NeuroEndocrine
Cancer New Zealand

SCAN 2025 · NEW ZEALAND

Among the best in the world – and still waiting

New Zealanders with neuroendocrine cancer rarely pay for their care, and access to treatments like PRRT is now among the best in the world. But they still wait longer than the rest of the world, and remain largely cut off from the trials and newer treatments others reach.

SCAN is the Survey of Challenges in Access to Diagnostics and Treatment for Neuroendocrine Cancer Patients, run by INCA, the International Neuroendocrine Cancer Alliance. A New Zealand reading of its 2025 results · 110 patients and carers · 73 clinicians · fielded September–December 2025.

July 2026 · v2, pending final sign-off

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New Zealand's quality-of-care score, level with the global average.

91%

of clinicians say PRRT is provided free of charge, against 40% globally.

37%

of patients have heard of a clinical trial, against 57% globally.

Foreword

Kia ora,

When you are told you have a cancer most people have never heard of, the first thing you lose is certainty. Neuroendocrine cancer is uncommon, often slow-growing, and easily mistaken for something else. For many of our people, the road to a name for it takes years, and only a fraction of the more than 400 New Zealanders diagnosed each year find their way to us.

The first SCAN survey, in 2019, gave us a global picture and some regional insight. Back then New Zealand had only just installed its first GaTate scanner – which we funded – and there was still no PRRT here; patients who needed it had to have the means to travel to Australia. We have come a long way since, as the next page sets out.

For SCAN 2025, thanks to our community of patients and health professionals, we had enough responses to split New Zealand out for the first time – and to set our patients' and clinicians' experiences beside the world's. Some of it made me proud: our people rarely pay for their treatment, we now have some of the best access to PRRT anywhere, and the care our nurses give is second to none. Some of it is harder to read. We still wait too long, and too many never hear about the trials and newer treatments others take for granted.

These gaps are exactly what our goals are built to close, and our team is working to lift the experience for New Zealand patients in every one of them. Neuroendocrine Cancer New Zealand was set up to walk this journey alongside patients, from the point of diagnosis, and together with our sister organisations around the world we work to bring the best of NET care to our shores.

This is a working draft, shared so we can get it right together. This is where we stand. Now let us do something with it.

Ngā mihi,

Dr Michelle Sullivan
Chief Executive, Neuroendocrine Cancer New Zealand

The road to here

New Zealand did not always have the care this survey measures. Much of it was won, step by step, by patients and their whānau refusing to accept the gaps. This is the ground SCAN 2025 measures from.

2012

Founded to fill a gap

Neuroendocrine Cancer NZ was started by patient Siobhan Conroy as the Unicorn Foundation, when New Zealand had no dedicated support for people with NET cancer. It was formally established the following year.

2015

New Zealand's first GaTate scanner

We fundraised for and installed the country's first GaTate PET scanner at Mercy Radiology, ending the need to travel to Melbourne just to check whether PRRT could help.

2016

Specialist nurses and peer support

Our first specialist NET nurse was appointed, and free one-to-one support and "cuppa catch-ups" for patients and whānau began around the country.

2017

The case for PRRT is won

Backed by our evidence and a 2,000-strong community, PHARMAC and the Government committed to publicly fund PRRT in New Zealand.

2019

Faster access while we waited

Our advocacy secured High Cost Treatment Pool funding so the most urgent patients could reach PRRT in Australia without paying their own way.

2020

PRRT arrives in Aotearoa

When COVID closed the Australian border, we helped spearhead an interim national PRRT service in Auckland, set up within weeks. PRRT is now delivered here at home.

> In a decade, New Zealand went from no scanner and no PRRT to some of the best treatment access in the world. SCAN 2025 measures what came next.

Read the full story at neuroendocrinecancer.org.nz/about-us.

Free to get, but slow — and short on the newest treatments

Care for neuroendocrine cancer in New Zealand comes from one public system. That system does two things at once: it takes the cost off patients, and it leaves them waiting — and going without the newest treatments.

That is the paradox running through this whole report. The same single, publicly funded system that makes New Zealand one of the more affordable places in the world to be treated is also the one that makes people wait, and that has been slower to fund the newer options. It is not two separate stories. It is one system, seen from two sides.

WHAT WE GET RIGHT

1 in 3 patients pay nothing at all

91% of clinicians say PRRT is free

Half saw a NET nurse this year

WHAT WE NEED TO IMPROVE

59% of clinicians report treatment delays

37% of patients have heard of a clinical trial

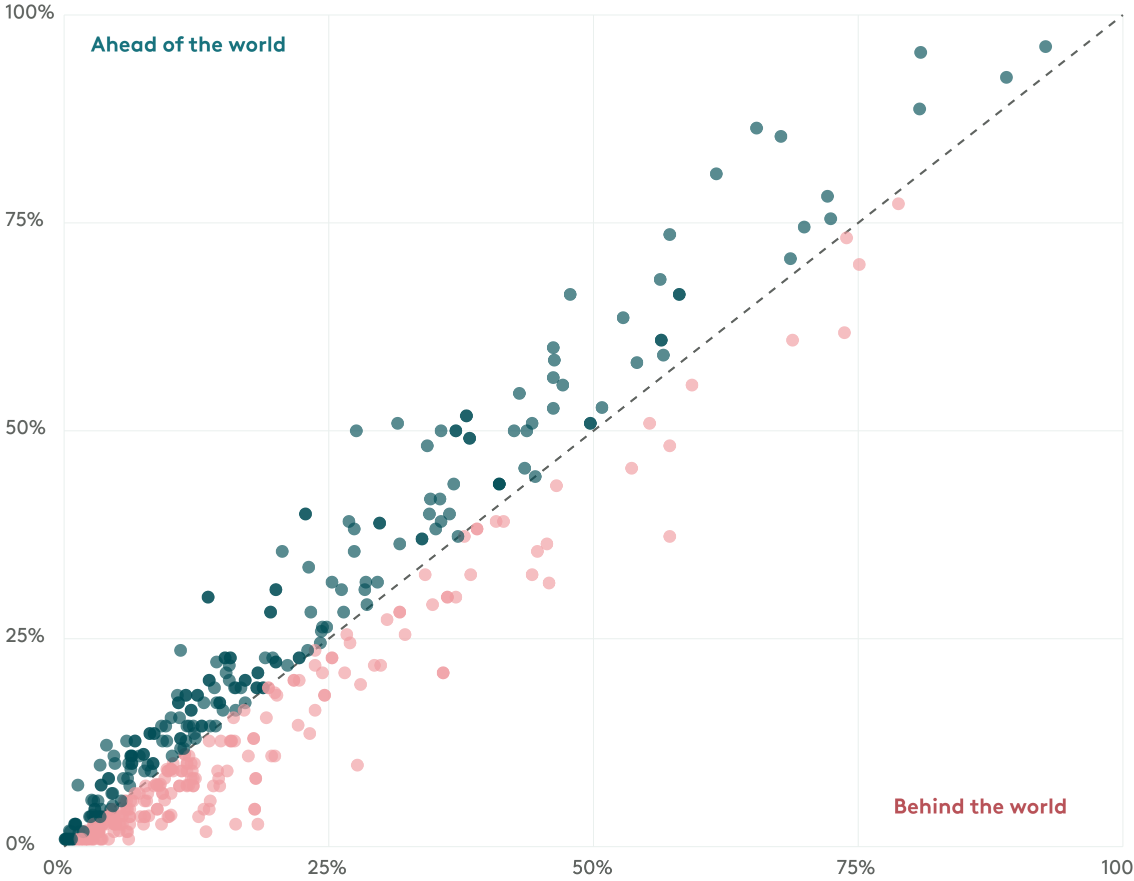
Under half can get precision medicine

Five things the numbers tell us

1. **Care is free, and that is New Zealand’s real strength.** 91% of clinicians say PRRT is provided free of charge, against 40% globally. Almost every therapy is free at the point of use, and one in three patients pays nothing at all.
2. **But New Zealanders wait.** Delay is the defining problem on both sides. 59% of clinicians report delays getting a treatment, against 33% globally; patients say the same across every stage of care.
3. **A clinical-trials blind spot.** Only 37% of patients have heard of NET clinical trials, against 57% globally, and only 43% of clinicians, against 68% globally. It is the clearest gap in the data.
4. **PRRT is available here when much of the world cannot get it.** 80% of patients say it is available in New Zealand (against 61% globally), and 24% are receiving it (against 11% globally) – double the global figure.
5. **A nurse-led model.** 50% of patients saw a NET clinical nurse specialist in the past year, against 28% globally, and decisions are made in partnership far more often than the global norm.

The whole survey in one picture

Every question in the survey, plotted: the New Zealand result against the global average. Dots above the dashed line are where New Zealand is ahead of the world; below it, behind. The two clusters are the story – strengths up the top-left, the gaps down the lower-right.



Global average (horizontal axis) against New Zealand (vertical axis) · one dot per survey measure · patients

The evidence, theme by theme

Care without cost

This is the most consistent finding in the survey. Treatment after treatment is reported as provided free of charge, at rates far above the global average. Where a NET patient in much of the world often pays privately, here our public system carries the cost.

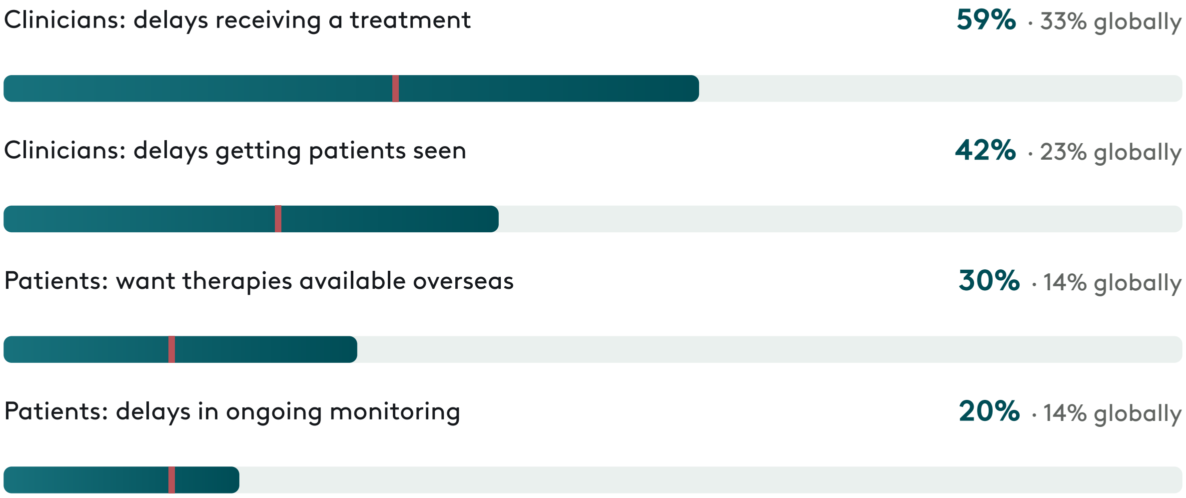
It is worth being careful about what this means. The global average includes many lower-income countries, so part of New Zealand's lead reflects being a high-income country rather than uniquely excelling. Even so, against comparable systems, free access to PRRT and specialist care is a genuine strength – and it is the thing patients worry about least.

That access is also recent. Until 2020, PRRT for New Zealanders meant travelling to Australia. The treatment was publicly funded, but it meant going overseas, and the travel could fall to patients and their whānau. In September 2020, with the border closed, an interim national PRRT service was set up in Auckland. In this survey, four in five New Zealand patients say PRRT is available here, and one in four are receiving it – double the global rate. We have proven that access can change when we make the right case.

The wait

If cost is New Zealand's advantage, time is its price. Delay is the one problem that patients and clinicians name more often than the rest of the world, across many steps of care. Asked what most needs fixing, New Zealanders do not point to money or information. They point to waiting.

The clinicians feel it most sharply. They report treatment delays 26 points above the world, where patients report six. Those working in the system are sounding an alarm that patients have not yet fully felt. And twice as many patients as the global average say the single most helpful change would be access to treatments they know exist overseas but cannot get here.

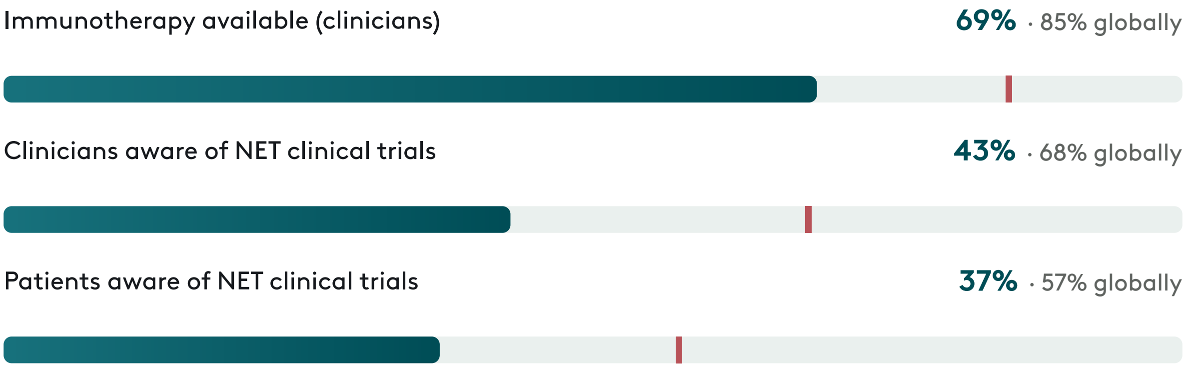


New Zealanders do not pay to be treated. They pay in time, and in going without what is new.

Behind on research and newer treatments

The clearest shortfall in the survey is knowledge of, and access to, clinical trials. It shows up the same way for patients and clinicians: fewer New Zealanders have even heard of a NET trial, let alone joined one. This sits inside a wider pattern – New Zealand tends to fund newer cancer medicines later than comparable countries, and the survey's picture of thin access to immunotherapy and precision medicine is consistent with that.

While our established therapies are strong, the newer options run thin. It is the trade-off of a small, publicly funded system: solid on the essentials, short on the newer stuff.



Precision medicine available (clinicians) **46%** · 82% globally

A nurse-led model

New Zealand’s care is built around clinical nurse specialists, multidisciplinary teams and support services, and patients feel the benefits of this approach. Half saw a NET clinical nurse specialist in the past year, nearly double the global rate. Multidisciplinary teams are all but universal, and care decisions are made in partnership far more often than the global norm.

New Zealand’s nurse-led model helps put patients at the centre of care, and this survey shines a spotlight on this quiet strength of our health system. It is also the space a patient charity can most directly support: the nursing, the information, and the connection to others going through the same thing.

Decisions made in partnership (clinicians) **86%** · 55% globally

Saw a NET clinical nurse specialist **50%** · 28% globally

A nurse actively involved in care **40%** · 23% globally

Diagnosed the long way

New Zealand does not have any accredited NET centre of excellence, and few dedicated NET tumour streams for patient care. Diagnosis usually happens through GPs, emergency departments and general hospitals rather than specialist units, which means getting an accurate diagnosis can be slow, much like the rest of the world. The route looks like this:

1. **First symptoms**
   Often vague, and easily mistaken for something common. NETs are the zebra that medicine is trained not to look for first.
2. **The GP**
   Here the GP suggests the diagnostic test for 28% of patients, against 20% globally – a more GP-led start than most of the world.
3. **A general hospital**
   Where diagnosis usually happens: 56% of cases, most often involving two to three specialists.
4. **Rarely a specialist NET centre**
   Just 3% of New Zealanders are diagnosed at a specialist NET centre, against 18% across the world.
5. **Diagnosis**
   A mean of 4.7 years to a correct diagnosis, about the same as the global 4.5. The wait is similar; the route is New Zealand's own.

Two witnesses, the same story

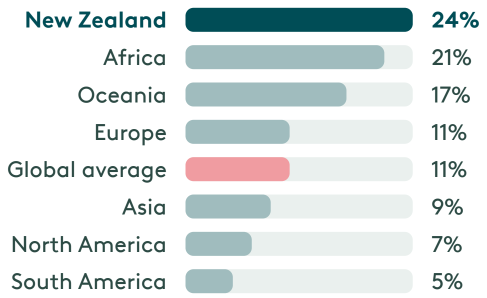
The SCAN 2025 survey asked patients one set of questions, and health professionals a separate but related set on the same topics. Where the two groups give the same answer, it amplifies the message. Access to PRRT is a great example: patients and clinicians alike agree New Zealand has excellent access to this pivotal treatment. In the same way our successes loom large, so too do our gaps – on clinical trials, both groups sit well below the world. The one place they part company is delay: clinicians feel it far more sharply than patients do.

Where New Zealand sits among the regions

It is worth looking past the single global average to how New Zealand compares with each world region. The picture is not uniform. On getting PRRT, New Zealand leads every region. On hearing about a clinical trial, it trails every one.

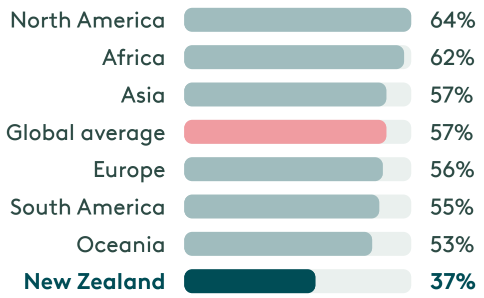
Patients getting PRRT

New Zealand leads every region



Heard of a clinical trial

New Zealand trails every region



Method and limitations

SCAN 2025 is the second edition of a global study first run in 2019, run by INCA, carried out through self-completion online questionnaires and reported against the 2019 baseline. This is a New Zealand reading, comparing the New Zealand responses with the global sample on each relevant question.

Field period	4 September to 1 December 2025
Global sample	3,411 participants across 103 countries (2,764 patients and carers; 647 clinicians)
New Zealand sample	110 patients and carers (4% of global respondents); 73 clinicians (11% of global respondents – a high share for a small country)

How sure are we? With 110 patients and 73 clinicians, a single figure carries a margin of roughly ±9 to ±11 points, a little wider for the smaller clinician group. We only headline gaps larger than about 15 points, and treat anything smaller as roughly level.

Who answered. This is an online survey recruited largely through global patient networks, so it leans towards people already connected to advocacy and support – such as those in the Neuroendocrine Cancer NZ community. That may highlight New Zealand's strengths – receiving PRRT, seeing a nurse, shared decisions – more than its gaps.

What "the world" means. The global average spans all 103 countries surveyed, ranging from the highest-income countries to many with lower incomes. Even so, some elements of New Zealand's care stood out, such as access to PRRT. The full list of countries is published by INCA.

What it cannot see. The survey is not broken down by ethnicity for any nation, and almost certainly under-represents the experience of first-nations peoples in many countries, including Māori and Pacific New Zealanders. Equity – who waits longest for diagnosis or treatment, and how people outside the main centres can access care – is a gap these numbers cannot show.

INCA International Neuroendocrine Cancer Alliance

With thanks. This report draws on SCAN 2025, run by the International Neuroendocrine Cancer Alliance (INCA). We are grateful to INCA for the survey, for generously sharing the data, and for their ongoing collaboration and friendship.

Source: SCAN 2025 global survey, New Zealand and global data tables. Analysis and reading prepared for Neuroendocrine Cancer New Zealand. Figures rounded; sample and field-period figures to be confirmed against INCA's published totals.

What this means for New Zealand

The survey does not tell New Zealand what to do. But read alongside what is already known about the country's cancer care, three things stand out, and each points somewhere.

First, the strengths are real and worth protecting. Free care, and free PRRT in particular, is not a given – it is the result of decisions that could have gone the other way, and of Neuroendocrine Cancer New Zealand leading the case for change. Holding that ground, and continuing to maintain access as new enhancements come onstream, matters.

Second, the gaps are the kind Neuroendocrine Cancer New Zealand is built to close. New Zealand tends to fund newer cancer medicines later than comparable countries, and bringing those treatments here is where we are focused – it is the case we are making in the run-up to the election. Alongside that, awareness of and access to clinical trials is the clearest shortfall in the data, and for a cancer this rare, few trials run here at all; growing NET research and trials in New Zealand is work we are actively raising funds for. Connecting people to trials here and overseas, good information early, and steady advocacy for access are the day-to-day work of a charity like ours.

Third, the survey cannot see everyone. A helicopter view of the system highlights the obvious strengths and weaknesses, but it cannot tell us who has fallen through the cracks – through delays in referral, or the barriers of travelling for treatment. These challenges matter for individual outcomes, and they are why one-on-one support will always be part of how Neuroendocrine Cancer New Zealand helps patients.

This survey reinforces the importance of patient support. For the people who come to us, the response is unchanged: good information early, a specialist nurse to lean on, and a community to share the journey with. For the system, the ask is about time and access – faster referral, and funding the treatments New Zealanders can already see working overseas. Our strategic goals – pushing for centre-of-excellence status, bringing more cutting-edge treatments to New Zealand, and growing NET research and clinical trials here – are exactly the needs this survey lays bare.

> The care is free. Closing the gaps in time, in trials, and in equity is the work ahead.

WHO WE ARE

No New Zealander should face this alone

Neuroendocrine Cancer New Zealand is Aotearoa's patient-led national charity for people living with neuroendocrine cancer. It began in 2012 as the Unicorn Foundation, started by a patient, and was renamed in 2020 so newly diagnosed New Zealanders could find it more easily. We take no government funding – the work runs on donations.

Support

Peer support and specialist nurses – Facebook groups, Zoom catch-ups, one-to-one calls, and a hardship fund for families doing it tough.

Information

Plain-language guides, symptom toolkits and clinical resources, written for patients and whānau rather than specialists.

Advocacy

Working with Pharmac, Te Whatu Ora and clinicians to improve diagnosis, access to treatment, and outcomes – the gaps this report sets out.

Stand alongside our community.

Every gift helps us support New Zealanders facing this cancer, and make the case for the changes this report calls for.

Donate at neuroendocrinecancer.org.nz

Appendix: the numbers behind this report

Every headline measure in this report, New Zealand against the global average, with the gap in percentage points. Full question wording and the 103-country breakdown are in the online version and in INCA's published tables.

	NZ	World	Gap
FREE AT THE POINT OF USE			
Emergency care, free of charge	**97%**	57%	+40
IV chemotherapy, free	**93%**	50%	+43
Access to a NET specialist, free	**93%**	48%	+45
PRRT, free of charge	**91%**	40%	+51
Palliative care, free	**91%**	53%	+38
Somatostatin analogues, free	**86%**	47%	+39
THE WAIT			
Clinicians: delays receiving a treatment	**59%**	33%	+26
Clinicians: delays getting patients seen	**42%**	23%	+19
Patients: want therapies available overseas	**30%**	14%	+16
Patients: delays in ongoing monitoring	**20%**	14%	+6
RESEARCH AND NEWER TREATMENTS			
Immunotherapy available (clinicians)	**69%**	85%	–16
Clinicians aware of NET clinical trials	**43%**	68%	–25
Patients aware of NET clinical trials	**37%**	57%	–20
Precision medicine available (clinicians)	**46%**	82%	–36
A NURSE-LED MODEL			
Decisions made in partnership (clinicians)	**86%**	55%	+31
Saw a NET clinical nurse specialist	**50%**	28%	+22
A nurse actively involved in care	**40%**	23%	+17

EXPLORE THE FULL SURVEY

The interactive version lives online

Every one of the 248 survey questions, plotted and searchable, with New Zealand set against the world and every region. Read it at neuroendocrinecancer.org.nz/reports/scan-2025.

NeuroEndocrine Cancer New Zealand

Support, information and advocacy for New Zealanders affected by neuroendocrine cancer.

neuroendocrinecancer.org.nz

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