cancer is now in remission. Now she's just trying to 'find a new normal'. She's planning to return to work in a few weeks, but she is very tired, cannot concentrate, and is very anxious. She wishes she knew which health care provider can help her best, and where she can meet with other cancer survivors to hear how they have managed to move on with their lives. She's concerned that her family doctor's office may not know how to help.

Some facts to think about

- People affected by cancer have said they experience a loss of support when their treatment ends.
- As cancer outcomes improve and more people are living longer with and beyond cancer, there is a need to consider how best to support these people and their whānau/family.

How important is it to focus on providing more support for survivors in New Zealand’s Cancer Action Plan?

Please select only one item

○ Not important ○ Slightly important ○ Moderately important ○ Important ○ Very important

Comments

Improving end-of-life care

End-of-life care is about helping patients have the best quality of life possible after their cancer treatment has stopped and they and their families prepare for their life to end. It includes helping with their pain and symptoms, as well as mental health support in coming to terms with death.

For example… After several rounds of chemotherapy, Adrian has learned that his cancer has spread. He has decided he wants to stay at home with his family until the end. Thankfully, many of the services he needs to support his decision are available in his community. Home care means a health care worker can check on him and his medications every week. He is comfortable and is just focused on spending time with his whānau/family.

Some facts to think about

- Many people die in hospital, even though many prefer to die at home.
- Palliative care practice is variable and not everyone can access high-quality, culturally responsive care when and where they need it.

How important is it to focus on end-of-life care in New Zealand's Cancer Action Plan?

Please select only one item

○ Not important ○ Slightly important ○ Moderately important ○ Important
○ Very important

Comments

What would you focus on?

Imagine that you had $100 'Cancer Plan Dollars' to spend to create the cancer care system you would like to see.

Thinking about what's most important to you, how would you allocate this $100?

(Tip: you can allocate your $100 any way you like. You can spread it out across some or all areas, or only invest in the areas most important to you).

Prevention

Early detection

Screening

Treatment

Palliative care

Survivorship

End-of-life care

What made you decide to allocate your $100 that way?

What would you focus on?

Now imagine that you work in the government and are tasked with spending this $100 as part of a cancer plan for New Zealand. You've been asked to focus on 'the big picture' and to think of the needs of all New Zealanders.

If you were in this position, how would you allocate this $100 to improve cancer care for all New Zealanders?

Prevention

Early detection

Screening

Treatment

Palliative care

Survivorship

End-of-life care

What made you decide to allocate your $100 that way?

Reasons for allocation

Improving on the patient experience

Some people think the problem with cancer care is our health care system itself. It can be hard to navigate and can sometimes feel like a maze patients and their families have to find their way through.

For example… Steve has just been diagnosed with prostate cancer. He's had to schedule many different follow-up appointments, all on different days and in different clinics. He finds the cancer care 'system' confusing. It's hard to know who to approach with questions and get help. Sometimes he feels whoever designed the system wasn't thinking at all about what it's like to be a patient!

Some facts to think about

Some cancer patients say:

- no one discussed different options for their cancer treatment with them
- health care workers did not ask about how they would travel to the appointment when planning their treatment
- they were not happy with the emotional support they received during their cancer care.

How important is it to focus on improving the patient experience in New Zealand's cancer plan?

Please select only one item

○ Not important ○ Slightly important ○ Moderately important ○ Important
○ Very important

Comments

Improving on the patient experience

Let's stay on the topic of how to improve the patient experience.

We have heard from patients and their families about the problems they have faced getting the cancer care and supports they need.

They have said it feels like the cancer care system just isn't designed with patients in mind. Patients say they want to be empowered to participate in their own care.

We'd like to hear your ideas about how we can improve the patient experience throughout the cancer journey.

Improving on the patient experience: diagnosis

Let's start with **diagnosis** –how and when people find out whether they have cancer or not, how people deal with the news and how people are supported in finding out more about treatment options.

How important are each of the following ways to improve a patient's experience during cancer diagnosis?

	Not important	Slightly important	Moderately important	Important	Very important
Faster test results *Please select only one item*	○	○	○	○	○
Better care from health care workers (which also helps cancer patients feel less anxious) *Please select only one item*	○	○	○	○	○
Better coordination among parts of the health system for patients and their family/caregivers *Please select only one item*	○	○	○	○	○
Better communication between health care providers and patients *Please select only one item*	○	○	○	○	○

What else can be done?

Improving on the patient experience: treatment

Now let's move onto **treatment** – the surgery, radiation, or drugs to fight cancer, as well as the appointments, travel, stress, pain, fear, nausea and everything else that comes with it for patients, families and caregivers.

How important are each of the following ways to improve experiences during cancer treatment?

	Not important	Slightly important	Moderately important	Important	Very important
Help for patients to navigate through the health system *Please select only one item*	○	○	○	○	○
Help taking time off work and the loss of income that comes with it *Please select only one item*	○	○	○	○	○
More support for family/friend caregivers *Please select only one item*	○	○	○	○	○
More visits from health care providers and/or workers to a patient's home *Please select only one item*	○	○	○	○	○
Help scheduling appointments so they work with patients' 'real lives' *Please select only one item*	○	○	○	○	○
More time spent by doctors clearly explaining all the treatment options along with risks and benefits so patients can make informed decisions about their care *Please select only one item*	○	○	○	○	○

What else should be done?

Why do we need a cancer plan for New Zealand?

A New Zealand cancer plan means better cancer care across the country, because we can have the greatest impact if we work together.

Research shows that countries with good, well-managed plans do a better job of preventing cancer, and of taking care of patients with cancer.

While New Zealand has made good progress towards achieving the goals of the Strategy, we can do better to achieve equitable outcomes for all New Zealanders. At a time when there are many changes and challenges facing cancer control in New Zealand, we need to renew our commitment and reinvigorate our approach to preventing and managing the disease.

New Zealand
Cancer Action Plan
2019–2029
Te Mahere mō te Mate
Pukupuku o Aotearoa
2019–2029

New Zealand's cancer plan: your input

A cancer plan is about the future.

Based on your own experience and the issues you have thought about in this survey…

Do you think the Cancer Action Plan 2019–29 will help to deliver what is most important to you for the next 10 years?

Thank you!

Thank you for your time and input to help shape New Zealand's Cancer Action Plan for the next 10 years. We are listening and will look very closely at what you and other New Zealanders tell us during this consultation. The new plan will be finished in early 2020.

What is your email address?

If you enter your email address then you will automatically receive an acknowledgement email when you submit your response.

Email

Would you like to get emails from us, including the final cancer plan when it's ready?

Please select only one item

○ Yes ○ No