



**Ovarian Cancer
Foundation NZ**

Te Kaikōkiri Mate Pukupuku Kākano-ā-Kopu ki Aotearoa

State of Ovarian Cancer Report Aotearoa New Zealand 2025

**He kōrero mo te ahuatanga o te
mate pukupuku kākano-ā-kopu
ki Aotearoa**

**Digging deeper for change
Te rapa hōhonu mō he huringa**

The content of this report may be emotionally challenging. It discusses topics related to ovarian cancer and may be distressing for some readers. Reader discretion is advised.

Mā te whakarongo, ka mōhio, mā te mōhio, ka mārama, mā te mārama, ka matau, mā te matau, ka ora.

Through listening, comes knowledge, through knowledge, comes understanding, through understanding, comes wisdom, through wisdom, comes wellbeing.

A word from our Patron

He kōrero nā tō mātou Kaiwhakarangatira

This State of Ovarian Cancer Report confronts one of New Zealand's most serious health crises. The toll ovarian cancer takes is devastating with an average of **306 new diagnoses each year**, and the death of **one woman every 48 hours**.

Behind the distressing facts and figures are real people. Most importantly, are the women living with the disease. Enduring treatment, grappling with painful uncertainty, and fighting for time. Then there are the family, friends, carers, and supporters who live under the shadow of the disease too, sharing the burden and fearing for the women they love.

When our daughter was diagnosed, I searched online. I came across survival rate stats expressed in weeks, I tried to convert that into years and gave up, knowing that no matter what the answer was, it would not be long enough for my 32 year old daughter.

I remembered when our sons died, aged 20 weeks and five years, my father said that it should have been him. When my daughter was diagnosed,

I echoed his words and thought this should be me. I'd enjoyed nearly three decades more life than her. I'd had children, travelled and had experiences that the disease could steal from her.

Nine years on I live with the fear of what might happen and hope that she will defy the odds, hope based on the need for action.

While ovarian cancer is an international challenge, the prognosis for New Zealand women is particularly stark, our five-year survival rates are unacceptably lower than in comparable countries like Australia and Canada.

Changing the outcomes requires urgent focus on what will make a positive difference.

As you read this report, keep these women and their loved ones in mind. The current trajectory is not hopeless, it is a solvable crisis. We can and must provide hope through increased awareness, earlier diagnosis, and targeted research funding.

Ele Ludemann



A word from our Founder – He kōrero nā tō mātou Kaiwhakapoupoua

No cancer diagnosis is easy, but women with ovarian cancer face an especially heavy burden.

In New Zealand, ovarian cancer is the least survivable women's cancer, with the highest rates of emergency diagnosis among comparable health systems. Treatment options are limited, clinical trials are rarely available, and it is one of the least researched cancers both nationally and internationally – slowing progress.

Three years ago, I presented a submission to Parliament on behalf of the Ovarian Cancer Foundation New Zealand and affected women, highlighting systemic

gaps in diagnosis, treatment, care, and survival. Over 65 women and their families shared their experiences, revealing the very real human cost of inaction.

Since then, there has been progress: national diagnostic guidelines are now in place, two new treatments have been funded, and survival is slowly improving. These steps matter but they are just the start of what is needed to address long-standing inequities.

This report outlines practical, evidence-based actions that can make a real difference. Some can be implemented immediately, while others will take time, but are no less vital. The only thing New Zealand can't afford to do is nothing.

Jane Ludemann



These steps matter but they are just the start of what is needed to address long-standing inequities.

Women and family voices – Ngā reo ā ngā wāhine me ā rātou whānau

Hearing the words that you have ovarian cancer is a moment in time that will never leave you.

Being diagnosed with a disease that most New Zealanders know very little about amplifies the fear and anxiety that come with any cancer diagnosis. You experience concern for the future, for whānau, work and self. Even years later, women often vividly retell the moment they were diagnosed with exceptional detail. They remember the details clearly: how the news was shared, what they were told, who stood beside them, and their immediate fears.

People who have faced ovarian cancer tell us that they often feel invisible. That their cancer feels silent in many ways, not well known or understood by the public and often not specifically mentioned or referenced in health policy and strategy.

Wāhine with lived experience of ovarian cancer have powerful voices that need to be heard.

Here in the *State of Ovarian Cancer Report 2025* we begin by honouring them and their experience of living with ovarian cancer.

Their experiences, their words

“ I know what I was feeling... I got a definite impression that my narrative was being dismissed. ”

“ I didn't know that discussing cancer would be part of my diagnosis based on the symptoms I was presenting. I would have felt embarrassed to mention cancer, as if I was over reacting. ”

“ I was lucky and caught it at stage 2 thanks to the doctor who sent me for a CA 125 (blood test) after 10 days from first symptoms. ”

What's inside

- > Voices of wāhine and families
- > An introduction to the Ovarian Cancer Foundation New Zealand
- > Home and away, stories and insights from Aotearoa and around the world
- > Facts and fiction about ovarian cancer
- > Key themes and insights
- > What's next? The actions that could transform outcomes
- > Final words from women and their whānau
- > Acknowledgements

You will find QR codes throughout the report.

Scan them to explore extra information, stories, and dive deeper into the work that fuelled this report.

"I feel that if I hadn't had medical insurance she wouldn't have sent me to see a specialist. The question should have been "I can send you to a specialist to make sure it's nothing serious. The cost would be around \$300, unless you have medical insurance".

"I went repeatedly to the doctor every month for almost 2 years before it was taken seriously and that was only because I had bleeding."

"I found that the hardest time was following my first treatment and surgery. I felt like everyone expected me to get back to normal and that was a difficult time when I probably needed the most support."

"A long and arduous recovery has left me very unsure of the future but determined to survive."



"The health-related person I have met has been amazing. I cannot speak highly enough of the people who I have dealt with and the care and empathy they provide."

"I'm doing OK, but it takes a lot of stamina to remain positive. I have a friend receiving treatment for breast cancer so we support each other."

"I will fight this as long as I can draw breath."



“Living with ovarian cancer has given me a deep understanding of how isolating and overwhelming this journey can be.

I’ve seen firsthand that while research is essential, so too is the need for practical, compassionate support that helps women feel seen and guided through every stage. Being part of this group is about helping shape that change — bringing real experiences to the table so no woman feels unheard or left behind.”

– Ruby Smith

As we reflect on these powerful words, we can see that women’s experiences vary greatly and that whilst sharing a diagnosis of ovarian cancer, their journeys through treatment and recovery are not the same. This can be impacted by many factors, including whether their initial symptoms are dismissed, how quickly they are referred to testing, which one of over 30 types of ovarian cancer they are diagnosed with, what treatments are available and their ability to pay for them.



**Learn more about
ovarian cancer**

Introduction to the Ovarian Cancer Foundation New Zealand

He kōrero mō te Kaikōkiri Mate Pukupuku Kākano-ā-Kopu o Aotearoa

Tēnā koutou and welcome to our latest report on ovarian cancer in Aotearoa. This report is framed by the voices of wāhine who have an experience of ovarian cancer, New Zealand's least survivable women's cancer.

Each voice symbolises the importance of inclusion and empowers women and their whānau. We are proud to have their guidance and essential input to improve our understanding of the present and change that is required in the future.

This report is grounded in kaupapa that values lived experience as knowledge, acknowledging that data alone cannot tell the whole story.

We bring together the voices of women living with ovarian cancer and the clinicians who care for them, alongside insights from the public. These voices reveal gaps in awareness and understanding, clarity of health pathways and explore how we will achieve meaningful change through transformational research. We illuminate lived realities, identify systemic barriers, and drive meaningful, evidence-based change in how ovarian cancer is recognised, diagnosed, treated and cared for in Aotearoa.

In 2025 the Ovarian Cancer Foundation New Zealand (OCFNZ) surveyed the public, General Practitioners (GPs) and wāhine with lived experience of ovarian cancer, seeking to understand where compassion, awareness, and access are succeeding. And where they are falling short.

This process reflects partnership: with women and their whānau, who generously shared their experiences, with GPs and clinicians who spoke candidly about the limits of the system, with members of the public who told us what they knew and OCFNZ's commitment to fairness, awareness, and reform.

Our intention is simple: to move from insight to action, creating a fairer, faster, and kinder system for all New Zealanders.

In preparing this report, we use the terms women and wāhine, but it is important to note that anyone born with ovaries can develop ovarian cancer, including members of the trans, intersex, and non-binary community, and that these communities face additional barriers not captured in our report.

Our Kōrero began in 2018

OCFNZ was established by Jane Ludemann after being diagnosed with ovarian cancer. Like many of the women who share their experiences in this report, Jane was diagnosed in the emergency department of a New Zealand hospital after presenting with symptoms in primary care for over two years.

Jane sought help for her symptoms, only to be misdiagnosed and dismissed, leaving her feeling like a hypochondriac. Then, at 32 years old she was diagnosed with low-grade serous ovarian cancer (LGSOC), a rare ovarian cancer with a likely prognosis of just five to fifteen years. She immediately recognised the need for change, and the importance of collaboration among women, connection with the research community, and building international networks to drive it.

Founding OCFNZ became part of Jane's journey to find answers, access reliable information, and drive progress. Over the next six years, Jane transformed her personal experience into a movement that continues to empower others, connect researchers, and inspire hope for all those affected by ovarian cancer.

OCFNZ's vision is for every woman to have the chance to live the life she wants, free from ovarian cancer.

Unfortunately, the reality is that many Kiwi wāhine living with ovarian cancer face challenges at every step of their diagnosis; for some, they will feel a sense of being left behind, for others, a sense of their cancer being invisible, and for others, there is an expression of frustration at being unable to access equitable healthcare compared to more common cancers and being haunted by "what if's".

Our mission is to improve ovarian cancer today while funding transformational research to find tomorrow's cure.

As the leading cause of gynaecological cancer death, ovarian cancer takes the lives of more women than all other gynaecological cancers combined, including cervical cancer. Improvement of survival rates has been stubbornly slow, and the investment in government research remains far below what is needed.



Low-Grade Serous Ovarian Cancer Initiative

A global initiative that honours OCFNZ's commitment to LGSOC with an aim to radically improve the survival of women with low-grade serous ovarian cancer.

We are committed to advancing research and providing our community with vital information to empower people to make informed decisions about their care.

The Four Pou – Ngā Pou e Whā

OCFNZ stands with women at the forefront of change, driving progress through four interconnected pillars: research, advocacy, awareness, and support.

Each pillar represents a vital part of the system: research to save lives, a voice that drives change, knowledge that is empowering, and care that sustains. Together, they form the backbone of our efforts to transform ovarian cancer outcomes in Aotearoa.

OCFNZ's work is centred around a holistic model comprising four interconnected pillars or pou. Each pou supports the others to stand together in a way that provides shelter during the journey of ovarian cancer. The shelter is designed to provide safe rest, support, and to empower wellbeing for wāhine and their whānau.

Research

We fund research to improve treatments with the ultimate aim of finding a cure.

OCFNZ invests in transformational research that delivers real impact for women living with ovarian cancer. In the last two years, we have funded more research than ever before, supporting both established and emerging researchers here in Aotearoa. Through a partnership with the Cancer Research Trust (CRT), OCFNZ is the largest ovarian cancer research funder in New Zealand, we ensure every dollar that we commit to research drives discovery, innovation, and equity.

Advocacy

We advocate with women for equitable healthcare.

OCFNZ is a powerful national voice for ovarian cancer. We advocate for faster diagnosis, fairer access to medicines, and increased research funding. We support women to turn their voices into meaningful change and drive system-wide accountability for equity and early diagnosis.

Awareness

We provide essential awareness and education about ovarian cancer.

Knowledge empowers people to advocate for their health and ensures health professionals are informed about an important women's issue. We drive awareness in pursuit of our goal that every New Zealander knows the symptoms and risk factors for ovarian cancer. Our campaigns reach the public, GP clinics, hospitals, and communities.

Support

We provide compassionate, practical support for women at every stage of their ovarian cancer journey, from diagnosis through treatment, recurrence, and survivorship.

Our peer-support groups, facilitated by a qualified counsellor, offer connection and resilience for women nationwide. We fund one-on-one counselling for individualised care and fund physical rehabilitation. By creating safe spaces and access to holistic care, OCFNZ ensures no woman faces ovarian cancer alone.





Home and away – I te kāinga, i tāwhiti hoki

Ovarian cancer is the least survivable women's cancer and the fifth leading cause of cancer death among wāhine in Aotearoa.



Dive deeper
into the stats

Each year in
New Zealand:

306
wāhine are
diagnosed

207
women die

30%
die within one
year of diagnosis

Five-year
survival rate:
42.8%

Emergency diagnoses

- > Nearly half (48%) of diagnoses are through emergency or unplanned hospital admissions, increasing one-year mortality from 17% to 42%
- > In Australia, the emergency diagnosis rate is 21–28%.

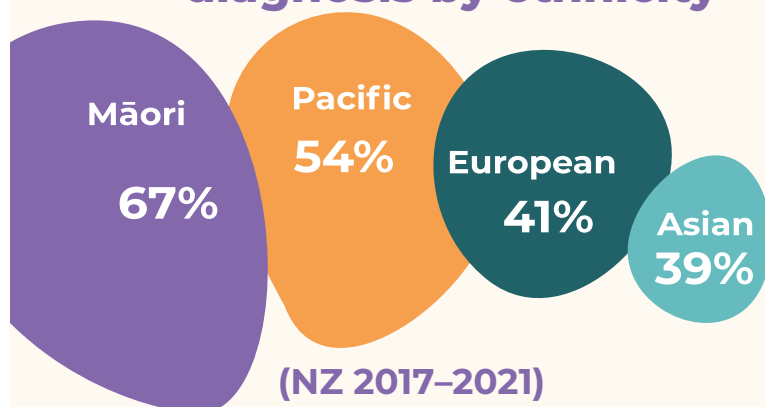
Treatment and research gaps

- > Three new treatments funded since 2020 but gaps remain particularly for platinum resistant and rare ovarian cancers
- > Clinical trial available: NZ 5 vs Australia 44
- > Lowest research funding (2006–2019) of 13 cancers supported by the Health Research Council

Global context

- > 324,000 women diagnosed and 207,000 die annually
- > Cases projected to rise 55% by 2050
- > Australia's five-year survival: 49%
- > Annual socioeconomic cost (Australia): \$3.8 billion, including 61,541 lost workdays
- > Receives 19× less research funding than prostate or breast cancer (relative to lethality)

Rate of emergency diagnosis by ethnicity



Key insights

- > Early diagnosis can save or extend lives, emergency presentation doubles one-year mortality.
- > There are persistent inequities for Māori and Pacific wāhine, with higher rates of emergency diagnosis, rare ovarian cancer diagnoses and younger ages at diagnosis.
- > New Zealand lags behind Australia in research and clinical trial access. Greater investment and equity are urgently needed to improve survival outcomes.

Facts and fiction – Ngā kōrero tika me ngā kōrero pōhēhē

Knowledge can empower wāhine to seek timely assessment with a health professional and dispel the misconception that ovarian cancer is a silent disease with no symptoms.

FACTS

- > One woman is diagnosed with ovarian cancer every day.
- > One woman dies from ovarian cancer every two days.
- > Ovarian cancer is more common in women over 60, but it can affect women, or anyone born with ovaries, of any age including children.
- > One-third of Māori and Pacific wāhine are diagnosed under 45.
- > Symptoms of ovarian cancer can include: bloating, eating less and feeling fuller, abdominal, back or pelvic pain, changes in bowel habits or urinary frequency.
- > Ovarian cancer can be detected with a CA125 blood test and ultrasound.
- > A family history of breast, ovarian or bowel cancer increases the risk of ovarian cancer.
- > If someone needs gynaecological surgery for another reason and is finished having children, removing the fallopian tubes can reduce their risk of ovarian cancer. This is called opportunistic salpingectomy.

FICTION

- > Ovarian cancer is silent.
FALSE – many people experience symptoms for a prolonged time before their diagnosis of ovarian cancer.
- > Cervical screening also checks for ovarian cancer
FALSE – there is no screening test for ovarian cancer, symptoms awareness is the primary detection method.
- > HPV vaccination prevents ovarian cancer
FALSE – unlike cervical cancer, ovarian cancer is not linked to the HPV virus.
- > A normal CA125 blood test means someone doesn't have ovarian cancer.
FALSE – CA125 is normal in half of all early ovarian cancer, and more often in younger women. An ultrasound is also needed to get a clear understanding of ovarian cancer risk when symptoms are present.

Themes and insights – Ngā whakaputa me ngā whakaaturanga

OCFNZ conducted three national surveys to inform the State of Ovarian Cancer Report 2025. The surveys were undertaken in August and September 2025.

Survey participation

- > 500 members of the public completed a survey which was administered by Public Voice, an external research and public consultation company.
- > 100 GPs completed a survey administered by OCFNZ.
- > 40 women with lived experience of ovarian cancer completed a survey administered by OCFNZ, with several participating in follow-up phone conversations to share their experiences in greater depth.



**Scan to see the
survey methodology
and questions.**



What wāhine told us:

- 
- > Most had heard of ovarian cancer before being diagnosed (70.27%), however, few knew any symptoms (10.53%).
 - > Experiences with the public health system were variable with some describing a very positive experience and others a negative experience.
 - > Feeling uncertain about what to expect during and after treatment was identified as a key issue.
 - > A focus on support to continue to live their lives at home and work was critical.
 - > Before diagnosis the majority (63.8%) were either unsure or thought that there was a screening programme for ovarian cancer and just over half (52.77%) were either unsure or thought that the cervical screening programme could detect ovarian cancer.

Themes

- > Ovarian cancer rarely announces itself clearly.
- > Symptoms such as bloating, fatigue, or back pain are easily dismissed as “normal female issues”.
- > The financial, physical and mental health impacts of ovarian cancer are extensive and often overlooked.
- > There is a large emotional and relational burden of the ovarian cancer journey on themselves and their whānau.
- > High levels of concern about not receiving comprehensive information about their treatment journey and the risk of recurrence. Many are left feeling like treatment plans are akin to throwing darts at a board to see what will work.
- > Some people experience gendered assumptions and minimisation of symptoms whilst others described excellent care and timely support.

The five biggest challenges experienced by women are:

- > Living with the uncertainty that my cancer may return
- > Dealing with treatment side effects
- > Finding the right treatment regime that works for me
- > Having limited treatment options and
- > Feeling like my life revolves around cancer.

Insights

Inequality in access and outcomes; inequity is evident across the public health system. This affects all aspects of an ovarian cancer journey, from timely access to primary care when experiencing symptoms, an increasing burden on patients to have the ability to have health insurance or privately fund ultrasounds and access to unfunded medicines.

Women are willing to be engaged in supporting others and to share their insights and experiences courageously. Peer-support is an essential component of wellbeing and brings comfort and reassurance.

There is an intersection between financial insecurity and psychological distress. Over three quarters of women reported that ovarian cancer impacted their ability to work, including working less hours, retiring early, missing work or reducing hours. Having health insurance or the ability to pay for unfunded treatments meant there are huge disparities in what treatments different women get access to.

“I have had to reduce work hours so income is heavily reduced and have paid for non-funded treatments.”

— **OCFNZ lived experience survey**

The emotional strain carried by women and their whānau benefits from compassionate communication and wellbeing support. These emotional burdens are rarely acknowledged in system design. Co-design opportunities exist that can support a patient driven system that is informed by women and unites them with stakeholders like OCFNZ to drive impact.

Wāhine could benefit from support at different points in their journey of treatment and care. Navigational assistance and support are required at key times. Support can help women continue living their life, manage work, fertility, choices and second opinions.



What GPs told us:

“It’s so bloody difficult, especially for high needs and vulnerable patients. This is an area where we need vast improvement.”

– Voice of a GP

- > Access to ultrasound is difficult. Only 9.2% of GPs say ultrasound access is easy, with 29.09% describing it as adequate and 60.82% describing access to ultrasound as difficult.
- > They said that it could be difficult to justify a referral and they require a very good reason such as a mass being present.
- > The main barriers to timely diagnosis were identified as poor access to ultrasound, and patients not coming back or finding it hard to get a timely appointment.
- > Some GPs suggest their patients pay for ultrasounds privately to improve access.
- > The growth of telehealth and virtual consults does not provide opportunity for pelvic examination which is an important component of initial assessment and affects the choice to refer for further testing.
- > GPs are very supportive of an educational component about ovarian cancer being added to cervical screening education with 76.8% in agreement and 15.7% unsure. The number opposed was small at just 7.3%.

Themes

- > In general GPs feel there is an opportunity to do better.
- > Access to imaging in the New Zealand system is a big problem especially in regards to equitable access.
- > The public health system is under strain and not able to respond quickly enough.
- > GPs are keen to directly engage with opportunities to improve the system and outcomes for their patients.

Insights

- > There is a willingness to engage in continuing medical education opportunities.
- > There is interest in supporting national guideline and policy development and opportunities to feedback on referral outcomes.
- > GPs acknowledged what they saw as structural failures in the system.
- > Issues of inequity exist and some women consistently experienced poorer outcomes than others.
- > Care options and outcomes are improved by being able to pay for them.
- > Nurses and Nurse Practitioners play a key role in supporting women. Access to quality professional development and programmes like the Survivors Teaching Students programmes in nursing and medical schools would add immediate value.

What the public told us

- > Most had heard of ovarian cancer (85%).
- > When asked if they knew the symptoms of ovarian cancer most said no (60%) or that they were unsure (21%).
- > Most incorrectly thought the cervical screening programme could detect ovarian cancer (63.8%) and 24% were unsure.
- > Many incorrectly thought the HPV (human papillomavirus) vaccine could prevent ovarian cancer (31% true) and (52% unsure).

Themes

- > While 85.4% of New Zealanders have heard of ovarian cancer, only 19.4% can identify warning signs and symptoms, representing a critical gap between awareness and any actionable knowledge that limits early detection opportunities. This suggests current messaging raises awareness but fails to translate into practical understanding.
- > The confusion between cervical screening and ovarian cancer is pervasive across all groups.

Insights

- > Building the awareness of ovarian cancer is a key theme and there is an opportunity to further bridge the awareness-knowledge gap by creating tailored and clear messaging.
- > **There is an advocacy and awareness opportunity to address screening misconceptions:**
 - > Age patterns show misconceptions peak in the 35-64 age group (58.6%-76.1%).
- > **There is a need to address ethnicity-based disparities with culturally informed approaches:**
 - > Māori respondents showed strong belief that screening programmes (74.6%) and cervical screening (78%), are a protective factor.
 - > Pacific respondents demonstrated highest symptom knowledge (33.3%, though a smaller sample), while relying heavily on personal networks and healthcare settings for information.
- > Asian communities show distinct patterns, with higher social media engagement (47.7%) as an information channel.
- > **Highlights opportunity for education to be provided through the cervical screening programme and the importance of health professional education initiatives like Survivors Teaching Students:**
 - > Healthcare providers require clear, evidence-based tools to communicate accurate ovarian cancer information, particularly given widespread public confusion about screening and detection methods.
 - > Healthcare settings account for 22% of information sources overall, rising to 50% for Pacific communities, making clinical touchpoints critical intervention opportunities.



Actions that can transform outcomes – Te anga whakamua

We are dedicated to transforming the ovarian cancer space in New Zealand. To achieve this we call for urgent, systemic change. A coordinated national response that ensures awareness, earlier diagnosis, equitable access, funded research and compassionate, evidence-based care that supports wāhine to feel seen and have their experience visible to us all.

These actions reflect what will truly shift the needle for ovarian cancer outcomes in Aotearoa.



Reduce the incidence of emergency diagnosis

Half of all women diagnosed with ovarian cancer experience an emergency diagnosis, that's about twice the rate of Australia, and the worst of comparable health systems.

Add ovarian cancer symptoms education to the national cervical screening programme and clarify that cervical screening does not detect other gynaecological cancers

Almost two-thirds of the New Zealand public incorrectly believe that cervical screening detects ovarian cancer. Ovarian cancer symptoms awareness is also low among the public.

Incorporating a brief educational component to clarify the purpose of cervical screening, and educate wāhine on the symptoms of ovarian cancer would be an effective and inexpensive way to address this misconception and improve symptoms awareness. The existing programme already includes cervical cancer symptoms, which have some

overlap with ovarian cancer symptoms. Māori and Pacific people have higher rates of belief that cervical screening checks for ovarian cancer, ensuring we partner with providers and reach these communities is essential.

Our GP survey found this proposal has the support of a majority of GPs, and the UK recently amended their screening programme to directly address this widespread misconception.

“It would be good to have resources for nurses to be able to give as handouts or refer to on the internet when explaining cervical screening. We do a lot of education, but often the bulk of it falls on the nurses due to time constraints.”

– OCFNZ GP survey

Health Pathways need to be amended to allow GPs to refer symptomatic women for an ultrasound at their first GP visit

The current Health Pathways guidelines are complex and can create barriers for GPs to diagnose symptomatic patients. 60% of GPs find ultrasound access difficult, and ultrasound access was the most commonly reported barrier to timely diagnosis. GPs should be able to order an ultrasound when someone first presents with symptoms, as in Australia.

“In my area all ultrasounds are triaged through radiology. It can be hard and many are declined. Often the referral is sent to gynaecology and then declined, or the wait is so long that many patients will self fund in private if they can afford too.”

– OCFNZ GP survey

“I paid for a private ultrasound. I was also in the public system and was told that the wait time could be around five months “

– OCFNZ lived experience survey

“It seems impossible getting timely access in the public health system. I now advise all of my patients to go private as the risk of missing something is way too high, especially for vague symptoms that don't meet the criteria. It's really scary as a practitioner to be unable to access the scanning required that could visualise something that might take someone's life in a matter of months.”

– OCFNZ GP survey

Address data gaps and make accurate, real-time data more accessible across the health system

We need an accurate picture of what is happening on the ground to identify areas of improvement and to effectively monitor and track outcomes.

The current lack of an ovarian cancer registry means we do not have accurate data about the different types of ovarian cancer and we do not have a

good picture on different experiences of women across ethnicities including Māori and Pacific. This hinders efforts to achieve equity and to honour Te Tiriti o Waitangi. Without this information, we cannot understand what treatments or approaches have worked for others, making it impossible to create effective blueprints for future patients.

Funding is needed to develop an ovarian cancer registry to link into Te Aho o Te Kahu's work with CanShare.

Identify people at higher genetic risk before they get ovarian cancer

10-15% of ovarian cancer is hereditary, with BRCA mutations being the most common genetic risk factor and Lynch Syndrome another important contributor.

In New Zealand people qualify for publicly funded genetic testing if they have a 10% or higher chance of having a hereditary cancer risk condition.

Our recommendations:

1. Reduce BRCA testing thresholds to align to National Institute for Health and Care Excellence (NICE) UK Guidelines.
2. Develop a familial cancer registry to track families with hereditary cancers and ensure interventions are timed appropriately.
3. Legislate against genetic discrimination by insurance companies to reduce deterrents to genetic testing.

Note:

BRCA1 and BRCA2 are genes that help repair damaged DNA and increase the risk of breast, ovarian, and other cancers.

Lynch Syndrome is a condition that increases the risk of many kinds of cancer. Hereditary risk can pass through either parent to their children.

Address gynae-oncology specialist shortages

Aotearoa currently has seven to eight full-time equivalent gynaecological oncologists. To meet international benchmarks, a country of New Zealand's population (5 million) should have 15 to 16 specialists.

Just one of the past eight gynae-oncology trainees has stayed to practice in New Zealand. Better pay in Australia has been identified as a key reason for the loss of these specialists.

Increasing investment in this workforce and supporting recruitment would enhance capacity and alleviate the heavy workload on existing specialists, who are doing their utmost to meet the needs they encounter daily.

Prioritise ovarian cancer clinical trials

Clinical trials are a critical part of ovarian cancer treatment. Participating in a clinical trial allows early access to treatments that may become the standard of care in the future. Only a small number of women qualify for the five trials currently open in New Zealand, while in Australia women can access 44 trials. Our lived experience survey found just 20% of respondents had been offered the opportunity to take part in a clinical trial.

“I have tried on a number of occasions but haven’t qualified for any of them. I would love to take part in a trial.”

– **OCFNZ lived experience survey**

“I said ‘sign me up’ at the beginning of it all... but there haven’t been any opportunities.”

– **OCFNZ lived experience survey**

Funding and resourcing for ovarian cancer clinical trials across New Zealand needs to be prioritised within the health system to give women more treatment options.

Increase funding and focus on ovarian cancer by the Health Research Council of New Zealand, Te Kaunihera Rangahau Hauora o Aotearoa

Research is essential to improving the survival rates of our deadliest women’s cancer. Yet ovarian cancer research has been significantly underfunded both at home and overseas. Ovarian cancer’s 42.8% survival rate means more women die from it than all the other gynaecological cancers combined. Our most deadly women’s cancer shouldn’t be one of our least researched.

OCFNZ has funded over \$400,000 of ovarian cancer research in New Zealand, but we can’t address decades of funding shortfalls on our own. Government funding of dedicated ovarian cancer research and researcher salary costs is needed.

Aotearoa needs to establish a National Ovarian Cancer Research Strategy and a coordinated national framework to

align researchers, clinicians, patients and advocates around shared priorities, building partnerships, and driving sustained investment in ovarian cancer research.

We also need a national Ovarian Cancer Biobank. This would safely collect and store tumour samples from women across Aotearoa and link them with treatment and outcome data in the ovarian cancer registry (CanShare). Connecting samples with real-world outcomes will help researchers translate discoveries into better care, faster.

When we surveyed 54 New Zealand researchers in 2022, 44% said they would consider researching ovarian cancer if dedicated funding was available.

Inclusion for people with lived experience, their whānau and patient advocacy groups in service design, policy and research.

Women and their whānau know what they need. Patient advocacy organisations also have clear insights into what is needed through their connections to the patient community. Greater efforts should be made for their inclusion and participation in co-design of services, policy and research.

Improve medicines access and investment

Since 2020, three new treatments, olaparib, niraparib, and bevacizumab, have been funded for ovarian cancer, reducing the gap with Australia. While these provide more options, gaps remain in eligibility and access, especially for women with platinum-resistant or rare ovarian cancers.

The length of time to approve new treatments is of particular concern. Bevacizumab took twelve years, and Caelyx (which is funded in Australia) is yet to be funded in New Zealand despite the application being made to Pharmac 18 years ago.

Women facing ovarian cancer are crowdfunding, selling assets and borrowing from family to access

treatments that are funded in Australia. Many can't raise the necessary funds at all. It's a terribly difficult situation that places extreme hardship on women and their whānau.

"I am maxed out due to the costs of unfunded medications and I cannot stop working full time and rest, as I can't afford to."

– OCFNZ lived experience survey

Pharmac's budget is low by international standards, and funding needs to be significantly increased to allow people to access modern treatments in a timely manner.



Scan to learn more about drug funding in Aotearoa



Voices of the ovarian cancer community identifying what matters most – Ngā take nunui e whakawaha e te iwi kawē te mate pukupuku kākano-ā-kopu

Just as we opened this report by centering on women's experiences, we now close with the voices of wāhine who have lived them. We acknowledge and thank everyone for their contribution to fostering understanding of what the experience of living with ovarian cancer means.

We recognise that some important voices are missing from this report due to the challenges of a disease where 30% of women die within the first year of diagnosis and only 43% live five years post diagnosis.

Women shared that the big challenges for them were about being heard and understood and that they needed to be able to ask questions, have opportunities for consultations face-to-face and access high quality information and education about their ovarian cancer.

“

We need to warn ladies about ovarian cancer and put it to the government and the health minister to help detect it early and save lives. It needs to be out there as much as breast cancer is.

”

We also heard that the support of other wāhine mattered:

| “Peer groups help a great deal to support”

– OCFNZ lived experience survey

Women want to feel empowered to make choices, to do all that they can day-to-day to support their treatment and to build understanding and knowledge whilst engaging with support from others with lived experience. Ongoing peer-support instills hope and means that outside of active treatment phases there is continuity of supportive allies in conjunction with their families, friends and their workplaces.

Hope sat at the forefront of women's perspectives and wishes for the future.

“ I can see the difference being made by research funding and awareness, thank you heaps! ”

“ As I didn't know a lot about this cancer – by sharing my story, I hope others will pick up signs earlier. ”

Wāhine are willing to courageously share their stories in the hope that it will be better for others. They see research and access to clinical trials as key to better care and finding a cure.

Women were also very clear that ovarian cancer pathways need to be connected at all points on the journey and that the way in which they received information, updates about care and results mattered a great deal as did how they received that information.

Many wrestled with constant “what ifs...” and “if only’s”. These thoughts were described as intrusive at times and affect mental health while trying to move forward.

There was a strong sense that it can be better than it is now.



“It's easy to talk about the need for more research and yes, we need it! But what women really need right now is support that feels human.

Clear pathways, honest conversations, and care that meets us where we are.

Awareness has to go beyond symptoms; it has to include what it means to truly live with ovarian cancer.”

Ruby Smith



Learn more about Ruby and her experience with ovarian cancer.

Ruby is a fierce ovarian cancer advocate who shared her experiences as part of this report and gifted her song Dig Deeper, to OCFNZ in 2025. Scan the QR code to listen.



A special thank you to the women facing ovarian cancer whose photographs are featured in this report:

Bronwyn, Erin, Leondra, Lisa, Ruby and Sarah

Anō te pai, te ahua reka,
o te nohoanga o ngā teina
me ngā tuakana i runga
i te whakaaro kōtahi

How wonderful it is, how
pleasant, when both the
influenced and the influencers
live together in harmony



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Previous State of Ovarian Cancer Reports

The National Ovarian Cancer Report – Steps to Save Lives was completed in 2022 and presented to the Health Select Committee. We called for urgent improvements to diagnosis, treatment, and the funding of research needed to help save women's lives.



View the 2022 report and watch the 2024 presentation to the Health Select Committee.

Connecting with us

If you are inspired by this report and are interested in partnering with us, then please reach out. We are 100% community funded, and every contribution directly supports our mission and the people we support.

There are a range of ways that you can support the drive for change –

- > host an event to raise awareness of ovarian cancer
- > become a supporter and receive regular updates on our work
- > become a regular giver and help fund our day to day work and operations
- > leave a legacy gift in your will to the work of OCFNZ
- > talk to us about being a corporate sponsor.

If you would like to know more about our work please reach out to us at office@ocfnz.org.nz

Visit our website www.ovariancancerfoundation.org.nz



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