State of the Nation: Uterine Cancers: Australia and Aotearoa New Zealand

Final Report

November 2025

ANZGOG | Advancing research saving lives

Insight Economics
Public Policy Corporate Strategy

Insight Economics Pty Ltd

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Foreword

This is a challenging report.

It lays bare a truth that has been hiding in plain sight — uterine cancers are rising faster than any other type of women's cancer. The steepest increase is among women aged just 25 to 44. These are women in the prime of their lives, raising families, building careers, contributing to their communities and now facing a disease many have never even heard of.

Uterine cancer is complex - in its causes, its treatment, and its impact. Yet our collective response has been insufficient. We have failed to communicate what was coming and to invest adequately in the research, data, and care that could have changed women's lives. That must change.

The *State of the Nation: Uterine Cancers in Australia and Aotearoa New Zealand 2025* report is more than data, it provides a window into the lives of women in both these countries. It confirms the critical national priority that uterine cancer diagnosis and mortality have become, the scale of the crisis unfolding and the opportunity we have to change that. Up to 60 per cent of uterine cancers are preventable, urgent action now could spare thousands of women from ever hearing the words "*you have uterine cancer*."

This report has gathered together the evidence, we have the expertise, and together we need to demonstrate the will. With national leadership, investment in research, and a commitment to equity, we can reverse the rise of this disease and save lives. Together, we can ensure women have the knowledge they need to protect their health and that no woman is ever again left unseen, unheard or unsupported.

Professor Clare Scott AM
Chair, ANZGOG

Alison Evans
Chief Executive Officer, ANZGOG

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Acknowledgements

Improving outcomes and quality of life for everyone with a lived experience of gynaecological cancer is the purpose of this work.

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Ella Gillis	Laura Galletta	Virginia MacEwan
Jane Snarskis	Ronny Verdiesen (bereaved)	

Their perspectives on the challenges and opportunities in prevention and early detection, treatment and survivorship, and research priorities were invaluable and directly informed the development of this report's recommendations.

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In New Zealand, Dr Bryony Simcock and Dr Claire Henry have provided significant support.

A/Prof Yoland Antill	ANZGOG Director and Deputy Chair, ANZGOG Research Advisory Committee and member of the ANZGOG EDEN Research Initiative Steering Committee; Medical Oncologist and Cancer Genetics Specialist – Cabrini Health, Peninsula Health, Royal Melbourne Hospital. Adjunct Clinical Associate Professor, Faculty of Medicine, Dentistry and Health Sciences, Monash University
Prof Linda Mileshkin	Chair of the ANZGOG EDEN Research Initiative Steering Committee Director of Medical Oncology, Peter MacCallum Centre. Clinical

	Trials Lead for Gynae-Oncology, Parkville Cancer Clinical Trials Unit

Finally, ANZGOG and Insight Economics would like to thank the more than 40 stakeholders, including researchers, clinicians, policy leaders, health professionals, and other experts, who generously contributed their time and insights through interviews, helping shape the *State of the Nation: Uterine Cancers in Australia and New Zealand* report:

Prof Alison Brand	ANZGOG Director, Co-chair Eden Research Initiative Steering Committee, Immediate Past Chair Gynecologic Cancer InterGroup Director of Department Gynaecological Oncology, Westmead Hospital, Clinical Professor, University of Sydney.
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Bridget Bradhurst	Acting Chief, Support and Advocacy, Ovarian Cancer Australia
Bronwyn Jennings	Gynaecology Oncology Clinical Nurse Consultant, Mater Health
Dr Bryony Simcock	University of Otago Christchurch; Clinical Director of the South Island and Wellington Regional Gynaecological Oncology Service; Gynaecological Oncologist - Christchurch Women's Hospital; Oxford Women's Heath
Prof Clare Scott	Chair of ANZGOG, Medical Oncologist, Peter MacCallum Cancer Centre, the Royal Melbourne, and Royal Women's Hospital. Joint Head, Clinical Discovery and Translation and Laboratory Head, Walter and Eliza Hall Institute of Medical Research. Professor of Gynaecological Cancer, University of Melbourne
Dr Claire Henry	Lecturer in the Department of Surgery and Anaesthesia, University of Otago Wellington Aoteoroa New Zealand. Group Lead at the Translational Gynaecology Research Group, Wellington Hospital
Prof David Thomas	Founder and Chief Science and Strategy Officer, Omico. Director of the Centre for Molecular Oncology, University of New South Wales
Debbie Shiell	CEO, Ovarian Cancer Australia
A/Prof Emma Allanson	Head of the Department of Gynaecological Oncology, King Edward Memorial Hospital
Georgina McPherson	Women's Health Nurse Practitioner, Waitemata District Health Board, Health New Zealand
Helena Rodi	Optimal Care Summits Program Manager, VICS Optimal Care Summits

Jill Butty	Director, Women's Health & Population Wellbeing, Victorian Department of Health
John Andrews	Manager of Research Programs and Pipeline, ANZGOG
Prof John Zalcberg	NGOR Academic Lead and Medical Oncologist, Alfred Health
Prof Jon Emery	Herman Professor of Primary Care Researcher, University of Melbourne
Dr Justine Clarke	Postdoctoral Research Fellow, The Kids Research Institute Australia
Dr Kurt Lacovic	CEO, Cancer Trials Australia
Kym Arthur	Executive Director, Population & Women's Health, Victorian Department of Health
Dr Lois Eva	Clinical Director of Gynaecological Oncology, National Women's Health, Te Toka Tumai, Auckland. Honorary Senior Lecturer, University of Auckland
Mark Nevin	Immediate past CEO, Cancer Council Australia
Maureen Turner	CEO, Biogrid
Dr Michael Burling	Gynaecological Oncologist, St George Private Hospital
Dr Michelle Wilson	Medical Oncologist, Auckland City Hospital
Prof Monika Janda	NHMRC Leadership Fellow. Director, Centre for Health Services Research. Professor in Behavioural Science, Faculty of Health, Medicine & Behavioural Science, University of Queensland
Prof Pamela Pollock	Professor, Faculty of Health, School of Biomedical Science, Queensland University of Technology
Prof Penny Webb	Group Leader, QIMR Berghofer Medical Research Institute
Dr Rosemary McBain	Gynaecological Oncologist, Royal Women's Hospital and Co-Chair of the Endometrial cancer expert advisory group for the VICS Optimal Care Summit
Prof Sandi Hayes	Director of Research, The Viertel Cancer Research Centre, Cancer Council Queensland
Dr Sathana Ponnampalam	Senior Medical Officer in Women's Health, Te Toka Tumai
Dr Shaoke Li	Research Fellow in Cancer Services & Data Science, Department of General Practice and Primary Care, University of Melbourne
Dr Sharnel Perera	Program Manager, National Gynae-Oncology Registry (NGOR)
A/Prof Simon Hyde	Director of Gynaecological Oncology, Mercy Hospital for Women in Melbourne, Co-Chair of the Endometrial cancer expert advisory group for the VICS Optimal Care Summit
Prof Sue Matthews	CEO, Royal Women's Hospital. Member of the Victorian Women's Health Advisory Council. Co-Chair of the Victorian Inquiry into Women's Pain. Member of the National Women's Health Advisory Committee and the National Women's Health Advisory Committee Research Sub-Committee.

Prof Susan Jordan	Professor of Epidemiology and NHMRC Leadership Fellow, School of Public Health, University of Queensland
Dr Tamara Butler	NHMRC Emerging Research Fellow, School of Public Health, University of Queensland
Dr Viet Do	Director, Liverpool Cancer Therapy Centre, South Western Sydney Local Health District
Prof Vivienne Milch	Medical Director, Cancer Australia
Victoria Donoghue	Manager, Cancer Alliance Queensland
Prof Zoe Wainer	Deputy Secretary for Public Health, Department of Health, Victorian Government

This report contains cancer data that is based on sex classifications (e.g., male and female), where uterine cancer is classified as occurring within the female sex. Accordingly, this report refers to 'females' in incidence, mortality and survival reporting to reflect this convention, and 'women' elsewhere in the report. It is respectfully acknowledged that not all uterine cancer patients may identify with this language.

Executive Summary

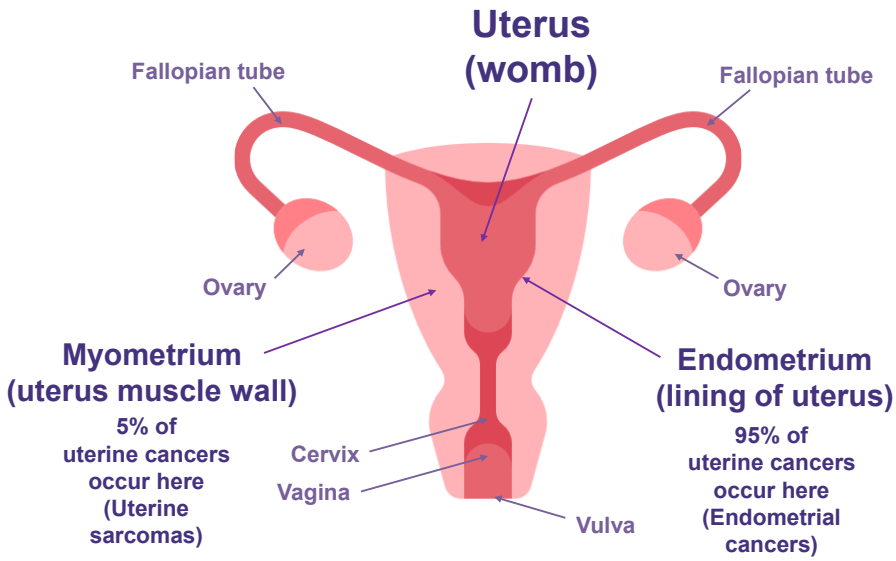
What is uterine cancer?

Uterine cancer is a type of cancer that occurs when abnormal cells in the uterus grow out of control (Figure 2). There are two main subtypes of uterine cancer:

- Endometrial cancers, which come from the lining of the uterus (endometrium) and account for approximately 95% of all uterine cancers
- Uterine sarcomas, which are rarer subtypes of uterine cancer that develop from either the connective tissue (stroma) of the endometrium, or from the muscle tissue layer of the uterus (myometrium) or very rarely from other tissue types in and around the uterus and account for the balance of cases.

It is also sometimes called womb cancer.

Figure ES.1: Where do uterine cancers occur?



Source: Insight Economics

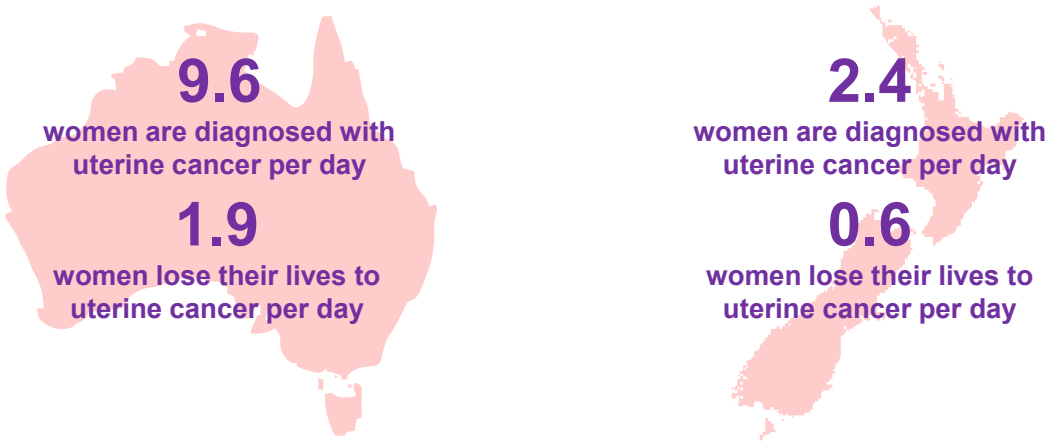
The most commonly diagnosed gynaecological cancer in Australia and New Zealand

Currently, over 17,700 women in Australia and Aotearoa New Zealand are estimated to be living with a uterine cancer, having received a diagnosis within the last five years.[i]

In 2025 alone, approximately 4,360 women are expected to face a new diagnosis, including more than 3,500 Australian women and nearly 900 Aotearoa New Zealand women.[ii] More than 900 women are expected to lose their lives to the disease this year.

This means every day, around 12 women will hear they have uterine cancer, and more than 2 women will die from this disease (Figure ES.2).

Figure ES.2: Uterine cancer in Australia and Aotearoa New Zealand by the numbers



Source: Insight Economics analysis of AIHW and Health New Zealand (Te Whatu Ora) data, see Appendix A.

Poor awareness of uterine cancer against a backdrop of a rising health crisis and significant equity challenges

Despite having a high incidence, twice that of the more widely known ovarian cancer and similar to that of lymphoma, uterine cancer remains under-recognised as a major health concern in Australian and Aotearoa New Zealand communities. Most women have never heard of uterine cancer – for example, research shows that 94 per cent of Australian women do not know what uterine sarcomas or endometrial cancers are.[iii]

But while awareness is low, the number of new cases is surging in Australia and Aotearoa New Zealand, becoming an under-appreciated but serious public health concern.

Globally, the incidence of uterine cancer has more than doubled over the past two decades. Over the past two decades, the global incidence of uterine cancer increased by 132 per cent, and this trend is expected to accelerate, with an additional 148 per cent increase projected by 2044.[iv] This means that in one generation, from 2004 to 2044, incidence will have increased 280 per cent globally.

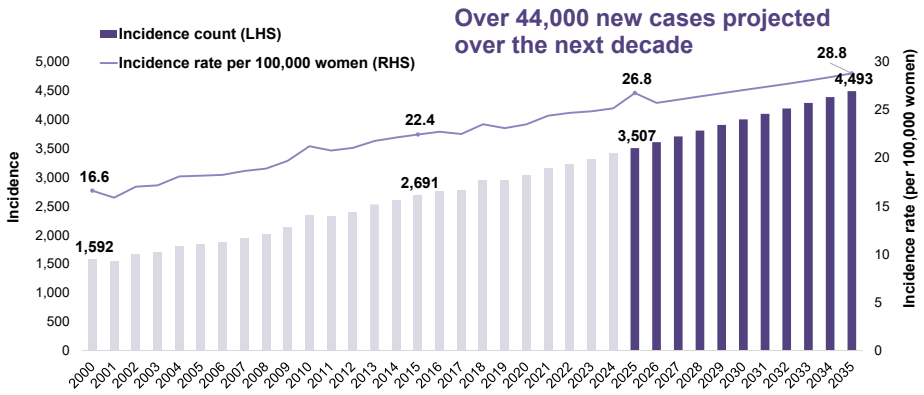
Here in Australia and Aotearoa New Zealand, similar patterns of growth are anticipated. The number of cases in Australia has grown 16 per cent in the last five years, while cases in Aotearoa New Zealand have grown even faster, by 20.3 per cent.[v]

Looking forward, more than 55,000 women are expected to be diagnosed with a uterine cancer over the 2025 and 2035 period (Figure ES.3), including over 44,000 Australian women and more than 11,500 women in Aotearoa New Zealand.

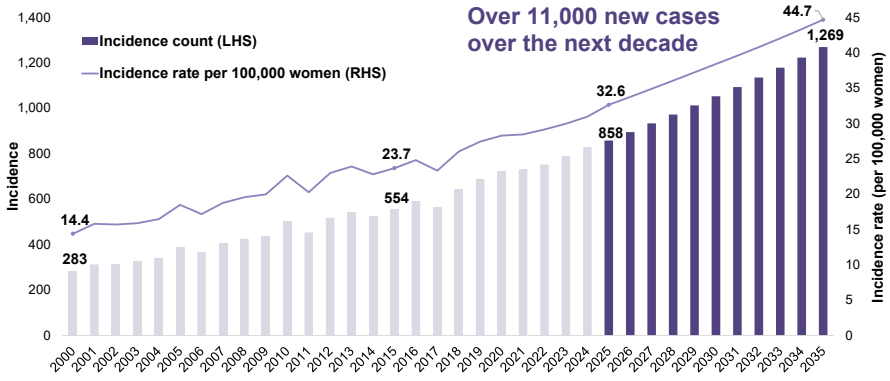
The rising incidence of uterine cancer, coupled with more women being diagnosed with advanced stage disease, is expected to lead to an increase in mortality, with over 11,800 women projected to lose their lives to the disease over the 2025-2035 period.

Figure ES.3: Projected uterine cancer incidence and mortality in Australia and Aotearoa New Zealand

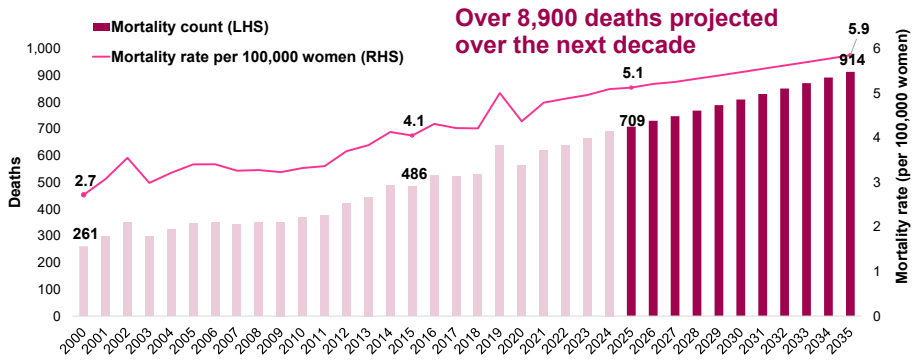
Incidence in Australia



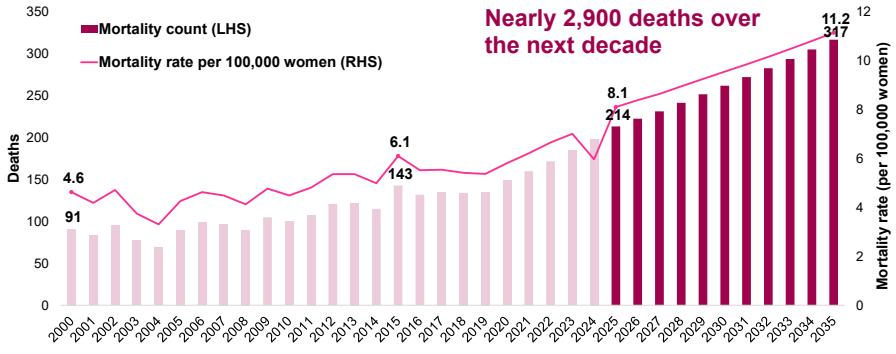
Incidence in Aotearoa New Zealand



Mortality in Australia



Mortality in Aotearoa New Zealand



Source: Insight Economics projections based on AIHW and Health New Zealand (Te Whatu Ora) data. Note that mortality over next 10 years is informed by incidence preceding 2025. See Appendix A for more details.

Critically, the rising burden of disease is not shared equally. Priority populations—including regional women, Aboriginal and Torres Strait Islander women in Australia, wāhine Māori and Pacific women in Aotearoa New Zealand, which include women that identify with Pacific ethnic groups such as Samoan, Cook Islands Māori, Tongan, Niuean, Fijian, Tokelauan, Tuvaluan, Kiribati, and other Pacific ethnicities, and women in lower socioeconomic groups—are at higher risk of uterine cancer, and have poorer outcomes (See Figures ES.4 and ES.5).

As shown in Figure ES.4, in Australia:[vi]

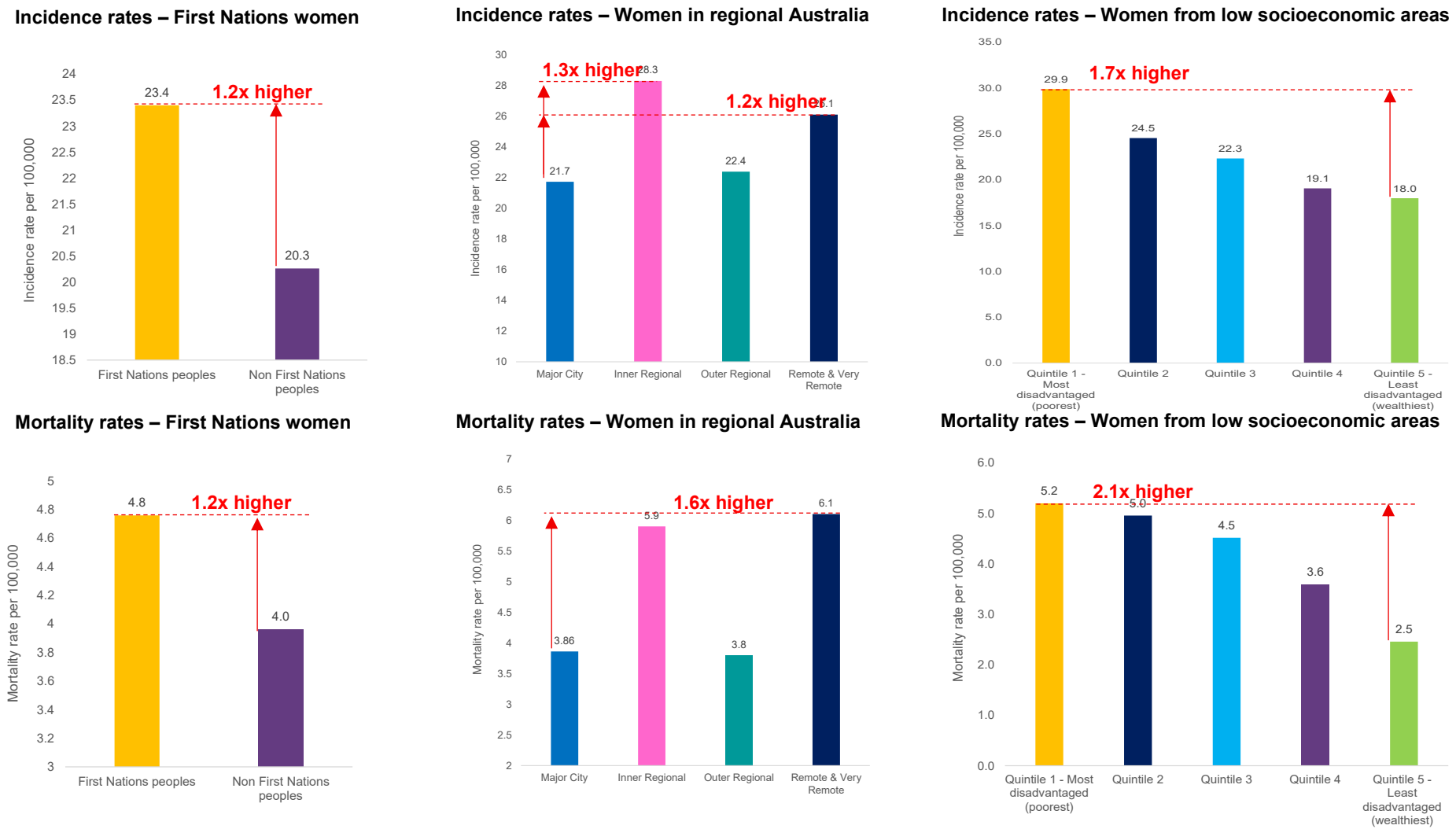
- Aboriginal and Torres Strait Islander women are 1.2 times more likely to be diagnosed with and die from uterine cancer compared to non-First Nations women
- Women of low socioeconomic status (SES) backgrounds are 1.7 times more likely to be diagnosed with uterine cancer and 2.1 times more likely to die from it compared to wealthier women
- Women living in regional and remote areas are 1.2 to 1.3 times more likely to be diagnosed with uterine cancer, and 1.5 to 1.6 times more likely to die from it, compared to women in metropolitan areas

Similarly, as shown in Figure ES.5, in Aotearoa New Zealand:[vii]

- Pacific women are 5.6 times more likely to be diagnosed with uterine cancer compared to non-Māori/Pacific women and 6.8 times more likely to die from uterine cancer compared to non-Māori/Pacific women
- Māori women are 2.2 times more likely to be diagnosed with uterine cancer compared to non-Māori/Pacific women and 2.8 times more likely to die from uterine cancer compared to non-Māori/Pacific women
- In Aotearoa New Zealand, low SES women are 1.08 to 1.5 times more likely to be diagnosed with uterine cancer and 1.8 to 2.2 times more likely to die from it compared to wealthier women

These findings highlight significant disparities in health outcomes, particularly for First Nations, wāhine Māori, and Pacific women, as well as those from rural or low socioeconomic backgrounds.

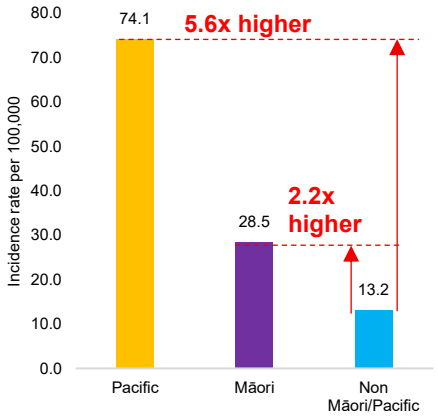
Figure ES.4: Increased incidence and mortality in uterine cancer for disadvantaged women in Australia



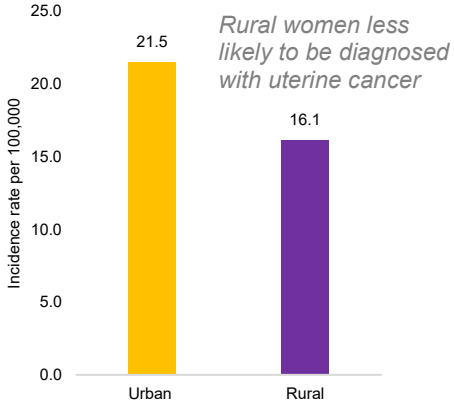
Source: Queensland Health. (2024). OASys.

Figure ES.5: Increased incidence and mortality in uterine cancer for disadvantaged women in Aotearoa New Zealand

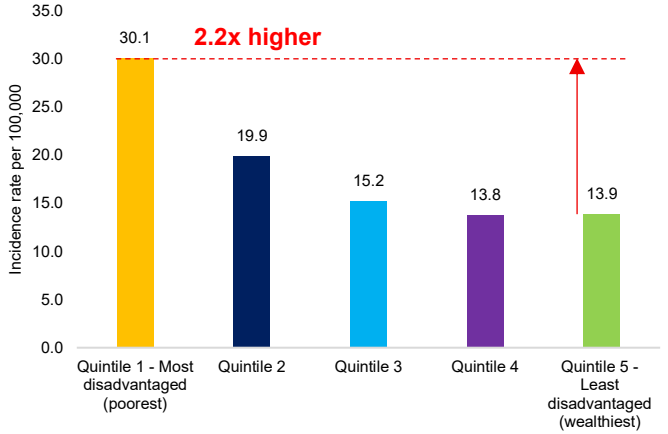
Incidence rates – Māori wahine & Pacific women



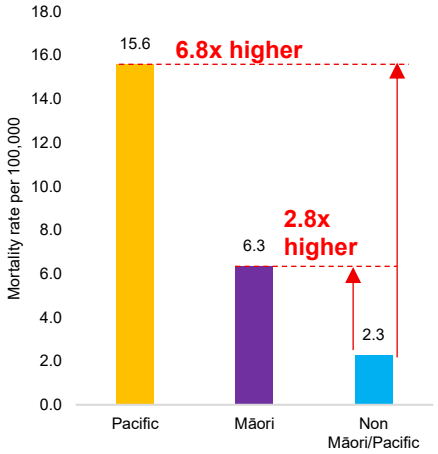
Incidence rates – Women in rural areas



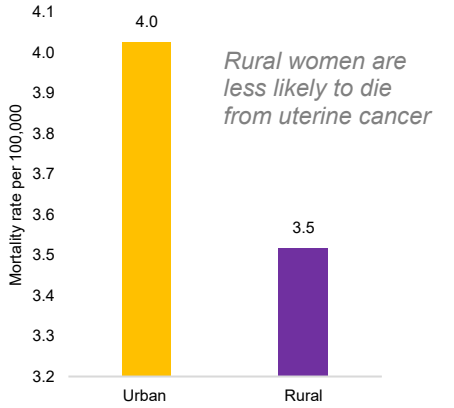
Incidence rates – Women from low socioeconomic areas



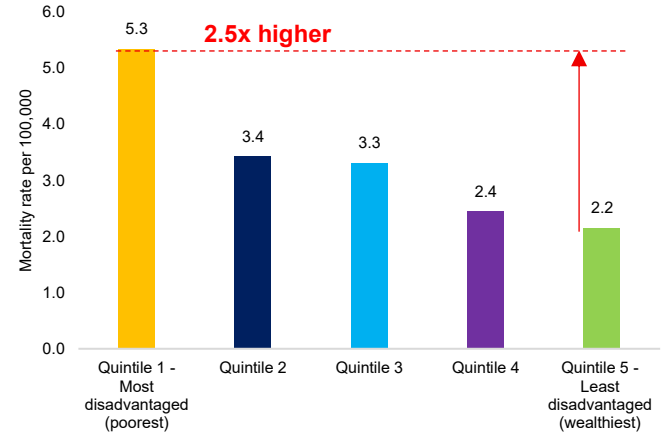
Mortality rates – Māori wahine & Pacific women



Mortality rates – Women in rural areas



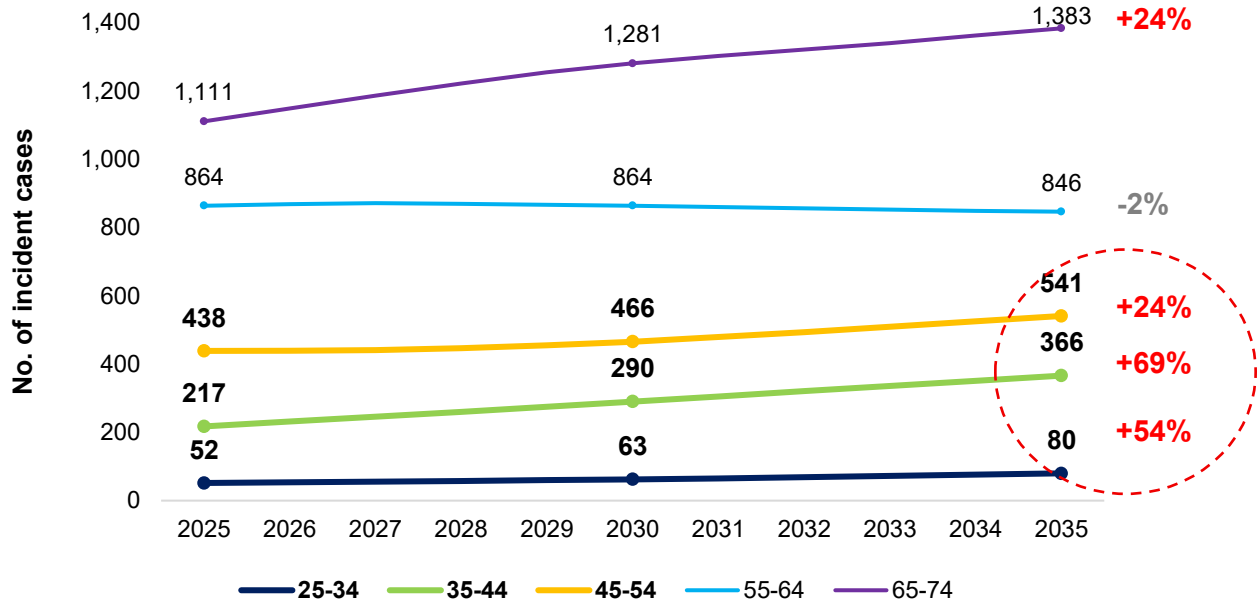
Mortality rates – Women from low socioeconomic areas



Source: Health Aotearoa New Zealand (Te Whatu Ora), Cancer data web tool 2018-2022.

Moreover, while uterine cancer remains most commonly diagnosed in women around the age of 65, rates among younger women are rising sharply. As shown in Figure ES.6, growth in incidence among women aged 35-44 expected to increase by 69 per cent over the next 10 years.

Figure ES.6: Projected uterine cancer incidence in young Australian women, 2025-2035



Source: Insight Economics projections based on AIHW data. See Appendix A for more details.

Uterine cancer is also one of the only cancers where the mortality rate is rising.[viii]

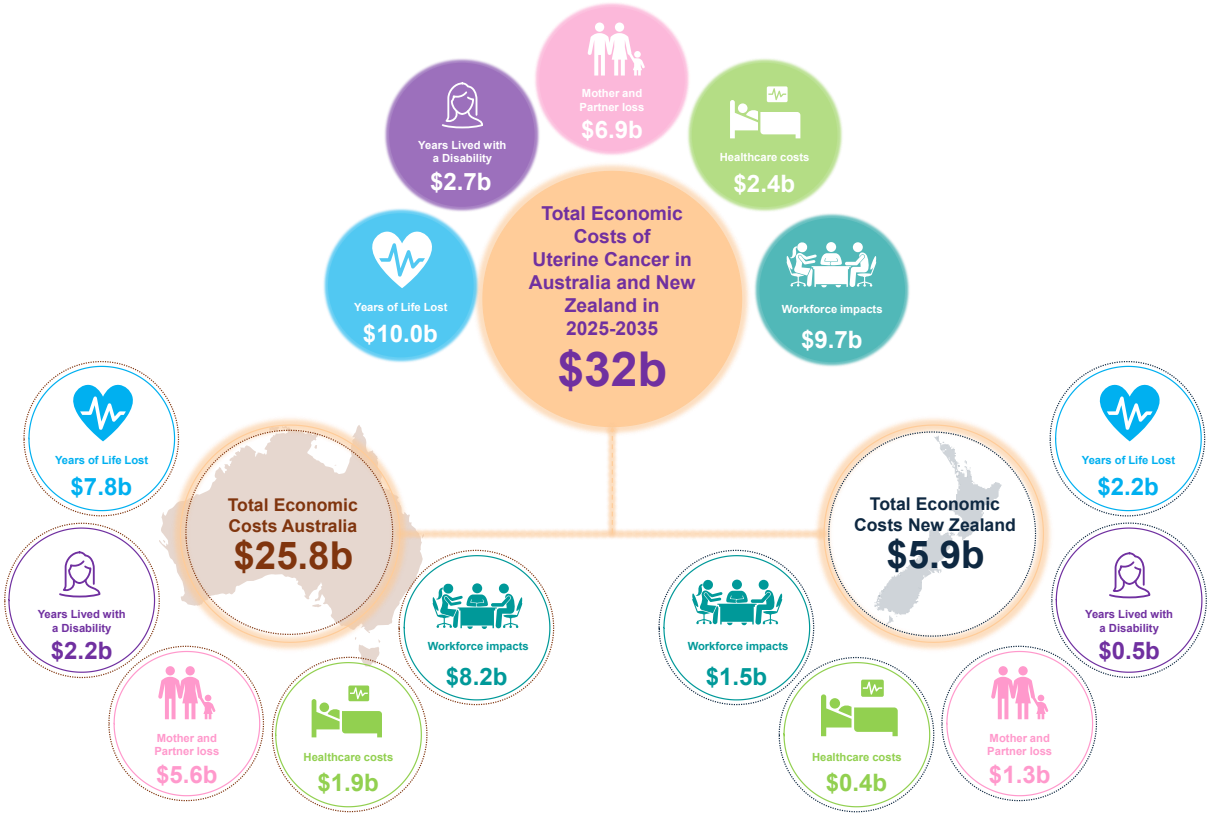
The rise in uterine cancers comes brings significant health, social and economic costs to Australian and Aotearoa New Zealand

The rising and inequitable incidence of uterine cancers is leading to the loss of women. Nearly 12,000 deaths are expected over the next 10 years based on Insight Economics' analysis of Australian Institute of Health and Welfare (AIHW) and Health New Zealand data.

These diagnoses and deaths bring with them significant health and economic costs. It is expected the costs of uterine cancer in Australia and Aotearoa New Zealand will total an estimated $32 billion in $NPV_{7\%}$ terms over the 2025-2035 period alone, comprised of potentially avoidable direct health care costs, preventable premature death, years lived with disease, workforce impacts and the impacts on families from mother and partner loss (Figure ES.7).

Without urgent, coordinated action, the growing incidence of uterine cancer will place increasing pressure on health systems and widen existing gaps in women's health equity. The improved control of uterine cancer therefore needs to become an urgent national priority for Australian and Aotearoa New Zealand governments and communities.

Figure ES.7: Economic costs of uterine cancer in Australia and Aotearoa New Zealand



Source: Insight Economics projections based on AIHW data. See Appendix A for more method and assumptions.

The need to make uterine cancer control a national priority for Australia and Aotearoa New Zealand: the State of the Nation in Uterine Cancers

In spite of the rapidly rising incidence and number of deaths, uterine cancer remains significantly under-recognised in public discourse, policy, and research funding. This is the result, in part, of silence and stigma surrounding gynaecological cancers, which can deter awareness-raising, early presentation, and advocacy. It is also the result of a lack of any patient support organisations in uterine cancer working to advocate on behalf of women impacted by uterine cancer.

The Australian and New Zealand Gynaecological Oncology Group (ANZGOG), which is the peak national gynaecological cancer research organisation, has commissioned this State of the Nation report address this gap in support for women. This report seeks to raise awareness of uterine cancer, to present evidence of barriers to world class outcomes and experience, to identify research priorities to improve outcomes and develop a vision and action plan to improve outcomes for women and their families. The report identifies needed investment and policy reform to improve the prevention, diagnosis, treatment and care of women at risk of, and living with, uterine cancer.

This report brings together findings from a literature and data review, economic impact analysis, two consumer roundtables with 19 women and carers impacted by uterine cancer, a survey of patients and carers impacted by uterine cancers, a survey of uterine cancer clinicians and researchers, and interviews with more than 40 stakeholders from across Australia and Aotearoa New Zealand. It identifies barriers to improved outcomes and opportunities to reverse the rising tide of incidence and to improve survival through policy reform and investment in research.

Barriers to improved outcomes for women and their families: key findings

Despite Australia and Aotearoa New Zealand's strong reputation for cancer care, the literature and data review, consumer roundtables, stakeholder consultations and surveys conducted for this report identified numerous, significant unmet needs and barriers in uterine cancer care for women in Australia and Aotearoa New Zealand to world class outcomes and experiences; these issues span across the spectrum of care, from prevention, to diagnosis and treatment, to survivorship (see Figure ES.7):

- *Underinvestment in research* — Poor awareness of uterine cancer contributes to complacency and lack of prioritising by policy makers and underfunding of research. Uterine cancers are among the poorest funded cancer in terms of research funding, both in absolute terms and in terms of disease burden. Cancer Australia data shown that less than $1 million per annum was invested over the 2003-2020 period in uterine cancer research;[ix] in New Zealand, only $310,000 has been invested over the 2015-2025 period.[x] This is part of a global pattern of underinvestment in uterine cancer research, that has resulted in the lowest 'funding to lethality' ratios of any major cancer and the lowest among gynaecological cancers. This highlights the *severe* disparity and levels of underfunding that lead to limited treatment options and poor outcomes for women and their families, especially for women with rare uterine cancers, and those with advanced/metastatic or recurrent disease.
- *Underinvestment in healthy living and chronic disease prevention* — Much of the rise in, and cost of, uterine cancer can be prevented — up to 60 per cent[xi] — and significant improvements in survival and quality of life are possible through improvements in clinical practice and research. But risk prevention is chronically underfunded in both Australia and Aotearoa New Zealand, with investment in preventative health in Australia being roughly half that of the OECD average.[xii] While both Australian and Aotearoa New Zealand governments have developed policy strategies recognising the growing risks from chronic disease, this has not been matched by the needed investment or implementation. The result is worsening trends in the social determinants of health and poor health outcomes for women and the wider community. Women diagnosed with uterine cancer are being left behind.
- *Major gaps in data and reporting* — Improving outcomes for women with uterine cancer depends on access to data: only through data is it possible to identify opportunities in prevention, early detection, treatment and care. Researchers and policy makers require reliable, comprehensive data to conduct the research that helps develop and implement new and effective treatments, while accessible and centralised patient data can help clinicians and medical workers deliver the best care to their patients. Australia and New Zealand do not collect and report the data needed to improve outcomes for women. Even basic data on incidence by stage is not consistently collected and reported, with data collection varying significantly across jurisdictions. Where data are collected, they often cannot be accessed and aggregated in such a way to inform research and policy to improve the treatment and care of uterine cancer. There are also no national, publicly available datasets available to understand patterns of care in primary care settings; this impedes improvements in the delivery of primary care. In the absence of sufficient data, both research and reform are hindered, and the lack of data available on uterine cancer patients and survivors stands in contrast to other chronic diseases, where data dashboards are more readily available.
- *Variation in clinical practice in cancer diagnosis, treatment and care in Australia* — Data and stakeholder interviews suggest there is substantial variation in clinical practice in Australia, beginning with the approach to diagnosis, with substantially different imaging and other diagnostic tests ordered from state to state. Variation was

also identified in adjuvant therapies, with some clinicians expressing serious concern related to the variable approaches to radiotherapy and a desire for a nationally consistent approach to optimise the benefit-risk profile of treatments for patients. Concerns were also raised in the access to fertility preservation and screening for supportive care. Moreover, there was also found to be a lack of access to bariatric services that might help women get rid of pre-invasive cancers and become fit enough for surgery. Additionally, significant and anxiety-producing variation was also reported in follow-up care and surveillance, with again the need for a nationally consistent approach Across all cancers, Aboriginal and Torres Strait Islanders experience significant delays compared to their non-Indigenous peers.

- *Barriers to genomic testing to inform treatment planning* — Preliminary clinical data collected by the National Gynaecological Oncology Registry (NGOR) in 2023[xiii] indicates that while most women do receive dMMR testing (98 per cent of women), which is MBS funded, testing for other potential precision medicine biomarkers is substantially less; for example:
  - 76 per cent of women receive ER/PR testing
  - 40 per cent of women receive P53 testing
  - Only 2.7 per cent of women receive *POLE* testing.

  Similarly, in Aotearoa New Zealand, while MMR testing is recognised as best practice for endometrial cancers, molecular profiling for other mutations beyond MMR testing was reported to be limited.[xiv]

  This gap means that, more often than not, uterine cancer patients do not receive a complete diagnosis of their specific uterine cancer molecular sub-type. While many women will be cured through surgery, a significant number of women will experience a more advanced form of the disease and may benefit from access to novel treatments.

- *Inconsistent screening for familial cancer risk* — Preliminary clinical data collected by the National Gynaecological Oncology Registry (NGOR) in 2023 indicates that, while some genetic testing is performed almost universally, or with a high degree of coverage, other genetic tests are not performed on all patients. For example, the data show that 98 per cent of women are screened for dMMR, which is the first step to a Lynch syndrome diagnosis, but only half of women with *MLH1* loss were subsequently referred for methylation testing, which is a necessary next step to confirm a Lynch Syndrome diagnosis. While this is based on a limited patient sample, this suggests that there is scope to improve screening for familial cancer risk. Diagnosis of Lynch Syndrome is important, influencing clinical management with surveillance and more radical surgery. It also provides for preventive surveillance among family members — not only for endometrial cancer, but also colorectal cancer, ovarian cancer, upper GI cancers, brain cancer, and skin cancers, which often occur at a young age.

- *Lack of treatment options and delays in access to novel therapies* — Chronic underfunding for uterine cancer research has translated into few treatment options for women diagnosed with a uterine cancer compared to other common cancers impacting women. Analysis of treatment options for Australian women with breast cancer have more than *seven times* as many treatment options as women with uterine cancer, and that women diagnosed with metastatic breast cancer have *11.5 times* the number of treatment options as women with advanced uterine cancer.[xv] This is a direct function of significantly more investment in research to identify new therapies for breast cancer than has occurred in uterine cancer.

Added to this, there are a number of therapies that are standard of care in other major developed nations for which access is not publicly-funded in Australia and New Zealand, further limiting women's treatment options.[xvi]

- *Acute workforce shortages in Aotearoa New Zealand* — The rapidly rising incidence of uterine cancer is putting health care teams under pressure on both sides of the Tasman, but workforce shortages in Aotearoa New Zealand have reached crisis levels with *only six* gynaecological oncologists employed *nationally* in Aotearoa New Zealand. As a result, the ratio of incidence to gynaecological oncologists is more than twice that of Australia, leading to risks that women that should be treated by a gynaecological oncologist are not.[xvii] These pressures are compounded by challenges in recruitment and retention. Regulatory barriers can deter overseas specialists from practising in Aotearoa New Zealand. Without urgent investment in the gynaecological oncology workforce, including competitive salaries, training pathways, surgical infrastructure (such as access to robotics), and recognition of international qualifications, Aotearoa New Zealand risks falling further behind in its ability to deliver timely, high-quality care for women with uterine cancer.
- *Lack of culturally competent care* — Women from priority populations, including First Nations women and women from culturally and linguistically diverse backgrounds, face unique barriers that can result in delays in seeking care and potentially contribute to poor outcomes. For example, a 2016 survey of Aotearoa New Zealand women found that 50 per cent of respondents cited a lack of cultural safety, and 44 per cent cited a lack of Māori health workers, as a reason for a delay in accessing screening services.[12] Similarly, 48 per cent and 41 per cent cited a lack of cultural safety and no Māori health workers, respectively, as a reason for a delay in accessing primary care when presenting with symptoms. In Australia, a study of the provision of care to Aboriginal and Torres Strait Islanders in Queensland with gynaecological cancers found a pressing need for improved access to culturally appropriate, person-centred care.
- *Risks of financial toxicity* — Additionally, women from lower socioeconomic backgrounds and those living in rural and remote areas are especially at risk of financial toxicity due to the added costs they must bear. These include transportation and accommodation, out-of-pocket expenses for treatment and supportive care, and the opportunity cost of not working while undergoing treatment. All this can add up to build an overwhelming financial burden and reduce take up of available treatment.
- *Lack of survivorship models of care and guidelines* — More than 50 per cent of women responding to the survey reported experiencing side effects from their cancer and its treatment, with major concerns including fatigue, anxiety, depression and lymphoedema. Women also reported wishing supportive care had been discussed with exercise, nutrition and weight management being the top three issues women wish they had had support for – and critically, were not able to access following treatment because they could not find support. This points to a serious gap in care. To date, only one gynaecological survivorship clinic is in operation nationally, in Western Australia, having been established in 2024. The lack of nationally consistent survivorship models of care and guidelines for clinicians constitutes a major missed opportunity to improve quality of life and wellness for women impacted by uterine cancer.

Improving outcomes for women and their families: key opportunities

Improving outcomes for women at risk of and living with uterine cancer requires a coordinated, whole-of-pathway approach that spans the entire continuum of care. From prevention and early detection through diagnosis, treatment, supportive care, and long-term

survivorship, each phase of the patient journey presents both unique challenges and critical opportunities for intervention.

Importantly, Australia and Aotearoa New Zealand are not starting from scratch — there is a growing body of evidence about what works. Despite this, improvements remain fragmented, inequitable, and under-implemented. Many women face delays in diagnosis, limited access to personalised care, and a lack of continuity in supportive and survivorship services. These gaps are compounded for women in priority populations, who experience some of the worst outcomes.

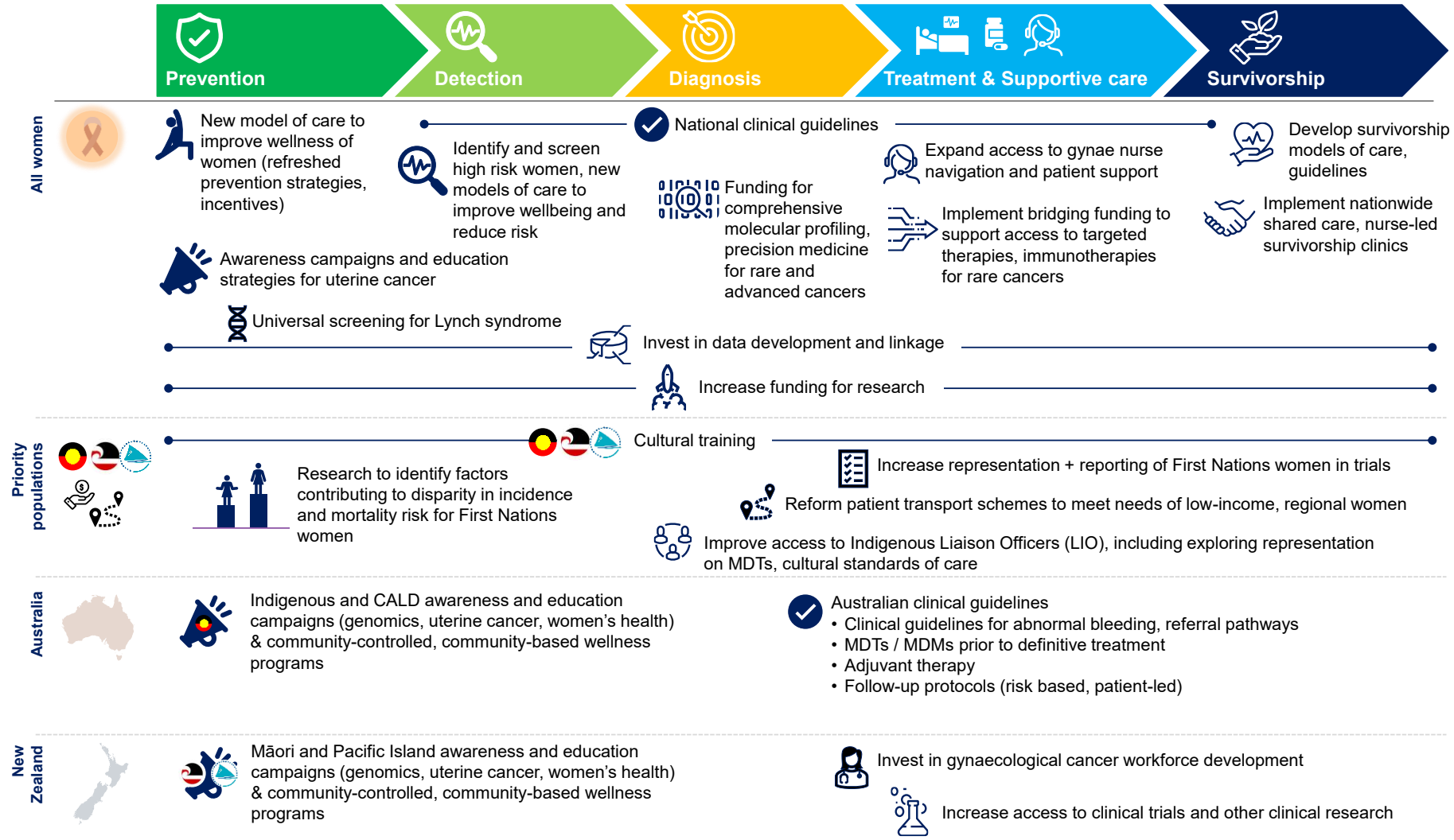
System-wide reform must build on the principles of health implementation science: translating evidence into everyday care, embedding equity at every step, and aligning health system levers—like funding, workforce, and data systems—to support sustainable change.

Major opportunities to improve outcomes for women include (Figure ES.8):

- Invest in research to improve outcomes across the care pathway
- Raise awareness of uterine cancer and embed education into new models of care for women
- Implement increased screening for Lynch among women identified to have dMMR
- Develop a new national strategy for healthy living and the prevention of metabolic and chronic disease
- Identify high risk women for targeted screening and preventative treatment
- Improve access to fertility preservation and bariatric services
- Develop clinical guidelines and improve adherence to best practice care in Australia
- Address workforce shortages in Aotearoa New Zealand
- Improve screening for and access to supportive care
- Reform Patient Transport Support Schemes to better meet the needs of low-income patients in regional areas
- Invest in data development and linkage
- Expand funded access to genomics and precision medicine for rare, advanced and recurrent cancers
- Embed equity across the pathway and expand access to research for priority populations.

These actions were strongly supported as priorities for reform and investment by patients, carers, clinicians and researchers alike.

Figure ES.8: Improving outcomes for women impacted by uterine cancer – major opportunities for research and reform



In surveys completed for this report, clinicians and researchers highlighted the need for increased funding for research, improved access to diagnostics—particularly molecular profiling—and strengthened efforts in risk prevention and reduction as among the highest priorities for action. These priorities were echoed by patients and carers, who identified greater investment in research, earlier detection, and improved awareness of risk factors and symptoms as the highest priorities for change. This convergence underscores the importance of a comprehensive, system-wide response that bridges scientific innovation, clinical reform, and public health engagement.

These actions have the potential to deliver very significant health and economic benefits to women and the wider community. For example:

- *Investing in research and policy reforms to improve prevention* have the potential to halve incidence through lifestyle modification and better precision prevention strategies, with 33 per cent[xviii] to 60 per cent[xix] of cases being potentially preventable. This would benefit between 2,800 to 10,000 women and families over 2025-2035 horizon, with a potential economic impact in the order of $1.4 billion to $5.0 billion over 2025-2035 horizon, with full benefits realised by 2040.[xx]
- *Investing in research and policy reforms to improve early detection through improved awareness, education and novel surveillance and screening*, particularly of high-risk cohorts would be expected to deliver significant benefits, given that the 5-year relative survival rate for Stage I cancers is estimated to be 95 per cent, while this falls to only 12 per cent for women diagnosed at Stages III and IV.[xxi] Increasing the proportion of Stage I diagnoses to 80 or 90 per cent would benefit between 2,500 to 4,200 women over 2025-2035 period, with a potential economic benefit of between $0.8 billion to $1.2 billion over the 2025-2035 horizon.[xxii]
- *Investing in research and policy reforms to improve early detection and treatment of women with early stage endometrial cancer and atypical hyperplasia*, with a complete response in 43 per cent to 67 per cent of early endometrial cases to treatment with a progestin secreting IUD, and a complete response in 82 per cent women having hyperplasia prior to a uterine cancer diagnosis,[xxiii] potentially benefitting 4,700 to 7,300 women over 2025-2035 period at an economic value of $1.8 billion to $2.6 billion over 2025-2035, with full benefits realised by 2040.[xxiv]
- *Investing in clinical trials research*, as well as other clinical research, is also associated with significant economic benefits in its own right, attracting private sector co-investment, improving the efficiency of health service delivery, and creating jobs. For example, ANZGOG data show that industry invests $2.30 for every $1 invested by government in clinical trials and MTPConnect data show that every clinical trial attracted to Australia creates an additional 4.2 jobs.[xxv]
- *Investing in consistent screening for Lynch syndrome of all women with uterine cancer that are found to have dMMR*. Preliminary NGOR data suggests the rate of testing for Lynch syndrome among women with uterine cancers is potentially running at roughly half of the ideal rate and there is scope to increase the consistency of screening. Modelling suggests that reducing the total incidence by 3 per cent could benefit 250 women between 2025 and 2035, with an economic benefit of $126 million.[xxvi]
- *Expanding access to targeted treatments, immunotherapies and combination therapies for rare, recurrent and advanced cancers*, noting that lines of therapy, already limited for uterine cancer, are significantly fewer than other cancers due to underinvestment in research. Investment in novel treatments will benefits the nearly 7,000 women that will experience advanced disease but suffer with few treatment options.

- *New models of care for survivorship* to potentially benefit more than 50 per cent of women diagnosed over the 2025-2035 period, which equates to more than 27,800 women that may otherwise struggle with limited support and potentially manageable side effects.

A critical national priority: Reversing the rise of uterine cancers

There is evidence that uterine cancer awareness is generally low[xxvii], that research into the disease is underfunded[xxviii], and that a high proportion of patients have significant unmet needs and lack appropriate support.[xxix] This lack of visibility and investment has contributed to a policy vacuum, which has led to growing inequalities in outcomes for women from the most disadvantaged backgrounds.

ANZGOG, together with women living with uterine cancer and the wider uterine cancer research community, is calling for investment by governments and the wider community in research and a comprehensive strategy to improve outcomes for women.

The vision for uterine cancer is that it transforms from a largely unknown and underfunded health crisis to an urgent priority for governments, which sees an end to the rise of uterine cancers.

Figure ES.9: Vision and goals for uterine cancer

This can be achieved through the implementation of action against five key strategic objectives:

- *Invest in research and data* — The highest priority for action to improve outcomes for women identified by patients, carers, clinicians and consumers alike was to invest in research. This reflected a strong understanding of the relationship between research investment and improved outcomes for cancer survivors. It also reflects a concern for the limited treatment options available to women with rare, recurrent and advanced cancers and an incomplete understanding of the underlying drivers of inequity for priority populations. To correct the very significant underfunding of uterine cancer against a backdrop of rising incidence and mortality, it is recommended that Australian and New Zealand governments prioritise uterine cancer research. In Australia, it is recommended that Commonwealth Government fund a national uterine cancer research strategy that is led by a national, collaborative taskforce or working group involving ANZGOG, state governments, philanthropy and related non-government organisations.

  Action is also needed to address the significant data gaps that exist for uterine cancer that impede an understanding of outcomes across Australian and Aotearoa New Zealand health systems. While important action is being taken at a national level to develop a National Cancer Data Ecosystem, alongside this work, which will take time to develop, improvements are needed in cancer registry data collection and reporting for uterine cancer, and continued investment is needed in data linkage to support consistent implementation of clinical best practice and research. Funding is also needed to improve the availability of primary care treatment data, to better understand potential variation in care that could further support education and training for GPs.

- *Halve the incidence of uterine cancer* — Up to 60 per cent of uterine cancer cases are preventable, but little investment in programs and strategies have been implemented to improve women's health. Prevention strategies like promoting healthy lifestyles, managing chronic conditions, and increasing awareness can lead to earlier detection and intervention, improving outcomes and reducing healthcare costs. Ultimately, prioritising prevention supports not only individual well-being but also public health and health equity. Key actions identified to improve prevention and reduce incidence include the development of:
  - National awareness campaigns in Australia and Aotearoa New Zealand to improve awareness of uterine cancer, risk factors and opportunities to reduce risk
  - Funding for education of risk factors for uterine cancer, potentially as part of the introduction of government-funded Women's Wellness Checks and women's health clinics
  - Invest in New National Strategies for healthy living
  - Pilot targeted screening high-risk women in selected care settings and develop models of care for prevention
  - Increased screening for Lynch syndrome.
- *Eliminate inequity* — Reducing disparities in the risk of and mortality from uterine cancer for Aboriginal and Torres Strait Islander women, wāhine Māori, Pacific women, regional women, and those from low socioeconomic backgrounds in Australia and Aotearoa New Zealand is a matter of health equity and social justice as well as core to the improvement of cancer outcomes. Addressing inequity is at the heart of the Australian Cancer Plan and given the significant challenge uterine cancer poses to First Nations women in particular, should be a priority for government investment in research and reform. Key actions include investment in culturally tailored research to understand risk factors and barriers to care specific to these populations, and the development of targeted public health initiatives, co-designed with these communities, to raise awareness, promote early diagnosis, and improve access to treatment. Policy reforms could support the expansion of mobile and community-based health services, equitable access to gynae-oncology

specialists, and the integration of Indigenous leadership and community voices in cancer care planning as well as the inclusion of Indigenous Liaison Officers or Indigenous nurse navigators (which is the model in Aotearoa New Zealand) to support culturally appropriate treatment planning and care. Enhanced funding for sovereign data collection and reporting, alongside workforce development that includes training and recruitment of First Nation health professionals.

- *Precision medicine for every woman* — Implementing and funding comprehensive molecular profiling for all rare, recurrent, and advanced uterine cancers is essential to improving patient outcomes and advancing equity in cancer care. These cancers often present with aggressive behaviour and limited treatment options, and traditional 'one-size-fits-all' approaches have failed to deliver significant survival gains for these women. Molecular profiling enables a precision medicine approach by identifying specific genetic and molecular alterations that can guide targeted therapies, predict treatment response, and avoid unnecessary toxicity. Again, this should be implemented as part of a wider uterine cancer research strategy. In addition to access to molecular profiling, governments should also commit to ensuring clinical guidelines are updated and maintained to reduce variation in care and ensure access to best practice. Governments should also ensure that MDTs are completed prior to definitive treatment.
- *Support for every woman to live well* — Unlike other gynaecological cancers, there is no patient support organisation raising awareness and championing policy reforms that will improve outcomes for women. Screening for supportive care remains inconsistent and many women struggle to find appropriate supportive care services as long term survivors. Key actions to improve outcomes against this strategic objective include ensuring adherence to clinical care standards of screening every woman for support care, expanding access to patient support, peer support and psychosocial services for women with uterine cancer by Ovarian Cancer Australia, progressively expanding on its Teal Nurse Support program and funding research to develop a model of care for uterine cancer survivorship.

This will require partnerships across Australian and Aotearoa New Zealand governments, the not-for-profit sector and philanthropy, with clinicians and researchers and with women and the wider community. But together, it is possible to take action and turn the tide against uterine cancer – for good.

Introduction

State of the Nation: Report objectives and method

A lack of advocacy and a need for change: objectives and approach to the State of the Nation report

Unlike many other cancers impacting women, uterine cancer lacks a dedicated, national patient support and advocacy organisation today. While several community support groups exist, such as the Cancer Council and Counterpart, as well as other smaller state-based organisations, there is no national advocacy or support organisation focused on uterine cancer.

As a result, women diagnosed with uterine cancer have not had the same ability to come together to raise their voices and awareness of the disease, to advocate for research funding, and to contribute to policy reforms as other cancers. As this report will show, this has contributed to poor awareness of the cancer and very limited policy focus by governments in Australia and Aotearoa New Zealand alike, with severely low funding for research.

Recognising this gap in support and need among women and families impacted by uterine cancer, the Australia New Zealand Gynaecological Oncology Group (ANZGOG), the peak national gynaecological cancer research organisation, commissioned this State of the Nation report. The objectives of this report are to raise awareness of uterine cancer, to present evidence of barriers to world class outcomes and experience, to identify research priorities to improve outcomes, and to develop a vision and action plan to improve outcomes for women and their families.

This report synthesises a range of evidence developed from the following tasks:

- *Literature and data review* — A comprehensive literature and data review, including information around trends in research, investment and outcomes.
- *Epidemiological and economic impact modelling* — Economic modelling based on epidemiological data provided to Insight Economics and available literature, designed to estimate the economic impact of uterine cancer on patients, the healthcare system and society at-large.
- *Consumer roundtables* — Two group roundtable discussions with 19 uterine cancer patients and survivors, seeking to elucidate consumer perspectives on uterine cancer care in Australia and Aotearoa New Zealand.
- *Stakeholder consultations* — Interviews with more than 40 stakeholders from Australia and Aotearoa New Zealand across the spectrum of uterine cancer expertise, from researchers and public health officials to clinicians and non-profit organisations.
- *Patient and Carer survey* — A patient and carer survey, seeking to obtain information about patient and carer experiences, and their thoughts on challenges and opportunities moving forward
- *Researcher and Clinician survey* — A researcher and clinician survey, seeking to obtain their opinions on possible challenges and opportunities moving forward.

- *Research Audit*—A review of a research project undertaken by Australian research institutions, including analysis of historical funding and topics of focus.

Report structure

The report follows the following structure:

- Chapter 1 serves as an educational primer on uterine cancer, with emphasis on understanding the major risk factors, how uterine cancer is detected and diagnosed, and the major treatment options for women with uterine cancer.
- Chapter 2 discusses the economic and social impact of uterine cancer in Australia and Aotearoa New Zealand, using Insight Economics' epidemiological and economic impact modelling, to demonstrate the potential value that could be realised by more focused investment in uterine cancer prevention, detection and treatment.
- Chapter 3 outlines a number of barriers faced by many women, all across their health journey. These barriers are present from prevention and early detection all the way through to treatment and survivorship and ultimately lead to poorer outcomes for many women.
- Chapter 5 presents a number of opportunities to improve outcomes for women with uterine cancer, addressing the barriers raised in Chapter 3. These suggestions encompass many points along a patient's journey, from improved screening, expanded access to genomics and precision medicine, and improved access to survivorship care.

The report is also supported by a number of detailed appendices including:

- Appendix A: Economic impacts of Uterine Cancers in Australia and Aotearoa New Zealand provides a methodological summary of the epidemiological and economic impact analysis used throughout this report.
- Appendix B: Surveys of Consumers, Clinicians and Researchers provides a summary of the surveys of consumers, clinicians and researchers conducted by Insight Economics.
- Appendix C: Consumer Roundtable Summary provides a summary of the community roundtables conducted by Insight Economics.
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- Appendix D: Stakeholder engagement provides a summary of the small group stakeholder consultations conducted by Insight Economics.
- Appendix E: Summary of policy landscape in Australia and Aotearoa New Zealand provides a summary of the healthcare policy landscape in Australia and Aotearoa New Zealand, discussing the relevance of these policies to uterine cancer.

Chapter 1
Understanding uterine cancers

This chapter presents a short primer in uterine cancer, which may also be frequently called endometrial cancer or womb cancer (because >95% of uterine cancers develop in the endometrium or lining of the uterus). This chapter outlines the basic facts and figures of uterine cancer, including how it is diagnosed and treated.

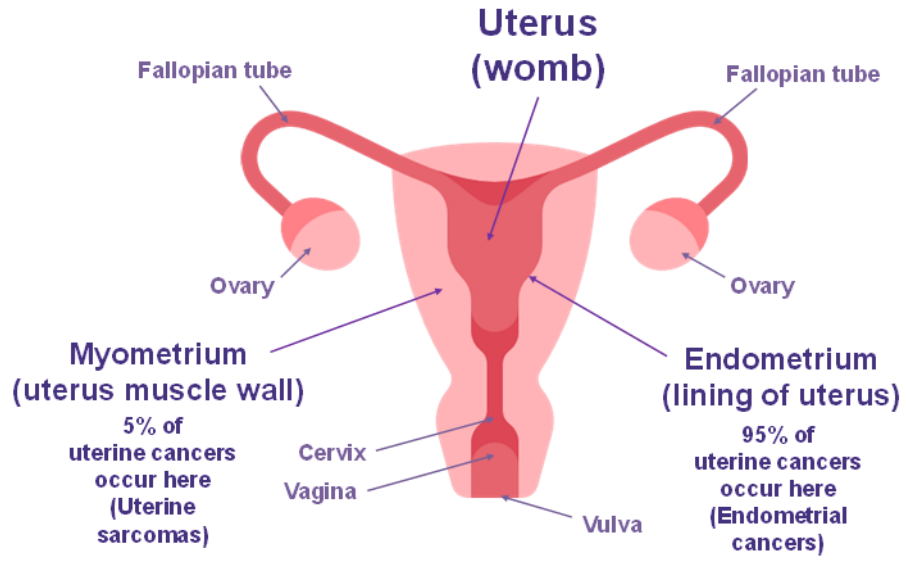
1.1 Uterine cancer: where does it occur?

Uterine cancer is a type of cancer that occurs when abnormal cells in the uterus grow out of control. There are two main subtypes of uterine cancer:

- Endometrial cancers, which come from the lining of the uterus (endometrium) and accounts for approximately 95 per cent of all uterine cancers. This is why uterine cancer are commonly referred to as 'endometrial cancer'.
- Uterine sarcomas, which are rarer subtypes of uterine cancer that develop from either the connective tissue (stroma) of the endometrium, or from the muscle tissue layer of the uterus (myometrium) and account for the balance of cases.

It is also sometimes called womb cancer.

Figure 1.1: Where do uterine cancers occur?

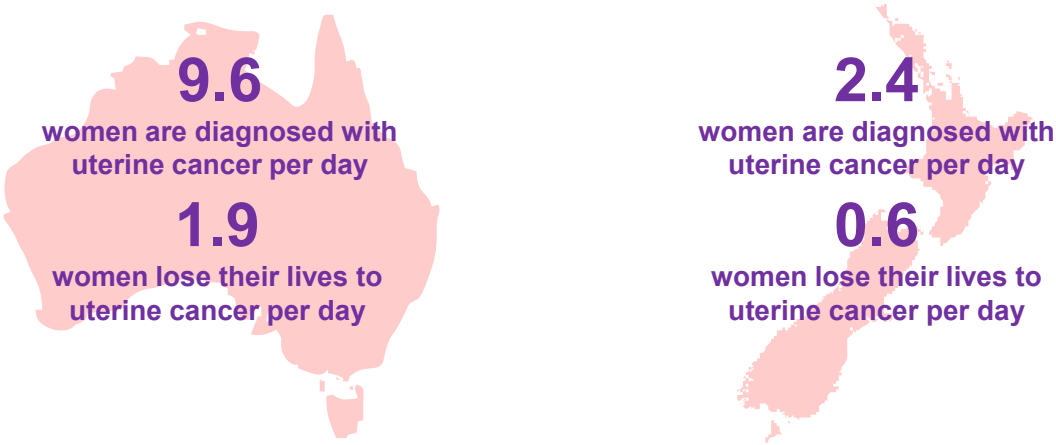


Source: Insight Economics.

1.2 Uterine cancer is the most commonly diagnosed gynaecological cancer in Australia and Aotearoa New Zealand

Currently, over 17,700 women in Australia and Aotearoa New Zealand are living with uterine cancer, having received a diagnosis within the last five years (Figure 1.2).[1] In 2025 alone, approximately 4,360 women are expected to be diagnosed with a uterine cancer, and more than 900 women will lose their lives to the disease. This means every day, around 12 women will be diagnosed, and more than two women will die from their cancer.

Figure 1.2: Uterine cancer in Australia and Aotearoa New Zealand by the numbers



Source: Insight Economics analysis of AIHW and Health New Zealand (Te Whatu Ora) data, see Appendix A.

Even within these two major groups, there are different subtypes, and each subtype can behave differently in terms of both prognosis and treatments.

Traditionally, the classification and diagnosis of uterine cancer rely on histological assessment (looking at tissues that have been removed from a patient under a microscope), supported by immunohistochemistry (IHC), which is a laboratory technique where pathologists look at tissue under a microscope to find evidence of cancer. Recent advances in molecular testing (laboratory analysis of a tissue's proteins and genetic structure), however, have introduced a more precise classification system, particularly for endometrial cancers, enabling more personalised and prognostically informative treatment. Limited availability of genomic sequencing means histological assessment remains the standard approach in most clinical settings (see Section 1.3 and Chapter 4 for further detail).

The next two sections provide further detail about endometrial cancer subtypes and uterine sarcoma subtypes.

1.3 Understanding endometrial cancers

As explained above, endometrial cancers are the main type of uterine cancer diagnosed. These cancers occur in the lining of the uterus (endometrium) and account for approximately 95 per cent of all uterine cancers.

In the past, endometrial cancers have been divided into two main types – Type 1 and Type 2 cancers. These groups were based on the grade and the cell type (histology) that made up most of the cancer.

- Type 1 tumours are the most common type of uterine cancer, expected to account for roughly 83 per cent of uterine cancer cases in Australia and Aotearoa New

[1] This is a conservative estimate of prevalence; a 10-year prevalence estimate based on a diagnosis within the last 10 years increases the estimate of uterine cancer survivorship to 35,500.

Zealand in 2025. These tumours are low grade and made up of endometrioid cell types (which means that under a microscope the cells closely resemble the normal lining of the uterus), also known as endometrioid adenocarcinomas, and are strongly associated with exposure to higher oestrogen levels. These cancers are often diagnosed at an early stage, tend to grow slowly, and are less likely to spread beyond the uterus. As a result, cancers in this category often have a favourable prognosis.

- Type 2 endometrial cancers are the less common, more aggressive form of endometrial cancer, characterised by non-endometrioid histology, high grade (which means that under a microscope the cells look very different to the normal lining of the uterus), and are less associated with oestrogen stimulation. Histological subtypes of these cancers include clear cell carcinomas and serous carcinomas.

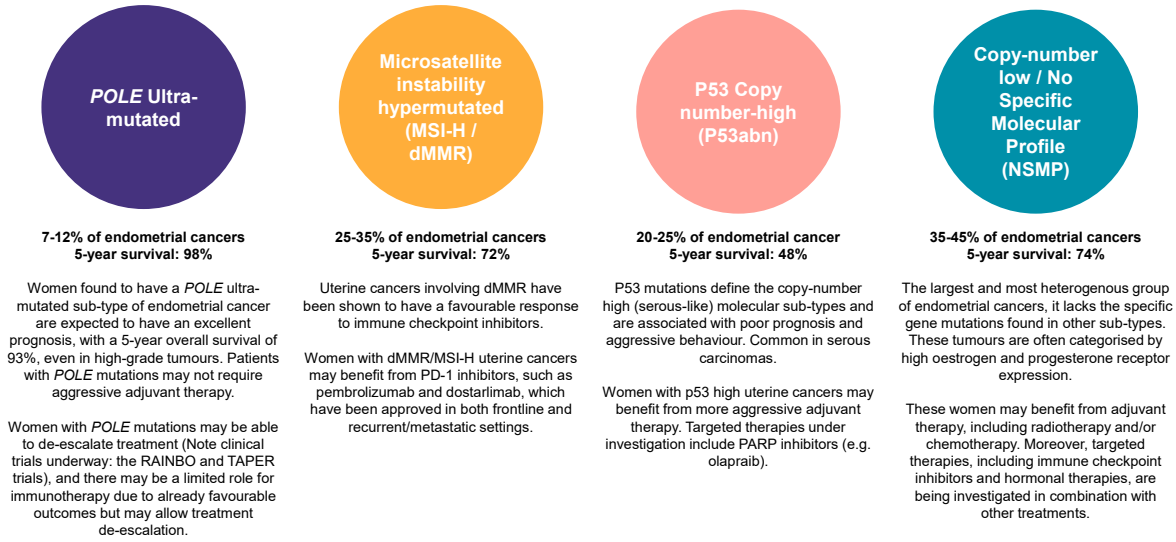
In the current era, however, this classification is no longer the gold-standard approach to the classification of uterine cancers. The preferred method for a more precise diagnosis is molecular classification. Using molecular sub-typing, made possible by genomic analysis (analysis of a tissue's proteins and genetic structure rather than looking at a sample under a microscope), endometrial cancer is divided into four main molecular subtypes: POLE ultra-mutated, microsatellite instability hypermutated (MSI-H), copy number-low (CN-L), and copy number-high (CN-H).[2] These subtypes have very distinct genetic profiles that have significant impacts for both clinical outcomes and treatment strategies (Figure 1.3):[3,4]

- *POLE ultra-mutated* – The *POLE* ultra mutated subtype is found in approximately 9–12 per cent of endometrial cancers. Women found to have this subtype of endometrial cancer are expected to have an excellent prognosis, with a 5-year overall survival of 93 per cent, even in high-grade tumours.
- *Microsatellite instability (MSI-High) or mismatch repair deficient (dMMR)* – The dMMR subtype is found in approximately 20–25 per cent of endometrial cancers. Women found to have this subtype of endometrial cancer are expected to have a moderate prognosis, with a 5-year overall survival of 63 per cent.
- *Copy number low (CN-L) or No Specific Molecular Profile (NSMP)* – The CN-L/NMSP subtype is found in approximately 27–34 per cent of endometrial cancers, forming the largest and most homogenous group of endometrial cancers. Women found to have this subtype of endometrial cancer are expected to have a moderate prognosis, with a 5-year overall survival of 40 per cent. It is categorised by a lack of specific gene mutations found in other subtypes and these tumours are often categorised by high oestrogen and progesterone receptor expression.
- *Copy number high (CN-H) or p53 mutant* – The CN-H/p53 mutant subtype is found in approximately 27–34 per cent of endometrial cancers. P53 mutations define the copy-number high (serous-like) molecular subtypes. Women found to have this subtype of endometrial cancer are expected to have a poor prognosis, with

[2] Levine, D., (2013). The Cancer Genome Atlas Research Network. Integrated genomic characterization of endometrial carcinoma. Nature 497, 67–73. https://doi.org/10.1038/nature12113.
[3] Stelloo, E., Bosse, T., et al. (2015). Refining prognosis and identifying targetable pathways for high-risk endometrial cancer; a TransPORTEC initiative. Modern pathology, 28(6), 836–844. https://doi.org/10.1038/modpathol.2015.43.
[4] Kommoss, S. et al. (2018). Final validation of the ProMisE molecular classifier for endometrial carcinoma in a large population-based case series, Annals of Oncology, Volume 29, Issue 5, 1180 – 1188; and Nijoku, K., Barr, C.E., and Crosbie E.J., (2022), Current and Emerging Prognostic Biomarkers in Endometrial Cancer, Volume 12, 10.3389/fonc.2022.890908.

a 5-year overall survival of 40 per cent; it is also associated with aggressive behaviour common in serous carcinomas (histology).

Figure 1.3: Major molecular subtypes of endometrial cancer



Source: Cancer Genome Atlas Research Network, et. al (2013) and León-Castillol, A., et al, (2020). Stelloo, E., et al. (2015). Refining prognosis and identifying targetable pathways for high-risk endometrial cancer; a TransPORTEC initiative. Modern pathology, 28(6), 836–844. https://doi.org/10.1038/modpathol.2015.43 and Kommoss, S. et al. (2018). Final validation of the ProMisE molecular classifier for endometrial carcinoma in a large population-based case series, Annals of Oncology, Volume 29, Issue 5, 1180 – 1188; and Nijoku, K., et al. (2022), Current and Emerging Prognostic Biomarkers in Endometrial Cancer, Volume 12, 10.3389/fonc.2022.890908.

1.4 Understanding uterine sarcomas

Uterine sarcomas are rarer subtypes of uterine cancer that develop from either the connective tissue (stroma) of the endometrium, or the muscle tissue layer of the uterus (myometrium) and account for the balance of cases. As noted above, uterine sarcomas are much less common than endometrial cancers and are expected to account for less than four per cent of all uterine cancer cases in Australia and Aotearoa New Zealand in 2025.

Uterine sarcomas tend to spread through the bloodstream, most commonly to the lungs, and are often diagnosed at a later stage due to delayed symptom onset (see Section 1.6). Management for uterine sarcomas is often more advanced, personalised, and differs significantly from that used for other types of uterine cancer (see Section 1.7).

Diagnosis continues to rely primarily on histology and immunohistochemistry, due to the genetic complexity and lack of consistent molecular markers. Molecular testing may be used for diagnostic clarification or to inform treatment but is not yet part of standard care.[5]

Uterine sarcomas are divided into two major histologic subtypes:

- *Leiomyosarcoma* – Leiomyosarcoma is the most common uterine sarcoma subtype, accounting for approximately 60–70 per cent of uterine sarcomas. The tumour is aggressive and prone to early spread. Women found to have this subtype of uterine sarcoma are expected to have a poor prognosis, with a 5-year overall survival of 20–30 per cent.[6]

[5] Roy, M., Wright, J. D., & Hensley, M. L. (2022). Uterine sarcomas: How to navigate an ever-growing list of subtypes. *American Society of Clinical Oncology Educational Book*, 42, 910–919. https://doi.org/10.1200/EDBK_350955.
[6] Zappacosta R, Fanfani F, Zappacosta B, Sablone F, Pansa L, Liberati M, et al. Uterine sarcomas: an updated overview. Part 1: smooth muscle tumors. Neoplasm. 2018. doi:10.5772/intechopen.76772

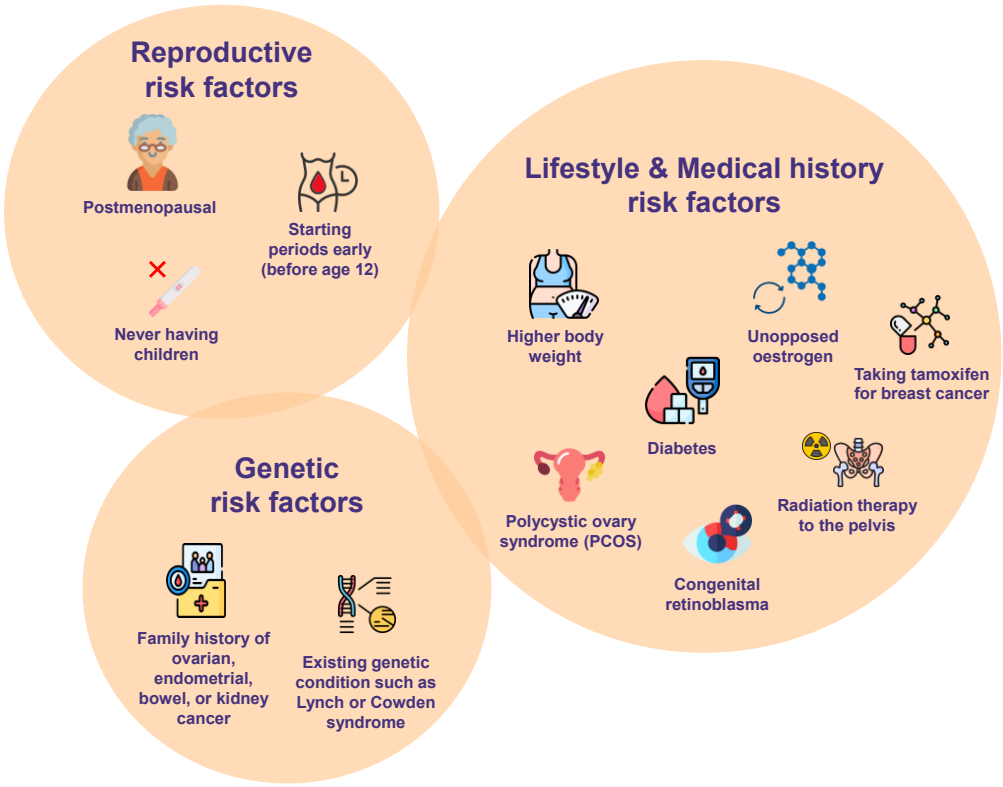
- *Endometrial stromal sarcoma (ESS)* – ESS is a less common uterine sarcoma subtype, accounting for 15 to 20 per cent of uterine sarcomas, the second most common after leiomyosarcoma. This is further divided into low-grade ESS and high-grade ESS. Women found with the low-grade ESS subtype of uterine sarcoma are expected to have an excellent prognosis, with a 5-year overall survival of 90.5 per cent, while women found with the high-grade ESS subtype of uterine sarcoma are expected to have a significantly inferior prognosis to low-grade ESS, with a 5-year overall survival of 33 per cent.[7]

Other rarer subtypes include undifferentiated uterine sarcoma and adenosarcoma.

1.5 What are the risk factors of uterine cancers?

Several factors increase the risk of developing uterine cancer, many of which involve hormonal imbalances between oestrogen and progesterone influenced by reproductive, lifestyle, and medical factors.

Figure 1.4: Overview of risk factors for uterine cancer



* Most of these factors are commonly associated with both uterine sarcomas and endometrial cancer (i.e., uterine cancer in general), except for a few that are specific to either endometrial carcinomas or uterine sarcomas, as discussed below.
Source: Insight Economics, based on risk factors identified by Cancer Australia.

While most risk factors overlap between endometrial cancers and uterine sarcomas, some are specific to each subtype.[8] For example, Lynch syndrome, Cowden syndrome, and family

[7] Pasricha S, Doval DC. Endometrial stromal sarcoma: a rare tumor with therapeutic conundrums. *Cancer Res Stat Treat*. 2020;3(3):583-585. doi:10.4103/CRST.CRST_228_20.
[8] Felix AS, Cook LS, Gaudet MM, Rohan TE, Schouten LJ, Setiawan VW, Wise LA, Anderson KE, Bernstein L, De Vivo I, Friedenreich CM, Gapstur SM, Goldbohm RA, Henderson B, Horn-Ross PL, Kolonel L, Lacey JV, Liang X, Lissowska J, Magliocco A, McCullough ML, Miller AB, Olson SH, Palmer JR, Park Y, Patel AV, Prescott J, Rastogi R, Robien K, Rosenberg L, Schairer C, Shu XO, van den Brandt PA, Virkus RA, Wentzensen N, Xiang YB, Xu WH, Yang HP, Brinton LA. The etiology of uterine sarcomas: a pooled analysis of the epidemiology of endometrial cancer consortium. *Br J Cancer*. 2013;108(3):727-734. doi:10.1038/bjc.2013.2

history of ovarian, endometrial, or bowel cancer are linked to endometrial cancers but are uncommon in uterine sarcomas. Conversely, prior pelvic radiation, family history of kidney cancer, and congenital retinoblastoma, a genetic mutation in the RB1 tumour suppressor gene, are associated with uterine sarcomas, but not endometrial carcinomas.

Understanding how these factors are connected to hormone levels helps provide a clearer picture of the potential risks. These factors can be grouped into three main categories (Figure 1.4):

- Reproductive
- Genetic
- Lifestyle/medical history.

It is important to recognise that many of these risk factors frequently co-exist. Many of them are interrelated and influence hormonal balance, with several acting as comorbidities. While many risk factors are hormone-related, some are not directly tied to hormonal changes. As a result, women are often exposed to multiple risk factors simultaneously, which collectively modify the body's hormonal environment and may also contribute through non-hormonal pathways. This combination of factors can work together to increase the risk of developing uterine cancer.

These risk factors are discussed in turn.[9,10]

Reproductive factors

Hormonal imbalances during a woman's reproductive years are key contributors to endometrial cancer risk. Some of the major reproductive factors include:

- *Later onset of menopause*— Longer exposure to oestrogen, over a woman's lifetime, increases the risk of endometrial cancer. As a result, the risk of endometrial cancer increases by around six per cent for every year older a woman is at menopause. This means that a woman who goes through menopause at the age of 55 years has around a 26 per cent higher risk of endometrial cancer than a woman who goes through menopause at age 51 years.[11]
- *Never having children* — The risk of endometrial cancer is about 25 per cent lower in women who have had one child compared with those who have never had children and decreases as the number of children that a woman has increases. This means that the risk of endometrial cancer in a woman with three children is about half that of a woman who has not had children. This is because when a woman is pregnant, her usual menstrual cycle is interrupted, which reduces the length of time her body is exposed to oestrogen. Other potential factors related to pregnancy include other hormone changes during childbirth and the removal of potential cancer-causing cells from the endometrium during delivery.[12]
- *Starting periods early (before age 12)* — Early onset of menstruation can lead to longer exposure to oestrogen over a woman's lifetime, which increases the risk of

[9] Rare Cancers Australia. Endometrial (Uterine) Cancer. Rare Cancers Australia. Published 2023. Accessed July 31, 2025. https://rarecancers.org.au/knowledgebase/cancer-types/endometrial-uterine-cancer/?cancer_categories=gynaecological-cancers#risk-factors

[10] Rare Cancers Australia. Uterine Sarcoma: Risk Factors. Rare Cancers Australia. Published 2023. Accessed July 31, 2025. https://www.rarecancers.org.au/knowledgebase/cancer-types/uterine-sarcoma/#risk-factors

[11] Cancer Australia. (2022). Age at menopause, accessed at: https://www.canceraustralia.gov.au/cancer-types/endometrial-cancer/what-are-risk-factors-endometrial-cancer/reproductive-factors/age#:~:text=The%20risk%20of%20endometrial%20cancer%20increases%20by%20around,who%20goes%20through%20menopause%20at%20age%2051%20years.

[12] Cancer Australia. (2022). Having children, accessed at: https://www.canceraustralia.gov.au/cancer-types/endometrial-cancer/what-are-risk-factors-endometrial-cancer/reproductive-factors-1.

endometrial cancer. The risk of endometrial cancer increases by about two per cent for each year younger a woman is when she starts having periods. This means that the risk of endometrial cancer in a woman who has her first period at age 11 is about four per cent higher than for a woman who has her first period at age 13.[13]

The use of oral contraceptives lowers a woman's risk of endometrial cancer by at least 30 per cent, with a greater risk reduction the longer oral contraceptives are used, persisting for many years after a woman stops using oral contraceptives.[14]

Genetic factors

Some genetic factors also contribute to the risk of endometrial cancer:

- *Family history of ovarian, endometrial, or bowel cancer* — A family history of these cancers can indicate a genetic condition such as Lynch syndrome or shared lifestyle factors that might relate to hormonal imbalances or prolonged and increased oestrogen exposure such as obesity. The cumulative risk of endometrial cancer to age 70 years in women with first-degree relatives with a history of endometrial cancer is estimated to be 3.1 per cent, compared to 1.8 per cent in the general population.[15]
- *Having a genetic condition such as Cowden syndrome or Lynch syndrome* — These inherited conditions, increase the risk of endometrial cancer. These conditions are often associated with abnormal DNA repair, leading to higher endometrial cancer risk. For example, the cumulative lifetime risk of endometrial cancer to age 70 years associated with carrying a MMR mutation has been estimated as 33 per cent, compared to 1.8 per cent in the general population, and the risk can vary from 15 per cent to 71 per cent depending on the specific MMR gene mutation and genotype.[16]
- *Family history of kidney cancer* – A rare family cancer syndrome called hereditary leiomyomatosis and renal cell cancer (HLRCC) has been linked to an increased risk of uterine sarcomas.[17]

Lifestyle and medical history factors

Lifestyle factors and medical history may also play a significant role in the risk of endometrial cancer; many of these are linked to hormone-related issues, which are linked to higher levels of oestrogen, which is linked to a higher risk of uterine cancer:

- *Being overweight or obese* — Excess body fat can lead to higher oestrogen levels, as fat tissue produces oestrogen, as well as inflammation; this has been shown to increase the risk of endometrial cancer. Critically, the risk of endometrial cancer increases at a non-linear rate as body weight increases. For example:

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[13] Cancer Australia (2022). Age when periods start, accessed at: https://www.canceraustralia.gov.au/cancer-types/endometrial-cancer/what-are-risk-factors-endometrial-cancer/reproductive-factors/age-0.
[14] Michels KA, Pfeiffer RM, Brinton LA, Trabert B. Modification of the associations between duration of oral contraceptive use and ovarian, endometrial, breast, and colorectal cancers. *JAMA Oncology* 2018; 4(4):516–521.
[15] Win AK, Reece JC and Ryan S. (2015). Family history and risk of endometrial cancer: a systematic review and meta-analysis. Obstet Gynecol. 2015;125 (1):89-98.
[16] Ligtenberg MJL, Kuiper RP, Geurts van Kessel A, et al. (2013). EPCAM deletion carriers constitute a unique subgroup of Lynch syndrome patients. Fam Cancer. 2013;12 (2):169-174, summarised in Cancer Australia. (2019). Risk factors for endometrial cancer: A review of the evidence, available at: https://www.canceraustralia.gov.au/sites/default/files/migrated-files/publications/risk-factors-endometrial-cancer-review-evidence-2019/pdf/rfecr_risk_factors_for_endometrial_cancer_-_a_review_of_the_evidence_2019.pdf.
[17] American Cancer Society. (2022). Risk Factors for Uterine Sarcoma, https://www.cancer.org/cancer/types/uterine-sarcoma/causes-risks-prevention/risk-factors.html.

  - The risk of endometrial cancer for women with a BMI of 30 kg/m² is *two times greater* than women at normal weight (BMI of 20–22 kg/m²)
  - The risk of endometrial cancer for women with a BMI of 35 kg/m² is *five times greater* than women at normal weight (BMI of 20–22 kg/m²)
  - The risk of endometrial cancer for women with a BMI of 40 kg/m² is *10 times greater* than women at normal weight (BMI of 20–22 kg/m²).[18]
- *Physical inactivity* — It is estimated that six per cent of endometrial cancers are attributable to insufficient physical activity and that the risk of endometrial cancer in women who do high levels of vigorous physical activity is about 20 per cent lower than in women who are not physically active.[19]
- *Having diabetes* — Diabetes often coexists with obesity and can disrupt normal hormonal balance. It has been associated with having a higher risk of uterine cancer; the increased risk for a woman with diabetes is estimated to be 1.89 times higher than a woman without diabetes.
- *Polycystic ovary syndrome (PCOS)* — PCOS can disrupt normal hormonal balance, leading to increased exposure to oestrogen which in turn may increase the risk of endometrial cancer.
- *Using oestrogen only menopause hormone therapy (MHT) previously known as hormone replacement therapy (HRT) or fertility treatment* — Hormone replacement therapy and some fertility treatments involve the use of oestrogen, which can raise the risk of endometrial cancer, if progesterone is not also used to balance the effects of oestrogen. Indeed, systemic oestrogen hormone replacement therapy should never be used without progesterone in a woman who has not had a hysterectomy.
- *Taking tamoxifen to treat breast cancer* — Tamoxifen, a medication used to treat breast cancer, can increase the risk of endometrial cancer in post-menopausal women, as it has pro-oestrogen-like effects on the uterus and activates a cell growth signalling pathway in cells in the uterus.[20] Tamoxifen increases the risk of endometrial cancer by two to seven times that of a woman who has not been exposed to tamoxifen, and is associated with more aggressive types of endometrial cancer.[21] It can also increase the risk of uterine sarcomas though the risk is small.[22]
- *Previous radiation therapy to the pelvis* — Women who have had radiation therapy in the pelvic area for other cancers may have an increased risk of developing uterine sarcomas. This is not directly related to the body's hormonal balance and is specific to uterine sarcomas.[23]

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[18] Aune D, Sen A and Vatten LJ. (2017). Hypertension and the risk of endometrial cancer: a systematic review and meta-analysis of case-control and cohort studies. Sci Rep. 2017;7 (44808); reported in Cancer Australia. (2019). Risk factors for endometrial cancer: A review of the evidence, available at: https://www.canceraustralia.gov.au/sites/default/files/migrated-files/publications/risk-factors-endometrial-cancer-review-evidence-2019/pdf/rfecr_risk_factors_for_endometrial_cancer_-_a_review_of_the_evidence_2019.pdf.

[19] Cancer Australia (2022). Physical Activity, accessed at: https://www.canceraustralia.gov.au/cancer-types/endometrial-cancer/what-are-risk-factors-endometrial-cancer/lifestyle-factors/physical.

[20] Dana Farber Institute (2025). New research sheds light on why Tamoxifen may lead to higher risk of uterine cancer, https://www.dana-farber.org/newsroom/news-releases/2025/new-research-sheds-light-on-why-tamoxifen-may-lead-to-higher-risk-of-uterine-cancer.

[21] Emons, G., Mustea, A., & Tempfer, C. (2020). Tamoxifen and Endometrial Cancer: A Janus-Headed Drug. *Cancers*, *12*(9), 2535. https://doi.org/10.3390/cancers12092535.

[22] American Cancer Society. (2022). Risk Factors for Uterine Sarcoma, https://www.cancer.org/cancer/types/uterine-sarcoma/causes-risks-prevention/risk-factors.html.

[23] Ibid.

- *Congenital retinoblastoma (RB1 mutation)* — Women with a history of congenital (heritable) retinoblastoma, caused by mutations in the RB1 tumour suppressor gene, have an increased risk of developing uterine sarcomas; the risk increases with age and the cumulative risk for women at 50 years of age with a history of hereditary retinoblastoma has been estimated to equal 3.2 per cent.[24]
- *Ovarian tumours* — Some very rare ovarian tumours (granulosa cell tumours) can produce oestrogen and are associated with endometrial cancer.

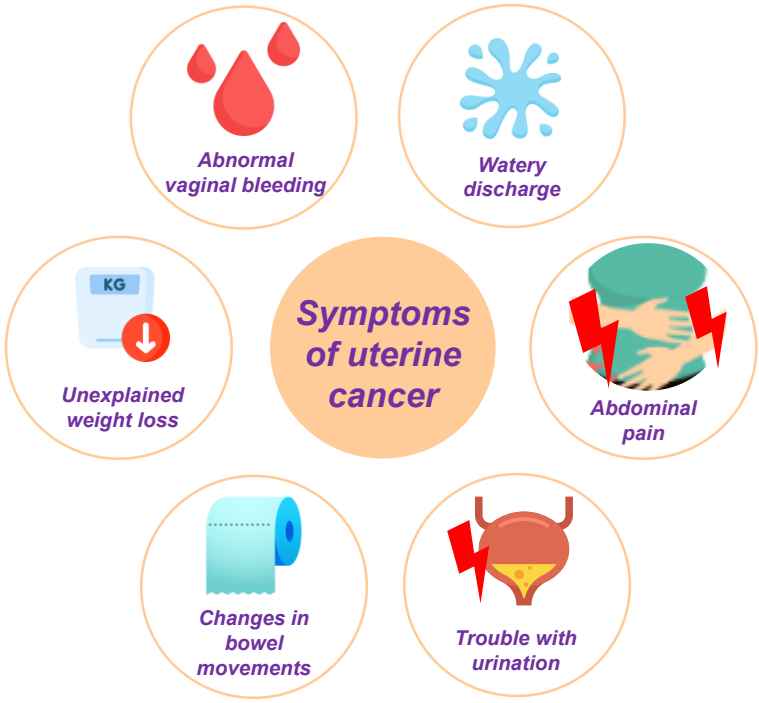
1.6 Detection and diagnosis: Key symptoms and diagnostic methods

Early signs and key symptoms

Recognising early signs of uterine cancer and seeking prompt medical care are critical for early diagnosis and improving outcomes (Figure 1.5).

One of the earliest and most common symptoms of uterine cancer is abnormal vaginal bleeding, particularly any bleeding that occurs after menopause (post-menopausal bleeding), when periods have already stopped. For women who have not yet reached menopause, warning signs may include heavier-than-usual periods, changes in the menstrual cycle, or bleeding between periods. Some may also notice periods that continue without a break, which can signal an underlying problem.

Figure 1.5: Symptoms of uterine cancer



Source: Insight Economics, based on symptoms identified by Cancer Australia.

While bleeding changes are the most frequent signs, other symptoms can develop as the disease progresses, including unexplained weight loss, difficulty urinating, pain on urination, changes in bowel habits, persistent abdominal, and pelvic pain. These symptoms

[24] Francis JH, Kleinerman RA, Seddon JM, Abramson DH. Increased risk of secondary uterine leiomyosarcoma in hereditary retinoblastoma. Gynecologic Oncology. 2012 Feb;124(2):254-259. DOI: 10.1016/j.ygyno.2011.10.019. PMID: 22027510; PMCID: PMC3264733.

are less common but can suggest more advanced disease and should not be ignored.[25] It is important to note that while these symptoms can suggest early-stage disease, they may also appear with more advanced cancers or even be caused by conditions other than cancer.

Diagnostic methods

After a patient presents with symptoms, a doctor typically begins by gathering a thorough medical history and performing a physical and pelvic examination. If initial findings suggest the possibility of uterine cancer, the doctor may recommend a series of diagnostic tests, usually beginning with non-invasive methods and progressing to more targeted procedures if needed.

The first-line assessments usually include:

- *Pelvic examination* — To examine the abdomen for any abnormalities or perform a pelvic exam to check for uterine swelling
- *Pap smear* — Although primarily a cervical cancer screening tool, it may occasionally detect abnormal glandular cells suggestive of uterine cancer
- *Transvaginal ultrasound (TVUS)* — This is often the first imaging test used. The non-invasive scan uses soundwaves to evaluate the thickness of the uterine lining (endometrium) and to identify any masses.

If initial tests raise suspicion of uterine cancer or if symptoms persist, the next major step is to obtain a tissue sample to confirm the diagnosis:

- *Endometrial biopsy (pipelle)* — The most used diagnostic test for uterine cancer. A thin tube is inserted through the cervix to collect a sample from the uterine lining to examine for cancerous changes. This minimally invasive procedure is typically done in a clinical setting with minimal discomfort. However, in some cases this may not be easily done in a clinic, and therefore a hysteroscopy (which is where a small camera is inserted into a woman's cervix) ± dilatation and curettage (surgical scraping) may be recommended.
- *Hysteroscopy ± Dilation and Curettage (D&C)* — If the biopsy is inconclusive, or if a more detailed examination is needed, the doctor may recommend a hysteroscopy, which is done under anaesthetic. This involves inserting a thin, lighted camera (hysteroscope) through the vagina and cervix into the uterus to directly visualise the uterine cavity. If necessary, tissue samples can be collected at the same time through dilation and curettage (D&C), where the cervix is gently dilated, and tissue is removed using a sharp instrument curette) or a suction device.

Once the uterine cancer is confirmed, a patient should be referred to a gynaecological oncologist, with reference to a multi-disciplinary team, for management of their cancer. In Australia, referral is the standard of care; in Aotearoa New Zealand, further triaging is undertaken to determine whether a patient is referred to a gynaecological oncologist.

Further imaging is then undertaken to help determine the extent of the disease and treatment needed:

- *MRI* — Imaging for detailed view of the uterus and surrounding tissues (required in some but not all cases such as fertility sparing treatment or to triage access to a gynaecological oncologist in Aotearoa New Zealand)

[25] Cancer Council Australia. (n.d.). *Uterine cancer signs and symptoms*. https://www.cancer.org.au/cancer-information/types-of-cancer/uterine-cancer.

- *CT scan* — Preferred test to rule out metastatic disease and preferentially done prior to surgery
- *PET scan* — Sometimes used in more advanced cases to detect distant metastases (there is no government reimbursement for PET scans for endometrial cancer, although it is reimbursed for uterine sarcomas).

If the biopsy of the D&C sample confirms uterine cancer, then women usually proceed to a hysterectomy, which is usually performed by a gynae-oncologist as discussed in Section 1.7. In some cases, the removal of other areas, such as both ovaries and fallopian tubes, is recommended.

Following tissue collection, detailed laboratory analysis becomes critical. Traditionally, uterine cancer diagnosis relies heavily on histopathology, where tissue samples are examined under a microscope by a pathologist. However, advances in cancer biology have shown that endometrial cancers are heterogeneous, and their behaviour cannot always be predicted by microscopic appearance alone. Therefore, molecular subtyping has also emerged as a vital component to the diagnosis and treatment of endometrial cancers and is recommended for all cases in international guidelines.

For instance, genomic sequencing to detect specific mutations like *POLE* is required. This is currently not reimbursed for funding in Australia, although an application for assessment of this has been submitted to MSAC. Currently, *POLE* mutation is only available to women if they can self-fund or if they attend a small number of academic units across Australia.

By classifying endometrial cancers at a molecular level, clinicians can better predict how a tumour is likely to behave and avoid misclassifying cancers that may appear similar under the microscope but act differently in the body. This helps reduce the risk of both undertreatment and overtreatment.

Ultimately, molecular profiling is paving the way for more personalised medicine where treatment decisions are tailored to the specific characteristics of an individual's cancer, rather than a one-size-fits-all approach.

Histopathology combined with molecular profiling allows clinicians to classify tumours more precisely. Through histopathology, several important features are determined which allows the appropriate classification of the uterine cancer:

- Grading describes how abnormal the cancer cells appear compared to normal uterine cells. Low grade endometroid tumours tend to grow more slowly and are less likely to spread, while high grade tumours are faster-growing and more likely to spread. Non-endometroid types of endometrial cancer such as serous, clear cell or carcinosarcoma are generally high-grade tumours.
- Immunohistochemistry testing of the cancer specimen is also performed to help determine the molecular subtype of the cancer (Section 1.6); specifically:
  - Mismatch repair expression to determine if the tumour is mismatch deficient or proficient. Women whose tumours are mismatch repair deficient need further assessment to determine if this is due to Lynch syndrome.
  - Oestrogen and progesterone expression.
  - P53 expression.[26]

[26] The mutational status of TP53 is the single most important molecular factor, which predicts prognosis in endometrial carcinomas, with the presence of a TP53 mutation being associated with an unfavorable outcome. See Köbel, M., Ronnett, B. M., Singh, N., Soslow, R. A., Gilks, C. B., & McCluggage, W. G. (2019). Interpretation of P53 Immunohistochemistry in

- Staging assesses how far the cancer has spread, both within the uterus and beyond. Staging is informed by imaging, surgical findings, and microscopic evaluations.
  - *Stage I (early or localised cancer)* — the cancer is found only in the uterus and does not have the relevant molecular or histopathological features to be categorised as Stage II.
  - *Stage II (regionalised cancer)* — the cancer has spread from the uterus to the cervix, but not beyond the uterus, or is confined to the uterus, but has the histopathological or molecular features to be categorised as Stage II.
  - *Stage III (regionalised cancer)* — the cancer has spread beyond the uterus and cervix to the ovaries, fallopian tubes, vagina, or regional lymph nodes in the pelvis or the abdomen.
  - *Stage IV (distant or metastatic cancer)* — the cancer has spread to distant organs such as the bladder, bowel, rectum, throughout the abdomen, or to other body parts such as lungs, bones, or distant lymph nodes in the groin.

  Unlike some other gynaecological cancers, most uterine cancers are detected at an early stage. While data are limited, Cancer Alliance Queensland and Cancer Institute NSW data show that an estimated 64 per cent and 71 per cent of all uterine cancers are diagnosed at Stage I, with a further 23 per cent detected at Stage II and 12 per cent at Stages III or IV.[27]

In summary, the diagnosis of uterine cancer progresses from initial clinical assessment to tissue diagnosis via biopsy or D&C, followed by histopathological and molecular analysis, culminating in staging to inform treatment.

1.7 How is uterine cancer treated?

Treatment for uterine cancer is tailored to each woman's cancer type, stage, overall health, and personal treatment goals. A multidisciplinary approach is essential, bringing together gynaecological oncologists, radiation and medical oncologists, nurses, genetic counsellors, GPs, pathologists, radiologists, psychologists and allied health professionals. This team works together to deliver coordinated medical care and support services throughout the cancer journey—from diagnosis through to survivorship.

Treatment options for uterine cancer by stage at diagnosis

The choice of treatment depends heavily on how far the cancer has spread and the tumour's characteristics (Figure 1.6) For early-stage (Stage I) disease, surgery is typically the first line of treatment. This usually involves a total hysterectomy (removal of the uterus), often along with the ovaries and fallopian tubes (bilateral salpingo-oophorectomy). In low-grade, early-stage uterine cancers, surgery alone may be curative, and no further treatment may be required. This is particularly the case for NSMP and *POLE* tumours.

Biopsies of the lymph nodes, called Sentinel Lymph Node Biopsy (SLNB), may also be performed to support staging. SLNB is increasingly employed to avoid the removal (dissection) of many lymph nodes, in order to reduce the risks of complications like lymphoedema (swelling in the body due to a build-up of lymphatic fluid). However, a node

Endometrial Carcinomas: Toward Increased Reproducibility. *International journal of gynecological pathology: official journal of the International Society of Gynecological Pathologists*, *38 Suppl 1*(Iss 1 Suppl 1), S123–S131. https://doi.org/10.1097/PGP.0000000000000488.

[27] See for example, Cancer Institute NSW. (2025). Detailed statistics: Cancer incidence and mortality, accessed at: https://www.cancer.nsw.gov.au/research-and-data/cancer-data-and-statistics/data-available-now/cancer-statistics-nsw/cancer-incidence-mortality-survival/detailed-cancer-incidence-mortality.Queensland and Cancer Alliance Queensland. (2025). Queensland Uterine Cancer Quality Index, Characteristics by stage at diagnosis, accessed at: https://canceralliancegld.health.qld.gov.au/reports/Uterine2024PublicWebsite-UterineReport2024/#tab3.

dissection might still be needed if the sentinel nodes are impacted. The gynae-oncologist would also remove any other areas of cancer within the abdomen if safe to do so.

For selected women, particularly younger patients who wish to preserve fertility, conservative (non-surgical) management using hormonal therapy may be considered, following thorough evaluation by a multidisciplinary team. This would only be recommended for early low-grade tumours with oestrogen expression.

While many Stage I patients will require surgery alone, additional treatments may be recommended in some cases, depending on individual risk factors. For example, adjuvant radiation therapy may be considered in certain intermediate- or high-risk cases to reduce the risk of local recurrence, but this is used increasingly selectively — especially for women with low-risk molecular subtypes, in whom overtreatment is a concern. Stage I patients with high-risk features, such as p53-mutant tumours, are now also recommended to receive chemotherapy, reflecting the more aggressive nature of these cancers.

For cancers that have spread regionally (Stage II or III), follow-up treatment called 'adjuvant therapy' may be recommended after surgery. This may include radiation therapy, which uses targeted X-rays to destroy remaining cancer cells and reduce the risk of local recurrence of cancer in the pelvis. In many cases, chemotherapy is also used—these are drugs that circulate through the body to kill cancer cells, which can be particularly useful for P53 mutant or more aggressive tumours.

In cases where the cancer is advanced or metastatic (Stage IV), treatment becomes more complex and systemic (affecting the whole body). Chemotherapy or hormone therapy (using high dose progestins to block the cancer's ability to grow) may be used to try and shrink the cancer and slow further disease progression. Immunotherapy treatment may also be used together with chemotherapy in the first-line treatment of advanced dMMR tumours. Radiotherapy may be used to treat areas of disease causing a local problem, such as pain from a deposit in a bone. However, not all therapies will be used in every patient.

As outlined in Section 1.6, the results of diagnostic tests play a vital role in guiding treatment choices. These include imaging scans like MRIs or CTs, lab tests, and a closer look at the tumour under the microscope. Molecular profiling is essential to guide these decisions, enabling more personalised treatment. This deeper understanding of tumour biology helps avoid over- or under-treatment and supports more precise, effective care.

Importantly, not all women have equal access to high-quality, individualised care. Variations in hysterectomy rates across Australia may reflect differences in access to early diagnosis, fertility preservation, or specialist care. In some areas, limited availability of advanced diagnostics or multidisciplinary teams may lead to more radical surgery or delayed treatment. This unwarranted variation in treatment is discussed in greater detail in Chapter 3. Addressing these disparities—by improving access to timely diagnosis, specialist input, and supportive services—is key to ensuring equitable care for all women.

Further details on treatment options by molecular subtype are provided in Chapter 4. For example, patients with *POLE* mutations may avoid aggressive adjuvant therapy due to favourable outcomes, while those with dMMR cancers respond well to immune checkpoint inhibitors like pembrolizumab and dostarlimab. Women with copy number low tumours may benefit from radiotherapy, chemotherapy, and emerging targeted therapies, including hormonal treatments. Patients with p53-high tumours often require more aggressive therapy, with PARP inhibitors and HER2-targeted agents being novel treatments still under investigation.

Supportive care across the treatment journey

High-quality care for uterine cancer goes beyond treating the tumour—it means supporting the whole person at every stage. From diagnosis through treatment and into recovery, a

multidisciplinary team—including oncologists, surgeons, nurses, GPs, allied health professionals, and supportive care providers—works together to provide personalised, compassionate care tailored to each woman's needs. Figure 1.7 provides a summary of key types of supportive care a woman may need from diagnosis and following treatment.

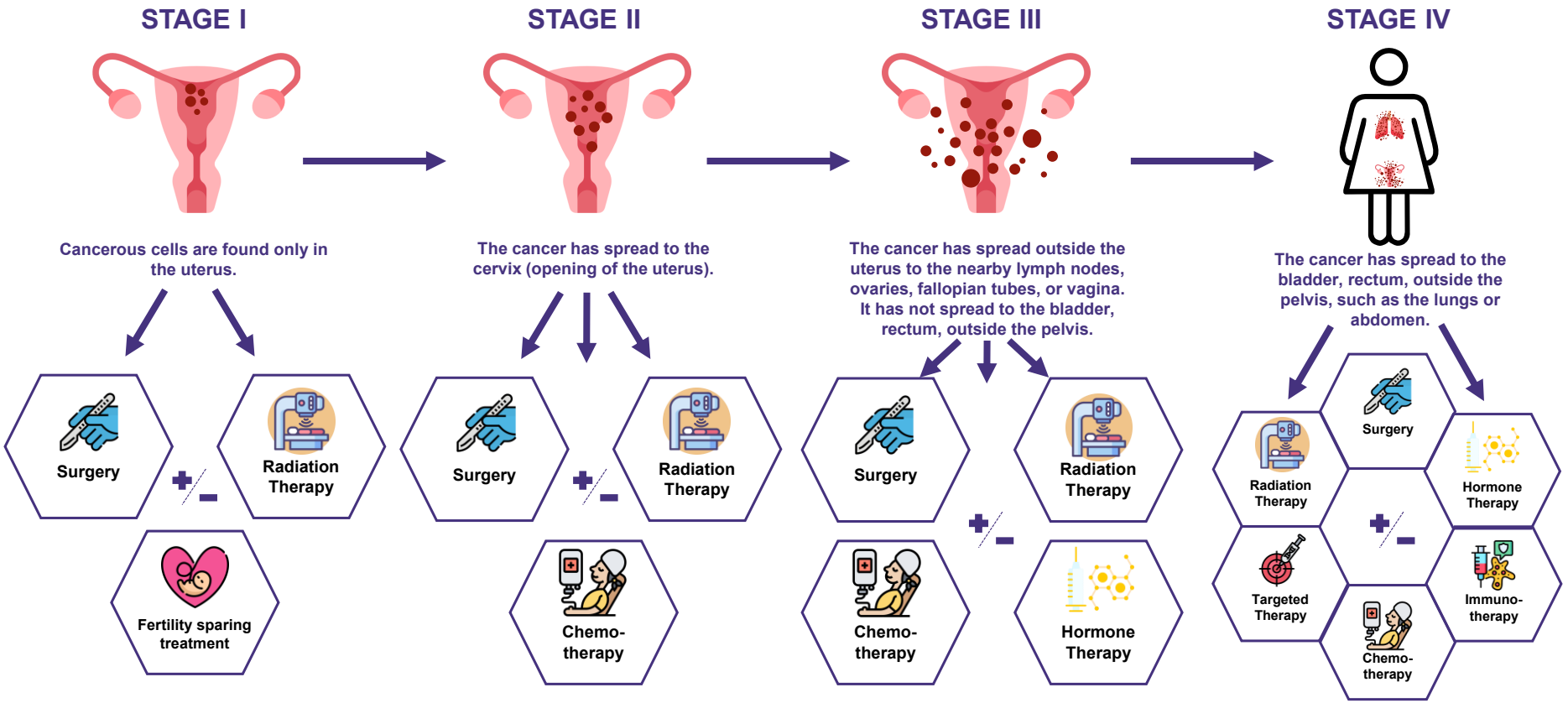
Before treatment begins, supportive care may focus on prehabilitation—helping patients prepare both physically and emotionally, which is critical in the context of women with pre-morbid health conditions such as obesity. In practice, stakeholders indicated this often happens infrequently. Prehabilitation may involve exercise plans, nutritional advice, financial counselling, peer, psychological, and social worker support, which can improve treatment tolerance and aid recovery.

During active treatment, managing side effects is critical to maintaining wellbeing. Women may experience fatigue, pain, lymphoedema, nausea, or emotional distress. Allied health professionals—including physiotherapists, dietitians, psychologists, pain specialists, and social workers—support patients in coping with these challenges and maintaining their quality of life. Practical supports, such as transport assistance and childcare services, are also important—especially for women juggling treatment with family responsibilities. Throughout this phase, the care team closely monitors how well the treatment is working through regular check-ups, blood tests, imaging scans, and discussions about symptoms and side effects, adjusting as needed. For those with advanced cancer where cure is not possible, palliative care plays a crucial role—offering comfort, symptom relief, and emotional support to help maintain dignity and quality of life.

After treatment ends, the focus shifts to recovery, surveillance, and survivorship care. If cancer returns, further treatments like surgery, radiation, or systemic therapies may be considered, depending on the individual case.

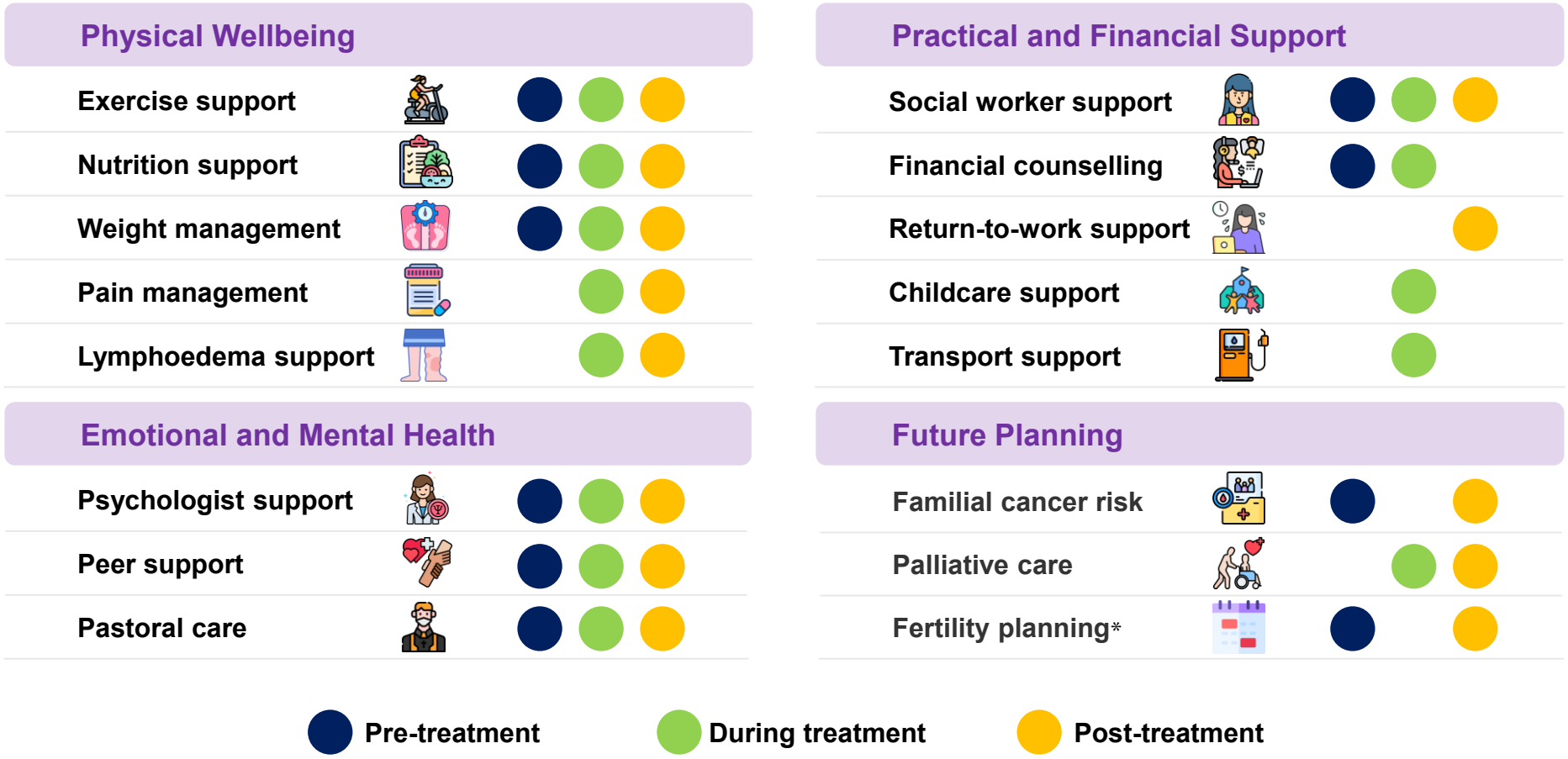
This phase also brings a range of physical, emotional, and practical needs. Survivors may need support with fertility, sexual health, return to work, financial issues, and emotional wellbeing. Services such as counselling, peer support, transport assistance, and childcare can help ease the transition back to everyday life. For women with hereditary cancer syndromes, family risk assessment and genetic counselling are also important.

Figure 1.6: Treatment options for uterine cancer by cancer stage



Source: Insight Economics.

Figure 1.7: Ideal emotional, sexual and mental health care for uterine cancer patients at different treatment phases



* In select cases where fertility preservation is desired and clinically appropriate.

Source: Insight Economics.

Chapter 2

The rising and inequitable tide of uterine cancer and its burden to the economy

This chapter explores the rapid growth in incidence and mortality in uterine cancer including the reasons for the rapid growth, and the populations who are particularly affected, such as younger women and Indigenous populations.

It also outlines the significant and increasing health and economic costs of the disease, underscoring the need for improved understanding of the disease and action by Australian and Aotearoa New Zealand communities and policy makers to prevent the loss of Australian and Aotearoa New Zealand women.

2.1 Increasing incidence, especially among younger women

Once considered a disease of older women, uterine cancer is now being diagnosed in younger populations, reflecting broader shifts in demographics, lifestyle and risk factors.

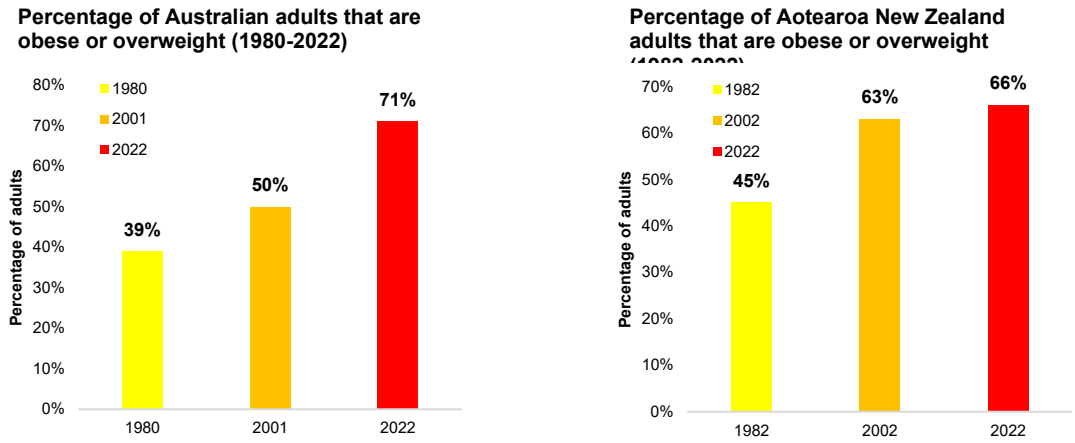
Over the past two decades, the global incidence of uterine cancer increased by 132 per cent, and this trend is expected to accelerate, with an additional 148 per cent increase projected by 2044.[28] This means that in one generation, from 2004 to 2044, incidence will have increased 280 per cent globally.

In Australia and Aotearoa New Zealand incidence is rising at a similar rate. The incidence of uterine cancer in Australia rose by 16 per cent from 2019 to 2024 alone, according to data from the Australian Institute of Health and Welfare.[29] In Aotearoa New Zealand, the incidence is estimated to have grown even faster: by 20.3 per cent over the same horizon.[30]

While there are many risks for uterine cancer, the rapid rise observed in Australia and Aotearoa New Zealand is likely the product of the increasing prevalence of obesity in the community. In Australia, the share of adults who are overweight or obese has nearly doubled since 1980, while in Aotearoa New Zealand, the proportion of adults with 'overweight or obesity' increased from 45 per cent in 1982 to 66 per cent in 2022 (Figure 2.1).

[28] Yang, L., et al. (2023). Time trend of global uterine cancer burden: an age-period-cohort analysis from 1990 to 2019 and predictions in a 25-year period, doi: 10.1186/s12905-023-02535-5.
[29] AIHW. (2025). Cancer Data in Australia.
[30] Health Aotearoa New Zealand (Te Whatu Ora) Cancer Data Statistics, Cancer Data Web Tool.

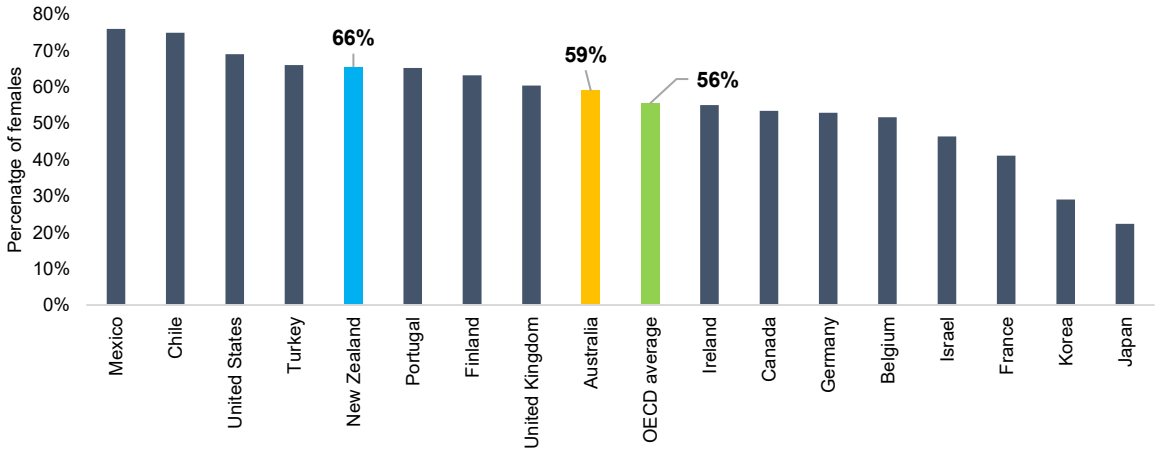
Figure 2.1: Increasing rates of obesity in adults in Australia and Aotearoa New Zealand



Source: AIHW. (2024). Overweight or obesity tables, 2022 data (latest data); AIHW. (2001). A growing problem: trends and patterns in overweight and obesity among adults in Australia, 1980 to 2001; Health New Zealand (Te Whatu Ora). (2025). Obesity data and statistics, Aotearoa New Zealand Health Survey.

Among *females* specifically, both Australia and Aotearoa New Zealand now report overweight and obesity rates above the OECD average (Figure 2.2).

Figure 2.2: Percentage of Australian and Aotearoa New Zealand females that are obese or overweight relative to OECD peers (2024)

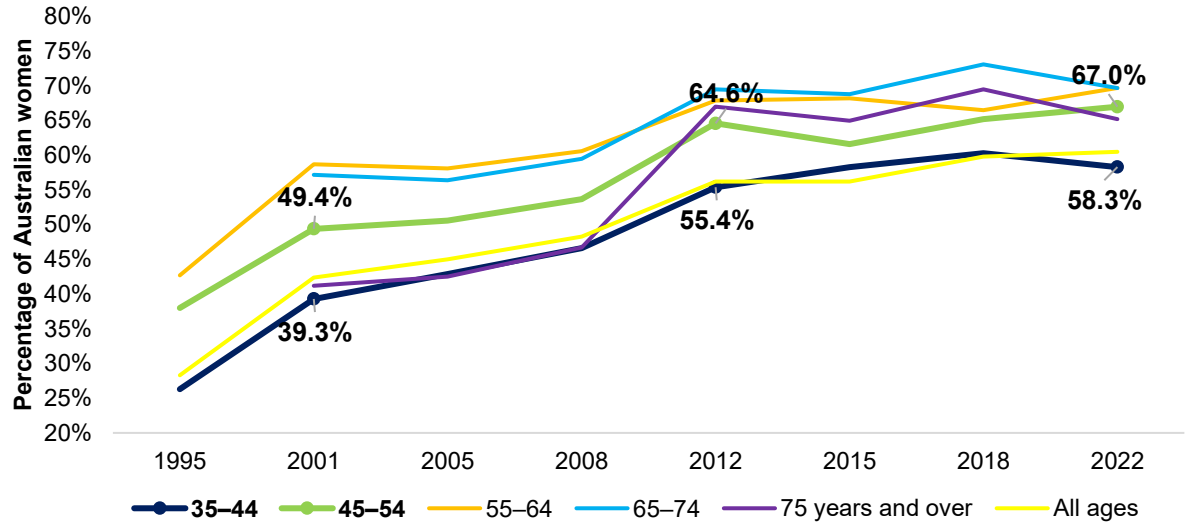


Source: AIHW. (2024). Overweight or obesity tables, 2022 data (latest data).

Additionally, more women are experiencing higher body weight at *younger ages*.

In 2001, 49.4 per cent of Australian women aged 45-54 were overweight or obese. By 2022, this rose to 67.0 per cent (Figure 2.3). Similar increases are seen in women aged 35-44, suggesting that higher BMI is now being established earlier in life. Similar trends are evident in Aotearoa New Zealand, where younger generations are experiencing earlier and more widespread obesity. This shift presents a growing public health challenge, particularly regarding the increased risk of uterine cancer.

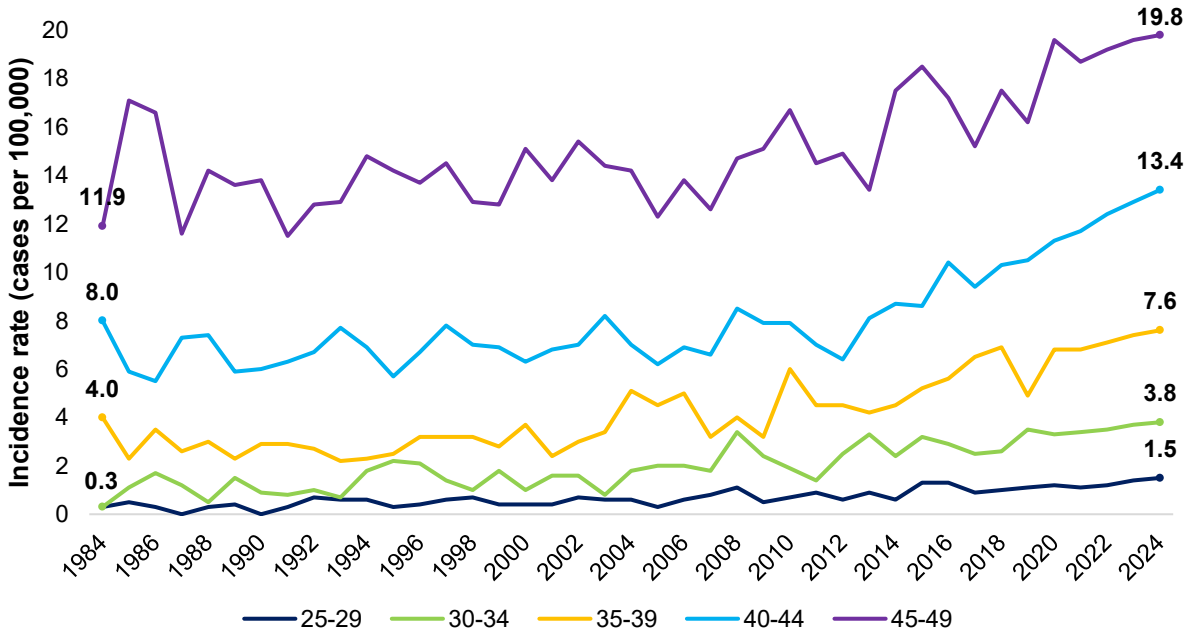
Figure 2.3: Rising obesity and overweight proportions among young Australian women, 1995-2022



Source: Australian Government, National Health Survey 1990, 2001, 2005, 2008, 2012, 2015, 2018, and 2022 (health.gov.au).

As a result, while uterine cancer remains most common in women around the age of 65, rates among younger women are rising sharply. According to the AIHW, the incidence rate among Australian women aged 40-44 has nearly doubled—from 8.0 cases per 100,000 in 1984 to 13.4 in 2024. Similarly, among women aged 35-39, the rate has nearly doubled over the same period as well, climbing from 4.0 to 7.6 cases per 100,000 (Figure 2.4).

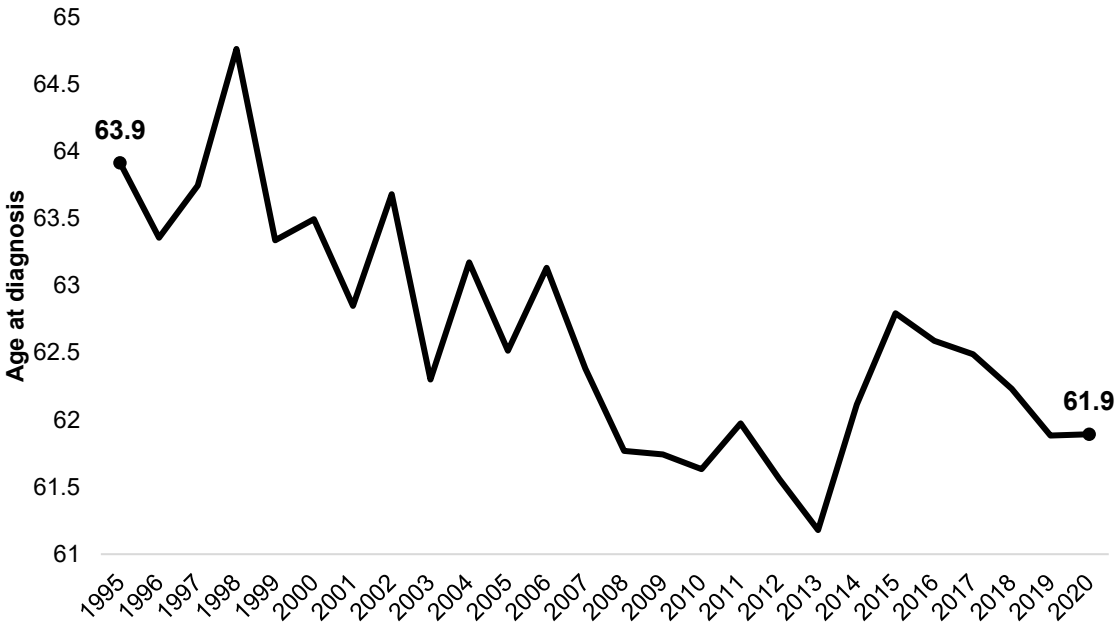
Figure 2.4: Increasing uterine cancer incidence in younger Australian women, 1984-2024



Source: AIHW, Cancer data in Australia 2024, https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/data.

Similar patterns are emerging in Aotearoa New Zealand, where the median age at diagnosis for uterine cancer has dropped from 63.9 years in 1995 to 61.9 years in 2020 as women are increasingly diagnosed with uterine cancer at a younger age (Figure 2.5).

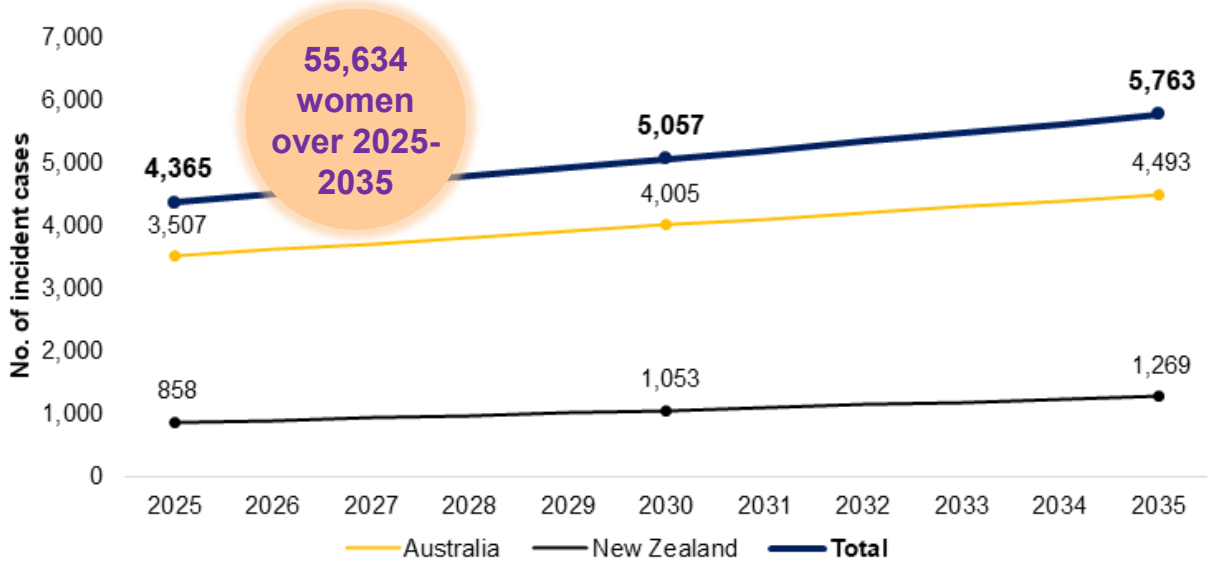
Figure 2.5: Median age at uterine cancer diagnosis among Aotearoa New Zealand women, 1995-2020



Source: Health NZ.

If current trends continue, the number of women diagnosed with uterine cancer will increase significantly (Figure 2.6). Between 2025 and 2035, over 44,000 Australian women are projected to be diagnosed with the disease, along with more than 11,500 women in Aotearoa New Zealand. This growing incidence, especially among younger cohorts, is expected to drive an increase in the number of deaths.

Figure 2.6: Projected uterine cancer incidence in Australia and Aotearoa New Zealand, 2025-2035

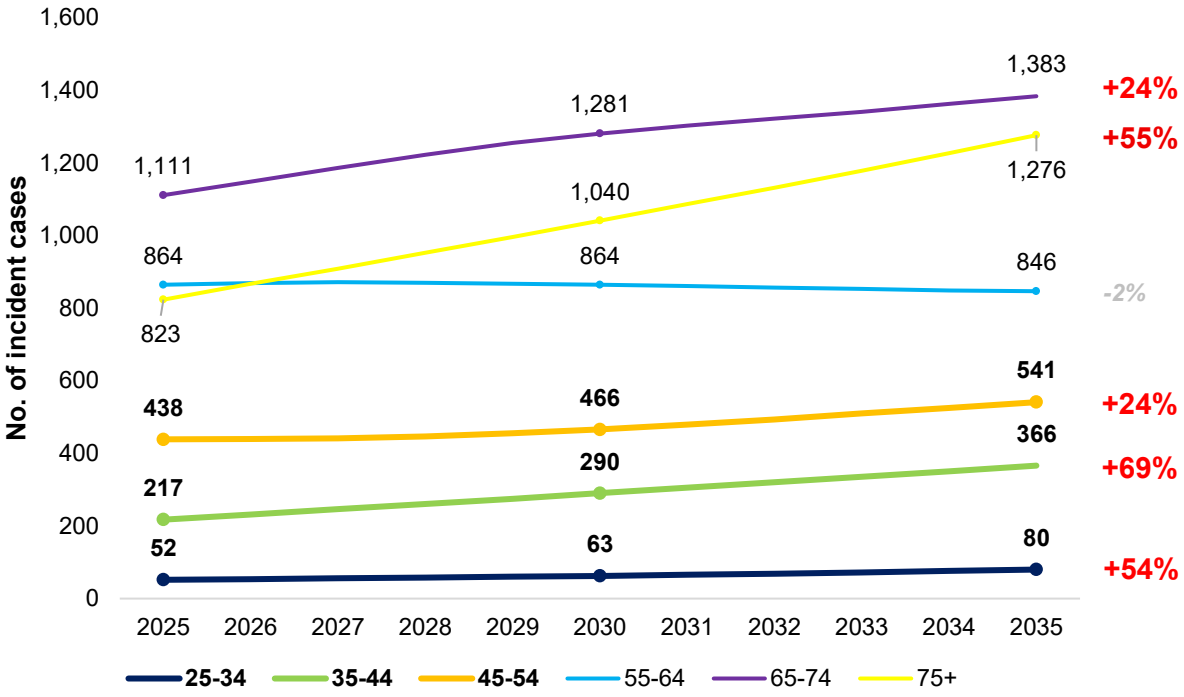


Source: Insight Economics projections. See Appendix A for more details.

In Australia, the incidence is expected to grow fastest among younger age groups over the 2025-2035 period (Figure 2.7). Among women aged 25-34, cases are projected to rise from 52 in 2025 to 80 in 2035—a 54 per cent increase. In the 35-44 age group, cases are expected to climb from 217 to 366, a 68 per cent increase. For women aged 45-54 and 55-64, more

modest growth is projected, with both groups seeing around a 24 per cent increase over the same period.

Figure 2.7: Projected uterine cancer incidence in young Australian women, 2025-2035



Source: Insight Economics projections. See Appendix A for more details.

While uterine cancer has relatively high survival compared to other gynaecological cancers, the number of women who die from uterine cancer has increased in recent years. Without corresponding gains in early detection or treatment, the rising number of cases will translate directly into a continue rise in the number of deaths.

2.2 Increasing deaths—not only due to more cases, but stagnating survival outcomes from systemic gaps in prevention, detection and treatment

The number of women diagnosed with uterine cancer has increased steadily over the past two decades across Australia and Aotearoa New Zealand, and so too has the number of deaths. In Australia, uterine cancer deaths rose from 639 in 2019 to 693 in 2024, a 15.5 per cent increase. A similar upward trend is expected in Aotearoa New Zealand.

This rising death toll reflects population growth and increasing incidence, as well as a deeper and more systemic challenge: the lack of progress in improving survival outcomes. While mortality rates have declined for other major cancers such as breast and cervical cancer—thanks to early detection and advances in personalised treatment—survival in uterine cancer has remained largely stagnant.

In 2014–2018, individuals diagnosed with uterine cancer had an 83 per cent chance of surviving for five years compared to their counterparts in the general Australian population. Between 1989–1993 and 2014–2018, five-year relative survival for uterine cancer is reported to have improved from 78 per cent to 83 per cent.[31] However, despite the reported

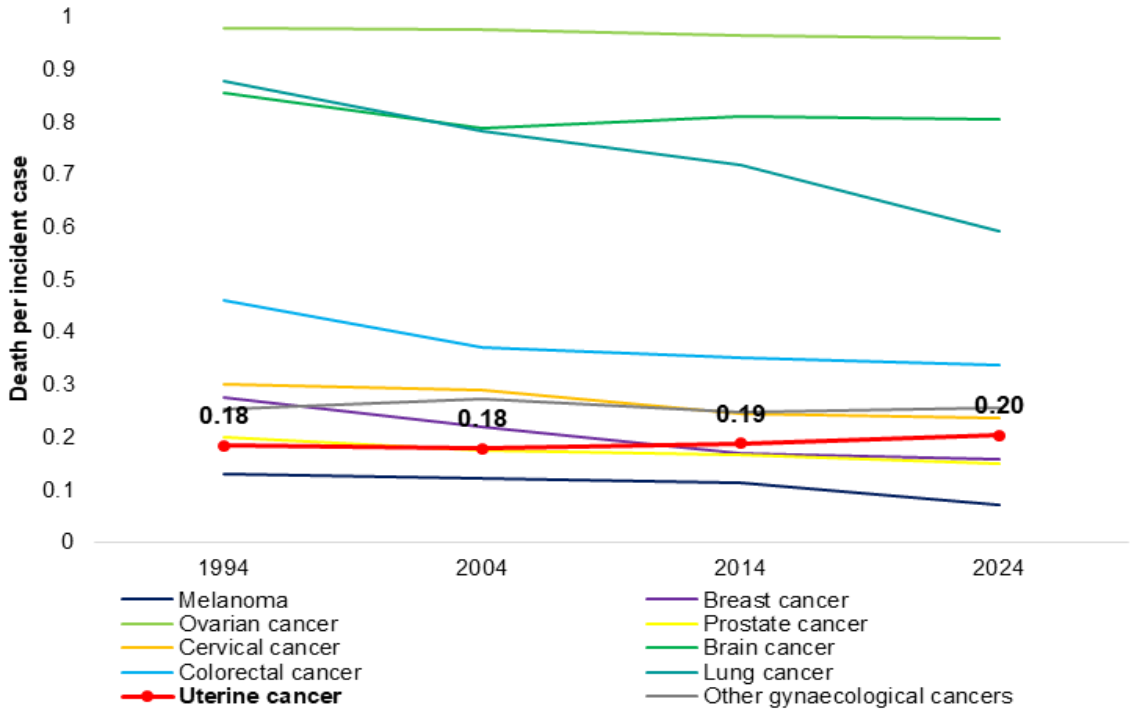
[31] Cancer Australia. Uterine cancer statistics. Cancer Australia. Published January 17, 2025. Accessed July 31, 2025. https://www.canceraustralia.gov.au/cancer-types/endometrial-cancer/uterine-cancer-statistics#survival.

improvement in relative survival, this has not translated into fewer deaths per incident case observed. Deaths per incident case has, in fact, increased.

As shown in Figure 2.8, the number of uterine cancer deaths per incident case rose steadily every decade from 0.18 deaths per incident case in 1994 to reach 0.20 deaths per incident case in 2024 – the only major cancer that has seen an increase in deaths per incident case over the same period. This pattern is also observed for early onset cancers in particular, with uterine cancer, pancreatic and testicular cancer identified as the only three cancers where early onset incidence and mortality are increasing.[32]

In fact, Gregory et al. (2022) pointed out that between 2001 and 2018, endometrial (uterine) cancer was the only gynaecological cancer where the number of deaths increased rather than decreased.[33]

Figure 2.8: Worsening survival in uterine cancer compared to other major and gynaecological cancers in Australia, 1984-2024: rising deaths per incident case

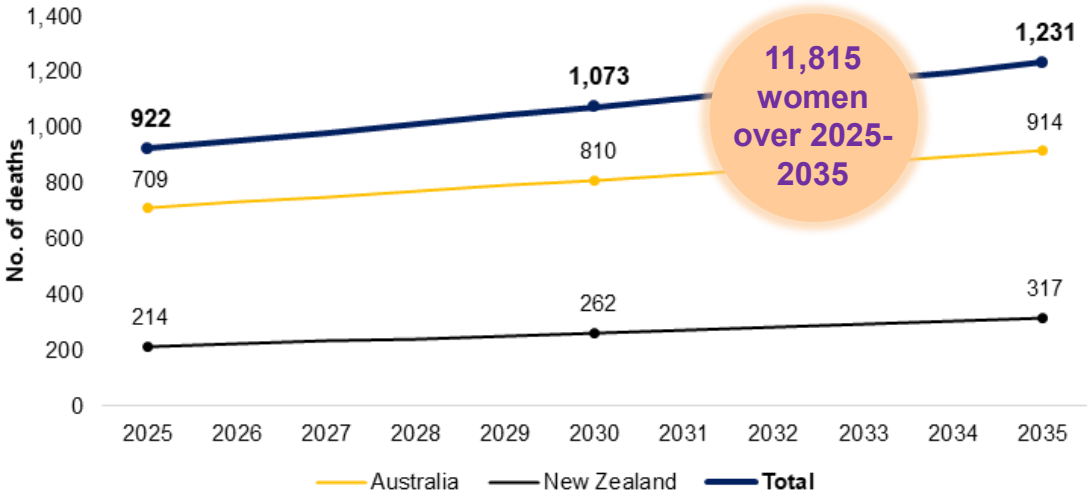


Source: AIHW, Cancer data in Australia 2024, https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/data.

If the current trend continues, the number of women that will lose their lives to uterine cancer will increase significantly. Sadly, more than 11,800 women are projected to die from the disease over the 2025-2035 period (Figure 2.9). Importantly, these mortality projections are conservative; obesity rates are assumed to remain stable across age groups, and the impact of other emerging risk factors is not accounted for. If current trends in overweight and obesity continue to worsen, and additional risk factors persist or intensify, the number of deaths could be even higher than forecasted (see Appendix A).

[32] Shiels, M.S., et al. (2025). Trends in Cancer Incidence and Mortality Rates in Early-Onset and Older-Onset Age Groups in the United States, 2010–2019. *Cancer Discov* 2025; https://doi.org/10.1158/2159-8290.CD-24-1678.
[33] Gregory, J., et al. (2022). The socioeconomic gradient in mortality from ovarian, cervical, and endometrial cancer in Australian women, 2001–2018: A population-based study. Australian and Aotearoa New Zealand Journal of Obstetrics and Gynaecology, 62(6), 714–719. https://doi.org/10.1111/ajo.13553.

Figure 2.9: Projected uterine cancer deaths in Australia and Aotearoa New Zealand, 2025-2035



Source: Insight Economics projections. See Appendix A for more details.

2.3 The hidden and rising health, economic and social costs to women, their families, governments and communities

Uterine cancer does not just affect the woman diagnosed; it also touches every part of her family and the wider community.

While the costs of hospital treatment and medical interventions are the most visible costs of the disease, they are estimated to account for only part of the total cost of the disease. The total costs of uterine cancer include not only direct healthcare costs but also the impacts on a woman's capacity to participate in the workforce, the costs of premature death and years lived with a disability and the wider psychosocial impacts on her family. As the incidence of uterine cancer is expected to grow, so too are these costs, which include (see Appendix A for detailed assumptions):

- *Direct healthcare costs* — As detailed in Chapter 2, a range of services and therapies are potentially involved in the diagnosis and treatment of uterine cancer, including pathology, imaging, surgery, systemic therapies, radiation, hormonal therapies and palliative care. In 2025, the direct cost of uterine cancer treatment to hospitals alone were estimated to be $0.2 billion. As the number of women diagnosed grows, so too will these healthcare costs. Between 2025 and 2035, public and private hospital systems are projected to spend $2.4 billion in Net Present Value $(NPV)_{7\%}$ terms[34], with annual costs climbing from $220 million in 2025 to more than $410 million in 2035—an 87 per cent increase.[35]
- *Impact on workforce participation* — For many women, a uterine cancer diagnosis disrupts their ability to work through time away from employment, reduced hours, or presenteeism (where they are at work but less productive due to treatment side-effects). Some may need carers, meaning that in 2025 alone, over 1,300 additional people will need to step back from work or be less productive as carers. Together these effects are estimated to result in $0.9 billion in lost productivity across Australia and Aotearoa New Zealand in 2025, rising to $1.6 billion by 2035, a 70 per

[34] NPV stands for net present value. It is a tool to represent the value of future benefits and costs in today's dollar terms, reflecting the time value of money. The social discount rate applied is 7 per cent, consistent with government guidance for discount rates in cost benefit analyses.
[35] All costs reported for individual years over the 2025-2035 period are expressed in 2025 dollars. Cumulative costs are presented in net present value (NPV) terms, discounted at 7 per cent, also in 2025 dollars.

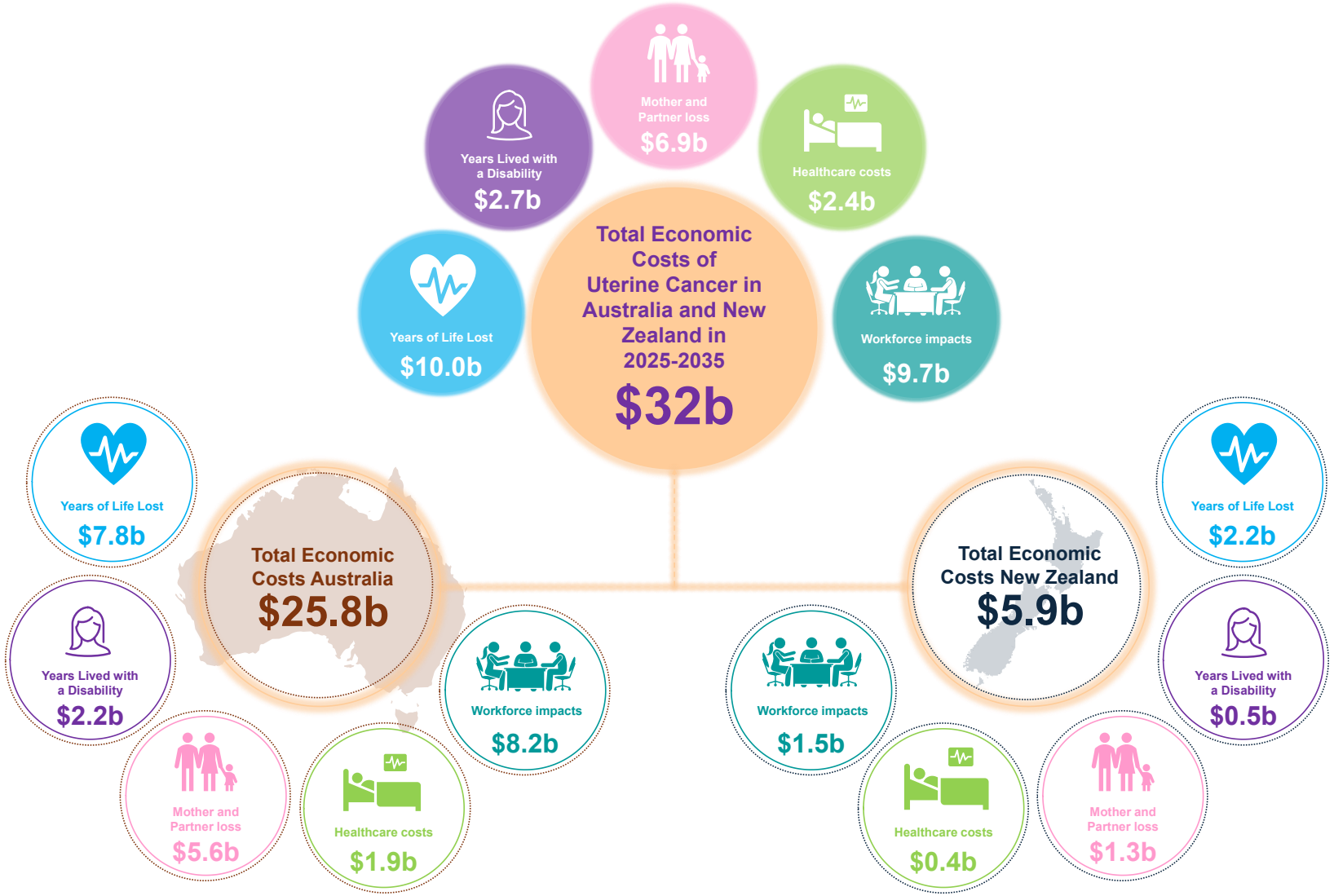
cent increase. In $NPV_{7\%}$ terms, these costs are estimated to total $9.7 billion over the 2025-2035 horizon.

- *Premature death and years lived with a disability* — In addition to financial costs, significant health costs arising from premature death and the loss of healthy years of life also add a significant cost to women and the wider community. The economic value of this burden is projected to be $1.2 billion. Losses from premature death (YLL) and time lived with disability (YLD) are expected to rise from $1.2 billion in 2025 to $2.2 billion in 2035, an 87 per cent increase. In $NPV_{7\%}$ terms, these costs are estimated to total $12.7 billion over the 2025-2035 horizon.
- *Psychosocial impacts on women of the loss of fertility* — While difficult to quantify in economic terms, this is important as younger women are increasingly being diagnosed with uterine cancer and many consequently lose the ability to have children.
- *Psychosocial impacts on families* — Families, too, suffer in profound and lasting ways. In 2025 alone, over 11,000 additional partners and children are expected to experience depression linked to a woman's diagnosis. The mental health toll is projected to cost the economy $6.9 billion (in $NPV_{7\%}$ terms) over the decade, with annual costs growing from $640.5 million in 2025 to $1.2 billion in 2035, an 88 per cent increase.

Taken together, the full economic impact is estimated to be $3.0 billion in 2025, growing to $5.4 billion by 2035. Over the 2025-2035 period, the economic and social toll of uterine cancer across Australia and Aotearoa New Zealand is projected to accumulate to a total of $32 billion in $NPV_{7\%}$ terms, highlighting the urgent need for a stronger, more coordinated response (Figure 2.11).

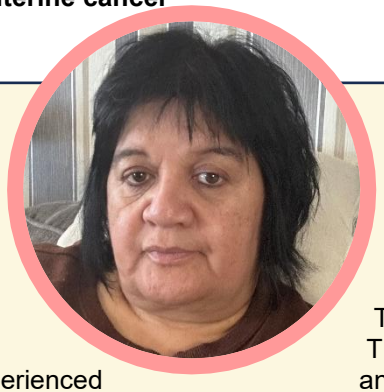
While these data help illuminate the numbers of women and the significant costs of inaction, it is important to remember that there are women with families behind every statistic. Boxes 2.1 to 2.6 present patient stories from women recently diagnosed with uterine cancer, highlighting the impact diagnosis has had on their lives.

Figure 2.10: Total Estimated Economic Costs in Australia and Aotearoa New Zealand Due to Uterine Cancer in 2025-2035 ($2025, $NPV_{7\%}$)



Source: Insight Economics, See Appendix A for more details.

Box 2.1: Jackie's story – A Māori woman's experience with uterine cancer



At 59, Jackie was a devoted wife, mother of ten children, with her youngest still at home, and caregiver to her 83-year-old mother. With 30 grandchildren and a career as a support worker for people with disabilities, she was used to putting everyone else first.

But when she started losing weight unexpectedly and experienced heavy and persistent post-menopausal bleeding, Jackie knew something was wrong. Her GP prescribed medication to stop the bleeding, assuring her it would settle down within weeks. But it didn't, and she was told to double the medication dose. The bleeding got heavier, and dissatisfied with her GPs lack of urgency, Jackie pushed for answers, eventually being referred to a gynaecologist for further investigation of her symptoms. A biopsy and CT scan revealed her diagnosis of Stage 1A Uterine Carcinoma.

The diagnosis was a shock. Having lost her father six weeks after his cancer was diagnosed, Jackie was consumed by fear. "When you hear the word 'cancer', your mind spirals and your thoughts go to the worst," said Jackie.

Jackie's treatment involved a hysterectomy+salpingo-oophorectomy followed by eight sessions of radiotherapy. With her home being four hours away from Wellington, Jackie spent significant time away from whānau to receive her treatment. Her husband was able to accompany her for the surgery, but his work commitments meant she attended radiotherapy alone.

This was difficult, but the support of her whānau never wavered. Messages, video calls and encouragement came daily through the family group chat.

The first day of radiotherapy brought her to tears. Three male staff were unexpectedly in the room, and she felt deeply uneasy. "Being a Māori woman, I felt so much more comfortable in the care of female health professionals, particularly dealing with very private women's health issues," said Jackie. Thankfully, this was respected in later sessions.

At first, she didn't want anyone outside of her immediate whānau to know about her diagnosis. But over time, Jackie opened up and found strength in shared stories from others. "I felt I wasn't alone anymore," said Jackie.

Though she has finished active treatment, Jackie is still dealing with long-term side effects including fatigue and loss of intimacy. She lives with the fear of recurrence but chooses not to let it control her. Instead, she focuses on her health, more aware of the risk factors for uterine cancer, and is exploring options to reduce her weight to give herself the best chance of staying well.

Jackie's hope is that health professionals act with urgency when women present with post-menopausal bleeding. "I was lucky my cancer was caught early. Others won't if we don't listen," she said. Above all, she encourages women to be aware of the symptoms of gynaecological cancers and to make their health a priority.

Box 2.2: Ella's story – Perspectives on a uterine cancer diagnosis at age 31

At age 31, Ella was working full-time as a Clinical Liaison Officer in the health system. With a background as a radiation therapist, Ella was no stranger to hospitals and dedicated to helping others navigate their illness. But nothing prepared them for their own diagnosis of endometrial adenocarcinoma.

Though their general health was good, Ella struggled with obesity, a side effect of long-term medication for a mental health condition. When periods became increasingly painful, Ella knew something wasn't right. "At one point I fell to my knees with the pain and thought I was going to have to call 000," they said.

Ella visited their GP, who ordered a transvaginal ultrasound which showed thickening of the endometrium, prompting a referral to the local gynaecological clinic. Despite describing the pain as severe, Ella felt dismissed, that their symptoms were downplayed and was told to treat it with painkillers. It was only due to Ella firmly advocating for themselves that a hysteroscopy was scheduled, albeit under a low priority category.

Fortunately, a cancellation allowed the procedure to happen sooner. "Three days after, I got a phone call asking me to come in to discuss the results – I knew that was a bad sign," said Ella. Even with their clinical background, Ella had never heard of endometrial cancer.

Thankfully, Ella's cancer was diagnosed at stage 1a, and surgery was curative, though it put them into menopause at the age of 31. While the early diagnosis meant a good prognosis, Ella struggled with the emotional aftermath.

The sudden loss of fertility hit harder than expected, especially as they processed it over time. Ella hadn't planned to have children, but losing the choice to do so was incredibly difficult. "It's like your biological clock keeps ticking even though you physically can't have children," said Ella. "I look at pregnant women and feel sad that I will never experience that or wonder what it is like to look at your own child and see your similarities."

Now, ten years later, Ella shares their story with Australia's next generation of health professionals through ANZGOG's Survivors Teaching Students® Program. They want women and health professionals to understand that severe period pain is not normal and should not be ignored. Ella also feels strongly that there should be open and honest conversations without stigma about obesity as a risk factor for endometrial cancer. And perhaps most importantly, greater awareness of endometrial cancer is needed, not just among women but among health professionals too. Ella's story is proof that early detection can save lives, but only if symptoms are taken seriously and investigated promptly

Box 2.3: Ruth's story - Facing Uterine Cancer in Regional Aotearoa New Zealand

Ruth, a retired GP from the North Island of New Zealand, knew the warning signs. When post-menopausal bleeding began in 2021, she recognised it as a symptom of endometrial cancer. But knowing didn't make acting any easier.

At 65, Ruth was living with morbid obesity, type 2 diabetes managed with insulin and a painful knee injury that made walking difficult. With her medical background, she knew she was at increased risk of endometrial cancer but like many others, was hesitant to go near a health facility during the Covid-19 pandemic. Her mobility issues also proved a significant barrier to seeking help. "I told myself it would go away," she said. "But it didn't."

A year passed and eventually Ruth's frustration with the ongoing bleeding forced her into action. A locum GP listened, understood her risk and took her concerns seriously, referring Ruth for an ultrasound and an appointment with a gynaecologist. A whirlwind of appointments followed confirming a diagnosis of stage 1 endometrial cancer. Thankfully the cancer hadn't spread, and a laparoscopic hysterectomy removed it entirely. Today, Ruth is cancer-free and on six-monthly follow ups.

As a former GP, Ruth knew the health system well still found it overwhelming.

"I was incredibly lucky but exhausted," she said. "The number of appointments, the travel, and the logistics are overwhelming. I have a husband, a car and people to stay with. What happens to the women who don't?"

While grateful for the outcome, Ruth was struck by what was missing throughout her diagnosis and treatment. No one talked to her about lifestyle, weight or diabetes in relation to her cancer risk. "I think that is such a missed opportunity," she said. "There is a huge assumption that someone else will address those issues. But many people in New Zealand don't have a regular GP, and if they do, they are often overwhelmed with acute care."

Now, Ruth is advocating for change. She believes the system must do more to bring prevention of endometrial cancer to the forefront. "Because of research, women have many more treatment options available to them today, but we're not doing enough to prevent diseases before they start. Women need clear information about risk factors like diabetes and obesity, and the support to do something about it."

Box 2.4: Facing Uterine Cancer in Regional Australia

In mid-2019, Alex Neville, a devoted mother of four, began noticing changes in her body—irregular periods, heavy bleeding, and clotting. She was told these symptoms were likely menopause. However, when the bleeding persisted, Alex trusted her instincts and sought a second opinion later that year.

A new GP ordered a transvaginal ultrasound (TVU), which revealed uterine thickening. While it wasn't considered alarming, Alex was referred to a gynaecologist for further investigation. A dilatation and curettage (D&C) was performed, and a biopsy confirmed early-stage endometrial adenocarcinoma—stage 1, grade 1. Alex was reassured that the cancer was low risk.

Living in a regional area meant long trips to the city for specialist appointments, tests, and ultimately a hysterectomy. The invasive procedure seemed to encapsulate the cancer, offering Alex and her family a glimmer of hope.

But just three weeks later, everything changed. A devastating phone call confirmed more cancer had been found. The uncertainty surrounding Alex's primary cancer site led to conflicting treatment advice, deepening her fear and feelings of isolation. She faced 27 rounds of radiation and six cycles of chemotherapy—gruelling treatments that left her exhausted and in pain.

By January 2021, Alex finished her first-line treatment. Yet the next two years brought persistent fatigue, pain, And occasional bleeding—symptoms that were dismissed with test results appearing normal.

In early 2023, Alex noticed a tender spot near her belly button. Initially, she thought it was a pulled muscle. But as her fatigue worsened, her GP ordered a CT scan.

The results were crushing: metastases in her spleen, liver, omentum, and lymph nodes. Her cancer was now incurable and inoperable.

Multiple treatment options were suggested. Determined to fight, Alex researched her options and decided on immunotherapy alongside chemotherapy, despite having to self-fund the six treatments at close to $3,000 per cycle.

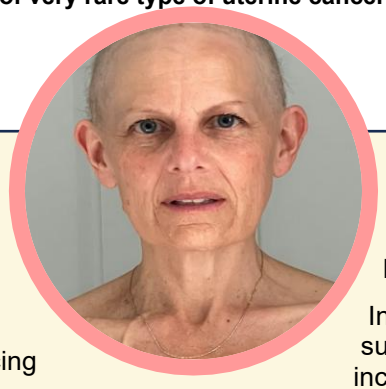
Living in a regional area only made things harder. Long hours of travel, extended wait times, and the emotional strain of being far from home weighed heavily on her. "It shouldn't matter where you live or what type of cancer you have," Alex reflected.

Alex became her own advocate; she relied on her health literacy and family support to navigate the complexities of her care. "*What happens to those without this knowledge or support?*" she asked.

Reflecting on her journey, Alex emphasised the need for change. "*If my treatment had been personalised from the start, it could have made all the difference between a recurrence and catching it in time*."

"*Our medical professionals are working in the dark*," Alex said. "*We need molecular profiling to provide them with the tools to accurately diagnose and guide the best treatment. It will save lives*."

Box 2.5: Ali's story - Fighting for Hope amidst a diagnosis of very rare type of uterine cancer



At 51, Ali Crawford—a loving mum of three teenagers, previously a psychologist—found herself thrust into a battle she never expected. Diagnosed with uterine leiomyosarcoma in March 2022, Ali's journey has been one of relentless determination, resilience and a fight to create change for others facing the same challenges.

Ali's peri-menopausal changes began in 2018. She recalls feeling dismissed during this time, with her concerns brushed off as "normal" for a woman of her age. When different symptoms began in 2021, she too brushed them off as possible peri-menopausal changes and she began a 'wait and watch' approach. But deep down, Ali sensed something wasn't right.

By early 2022, Ali couldn't ignore the nagging "full bladder" sensation and the unsettling discomfort in her abdomen. It wasn't until a bout of dizziness forced her to her GP that things began to unravel. A transvaginal ultrasound revealed a mysterious pelvic mass, but that was just the beginning of her ordeal.

What followed was a heartbreaking maze of delays and indifference. Her case wasn't treated as urgent; appointments were pushed out due to unavailability, critical tests were delayed, and answers felt impossibly out of reach. Ali was left to navigate this chaos alone, feeling powerless, forgotten, and utterly isolated. "I felt lost in the system," she admits.

It wasn't until her father intervened, using his connections to fast-track essential scans and appointments that the reality of her situation came to light.

"I knew I had a ticking time bomb," Ali says. "We had to fight for answers—for me, but most importantly, for my kids.

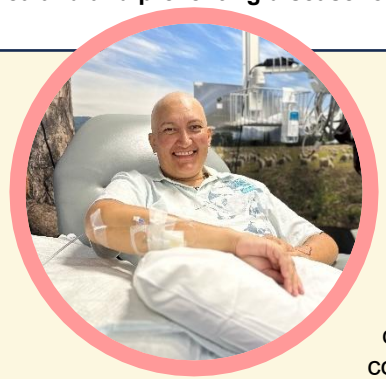
In April 2022, Ali underwent a major debulking hysterectomy surgery, removing her uterus and all surrounding organs, including ovaries, fallopian tubes, cervix. In May 2022 she underwent even further major surgery to have her bladder, rectum, pelvic floor and part of her abdomen removed, known as pelvic exenteration. The procedure was invasive and life-altering, followed by gruelling chemotherapy. The physical toll was immense, especially as she adjusted to life with significant changes to her body, including a colostomy, urostomy. But Ali remained steadfast in her hope. When her initial treatment declared her no evidence of disease (NED), it felt like a reprieve.

However, just over a year later, recurrences began, each one bringing new surgeries and rounds of different treatments following standard protocol. Ali's condition was Stage 4, with radical treatment, has had time with no sign of disease but is now requiring maintenance treatment for the rest of her life, for as long as that is.

Ali's journey exposed gaps in cancer care—delays in diagnosis, limited access to molecular profiling, and fragmented treatment pathways.

"No one should have to fight through this chaos while battling cancer," she says. "We need better systems for triaging, urgency for rare or advanced cancers, accessible cancer nurse consultants, and holistic support for patients," Ali urges. "Our children are waiting for their mothers to come home. This transformation program isn't just about treatment—it's about giving families the time and connection they deserve.

Box 2.6: Jaymi's story – Self-funding immunotherapy in New Zealand and preventing disease for her sisters through genetic testing



At age 42, Jaymi was living a full, active life in the North Island of New Zealand. She had just returned from an overseas holiday, was riding horses regularly, going to the gym and enjoying her work as a logistics manager. Everything seemed normal until a deep abdominal ache appeared out of nowhere.

At first it felt like a pulled muscle. But after two weeks the pain became unbearable. Blood tests ordered by her GP were concerning, and a CT scan later that day revealed a large mass more than 20cm in diameter. Jaymi was admitted to hospital immediately.

What she thought was bloating from travel turned out to be something far more serious. Jaymi was diagnosed with advanced endometrial cancer, which had spread to her bladder and the lining of her abdomen wall. The news was devastating.

"Emotionally, it's overwhelming. When you first get diagnosed, your mind goes everywhere. You immediately think the worst. Having a good support network is everything.

"It's not something you go through alone. It affects your whole family and your friends," says Jaymi who is thankful for the strong bonds within her Māori whānau.

Jaymi began treatment immediately: six rounds of chemotherapy on a 21-day cycle with her older sister by her *side* every step of the way.

This was followed by major debulking surgery including a hysterectomy.

When her medical oncologist advised that further chemotherapy was unlikely to help, Jaymi's only hope was a course of immunotherapy with a drug not publicly funded in New Zealand. "For me to survive and beat the cancer, I had to fund the treatment myself, and I know a lot of other women have to do the same thing. That was one of the hardest things, knowing that not everyone has this choice," said Jaymi. Thankfully the treatment has been successful and Jaymi's most recent scan showed no evidence of disease.

Genetic testing revealed Jaymi carries the *MSH6* gene mutation, which is associated with Lynch syndrome, an inherited condition that predisposes individuals to certain cancers, including endometrial cancer. This has been potentially lifesaving information for her sisters who have since taken proactive steps to reduce their personal risk.

Since her treatment, debilitating fatigue has become one of Jaymi's biggest challenges alongside joint pain and skin issues. "It's not something that just ends," she says. "Even now, it feels like an ongoing thing waiting for my next scan. Fingers crossed the next one is clear. But if it's not, you just go back to doing what needs to be done."

Jaymi is passionate about raising awareness of gynaecological cancers, particularly endometrial cancer, which she says receives little attention. She believes more information needs to be available, not just about the disease, but about the real, ongoing impact it has on women and their families.

2.4 Significant disparities for disadvantaged and vulnerable women

The risks and impact of uterine cancer are not uniformly distributed among Australian and Aotearoa New Zealand women, but disproportionately impact priority populations including:

- Aboriginal and Torres Strait Islander women in Australia
- Māori and Pacific women in Aotearoa New Zealand
- Australian and Aotearoa New Zealand women living in regional and remote communities
- Australian and Aotearoa New Zealand women from low socioeconomic areas.

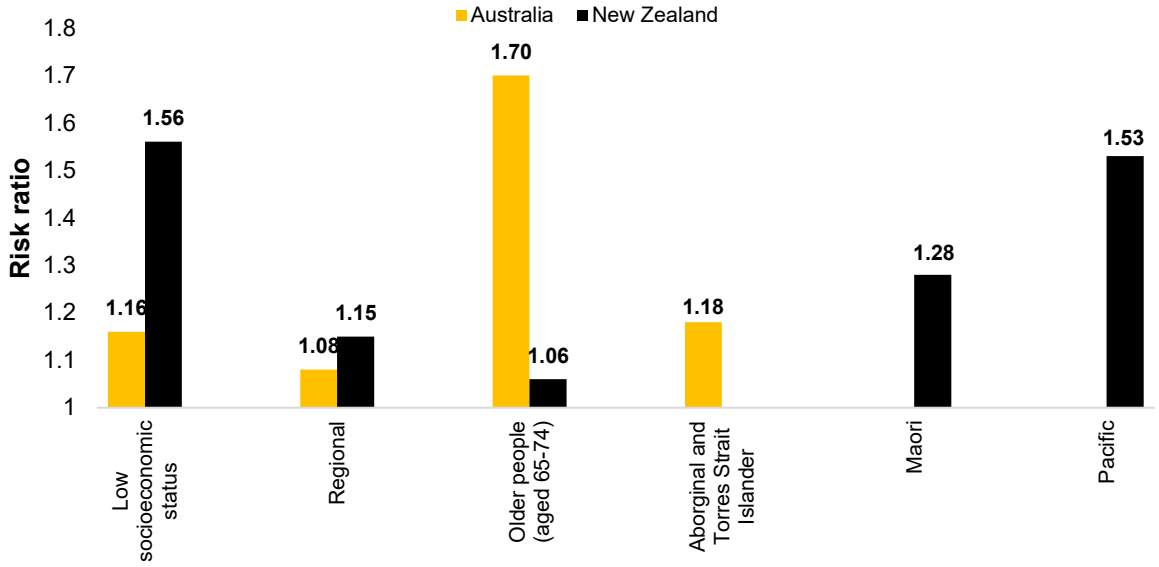
These priority populations often experience lower levels of health literacy and higher barriers to accessing care, which can result in increased risk of incidence, later stage of diagnosis, high levels of unmet need and poorer survival outcomes.

AIHW and Aotearoa New Zealand Health Survey data show that the underlying risk factors of higher body weight can be higher among these priority populations (Figure 2.11):

- People from areas of low socioeconomic advantage are 1.16 and 1.56 times more likely to be overweight or obese in Australia and Aotearoa New Zealand, than women from areas of high socioeconomic advantage, respectively.
- Women in regional communities are 1.08 and 1.15 times more likely to be overweight or obese in Australia and Aotearoa New Zealand than women in metropolitan areas, respectively.
- First Nations Australian women are 1.18 times more likely to be overweight or obese than non-Indigenous women.
- Māori and Pacific women are 1.28 and 1.53 times more likely to be overweight or obese compared to non-Māori or non-Pacific women, respectively.

Elderly Australian women face higher risk, being 1.7 times more likely than the average Australian woman to be overweight or obese. In Aotearoa New Zealand, elderly women are 1.06 times more likely to be overweight or obese compared to the national average. While obesity and overweight rates are relatively consistent across older age groups in both countries, significant disparities persist in other vulnerable communities.

Figure 2.11: Risk factors for uterine cancer are higher for women from vulnerable communities in Australia and Aotearoa New Zealand



Source: Australian Government. (2022). National Obesity Strategy 2022-2032 (health.gov.au). Aotearoa New Zealand Government. (2024). Aotearoa New Zealand Health Survey 2023/24 and 2006/07 for Urban-Rural comparisons (health.govt.nz).

There may also be other genetic risk factors that contribute to higher incidence among some ethnic and racial groups, but unlike other developed nations, Australia and Aotearoa New Zealand lack data to determine specific genetic risks for these populations. Research has also identified that there are significant differences between early-onset endometrial cancer and late-onset disease,[36] as well as differences between racial and ethnic groups.[37] For example, research in the US has found that rare and more aggressive uterine cancers are more common in non-white, older, and less obese patients and associated with higher mortality and recurrence.[38] Other research has also identified variation by race, with women of Black or African American descent having double the mortality of Caucasian American women, and their tumours tend to be of higher grade, especially among younger Black women.[39] However, no similar work has been completed for Aboriginal and Torres Strait Islander, wāhine Māori or Pacific women.

Queensland cancer registry data show these risk factors (e.g., higher body weight), combined with other systemic inequities in the health system, translate into both higher rates of incidence and mortality for First Nations women, regional women, and women from socio-economically disadvantaged backgrounds (Figure 2.12). For example, in Australia:

[36] Choi, J., Holowatyj, A. N., Du, M., Chen, Z., Wen, W., Schultz, N., Lipworth, L., & Guo, X. (2022). Distinct Genomic Landscapes in Early-Onset and Late-Onset Endometrial Cancer. *JCO precision oncology*, *6*, e2100401. https://doi.org/10.1200/PO.21.00401

[37] Setiawan, V. W., Pike, M. C., Kolonel, L. N., Nomura, A. M., Goodman, M. T., & Henderson, B. E. (2007). Racial/ethnic differences in endometrial cancer risk: the multiethnic cohort study. *American journal of epidemiology*, *165*(3), 262–270. https://doi.org/10.1093/aje/kwk010

[38] Feinberg, J. et al. (2019). Ten-Year Comparison Study of Type 1 and 2 Endometrial Cancers: Risk Factors and Outcomes, Gynecol Obstet Invest (2019) 84 (3): 290–297. https://doi.org/10.1159/000493132

[39] Guttery, D. S., Blighe, K., Polymeros, K., Symonds, R. P., Macip, S., & Moss, E. L. (2018). Racial differences in endometrial cancer molecular portraits in The Cancer Genome Atlas. *Oncotarget*, *9*(24), 17093–17103. https://doi.org/10.18632/oncotarget.24907; and Mukerji, B., Baptiste, C., Chen, L., Tergas, A. I., Hou, J. Y., Ananth, C. V., Neugut, A. I., Hershman, D. L., & Wright, J. D. (2018). Racial disparities in young women with endometrial cancer. *Gynecologic oncology*, *148*(3), 527–534. https://doi.org/10.1016/j.ygyno.2017.12.032

- Aboriginal and Torres Strait Islander women are 1.2 times more likely to be diagnosed with and die from uterine cancer compared to non-First Nations women.
- Women from low socioeconomic status (SES) backgrounds are 1.7 times more likely to be diagnosed with uterine cancer and 2.1 times more likely to die from it compared to wealthier women.
- Women living in regional and remote areas are 1.2 to 1.3 times more likely to be diagnosed with uterine cancer, and 1.5 to 1.6 times more likely to die from it, compared to urban women.

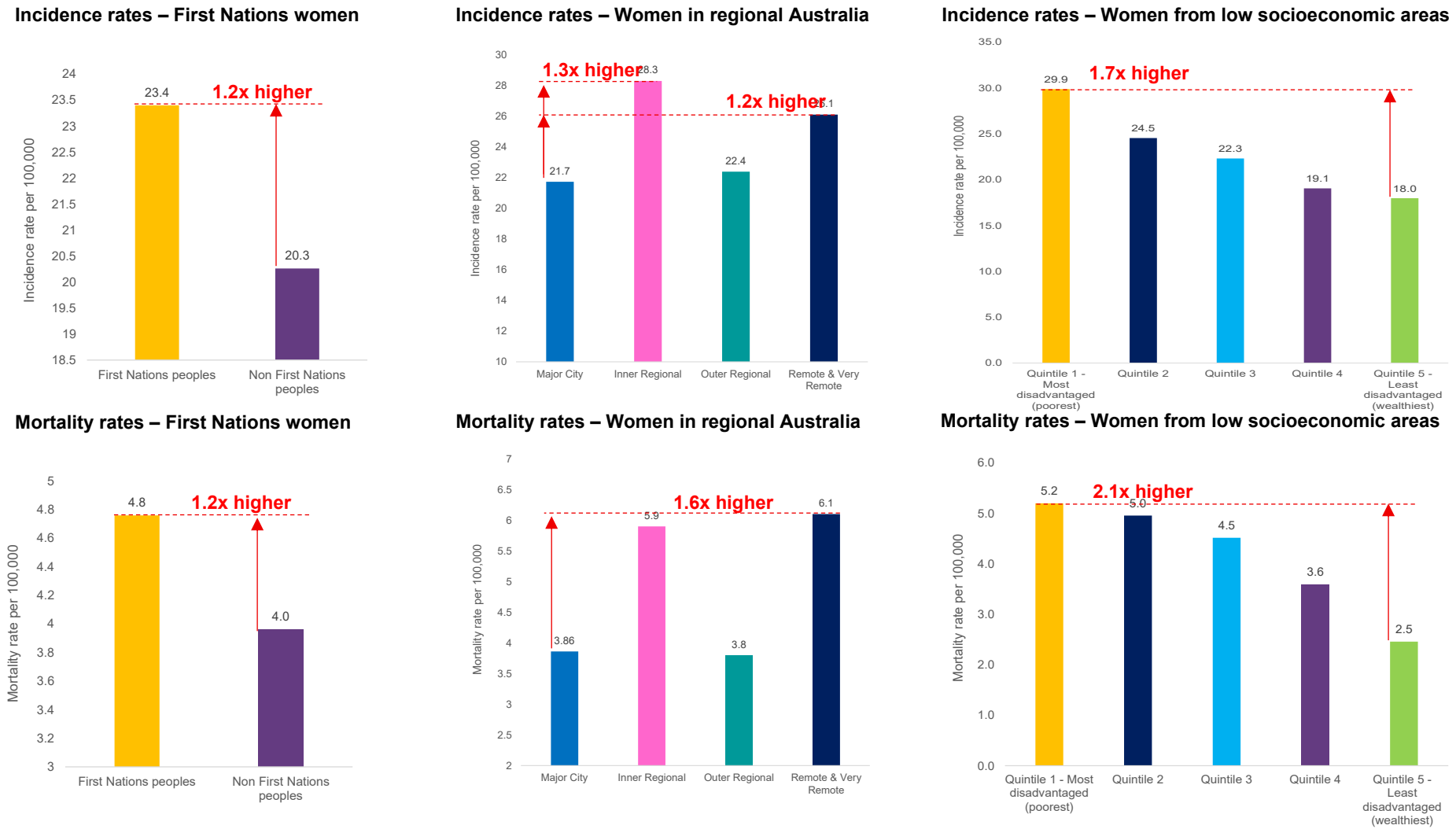
A similar pattern is observed in Aotearoa New Zealand (Figure 2.13). For example, in Aotearoa New Zealand:

- Māori women are 2.2 times more likely to be diagnosed with uterine cancer compared to non-Māori/Pacific women and 2.8 times more likely to die from uterine cancer compared to non-Māori/Pacific women.
- Pacific women are 5.6 times more likely to be diagnosed with uterine cancer compared to non-Māori/Pacific women and 6.8 times more likely to die from uterine cancer compared to non-Māori/Pacific women.
- In Aotearoa New Zealand, low SES women are 1.08 to 1.5 times more likely to be diagnosed with uterine cancer and 1.8 to 2.2 times more likely to die from it compared to wealthier women.

In Aotearoa New Zealand there is one notable exception; women living in urban areas are more likely to be diagnosed with and die from uterine cancer than their rural counterparts.[40]

[40] This is dependent on the Aotearoa New Zealand Geographic Classification of Health (GCH) and may yield different results under varying urban-rural classifications.

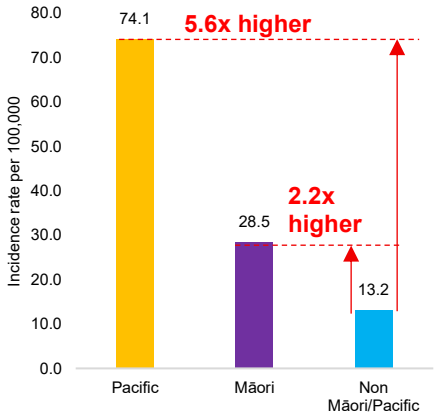
Figure 2.12: Increased incidence and mortality in uterine cancer for disadvantaged women in Australia



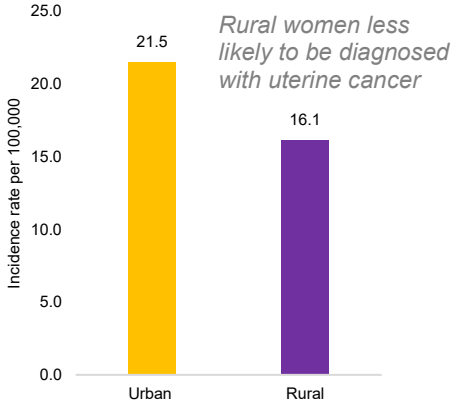
Source: Queensland Health. (2024). OASys.

Figure 2.13: Increased incidence and mortality in uterine cancer for disadvantaged women in Aotearoa New Zealand

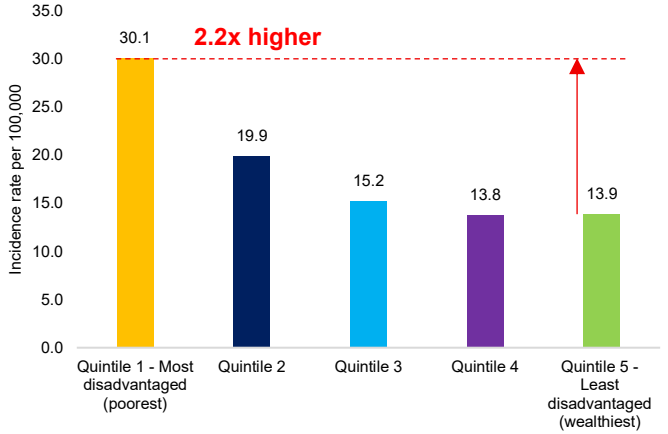
Incidence rates – Māori wahine & Pacific women



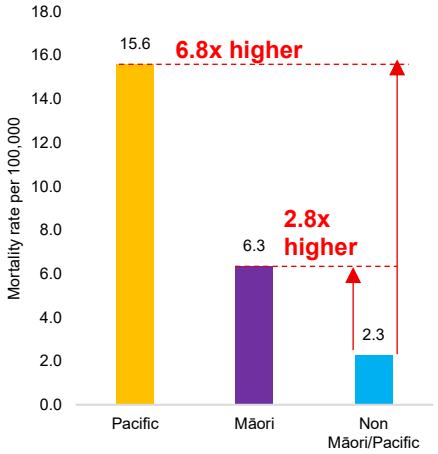
Incidence rates – Women in rural areas



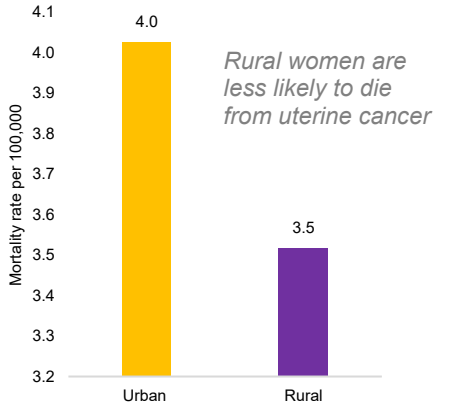
Incidence rates – Women from low socioeconomic areas



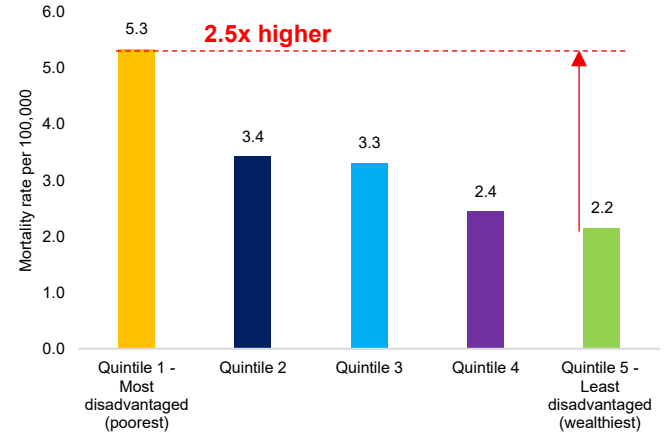
Mortality rates – Māori wahine & Pacific women



Mortality rates – Women in rural areas



Mortality rates – Women from low socioeconomic areas



Source: Health Aotearoa New Zealand (Te Whatu Ora), Cancer data web tool 2018-2022.

These disparities are indicative of broader systemic issues in healthcare access and outcomes for underrepresented populations. Contributing factors include limited access to early detection and diagnosis, socioeconomic barriers to healthcare, and geographic isolation affecting access to specialised care. Added to this, there are also deeper social, cultural and commercial determinants of health that disproportionately impact disadvantaged and vulnerable groups.

For example, the food environment plays a critical role in shaping uterine cancer risk, with unhealthy diets and low physical activity contributing to increased body weight and metabolic disease that increase the risk of uterine cancer. Fast food companies and other commercial actors often target low-income and priority populations through aggressive marketing and a higher density of outlets in vulnerable communities. Professor Louise Signal's work and recent findings highlight how such practices can exacerbate existing health disparities, contributing to the unequal burden of disease observed in Aotearoa New Zealand and globally.[41]

Addressing these inequalities is essential for improving overall health equity. These structural and commercial drivers, and their implications for prevention, detection and treatment, are explored further in Chapter 3.

[41] Worters, T., McKerchar, C., Watkins, L., Gage, R., & Signal, L. (2025). Public health and harmful advertising: The nature and extent of children's real-time exposure to unhealthy commodity marketing. *Social Science & Medicine, 375*, 118055. https://doi.org/10.1016/j.socscimed.2025.118055.

Chapter 3

Barriers to world class outcomes and precision care

This chapter presents the major barriers to improved outcomes and equity in uterine cancer.

3.1 Major barriers to world class outcomes and survival for women impacted by uterine cancers in Australia and Aotearoa New Zealand: overview

Despite Australia and Aotearoa New Zealand's strong reputation for cancer care, the literature and data review, consumer roundtables, stakeholder consultations and surveys conducted for this report have identified numerous, significant unmet needs and barriers in uterine cancer care for women in Australia and Aotearoa New Zealand to world class outcomes and experiences.

These issues span across the spectrum of care, from prevention to diagnosis and treatment, to survivorship (see Figure 3.1) and include:

Underinvestment in research and data

- Underinvestment in research
- Lack of data to inform research and health systems reform
- Poor access to clinical trials

Missed opportunities to improve prevention

- Poor awareness of uterine cancer, risk factors. symptoms and prevention
- Gender bias in healthcare and inconsistent access to gender sensitive services
- Underinvestment in risk prevention and women's wellness over their life course
- Shame, stigma and a lack of sensitivity to supporting healthy lifestyles among women
- Inconsistent screening for familial cancer risk

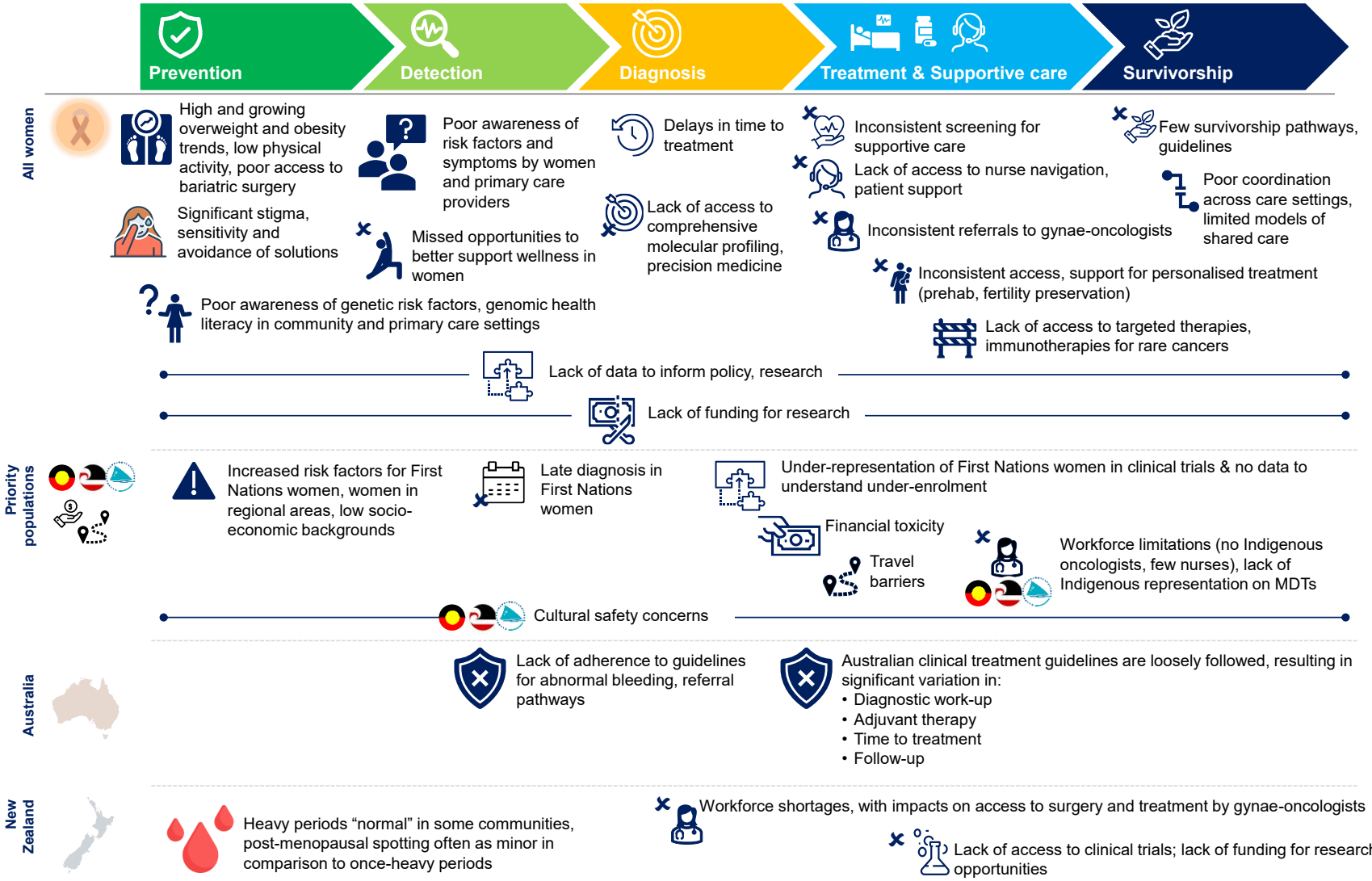
Barriers to world-class treatment and support

- Variation in clinical practice nationally
- Limited treatment options compared with other cancers due to underinvestment in research
- Lack of PBS and PHARMAC funding for medicines that are available in Australia's developed nation peers

- Lack of funded access to essential tests including *POLE* mutation testing for all cases, methylation testing for dMMR tumours, and PET and/or MRI scans in some cases
- Little to no screening for supportive care
- Lack of patient support and navigation services
- Risks of financial toxicity
- Significant workforce shortages, particularly in Aotearoa New Zealand
- Lack of evidence-based survivorship pathway.

These issues contribute to both poor survival and quality of life for patients and are discussed in turn in the following sections.

Figure 3.1: Major barriers to world class outcomes and survival for women impacted by uterine cancers in Australia and Aotearoa New Zealand



3.2 Poor awareness of uterine cancer, risk factors, symptoms and prevention

With rising prevalence of preventable risk factors and incidence among women of all ages and backgrounds, prevention and early detection of uterine cancers are critical to improving outcomes for women with uterine cancer in Australia and Aotearoa New Zealand.

Critically, however, one of the most fundamental barriers to improving prevention, early detection and outcomes for women is that most women are not even aware of uterine cancer as a condition. While data are limited, what data are available suggests that awareness of uterine cancer is alarmingly low; for example, a study of Australian women in 2014 found that:[42]

- Fewer than 10 per cent of women recognise that symptoms like vaginal discharge or abnormal bleeding may signal uterine cancer
- 94 per cent of women report having no awareness of the disease at all.

Similar results were observed in a recent UK study,[43] which found that, in a well-educated female population, only 13 per cent and 25 per cent were able to identify more than two risk factors or warning symptoms for endometrial and uterine cancer, respectively.

Across the consumer roundtable and stakeholder interviews there was also strong consensus that this poor awareness of uterine cancer constituted one of the most significant barriers to improving outcomes, with poor awareness contributing to delays in prevention, early detection, and diagnosis, ultimately leading to worse outcomes for women and their families. Even women who were otherwise proactive about their health or aware of familial cancer risk reported that uterine cancer was 'simply not on their radar' (Figure 3.2).

Figure 3.2: Consumer perspectives – poor awareness of uterine cancer

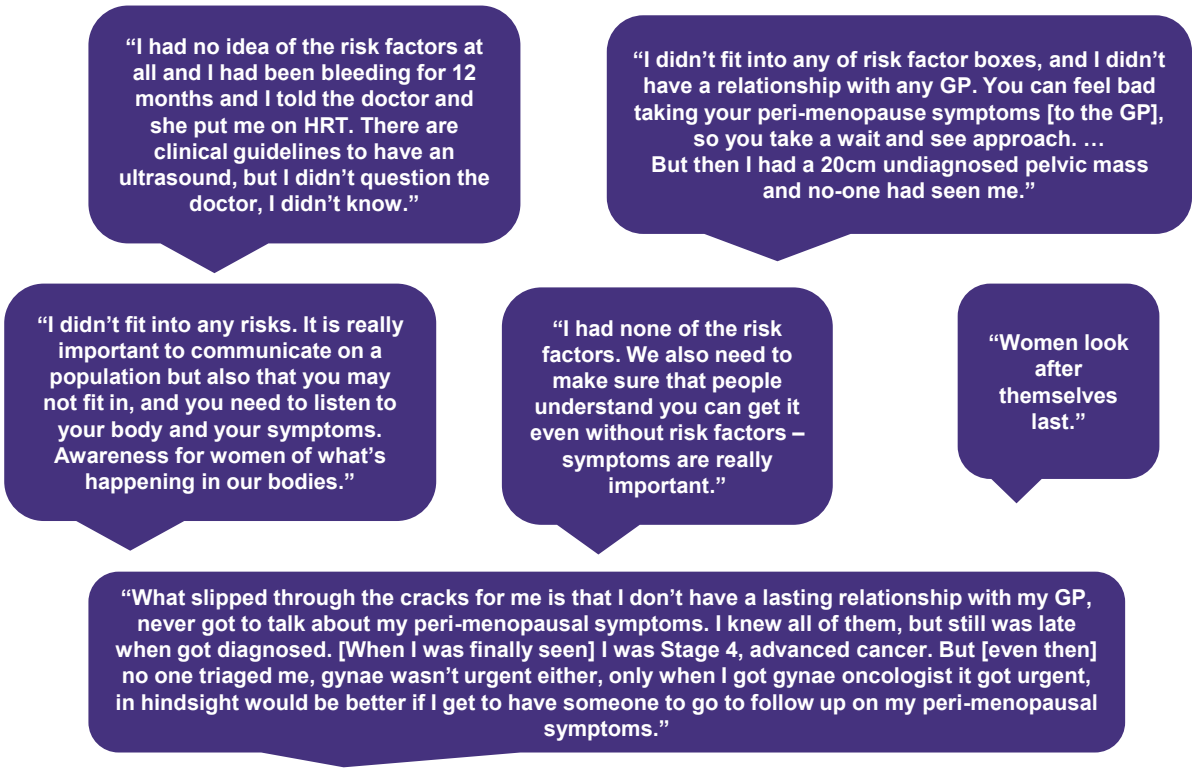
Source: Insight Economics Consumer Roundtables

[42] George, M., Abu Asab, N., et al. (2014). Risk Awareness on Uterine Cancer among Australian Women. Asian Pacific Journal of Cancer Prevention. 2014. 15(23). http://dx.doi.org/10.7314/APJCP.2014.15.23.10251
[43] Womb Cancer Awareness Measure (WCAM) Study. (2024). The Womb Cancer Awareness Measure (WCAM): development of an instrument to assess public awareness of endometrial cancer. International Journal of Gynecological Cancer. http://dx.doi.org/ 10.1136/ijgc-2023-004796

Many shared that they had never heard of the disease until their diagnosis, despite having relevant risk factors. A recent study among women with advanced or recurrent endometrial cancer, for example, found that only 29 per cent of women reported having been told that their cancer might have an underlying genetic condition, and only 14 per cent reported having been referred to a Familial Cancer/Genetics Clinic.[44] This highlights a major gap in risk-based education, both in general practice and broader public health campaigns.

Moreover, while understanding risk factors is important, many women diagnosed with uterine cancer do not fit into known risk categories. This highlights the critical need to empower all women—and their healthcare providers—to listen to their bodies and take symptoms seriously, regardless of perceived risk (Figure 3.3). Stakeholders also reported consistent concerns that many women are unaware of the symptoms of uterine cancer, and as a result may not present these symptoms to a GP. Post-menopausal bleeding, for example, was commonly cited as a symptom that women may dismiss leading to delays in diagnosis. As a result, many women do not seek medical help for their symptoms early and fail to receive a diagnosis until after the cancer has spread.

Figure 3.3: Consumer perspectives – Poor understanding of symptoms



Source: Insight Economics consumer roundtables

Clinicians consistently identified the need to educate women that post-menopausal bleeding was never normal as a high area of need.

[44] Data provided courtesy of ANZGOG based on unpublished data from the PHAEDRA clinical trial.

Figure 3.4: Stakeholder perspectives – Poor awareness of uterine cancer, risk factors and symptoms

Source: Insight Economics stakeholder consultations

Stakeholders also indicated that even GPs may not always be well informed about uterine cancer and its symptoms or may fail to consistently investigate and appropriately refer patients for testing to exclude cancer risk. Further research is needed to support the public reporting of investigation rates of women's symptoms, with Government-led reviews into women's health, such as the Inquiry into Women's Pain in Victoria[45], as well as stakeholder feedback and other early studies suggesting there may be opportunities to improve symptom investigation. This can lead to delays in receiving diagnosis, or an absence of diagnosis entirely.

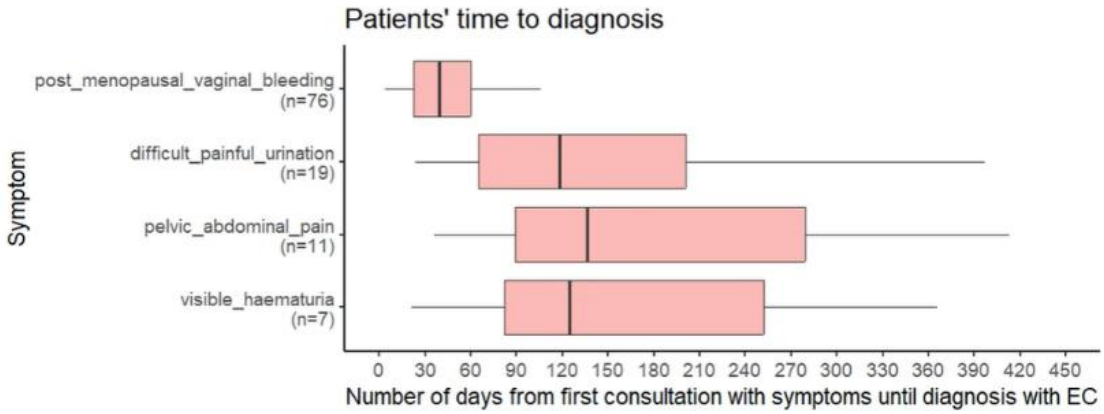
While there are available guidelines for GPs to use for the investigation and management of post-menopausal bleeding in both Australia and New Zealand, for other symptoms associated with uterine cancer diagnosis and for patients presenting at a premenopausal

[45] Department of Health. (2024). Inquiry into Women's Pain. Victorian Government. Accessed at: https://www.health.vic.gov.au/inquiry-into-womens-pain

age; the recommendations for investigation and management are far less cohesive. For example, unpublished data collected by the University of Melbourne suggest that apart from post-menopausal bleeding, there is a wide variation in the time to diagnosis of uterine cancer across different symptoms (Figure 3.5).

In stakeholder consultations and consumer roundtables, women frequently described situations where their symptoms, particularly during perimenopause or post-menopause, were dismissed or not investigated thoroughly (Figure 3.6). Many experienced a 'wait and see' approach in primary care, with little urgency or follow-up. Abnormal bleeding, pelvic pain, or unusual discharge were minimised, misattributed to hormonal fluctuations, or not followed up at all. This lack of timely investigation resulted in delays to diagnosis, often until the disease had progressed, ultimately leading to poorer health outcomes.

Figure 3.5: Most common symptoms reported vs time to diagnosis



Source: University of Melbourne PATRON data.

Concerns for the inconsistent investigation of symptoms links to wider concerns about gender bias in the healthcare system and lack of access to gender-aware care. These examples underscore the urgent need for national and regional strategies that centre gender equity, cultural safety, and intersectionality. For example, in 2024, the Australian Government released results from its #EndGenderBias survey, wherein women spoke on their experiences with both interpersonal sexism and structural barriers.[46]

[46] National Women's Health Advisory Council. (2024). #EndGenderBias Survey Summary Report. Australian Government. Accessed at: https://www.health.gov.au/sites/default/files/2024-03/endgenderbias-survey-results-summary-report_0.pdf

Figure 3.6: Consumer perspectives – Dismissal of women's concerns

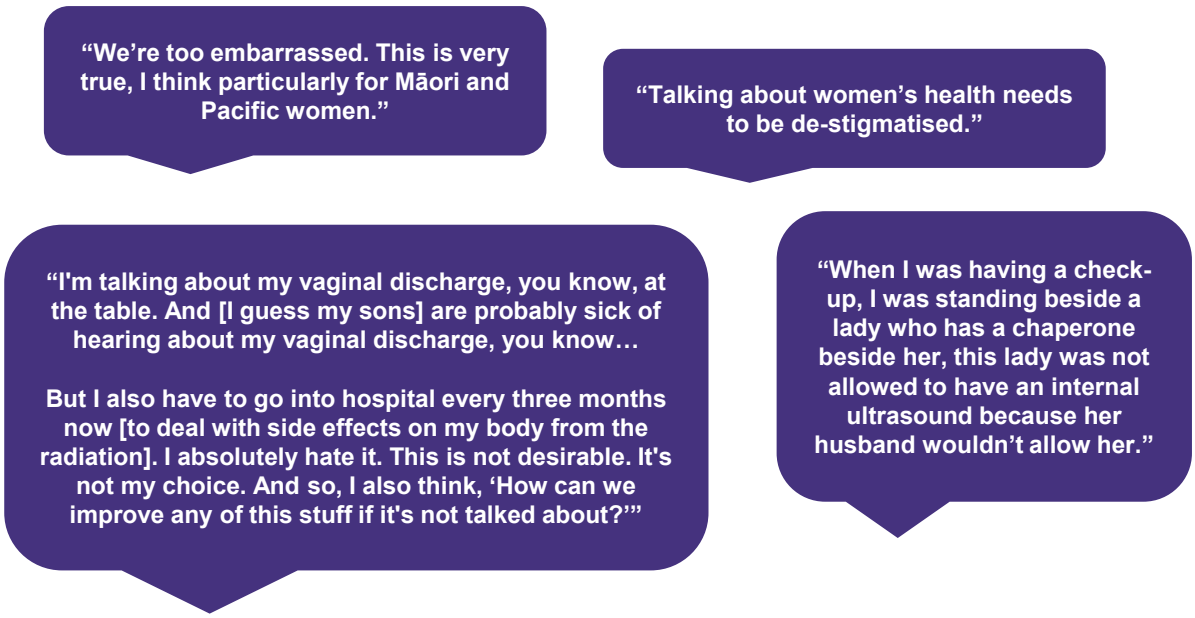
Source: Insight Economics consumer roundtables

These issues can also often be amplified for women from priority populations. Aboriginal and Torres Strait Islander women, wāhine Māori and Pacific women, those living in regional or remote areas, and women with lower socioeconomic status face intersecting barriers that increase the risk of late diagnosis. These include limited access to culturally safe care, language barriers, lower baseline awareness of symptoms, historical distrust in medical institutions, and financial hardship or "financial toxicity" associated with seeking care.

3.3 Stigma and embarrassment around symptoms of uterine cancer

Stigma and embarrassment around reproductive health issues can also add to delays in diagnosis. Discussing symptoms like bleeding or discharge is still considered taboo in many communities, especially among women from culturally and linguistically diverse backgrounds or those with low health literacy. Shame, discomfort, and fear of being dismissed again often prevent women from seeking care in the first place.

Figure 3.7: Consumer perspectives – stigma and embarrassment prevent women from talking about uterine cancer, seeking advice



Source: Insight Economics consumer roundtables

One stakeholder highlighted that she was unable to receive care in a location that provided sufficient privacy given the sensitive nature of her symptoms (Box 3.1).

Box 3.1: Lack of access to supportive care and gender-sensitive healthcare

> At the end of June 2016, I was diagnosed with uterine cancer [and] underwent a total hysterectomy with the removal of 15 lymph nodes.
>
> During the past five years, I have been acutely aware of the challenges that women with gynaecological and intimate health issues face in our state.
>
> Since my surgery in 2016, I have been experiencing lymphoedema, a chronic condition which requires supervision, vigilance, and support from the lymphoedema physiotherapists. It was [the Specialist Clinical Nurse Consultant] who alerted and guided me as to the therapy needed to manage my lymphoedema.
>
> When I initially started attending six monthly appointments at the Community Health Centre it was a large treatment room with cubicles separated only by pull-round curtains. The physios met with both male and female patients in the same common space at the same time. The lack of privacy for women such as myself was confronting to say the least and it was extremely uncomfortable and degrading to put it mildly to talk about swollen genital issues in the confined space with other patients, including males in literally arm's length proximity overhearing the conversation.
>
> No doubt it was uncomfortable for them as well as me. One should never have to whisper to your primary health care practitioner about how to manage the intimacies of a sensitive and debilitating condition for which there is no known cure.
>
> I am sure that there are many women who also because of cultural beliefs, who may be elderly, shy and intimidated are very unwilling to talk to their medical practitioner about sensitive issues in such an environment. In fact, any woman undergoing treatment for gynaecological and/or intimate health issues would find it confronting to discuss their health concerns openly and frankly with their health practitioner in a mixed sex ward in

> our hospital settings. Our lymphoedema physios are our lifeline and the only ones with the expertise to help us navigate this confronting condition.
>
> Lymphoedema is a chronic condition that requires a holistic approach in its management and perhaps we have reached a point where a designated health professional with an overarching role is needed in the state.

Source: Letter to Minister shared by a uterine cancer survivor

3.4 Underinvestment in risk prevention and wellness

As outlined in Chapters 1 and 2, one of the most significant risk factors to the incidence of uterine cancer is having a higher body weight and other unhealthy lifestyle factors, including low levels of physical activity. As a result, much of the rising incidence of uterine cancer is preventable—potentially up to 60 per cent of incidence[47]—but only through investment in policies and programs that promote health body weights and health lifestyles, including participation in physical activity in the community.

Both Australia and Aotearoa New Zealand alike invest a small amount of budget funding on prevention and improving the wellness of the community.

For example, while health expenditure per capita in Australia overall is higher than the OECD average, expenditure on preventive health measures accounts for only 1.3 per cent of total healthcare expenditure, compared to an average of 2.8 per cent in OECD countries — that's 54 per cent less than Australia's developed nation peers. Expressed as a percentage of GDP, Australia spends only 0.13 per cent of GDP on prevention. By contrast, in the EU, spending on preventive healthcare accounted for 0.65 per cent of GDP in 2021.[48]

The story is similar in Aotearoa New Zealand. In 2019, the Government delivered a "Wellbeing Budget", which included a $1.9 billion investment in mental health, alongside a boost in funding for school and hospital buildings, and climate projects.[49] However, after the disruption made to the health system by COVID, the ability of the Government to deliver the services committed to under the Wellbeing Budget has diminished.[50]

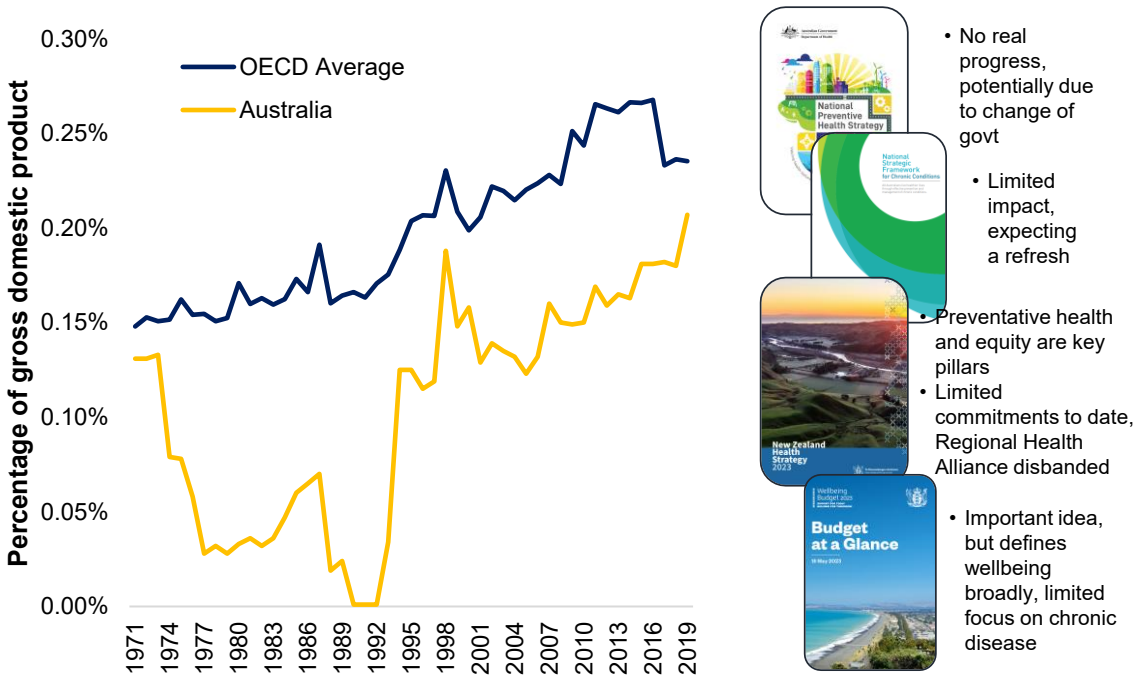
[47] Kabat GC, Matthews CE, Kamensky V, Hollenbeck AR, Rohan TE. (2015). Adherence to cancer prevention guidelines and cancer incidence, cancer mortality, and total mortality: a prospective cohort study. Am J Clin Nutr. 2015;101(3):558–569; Kitson, SJ., Khan, U., and Crosbie, EJ. (2024). Lay and general practitioner attitudes towards endometrial cancer prevention: a cross-sectional study, *Family Practice*, Volume 41, Issue 6, December 2024, Pages 949–955, https://doi.org/10.1093/fampra/cmad076

[48] GBC 2019 Australia Collaborators, The burden and trend of diseases and their risk factors in Australia, 1990-2019: a systematic analysis for the Global Burden of Disease Study 2019, Lancet Public Health 2023; 8: e585-99.

[49] Mintrom, M. (2019). Aotearoa New Zealand's Wellbeing Budget Invests in Population Health. The Milbank Quarterly. October 2019. 24;97(4): pp. 893–896.

[50] Controller and Auditor General. (2024). Meeting the mental health needs of young Aotearoa New Zealanders. Office of the Auditor General. Accessed at: https://www.oag.parliament.nz/2024/youth-mental-health/docs/youth-mental-health.pdf

Figure 3.8: Australian investment in preventative care compared to OECD average, percentage of gross domestic product



Source: AIHW and OECD data. Note data for Aotearoa New Zealand was inconsistently available and so not reported in this graph.

Critically, this underinvestment in prevention is occurring within a wider food and built environment that contributes to increasing body weight and rising rates of chronic disease and health inequity (Figure 3.9). Discussions of trends in obesity can sometimes have an outsized emphasis on personal choice and lifestyle behaviour that overlooks the larger social, commercial and economic determinants of health, which are only beginning to be fully recognised.

Data show that the food and built environments of Western countries, including Australia and New Zealand, significantly contribute to increasing prevalence of overweight and obesity trends (obesogenic environments) and, in turn, chronic disease, including cancer:

- *A food environment saturated with unhealthy food choices* — There is mounting global evidence shows that ultra-processed foods (UPFs), which are energy-dense, nutrient-poor, and aggressively marketed, are strongly associated with obesity, metabolic syndrome, cardiovascular disease, and certain cancers, including breast and uterine cancers.[51] Meta-analyses link UPF consumption with elevated risk of overweight, abdominal obesity, all-cause mortality, and metabolic conditions across both adults and adolescents.[52]

[51] AIHW data show dietary risk factors were linked to 16 diseases and contributed to: 50% of coronary heart disease total burden, 26% of bowel cancer total burden, 26% of type 2 diabetes total burden, 26% of stroke total burden, and 49% of uterine cancer total burden. In 2018, physical inactivity contributed to: 20% of type 2 diabetes disease burden, 16% of coronary heart disease burden, 16% of the uterine cancer burden, 12% of bowel cancer burden, 12% of dementia burden, 9.2% of stroke burden and 3.2% of breast cancer burden. Physical inactivity also contributed to around 8,300 deaths (5.2% of total deaths) See AIHW. (2021). Australian Burden of Disease Study 2018: Interactive data on risk factor burden.

[52] Popkin, B. M., & Ng, S. W. (2021). The nutrition transition to a stage of high obesity and noncommunicable disease prevalence dominated by ultra-processed foods is not inevitable. *Obesity Reviews, 23*(S1), e13366. https://doi.org/10.1111/obr.13366

These foods are increasingly dominant in high-income, Western diets.[53] In Australia, for example, National Health Surveys have shown that UPFs accounted for 42 per cent of total energy intake, while expenditure on UPFs was estimated to have risen by five percentage points from 1989 to 2010.[54] It has been argued that confusing food labels the Australian Health Star Rating System have not been as effective as hoped to reduce the consumption of ultra-processed foods.[55] Similarly, in Aotearoa New Zealand, a range of audits as part of the State of the Food Supply reports have identified that 70 per cent of packaged products in NZ supermarkets are classified as ultra-processed, indicating a highly UPF-dominated food supply.[56]

- *A built environment that discourages physical activity* — Low levels of physical activity also play a role in increasing body weight and metabolic disease that contributes to chronic health conditions like diabetes, cardiovascular disease and cancer. Reducing physical activity levels are attributed to a number of factors including urban design that encourages the use of cars and discourages walking, as well as the increasingly sedentary nature of the modern work, which means many people now spend most of their day seated at a desk, reducing opportunities for regular physical activity.[57]

  In Australia, AIHW data show that an estimated 78 per of adults aged 18–64 were insufficiently physically active and also did not meet the muscle-strengthening component of the physical activity guidelines. This proportion was found to be higher in women (80 per cent) than men (75 per cent). Moreover, there has been a large decrease in the proportion of adults aged 18 and over who did not meet the physical activity guidelines in recent years, falling to only 46 per cent of adults meeting the guidelines in 2022, compared to 69 per cent in 2008.[58] Similarly, in 2024 the New Zealand Health Survey reported that only 47 per cent of adults met the national physical activity guidelines, compared to 51 per cent of adults meeting the guidelines in 2019. Roughly 14 per cent of adults doing little or no physical activity at all. Like Australia, women were more likely to be physically inactive, with only 44 per cent of women aged 25–34 meeting the guidelines compared to 53 per cent of men in the same age group.[59]

Unhealthy behaviours are often established at a young age, with young people often heavily targeted through advertising and other marketing; for example:

- An Otago study reported Kiwi children obtain about half of their energy from UPFs by 12 months of age, increasing further by age five.[60]

[53] Machado, P. P., Steele, E. M., Levy, R. B., Sui, Z., Rangan, A., Woods, J., Gill, T., Scrinis, G., & Monteiro, C. A. (2019). Ultra-processed foods and recommended intake levels of nutrients linked to non-communicable diseases in Australia: evidence from a nationally representative cross-sectional study. BMJ open, 9(8), e029544. https://doi.org/10.1136/bmjopen-2019-029544
[54] Ibid.
[55] Ibid.
[56] Mackay, S., Ni Mhurchu, C., Swinburn, B., Eyles, H., Young, L., and Gontijo de Castro, T. (2019). State of the Food Supply New Zealand 2019. The University of Auckland. https://doi.org/10.17608/k6.auckland.9636710.v1
[57] Department of Health and Aged Care. (2022). National Obesity Strategy 2022-2032, accessed at: https://www.health.gov.au/sites/default/files/documents/2022/03/national-obesity-strategy-2022-2032_0.pdf
[58] AIHW. (2024). Physical Activity. AIHW analysis of ABS 2023 data, accessed at: https://www.aihw.gov.au/reports/physical-activity/physical-activity
[59] New Zealand Ministry of Health. (2024). Annual Update of Key Results 2023/24: New Zealand Health Survey, accessed at: https://www.health.govt.nz/en/node/5691
[60] Fangupo, Louise J. et al. (2021). Ultra-Processed Food Intake and Associations with Demographic Factors in Young New Zealand Children, Journal of the Academy of Nutrition and Dietetics, Volume 121, Issue 2, 305 - 313

- An Aotearoa New Zealand study found that 68.5 per cent of urban schools had a convenience store within 800 m, while 62 per cent urban schools had a fast food or takeaway outlet within 800 m.[61]
- Physical activity among children was also found to be low. For example, in Australia:
  - Over 8 in 10 (83 per cent) children aged 2–5 did not meet both the physical activity component and the screen-based activity component – 39 per cent did not meet the physical activity component and 75 per cent did not meet the screen-based activity component.
  - Nearly 9 in 10 (88 per cent) children aged 5–12 did not meet both the physical activity component and the screen-based activity component – 74 per cent did not meet the physical activity component and 65 per cent did not meet the screen-based activity component.
  - Most young people (96 per cent) aged 13–14 did not meet both the physical activity component and the screen-based activity component – 89 per cent did not meet the physical activity component and 77 per cent did not meet the screen-based activity component (AIHW 2018).

  In New Zealand, Sport NZ's Active NZ data reports that only about seven per cent of children and young people (ages 5–18) meet the physical activity guidelines through PE, sport, exercise, or active recreation.[62] It was also reported that fewer children were walking and cycling to school with only 39 per cent using active transport (e.g., walking and cycling) compared to 44 per cent in 2018/19.

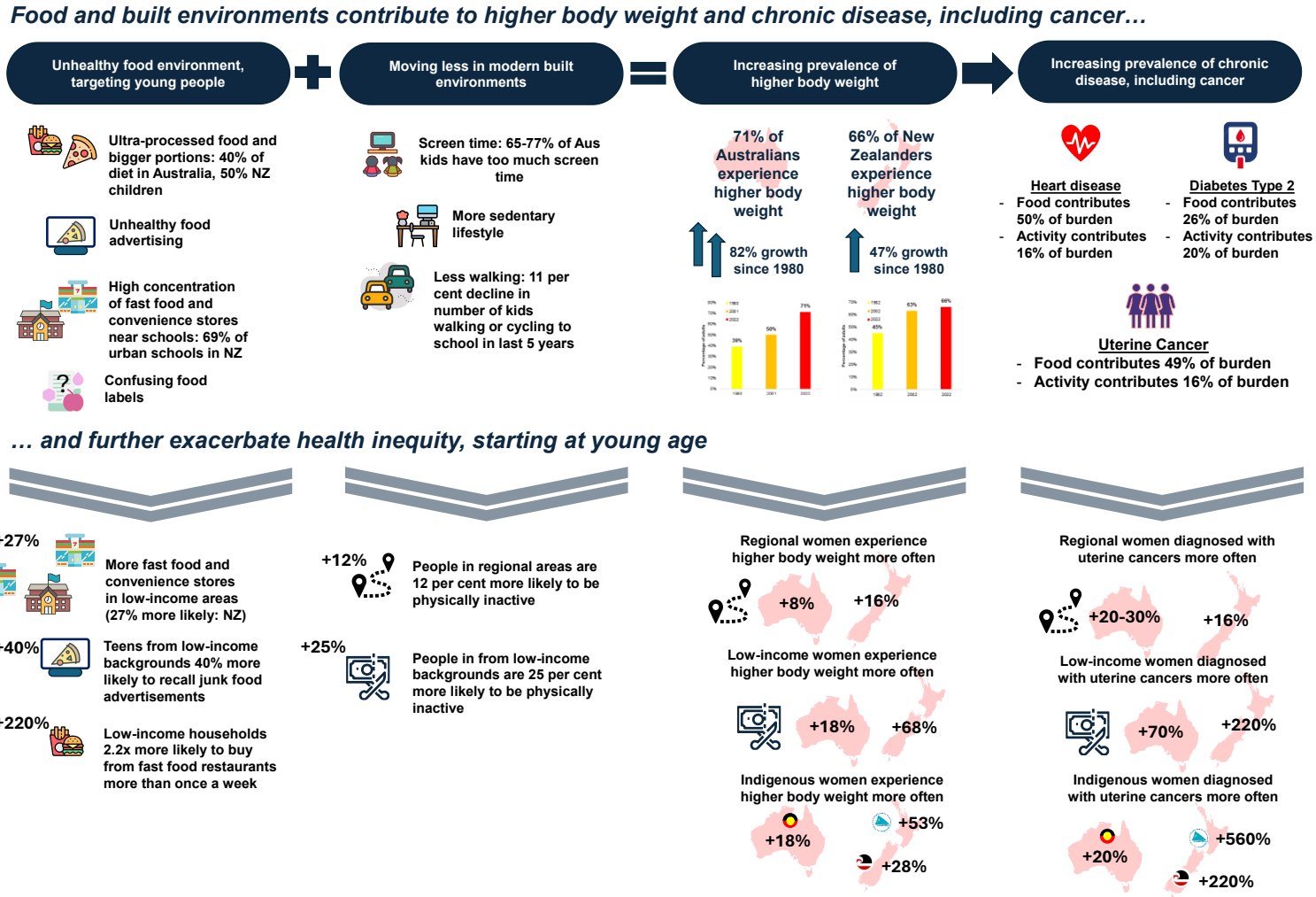
Increased screentime among children can also contribute to exposure to advertising that is difficult to avoid that encourages unhealthy food choices. For example, Cancer Research UK found that a child's ability to recall just one junk food advertisement was associated with that child consuming an additional 350 calories per week.[63]

These unhealthy behaviours also significantly contribute to health inequity.

- Research has shown that people from lower socioeconomic status areas are more likely to consume ultra-processed foods. For example, research in Australia has shown that low-income earners more frequently consume meals within fast-food outlets.[64] This was deduced to be a function of cost, with cost being the second most important factor in food choice behind taste, and noting that energy-dense foods served fast-food restaurants are 'generally cheaper and therefore more accessible' to people on lower incomes. Similarly, the concentration of fast food and convenience stores near urban schools was found to be substantially higher in low-income areas.[65]
- The Cancer Research UK study that demonstrated a link between a child's ability to recall a junk food advertisement and increased caloric consumption also found that teens from low socioeconomic status communities were 40 per cent more likely to recall a junk food advertisement, compared to teens from better off families.

[61] Vandevijvere, S. Sushil, Z., Exeter, DJ., and Swinburn, B. (2016). Obesogenic Retail Food Environments Around New Zealand Schools, American Journal of Preventive Medicine, Volume 51, Issue 3, e57 - e66.
[62] Sport NZ. (2025). Children and young people Ngā tamariki me ngā taiohi, accessed at: https://sportnz.org.nz/get-active/children-and-young-people.
[63] Cancer Research UK. (2019). Junk food marketing and childhood obesity: the evidence. Cancer Research UK. Accessed at: https://www.cancerresearchuk.org/sites/default/files/jfm_briefing_jan_19.pdf
[64] Thornton, L. E., Crawford, D. A., & Ball, K. (2011). Who is eating where? Findings from the SocioEconomic Status and Activity in Women (SESAW) study. *Public Health Nutrition*, *14*(3), 523–531. doi:10.1017/S1368980010003022.
[65] Vandevijvere, S. Sushil, Z., Exeter, DJ., and Swinburn, B. (2016). Obesogenic Retail Food Environments Around New Zealand Schools, American Journal of Preventive Medicine, Volume 51, Issue 3, e57 - e66.

Figure 3.9: The way we live makes it hard to stay healthy – how food and built environments contribute to higher body weight and chronic disease



Source: Insight Economics. See previous section for references to data.

- People from outer regional areas were 12 per cent more likely to be physically inactive, while people from the lowest socioeconomic status group were 25 per cent more likely to be physically inactive than people from the highest socioeconomic status group.[66]

These sociological determinants require recognition and targeted government intervention. Inadequate urban planning, limited access to exercise facilities, weak food formulation and labelling standards, a lack of taxation policies promoting healthy choices, and chronic underinvestment in both public health systems and research all contribute to the rising risk of uterine cancer.

3.5 Shame, stigma and (lack of) sensitivity with respect to higher body weight

Against a backdrop of underinvestment in healthy lifestyles, women with higher body weight can also experience a culture of blame, shame and stigma, not just from people in their everyday life, but also from doctors that are meant to have their best interests at heart. Insensitive, unprofessional and unhelpful comments can often be made that overlook these larger systemic forces and potential genetic factors for increased body weight at work — and this can prevent women from getting the support they need to improve their health.

Women at roundtables shared examples of how higher body weight was either ignored or handled insensitively by healthcare providers—both of which could have serious implications (Figure 3.10). Some described disengaging from the healthcare system after a poor experience: "And I never went back to that person." Others lamented that weight was never discussed, leaving them to manage it alone without support: "It was never raised because people didn't want to 'go there'."

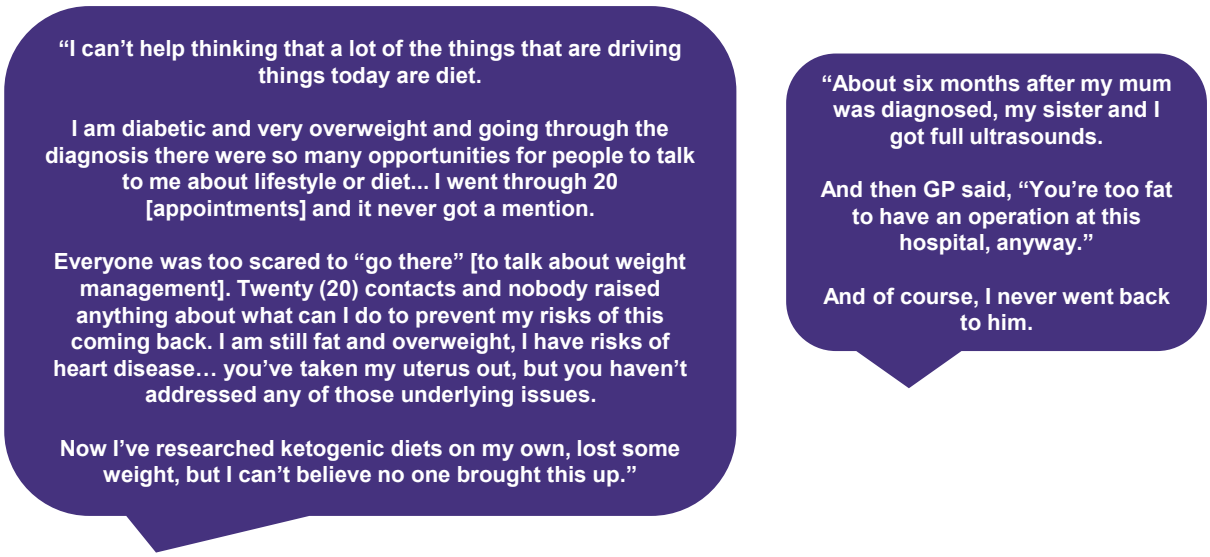
These experiences highlight the need for healthcare providers to engage in weight management discussions with empathy, sensitivity, and without judgement. Supportive conversations, tailored programs, and community-based initiatives focused on healthy lifestyle changes were identified as a high priority to improve outcomes—particularly given the well-established link between obesity and uterine cancer risk.

A culture of shame and stigma also minimises the potentially significant psychological stress that, for some women, may be contributing to higher body weight. Conversely, women also indicated that when they wanted help, it was hard to find. There was strong consensus among stakeholders that the delivery of quality care in women's health requires more than 15 minutes with a GP, particularly when that GP may or may not be their consistent primary care provider.

For many women experiencing higher body weight, specialist support is needed to help support the lifestyle changes that can help them to live their best life.

[66] AIHW, (2023). Proportion of adults aged 18 and over who are insufficiently physically active, by selected population characteristics, 2022., AIHW analysis of ABS 2023 data, available at: https://www.aihw.gov.au/reports/physical-activity/physical-activity

Figure 3.10: Consumer perspectives – stigma and lack of sensitivity create barriers to quality care, and point to a need for a more specialised approach



Source: Insight Economics consumer roundtables.

3.6 Inconsistent screening for familial cancer risk

Based on preliminary clinical data from 2023, NGOR has indicated that, while some genetic testing is performed almost universally, or with a high degree of coverage, other genetic tests are not performed on all patients.

For example, preliminary NGOR data show that 98 per cent of women are screened for dMMR, which is the first step to a Lynch syndrome diagnosis; this is a high rate of screening in Australia and an indication of high-quality care enabled by MBS funding of dMMR tests. While data were not available for New Zealand, clinicians indicated this was a standard of care and routinely done.

But MMR testing is only the first step to determining whether a woman has Lynch Syndrome.[67] Immunohistochemistry (IHC) testing for mismatch repair genes (*MLH1*, *MSH2*, *MSH6*, or *PMS2)* will provide information with regard to the pattern of gene loss. If the result indicates a *MLH1* loss, further methylation testing is needed to determine whether the loss was sporadic or the result of a Lynch Syndrome.

Preliminary data from NGOR shows that only half of women with *MLH1* loss were referred for methylation testing. While this is based on a limited patient sample, this suggests that there is scope to improve screening for familial cancer risk. NGOR currently lacks funding to conduct a full analysis of these data to identify the precise rate of referral and the reasons for non-referral, which could be due to cost (additional tests are not MBS funded in Australia) or long waiting lists. Importantly, these data, while preliminary, are consistent with previous analysis completed by COSA, which estimated that improved screening for Lynch Syndrome would increase diagnoses by 50 per cent.[68] These data are also consistent with the PHAEDRA study of advanced endometrial cancer, which found that of women with potential

[67] Leclerc, J., Vermaut, C., & Buisine, M. P. (2021). Diagnosis of Lynch Syndrome and Strategies to Distinguish Lynch-Related Tumors from Sporadic MSI/dMMR Tumors. *Cancers*, *13*(3), 467. https://doi.org/10.3390/cancers13030467
[68] COSA. (2022). Universal tumour screening for evidence of mismatch repair deficiency in colorectal and endometrial cancer: A national strategy to identify families with Lynch Syndrome, Joint position statement COSA and HGSA, accessed at: https://www.cosa.org.au/media/5qblxefb/lynch-syndrome-position-statement_final_approved-by-council-20052022.pdf.

hereditary risk only two thirds of participants reported having had their family history taken and only 35 per cent of women were referred to genetic services.[69]

Diagnosis of Lynch Syndrome is important, influencing clinical management with surveillance and more radical surgery. It also provides for preventive surveillance among family members — not only for endometrial cancer, but also colorectal cancer, ovarian cancer, upper GI cancers, brain cancer, and skin cancers, which often occur at a young age.

Figure 3.11: Stakeholder perspectives on the need for genetic screening

[69] Lee, YC., Dow, E., Mileshkin, L., Peey SK., Robledo, KP, Barnes, EH, Friedlander, M., Yip, S., Smith, D., Spurdle, AB, Cummins, M., Andrews, J., Stockler, MR., and Antill, Y., Australia New Zealand Gynaecological Oncology Group (ANZGOG), Follow up implications of mismatch repair deficient endometrial cancer in the PHAEDRA trial.

3.7 Barriers to comprehensive molecular profiling

As explained in Chapter 1, the last 15 years have seen tremendous advances in the understanding of uterine cancers, leading to a paradigm shift in treatment methods, spearheaded by a focus on molecular biology and precision medicine. An increasing focus on molecular profiling of cancer patients is now part of a broader shift to a precision medicine paradigm, encompassing everything from the selection of treatment (including alternative treatments that maintain a woman's fertility) to the use of targeted immunotherapy, to a focus on limiting the toxicity of treatment.[70]

In spite of the benefits evident in precision medicine, however, very few uterine cancer patients in Australia and Aotearoa New Zealand undergo comprehensive molecular profiling.

Estimates of genomic testing rates in Australia provided by NGOR indicate that while most women do receive dMMR testing (98 per cent of women), which is MBS funded, testing for other potential precision medicine biomarkers is substantially less, with initial NGOR[71] estimates showing that:

- 76 per cent of women receive ER/PR testing
- 40 per cent of women receive P53 testing
- Only 2.7 per cent of women receive *POLE* testing.

Similarly, in Aotearoa New Zealand, while MMR testing is recognised as best practice for endometrial cancers, molecular profiling for other mutations beyond MMR testing was reported to be limited.[72]

This gap means that, more often than not, uterine cancer patients do not receive a complete diagnosis of their specific uterine cancer molecular sub-type. While many women will be cured through surgery, a significant number of women will experience a more advanced form of the disease and may benefit from access to novel treatments.

The slow adoption of best practice technologies in routine clinical practice arises from significant barriers to research translation; these barriers include:

- Lack of funding for routine genomic testing recommended for all women newly diagnosed with uterine cancer
- Gaps in knowledge for interpreting test results and complex genomic data
- High costs and limited reimbursement for comprehensive molecular profiling
- Lack of resources and systems for patient consenting and sample collection, particularly in resource-constrained healthcare settings
- Limited treatment options if drugs and drug combinations are not available for a specific patent (which is why funding for research is needed).

Fundamentally, Australia lacks a coordinated framework and translational pipeline for molecular data to drive best treatment into routine care, such that innovation in

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[70] The Cancer Genome Atlas (TCGA) has collected samples to molecularly categorise 33 different types of cancer, including uterine cancer. Through this analysis, TCGA was able to identify four molecular subtypes of endometrial cancer, which provide clinicians with crucial information on a woman's likelihood of survival, as well as helping to identify a treatment regimen that improves her long-term quality of life. The Proactive Molecular Risk Classifier for Endometrial Cancer (ProMisE) has also been developed, confirmed and validated according to the Institute of Medicines algorithm with four genomic subgroups with distinct clinical outcomes identifiable. This model, using IHC assessment for p53 and MMR expression together molecular testing for POLE and has been validated for applicability in standard cancer centre practice. For endometrial cancers with more than one molecular subgroup (~3%), ProMisE is able to best classify for the predominant feature.

[71] NGOR initial data estimates for uterine cancer 2023-2025.

[72] Naqisio, S. L. S., Moses, J. et al. (2024). Universal screening for Lynch syndrome in endometrial cancer diagnoses in Auckland, Aotearoa New Zealand: The initial experience. Australian and Aotearoa New Zealand Journal of Gynaecological Oncology. February 2025: 65(1): pp. 47–54. https://doi.org/10.1111/ajo.13857

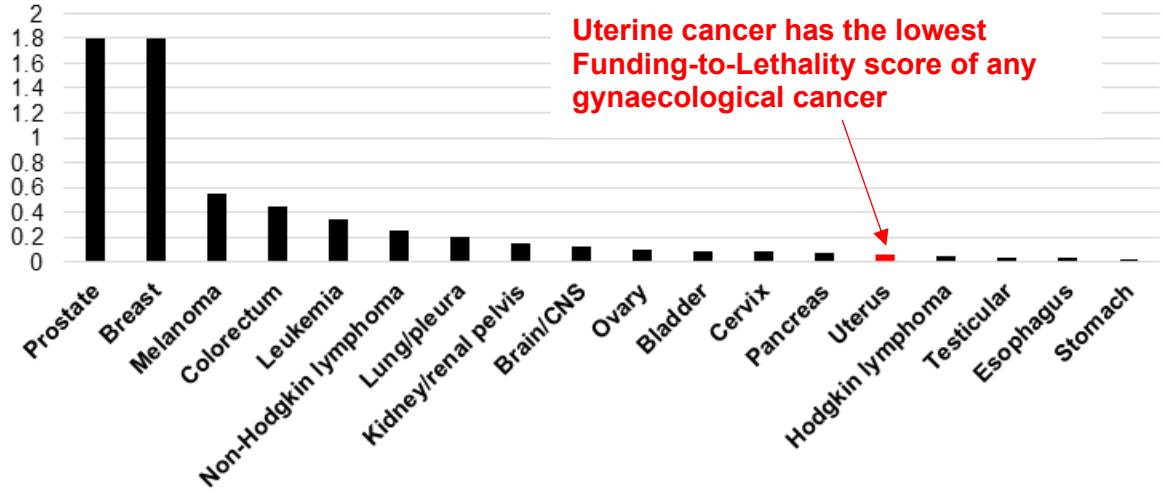
personalised testing and treatment is failing to be harnessed to provide benefit, particularly to women.

3.8 Underinvestment in research

Low public awareness of uterine cancers has been accompanied by a lack of interest among grant-awarding bodies and even historically among leading gynaecological oncology researchers, as well as the pharmaceutical industry. This is reflected in a smaller share of research funding than is warranted by the rising incidence and mortality.

For instance, the United States' National Cancer Institute demonstrated, through its 'Funding to Lethality' scores, that funding for uterine cancer has been significantly lower than other cancers, both historically,[73] and more recently, with a significant disparity in funding allocation in the eight years to 2014 (Figure 3.12).[74] This dearth of funding has continued, in spite of increasing incidence and mortality, particularly for disadvantaged women.[75]

Figure 3.12: National Cancer Institute (US) Funding-to-Lethality Scores (2007-2014)



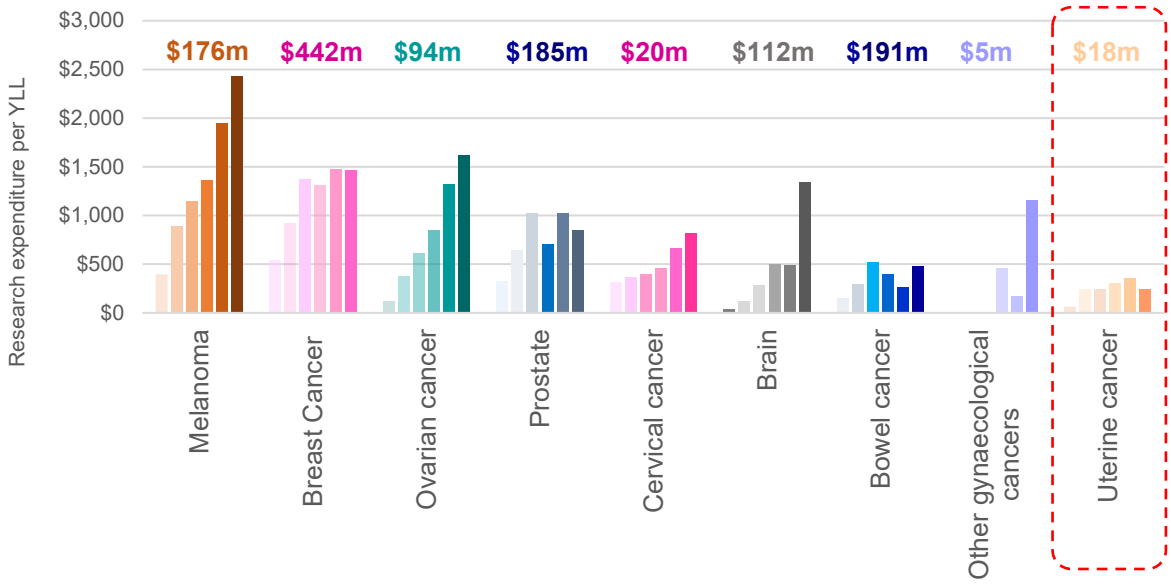
Source: Spencery, R.J. (2019). Disparities in the allocation of research funding to gynaecologic cancers by Funding to Lethality scores, Gynecologic Oncology, Volume 152, Issue 1, 106 - 111

These global investment patterns of underinvestment in uterine cancer have also been repeated here at home in Australia and New Zealand. In fact, investment in uterine cancer research has been stagnant since 2006, and funding for the 2018-2020 period was lower than the prior three years. Between 2003 and 2020, uterine cancer was among the poorest funded cancers, receiving less in direct funding than melanoma, breast, prostate, brain and bowel cancer, as well as other gynaecological cancers like ovarian and cervical cancer (Figure 3.13).

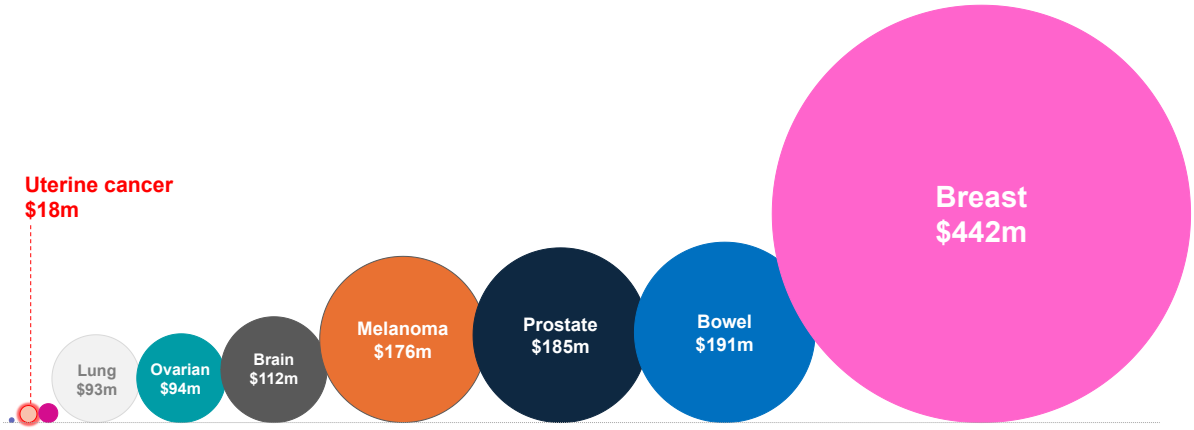
[73] Carter, AJ, and Nguyen, CN, 2012, A comparison of cancer burden and research spending reveals discrepancies in the distribution of research funding, BMC public health, 12, 526. doi: 10.1186/1471-2458-12-526.
[74] Spencery, R.J. (2019). Disparities in the allocation of research funding to gynecologic cancers by Funding to Lethality scores, Gynecologic Oncology, Volume 152, Issue 1, 106 - 111
[75] Katcher, A. et al. (2024). Research funding disparity in uterine cancer: An analysis of funding and race in relation to the burden of disease, Gynecologic Oncology, Volume 190, S70 - S71

Figure 3.13: Australian underinvestment in uterine cancer

Expenditure per Years of Life Lost (YLL) through time (columns from left to right show 2003-2005, 2006-2008, 2009-2011, 2012-2014, 2015-2017, 2018-2020 funding), with total funding from 2003-2020 reported above each cancer



Aggregate expenditure 2003-2020



Notes: The columns present a simple ratio of direct research funding reported for each of the following time periods 2003-2005, 2006-2008, 2009-2011, 2012-2014, 2015-2017, 2018-2020, relative to the number of YLLs estimated by the AIHW in 2022 for each cancer. Source: Insight Economics reporting of Cancer Australia. (2023). Cancer Research in Australia: https://www.canceraustralia.gov.au/sites/default/files/publications/cancer-research-australia-overview-funding-cancer-research-projects-and-programs-australia-2012-2020/pdf/cancer_of_funding_for_cancer_research_projects_and_programs_in_australia_2012_to_2020_final.pdf, and AIHW.

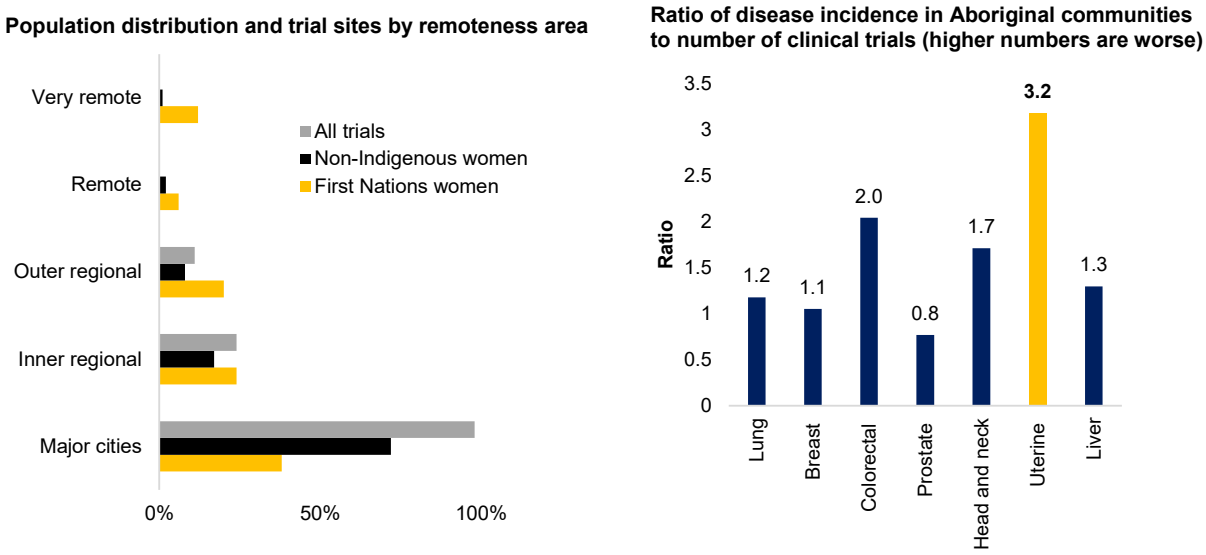
The result is that nearly every woman who dies of uterine cancer cannot be saved today; research is needed to develop new therapeutic approaches to overcome these barriers.

Added to this, funding for research and the collection and storage of data on First Nations peoples has been woefully underserved, especially in an Australian context. As can be seen in Figure 3.14, Aboriginal and Torres Strait Islander women in Australia are underrepresented in clinical trials, compared to non-indigenous women, especially in major population centres. This can inhibit the quality of research conducted on Aboriginal and Torres Strait Islander women, making it more difficult for researchers and policymakers to gather useful

research. At present, there is no research on how the genetic makeup of indigenous women might lead to unique risk factors facing these women.

Furthermore, there is a systemic lack of availability for Aboriginal and Torres Strait Islander health data. Recent reforms to indigenous data governance, focusing on data sovereignty and inclusivity, are important changes for self-determination and empowerment of Indigenous communities; at the same time, it can be difficult for non-indigenous groups, including researchers and policymakers, to access and use these data. This poses an even greater challenge in closing the gap for uterine cancer-related outcomes, as access to data is important in both policy design and tracking against goals.

Figure 3.14: Barriers to participation in clinical trial for priority populations



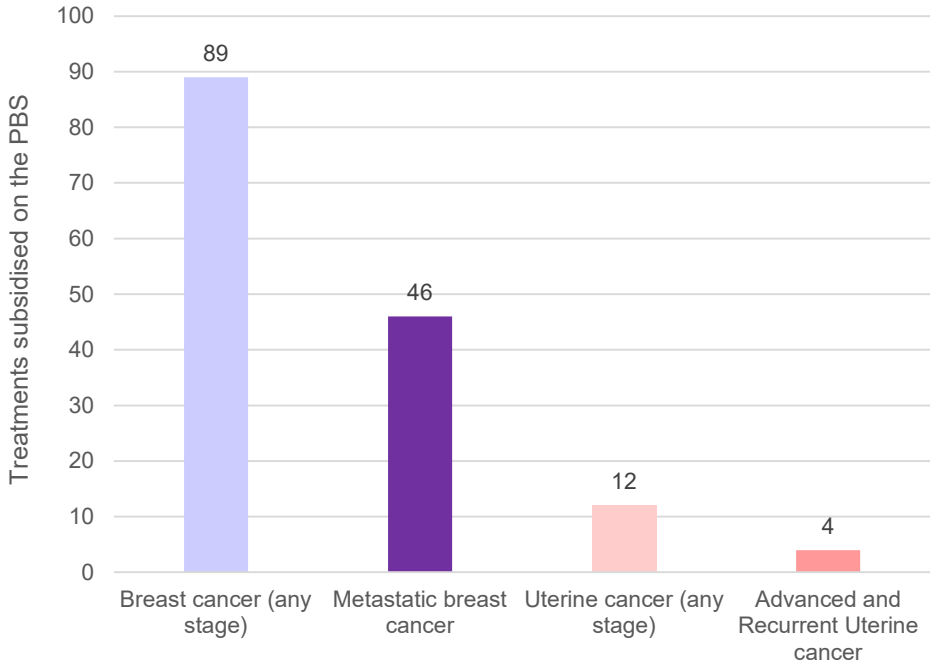
Source: Cunningham & Garvey, 2021, Are there systematic barriers to participation in cancer treatment trials by Aboriginal and Torres Strait Islander cancer patients in Australia? Aust NZ J Public Health. 2021; 45:39-45; doi: 10.1111/1753-6405.13059

3.9 Limited treatment options for advanced, recurrent and metastatic uterine cancer

This underfunding for uterine cancer research has translated into few treatment options for women diagnosed with a uterine cancer compared to other common cancers impacting women. Analysis of treatment options for Australian women diagnosed with breast cancer compared to women diagnosed with uterine cancer, for example, shows that women with breast cancer have more than *seven times* as many treatment options as women with uterine cancer, and that women diagnosed with metastatic breast cancer have *11.5 times* the number of treatment options as women with advanced uterine cancer (See Figure 3.15). This is the product of significantly more investment in research to identify new therapies for breast cancer than has occurred in uterine cancer.

Taken together, this points to a need to invest in research, to expand treatment options, attract clinical trials to Australia and Aotearoa New Zealand, to gain access to the emerging pipeline of new therapies and to ensure Health Technology Assessments (HTA) pathways are streamlined to allow for timely access to therapies as evidence is developed.

Figure 3.15: Understanding the impact of underfunding of research on treatment options - comparing treatment options for women with breast cancer to treatment options for women with uterine cancer



Source: eviQ. (2025). Medical oncology, breast cancer and uterine cancer, accessed at: https://www.eviq.org.au/medical-oncology.

3.10 Delays to accessing novel treatment approaches for advanced, recurrent and rare cancers

Complicating the landscape for women living with uterine cancer in Australia and New Zealand is a lack of access to novel therapies that are standard of care in other developed nations like the UK, United States, Canada and Europe.

In Australia and Aotearoa New Zealand, drugs like carboplatin and paclitaxel are subsidised through the Pharmaceutical Benefits Scheme (PBS). These drugs are recognised the most effective chemotherapies for the treatment of advanced endometrial cancer, especially among dMMR patients, and have been shown to improve survival among patients.[76,77]

In recent months, there have also been approvals for immune checkpoint-inhibitor therapies in first line settings and in combination with platinum-based chemotherapies, but this has been limited to those tumours with dMMR.

Beyond this, the only other medication that has been approved in Australia is the combination of pembrolizumab with lenvatinib as a second line therapy regardless of dMMR status; in New Zealand this therapy is not funded through the Community Schedule. This is significantly limited to the treatment options available in other parts of the developed world (Table 3.1). Women with uterine cancer in the US, UK and Canada, for example, have funded access to a greater number of targeted therapies.

[76] Pectasides, D., Xiros, N., et al. (2008). Carboplatin and Paclitaxel in advanced or metastatic endometrial cancer. Gynaecol Oncol. May 2008. 109(2). https://doi.org/10.1016/j.ygyno.2008.01.028
[77] Miller, D. S., Filiaci, V. L., et al. (2020). Carboplatin and Paclitaxel for Advanced Endometrial Cancer: Final Overall Survival and Adverse Event Analysis of a Phase III Trial (NRG Oncology/GOG0209). Journal of Clinical Oncology. September 2020. 38(33). https://doi.org/10.1200/JCO.20.01076

Table 3.1: Therapies approved for use in Australia and comparator nations: Endometrial cancer

	UK	USA	Canada	Aus	NZ
Pembrolizumab with carboplatin and paclitaxel	✓	✓	✓	×	×
Dostarlimab with platinum-based chemotherapy – MSI-high or dMMR only	✓	✓	✓	✓	×
Pembrolizumab - MSI-high or dMMR only	✓	✓	✓	✓	×
Pembrolizumab plus lenvatinib	✓	✓	✓	✓	×
Durvalumab – dMMR only	✓	✓	✓	✓	✓*

Note: Durvalumab is listed on the Community Schedule as an Authority listing and does not have exclusion for uterine cancer.
Source: NICE Technical Appraisal Guidance, (2025). Endometrial cancers, accessed at: https://www.nice.org.uk/guidance/conditions-and-diseases/cancer/endometrial-cancers/products?GuidanceProgramme=guidelines&Status=Published&GuidanceProgramme=TA; National Cancer Institute. (2024. More Immunotherapy Options Approved for Treating Endometrial Cancer, https://www.cancer.gov/news-events/cancer-currents-blog/2024/endometrial-cancer-durvalumab-pembrolizumab-chemotherapy; Health Canada. (2025). Drug and Health Product Portal, https://dhpp.hpfb-dgpsa.ca/review-documents?search=endometrial+cancer; eviQ. (2025). https://www.eviq.org.au/medical-oncology/gynaecological/endometrial; PHARMAC. (2025). Community schedule, Pembrolizumab accessed at https://schedule.pharmac.govt.nz/2025/09/01/SA2498.pdf.

Ensuring Australian and Aotearoa New Zealand women have access to novel therapies, through streamlined regulatory access and investments in clinical trials, is critical to improving outcomes for women with advanced, rare and recurrent cancers and addressing the significant gaps in access between Australia and Aotearoa New Zealand and the rest of the world.

3.11 Delays in time to treatment

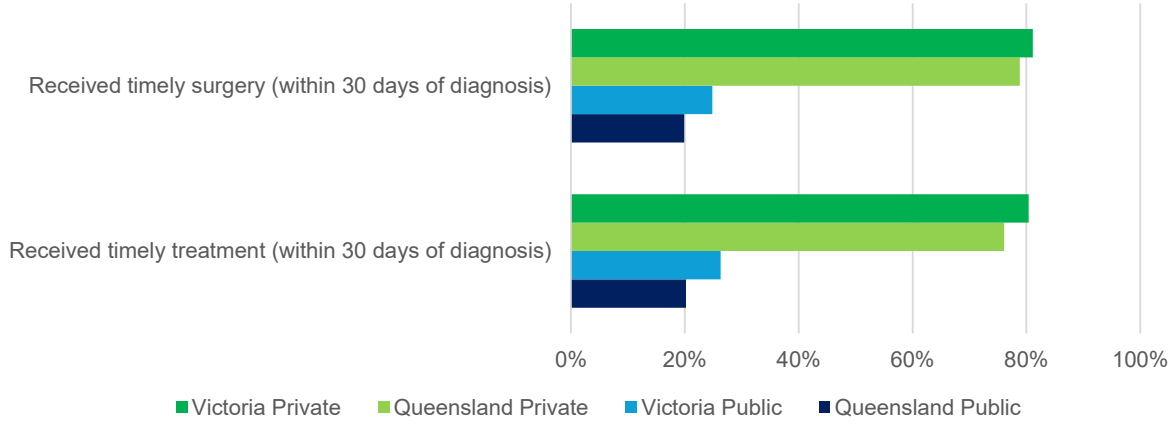
There are very limited data on patterns of clinical care, with Victoria and Queensland being the only two jurisdictions providing information on patterns of clinical care. These data suggest that:

- Women receiving treatment in the public sector are less likely to receive care in line with clinical targets (Figure 3.16)
- Women living in regional areas are also more likely to experience longer delays to treatment (Figure 3.17).

The data suggest there is also some degree of variation in treatment timing from state to state. Between 2017 to 2021, 52 per cent of all Victorian uterine cancer patients received treatment within 30 days, and 51 per cent received surgery. These numbers are both higher than the rate in Queensland, where only 48 per cent of patients received treatment within 30 days, and only 46 per cent received surgery.[78]

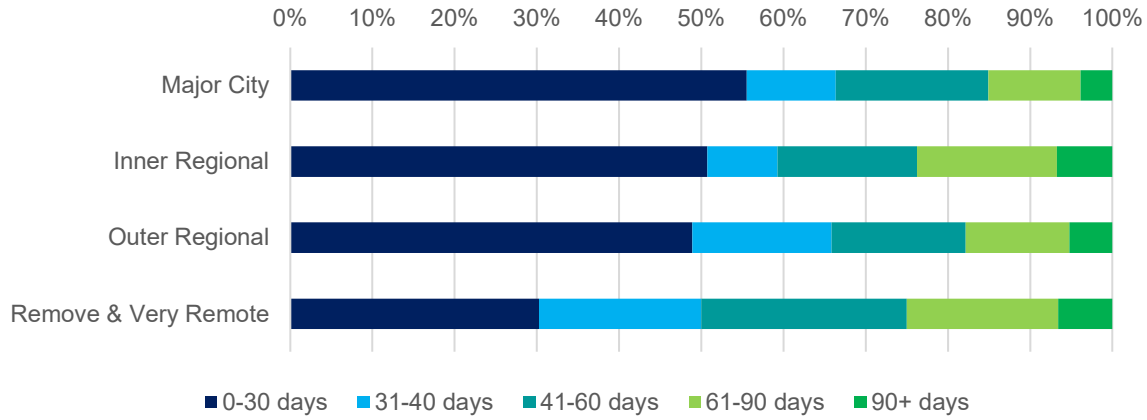
[78] Queensland Cancer Data Alliance. (2025). Uterine Cancer Quality Index: Practice indicators of safe, quality cancer care, public and private hospitals 2013 to 2022 and Victorian Integrated Cancer Services. (2024) Victorian Optimal Care Summits: Prioritisation of Unwarranted Variations in Endometrial Cancer.

Figure 3.16: Proportion of women receiving treatment within 30 days of diagnosis, Victoria and Queensland



Source: Queensland Cancer Data Alliance and VICS Optimal Care Summit report

Figure 3.17: Queensland uterine cancer patients who receive treatment within a band of time, by remoteness



Source: Queensland Cancer Data Alliance and VICS Optimal Care Summit Report.

Further, these outcomes have not improved in recent years, based on available data; rather, in some instances, outcomes have gotten worse. In Queensland, the proportion of uterine cancer patients who received treatment within 30 days of diagnosis was higher in the period 2013-17 (56 per cent) than in the period 2018-22 (51 per cent). These statistics are echoed in Victoria, where women diagnosed with high-grade tumours in 2013-17 had a median waiting time of 27 days between diagnosis and treatment, compared to 30 days among women diagnosed in 2018-22. In some regional areas, this gap is particularly pronounced.

Alongside the unwarranted variation experienced by women based on location, there are other factors that are strongly correlated with barriers to receiving timely treatment. In Queensland, from 2013-2022, only 29 per cent of Aboriginal and Torres Strait Islander Queenslanders waited fewer than 30 days from diagnosis to treatment, compared to 54 per cent among other Queenslanders.[79] Furthermore, 29 per cent of Aboriginal and Torres Strait Islander women had to wait longer than 60 days to be treated.

[79] Victorian Integrated Cancer Services. (2024) Victorian Optimal Care Summits: Prioritisation of Unwarranted Variations in Endometrial Cancer.

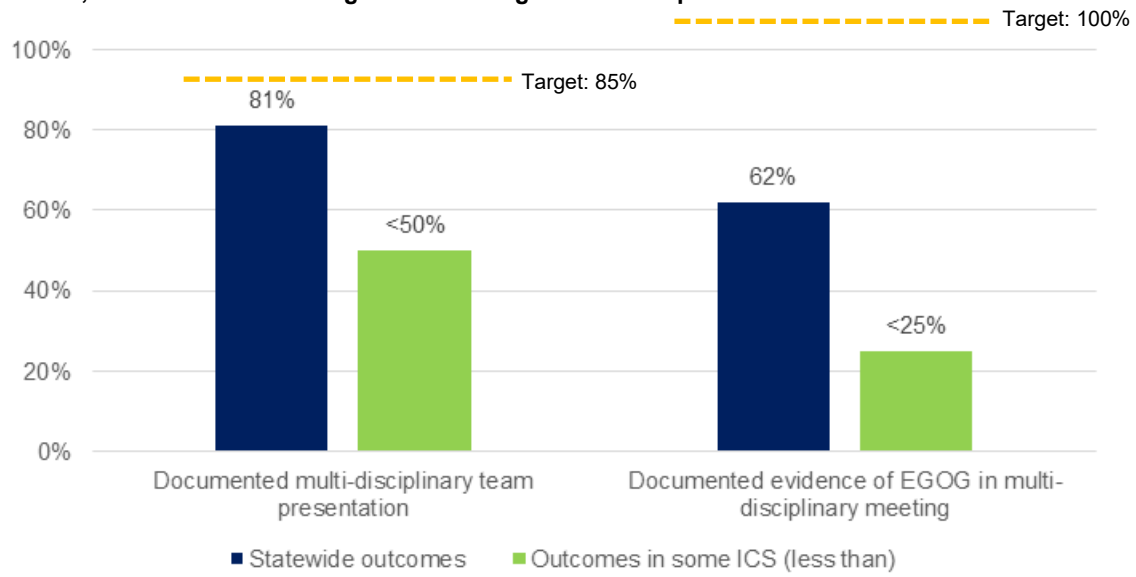
Moreover, 70 per cent of affluent Queenslanders receive treatment within 30 days of diagnosis, independent of where in the state they are located. This rate falls off quickly among women in lower socioeconomic groups, with only 54 per cent middle-income women and less than half (44 per cent) of disadvantaged women receiving timely treatment.

3.12 Variation in access to MDTs

A multi-disciplinary team (MDT) is a group of medical professionals who coordinate care for patients. Australian and Aotearoa New Zealand governments both consider multidisciplinary care to be best practice in the planning of treatment and care for patients with cancer. Again, while data are limited, with only Victoria reporting outcomes on rates of MDTs, these data, combined with stakeholder interviews, indicate there is variation in the utilisation and outcomes of multidisciplinary teams in treating uterine cancer patients.

Victorian data suggest these variations are most pronounced in regional areas; there are some regional health areas (Integrated Cancer Services of ICS regions) where rates were less than 50 per cent (Figure 3.18).

Figure 3.18: Utilisation of MDTs, and sharing of patient status within multi-disciplinary meetings in Victoria, statewide outcomes against state target and worst performers



Source: Victorian Integrated Cancer Services. (2024) Victorian Optimal Care Summits: Prioritisation of Unwarranted Variations in Endometrial Cancer.

3.13 Variation in diagnostics and treatment: 'Treatment by postcode'

Clinical stakeholders significant expressed consistent concern that within Australia there is significant variation in clinical practice along the care pathway. While clinical guidelines for uterine cancer were first developed in 2012 and last updated in 2020, these guidelines are now considered to be out of date and subject to significant variance in interpretation.

The lack of guidelines was reported to contribute to significant variation in clinical practice across Australia (Figure 3.19); Key examples included:

- *Diagnostic work-up* — While potentially not impacting on oncological outcomes, stakeholders noted there were substantially different approaches with varying exposure to radiation involved in the diagnosis of uterine cancer across Australia and Aotearoa New Zealand

- *Access to fertility preservation* — Despite the fact that most women diagnosed with uterine cancer are still post-menopausal, more and more younger women are receiving diagnoses, making fertility preservation a more pressing concern. In spite of this, only 15 per cent of young women with cancer undergo fertility preservation before treatment.[80] Moreover, in the VICS survey introduced above, 29 per cent of respondents had identified lack of access to fertility prevention as an unwarranted variation in care.[81]
- *Access to weight management, exercise and nutritional support* — Weight management is not properly incorporated into the care strategy for women with uterine cancer. For example:
  - In a survey of Victorian patients, more than half of respondents (51 per cent) felt that access to bariatric surgery was a key unwarranted variation to people with endometrial cancer in Victoria.[82] Clinicians and care providers found that the lack of access to weight loss management and a streamlined process to include obesity management in the care pathway made it difficult to optimise care for endometrial cancer patients who will often have comorbidities related to obesity and cardiovascular disease.
  - Similarly, almost 19 per cent of respondents to the Insight Economics survey indicated that weight management was not discussed with them at treatment planning, even though they wish it had been. Additionally, more than 70 per cent of respondents for whom weight management was identified as a relevant concern also identified barriers that prevented them from accessing weight support services, including 54 per cent who were simply not offered the service. Stakeholders also suggested that variation in the treatment provided to patients is widespread
- *Use of adjuvant therapies* — There was strong consensus that a major area of need was the development of evidence-based best practice for adjuvant therapy, with some clinicians concerned women were being unduly exposed to treatments that may carry higher risk of long-term side effects for little clinical benefit. Comprehensive molecular profiling, especially accompanied by *POLE* testing, can play an important role in adjuvant treatment de-escalation.
- *A lack of adoption of the molecular classification system* — Even as molecular profiling has become best practice for the diagnosis and treatment of women with uterine cancer to for allow appropriate treatment planning in early and advanced disease, NGOR data and clinicians indicated that it is inconsistently used in practice.
- *Follow-up* — Consumers at the roundtables in particular expressed consistent concern for significant and anxiety-inducing variation, which clinicians agreed was an important area of need. Clinicians also highlighted that a more consistent approach to risk-based follow-up could free up resources to be redirected to high-value survivorship care.

These variations give rise to concerns that women may not be consistently able to access best practice treatment and care.

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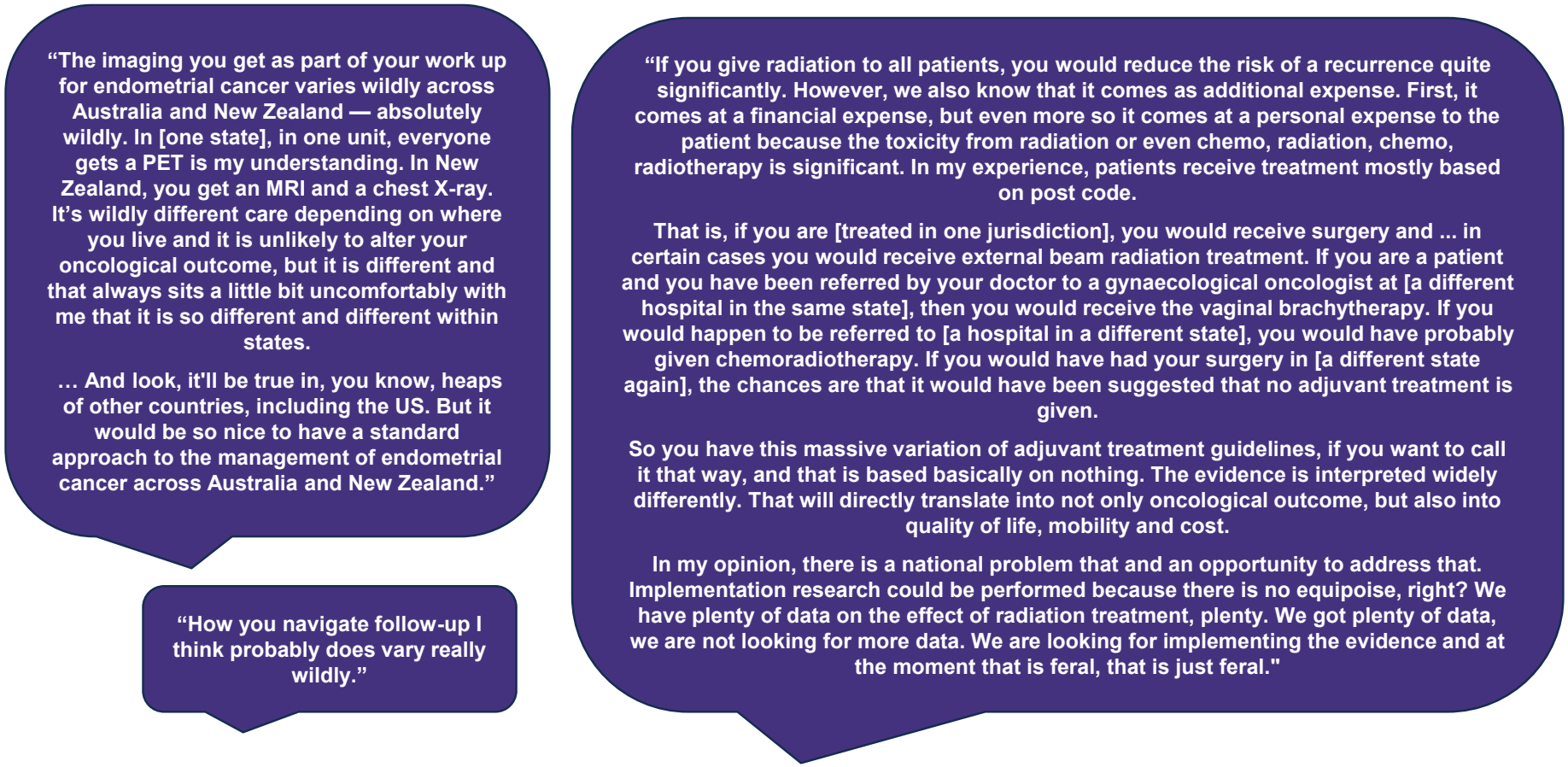
[80] Victorian Integrated Cancer Services. (2024). Review of the Current Evidence. Accessed at: https://cms.vics.org.au/wp-content/uploads/2024/12/VICS-REPORT_Optimal-Care-Summits-endometrial-cancer-lit-review_Nov-2024.pdf

[81] Victorian Integrated Cancer Services. (2024). Victorian Optimal Care Summits: Endometrial Cancer Barriers, Enablers, and Preferences Survey. Accessed at: https://cms.vics.org.au/wp-content/uploads/2024/09/VICS-REPORT_Endometrial_Cancer_Barriers_Enablers_Preferences_-2024.pdf

[82] Victorian Integrated Cancer Services. (2024). Victorian Optimal Care Summits: Endometrial Cancer Barriers, Enablers, and Preferences Survey. Accessed at: https://cms.vics.org.au/wp-content/uploads/2024/09/VICS-REPORT_Endometrial_Cancer_Barriers_Enablers_Preferences_-2024.pdf

Figure 3.19: Stakeholder perspectives – Variation in clinical practice



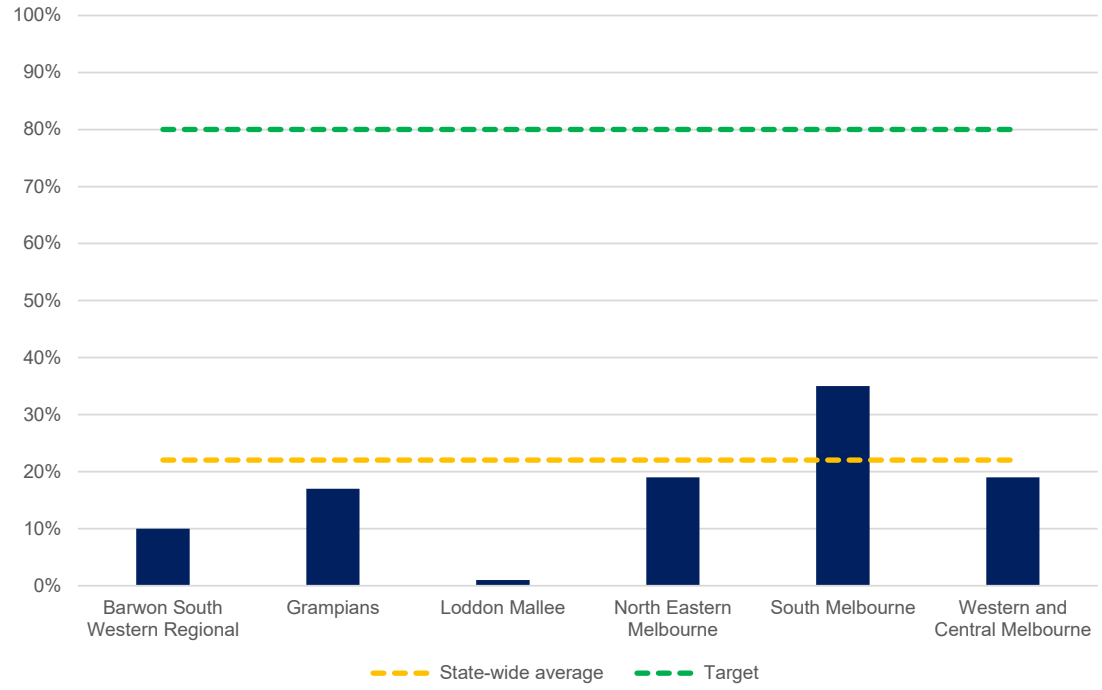
Source: Insight Economics stakeholder consultations

3.14 Barriers to supportive care

In addition to variation and inequity in treatment, access to supportive care, which encompasses all aspects from diagnosis to beyond the completion of treatment to improve survivorship and quality of life, is also inconsistent, inadequate and inequitable.

Again, while data are limited, analysis of Victorian clinical data found that the average rate of screening across Victoria was only 22 per cent, against the state target of 80 per cent (Figure 3.20).[83] In some areas, such as Loddon Mallee, this rate reached as low as 1 per cent. If these trends hold true across the country, and in Aotearoa New Zealand, this suggests many women are not being screened for supportive care needs who would otherwise benefit from receiving such support. Stakeholders indicated this was consistent with wider patient experience.

Figure 3.20: Rates of supportive care screening completed and documented for endometrial cancer patients in Victoria, by region, 2020-22.

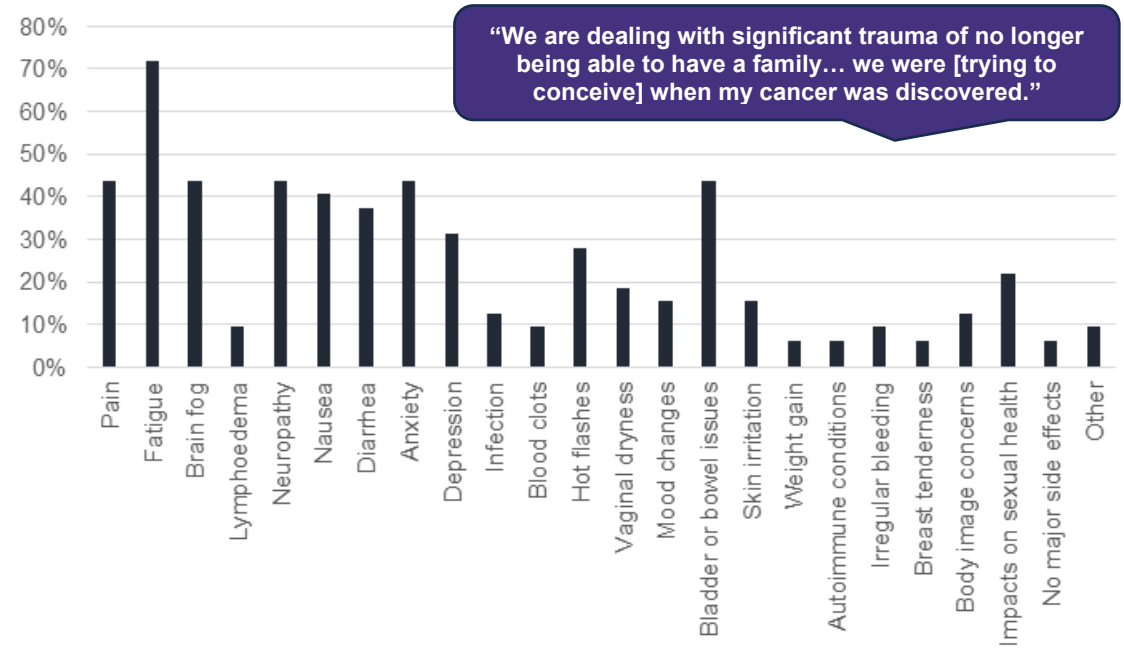


Source: Victorian Integrated Cancer Services

This is concerning because while many women can be cured through surgery with a low symptom burden following treatment, many women experience side effects following treatment. For example, Figure 3.21 demonstrates the prevalence of side effects among uterine cancer patients and carers, collected through Insight Economics' survey as part of this report. Based on these data, only six per cent of uterine cancer patients experienced no major side effects. Conversely, 72 per cent of uterine cancer patients experienced fatigue through their treatment journey, while almost half experienced some pain, brain fog, neuropathy and anxiety, as well as bladder or bowel issues.

[83] Graham, F., Hyde, S., et al. 2025. Unwarranted variations in Victorian endometrial cancer care – a comparative analysis between 2013-17 and 2018-22. Victorian Integrated Cancer Services.

Figure 3.21: Side effects experienced by women with uterine cancer



Source: Survey of Patients and Carers Living with Uterine Cancer

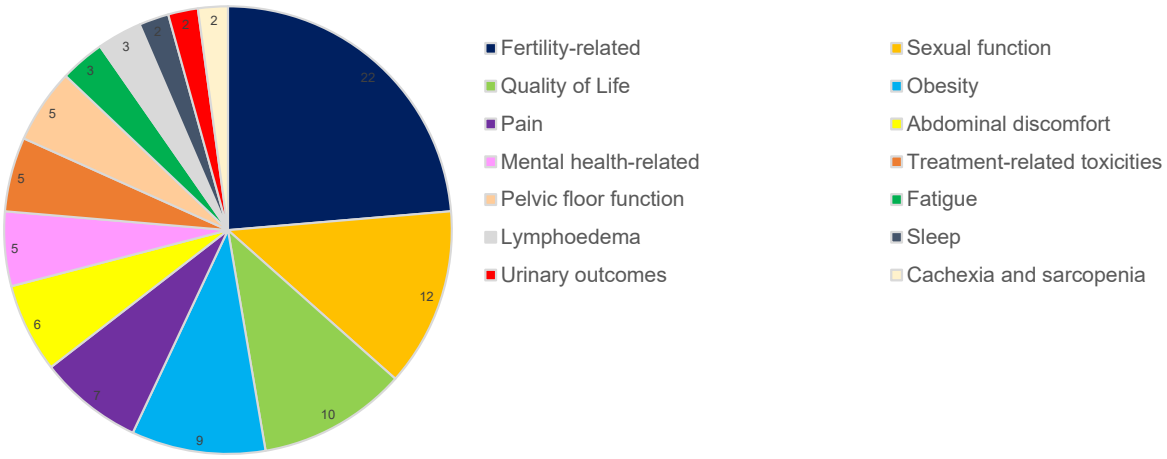
These survey data also broadly accord with other research on the types of side effects that may benefit from supportive care. For example, a study called EmQuest[84] indicated that many women treated for endometrial cancer can experience a high symptom burden following the completion of treatment.[85] Forty-six per cent of women participating in the study reported experiencing ongoing neuropathy, and 20 per cent reported this to be moderate to severe. Additionally:

- 25 per cent reported mild-moderate depression
- 29 per cent reported experiencing mild-moderate anxiety
- 3 per cent reported experiencing severe anxiety
- 20 per cent reported moderate to severe insomnia.

Similarly, a report commissioned by ANZGOG evaluated major survivorship-related issues facing women with endometrial cancer. The report used existing endometrial cancer literature to develop and prioritise survivorship issues relevant in the literature. This analysis found fertility-related concerns to be the most commonly investigated survivorship issue in published research, followed by sexual function, quality of life and obesity (Figure 3.22).[86] Other major survivorship issues frequently investigated included pain, abdominal discomfort, mental-health related issues and treatment-related toxicities. The report concluded that current data is limited in both quality and quantity, restricting the ability of clinicians, researchers and policymakers to understand the concerns of women who experience endometrial cancer.

[84] ANZGOG. (2025). New survey seeks experiences of endometrial cancer survivors, accessed at: https://www.anzgog.org.au/emquest-survey/
[85] Burdett, N., Wilson, M, McQuire, L., Xie, J., Campbell, R., King, M., and Mileshkin, L. (2025), EmQuest – Identifying factors health-related quality of life deficits and increased symptom burden in women who have been treated for endometrial cancer.
[86] DiSipio, T.; Turner, J.; Da Silva, W.; Driscoll, E.; Preston, M.; Tran, K.; Varnier-Lui, N.; Yeoh, H.-L.; Kaur, D.; Alsop, K.; et al. Understanding Contemporary Endometrial Cancer Survivorship Issues: Umbrella Review and Healthcare Professional Survey. Cancers 2025, 17, 2696. https://doi.org/10.3390/cancers17162696

Figure 3.22: Survivorship issues reported in reviews between 2013-2023



Source: Spence, R. et al. (2024). Identifying the contemporary survivorship issues among women diagnosed with endometrial cancer: an overview of reviews, ANZGOG and DiSipio, T.; Turner, J.; Da SSilva, W. Driscoll, E., Preston, M., Tran, K., Varnier-Lui, N., Yeoh, H.-L., Kaur, D., Alsop, K., et al. (2025). Understanding Contemporary Endometrial Cancer Survivorship Issues: Umbrella Review and Healthcare Professional Survey. Cancers, 17, 2696. https://doi.org/10.3390/cancers17162696.

The study also surveyed healthcare providers to identify survivorship issues to be relevant to endometrial cancer survivors. More than 85 per cent of healthcare providers indicated the following survivorship issues were relevant:[87]

- Body weight/obesity
- Fatigue
- Sleep quality
- Pelvic floor function
- Sexual function
- Functional wellbeing
- Emotional wellbeing
- Physical wellbeing
- Sexual wellbeing
- Social wellbeing
- Anxiety
- Depression.

Participants in consumer roundtables expressed significant frustration with the lack of information, screening and support (Figure 3.23).

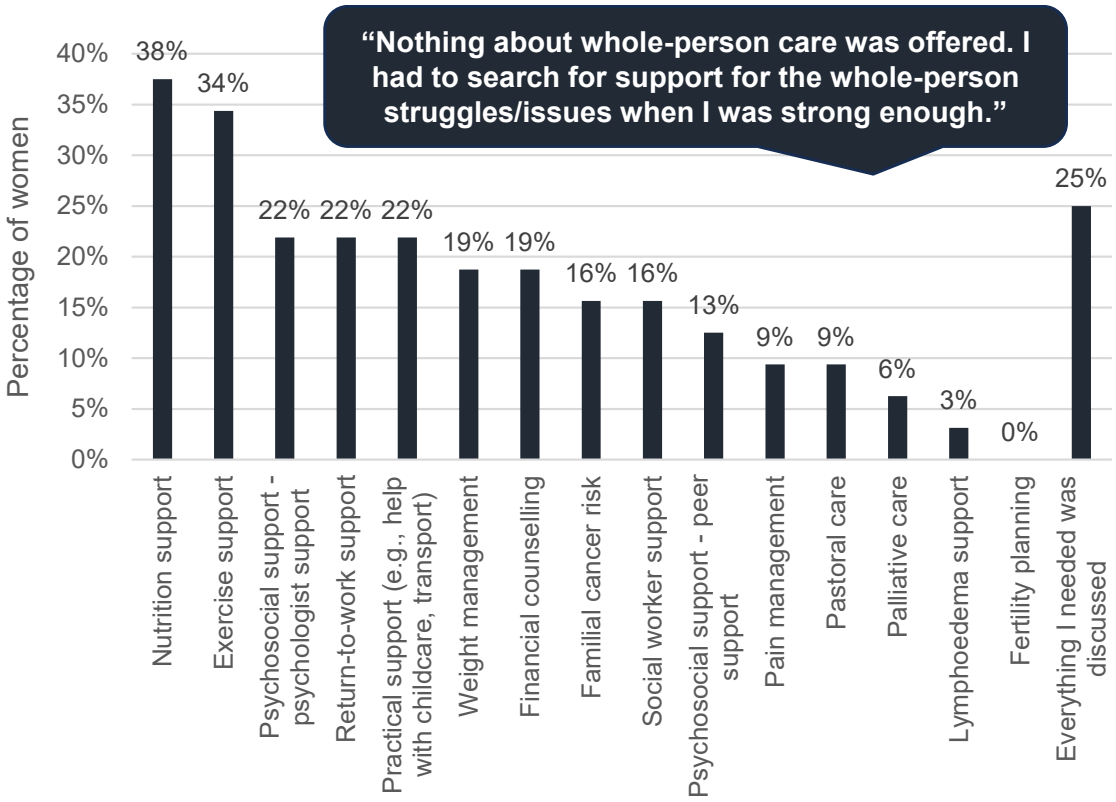
[87] DiSipio, T.; Turner, J.; Da Silva, W.; Driscoll, E.; Preston, M.; Tran, K.; Varnier-Lui, N.; Yeoh, H.-L.; Kaur, D.; Alsop, K.; et al. Understanding Contemporary Endometrial Cancer Survivorship Issues: Umbrella Review and Healthcare Professional Survey. Cancers 2025, 17, 2696. https://doi.org/10.3390/cancers17162696

Figure 3.23: Consumer perspectives – Inconsistent discussion of treatment options and potential side effects, barriers to understanding

Source: Insight Economics consumer roundtables

Respondents to the Insight Economics State of the Nation in Uterine Cancer Survey indicated that there were a range of services that women would have liked to access — particularly services to improve their long-term health. For example, 38 per cent and 34 per cent of respondents indicated they would have liked nutrition support and exercise support, respectively (Figure 3.24). Other supportive care women would have liked to have offered included psychologist support, return-to-work support and practical support. Only 25 per cent of women said everything they needed was discussed with them.

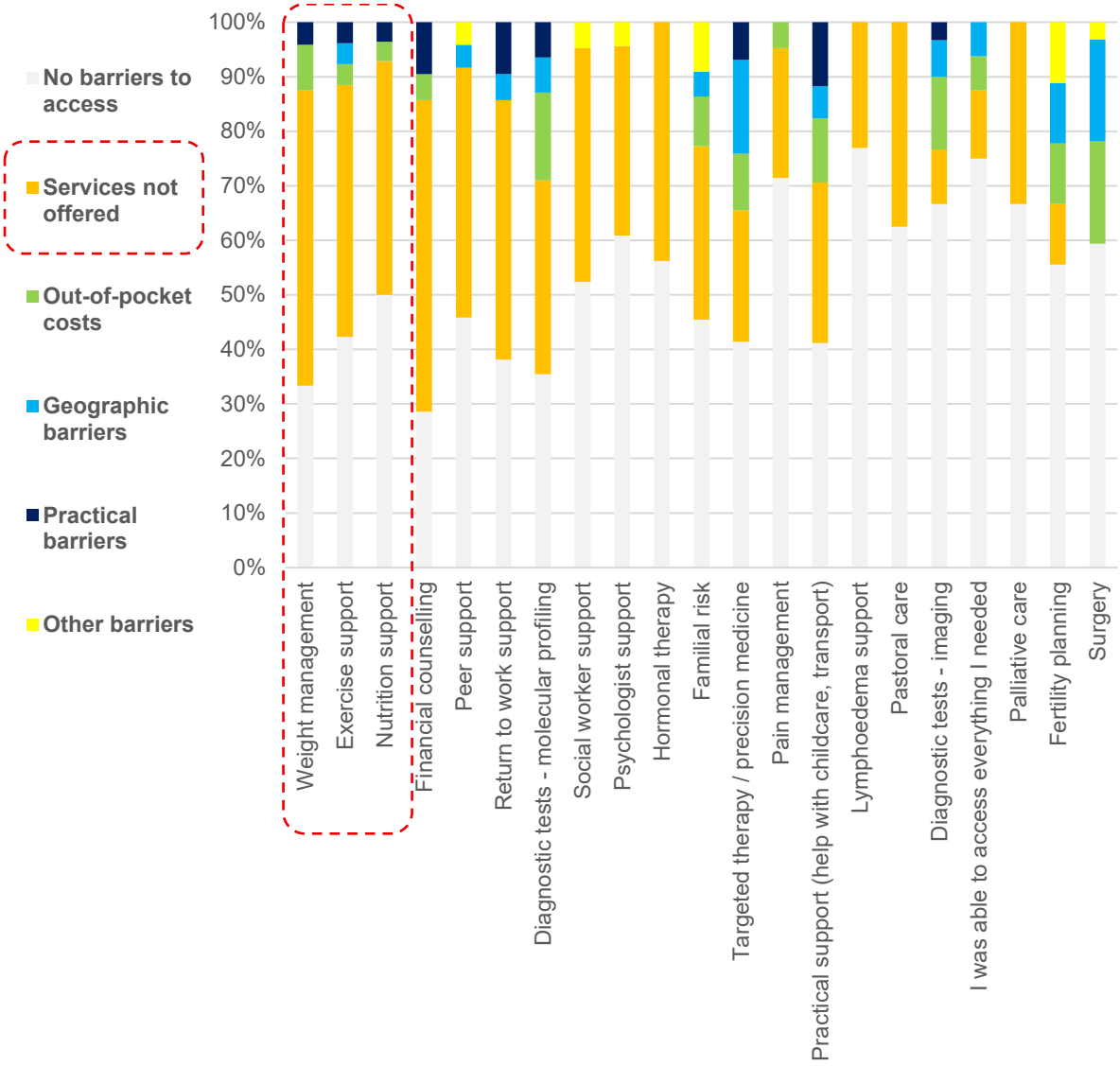
Figure 3.24: Support services not offered to women with uterine cancer



Source: Survey of women with uterine cancer; See Appendix B.

Beyond screening for supportive care, women also faced other barriers to accessing supportive care. The most common barrier to accessing support was that the service was not offered (Figure 3.25); other barriers included financial barriers (out of pocket costs) or practical barriers, such as organising childcare or transport. Taken together, these data suggest there are unmet needs among uterine cancer patients to improve their health following a uterine cancer diagnosis.

Figure 3.25: Barriers to accessing support services among women with uterine cancer



Source: Survey of Patients and Carers Living with Uterine Cancer

3.15 Lack of patient support and navigation services

Unlike ovarian and breast cancer survivors, women diagnosed with uterine cancer may not be able to access gynaecological cancer-specific patient support services.

In Aotearoa New Zealand, the model of care is such that every patient is referred to a cancer nurse following treatment; overall, access to nursing care was reported to be adequate in Aotearoa New Zealand. But in Australia, support was reported to be less consistent.

As a result, many uterine cancer survivors are unaware of why their cancer occurred, what options they have for care, and how to access those options. For many who are aware of the discrepancy in options available to patients with other cancers (e.g. ovarian cancer), this can leave them feeling frightened and overwhelmed about recommended treatments, or unaware of and therefore unable to access much needed services both during and after treatment.

In Australia, the Australian Government is developing the Australian Cancer Nursing and Navigation Program, which represents an important first step to improving nursing and

navigation support for women that have historically had limited access to support. The model of care is still in development at the time of writing this report, and stakeholders have indicated some concerns for the implementation of the Program, including risks of underinvestment in gynae nursing support, with a proposal for only three gynae-oncology nurses to be funded through the model to meet the needs of more than 7,000 women that will be diagnosed with gynaecological cancers every year.[88] It is likely that these roles will be supported through gynaecology specialist services; therefore, patients that receive care through general gynaecology services, rather than a gynae-oncologist, may miss out on support.

Currently, Ovarian Cancer Australia (OCA) stands out as the only real patient support organisation for a gynaecological cancer; however, its mission to date has been the support of only women with ovarian cancer. As a result, women diagnosed with uterine cancer do not have an equivalent supportive care service. For these women, the lack of support increases the risk of unnecessary suffering and poor health outcomes.

As can be found in Figure 3.26, survivors spoke to their experiences accessing patient support services and expressed a general difficulty in finding assistance to navigate treatment and supportive care pathways. Moreover, some areas simply did not have the right people or resources to be able to serve the women who needed to access support. However, when specialist gynae-oncology nurses were on hand, survivors emphasised how useful they can be in finding and arranging the best possible informed care. Researchers shared the sentiments of survivors, talking about a lack of patient support, leaving women feeling lost and abandoned.

[88] See ANZGOG, 2025, Gynaecological Cancer Transformation Initiative.

Figure 3.26: Consumer perspectives – More patient support to navigate health system, manage side effects is needed

Source: Insight Economics consumer roundtables

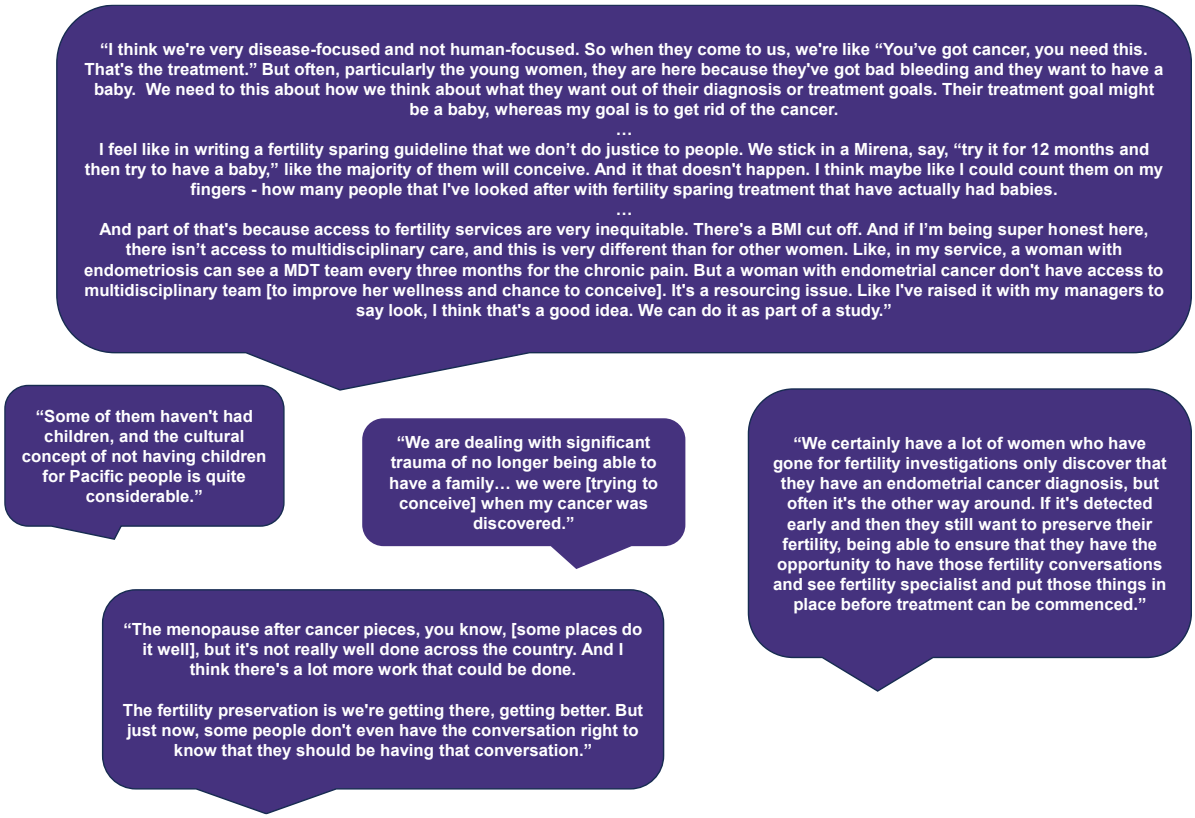
3.16 Barriers to fertility preservation services

Most of the treatments for uterine cancer present a risk to younger women's fertility. Radiotherapy and chemotherapy are highly detrimental to a woman's ovarian reserve and reproductive lifespan and can usually result in menopause or permanent loss of ovarian function. Hysterectomy leads to permanent infertility.

Cancer treatment in pre-menopausal women is associated with lower pregnancy and live birth rates, and women who undertake chemotherapy or radiotherapy are more likely to give birth pre-term. Despite this knowledge and the availability of fertility preservation services, [89] only 15 per cent of young cancer patients in Australia access specialised consultation and undergo fertility preservation before cancer treatment.[90]

As more young women are diagnosed with abnormal endometrial hyperplasia or early-stage endometrial cancer, there is an increasing need to consistently explore opportunities to bear children. Continued research is needed to optimise treatment planning in these women, but it is also clear that more work could be done to better support women that chose to seek pregnancy prior to surgery to achieve this treatment goal (Figure 3.27).

Figure 3.27: Stakeholder perspectives – Need for fertility planning in light of younger women being diagnosed



Source: Insight Economics consumer roundtables.

[89] Victorian Integrated Cancer Services. (2024). Understanding Endometrial Cancer Patient Experience in Australia: A Rapid Review of the Current Evidence. Accessed at: https://cms.vics.org.au/wp-content/uploads/2024/12/VICS-REPORT_Optimal-Care-Summits-endometrial-cancer-lit-review_Nov-2024.pdf

[90] The Royal Women's Hospital. (2025). Fertility preservation for children & young adults with cancer, accessed at: https://www.thewomens.org.au/health-professionals/womens-health-services/sexual-reproductive-health/reproductive-services-main/fertility-preservation-children-cancer

For endometrial cancer, treatment with hormonal therapies such as a progesterone implanted IUD has been found to be effective at helping young women with low-grade early-stage endometrial cancer to preserve fertility, regardless of her primary treatment regimen. [91] The more advanced the disease, however, the more difficult it is to preserve fertility during treatment. Additionally, women can opt to preserve their fertility through embryo and oocyte preservation, cryopreservation, and autografting.

But even when offered, many women that follow fertility sparing treatment can struggle to become pregnant. Many young women with abnormal endometrial hyperplasia or early-stage endometrial cancer also experience polycystic ovarian syndrome (PCOS) and anovulatory infertility, which makes them in need for assisted reproductive technologies to actively get pregnant. Women with a higher body weight may also require additional specialist supportive care services or surgery to realise her treatment goals, but unfortunately, access to fertility services may be restricted and is not always successful. Public fertility services require a BMI of under 35 as a criterion to accept a referral, due to likelihood of successful treatment, which can preclude women with higher body weight from being seen by a fertility specialist. Stakeholders indicated women with a higher body weight may not be eligible to access IVF under current criteria and may not receive the specialist support to improve her overall wellness to support conception.

Specialist support to improve wellness and access fertility support offers an important opportunity to improve quality of life for young women impacted by uterine cancer.

3.17 Barriers to culturally competent care

Outcomes for priority populations are consistently worse than for the general population; this is true for health care broadly, as well as for uterine cancer specifically.

Aboriginal and Torres Strait Islanders, wāhine Māori, Pacific women and other culturally and linguistically diverse groups of people may face a range of barriers some of which are shared and some of which are unique to their particular racial or cultural background. For example, Muslim women throughout the western world[92] (including in Australia)[93] experience lower rates of screening for breast and cervical cancers, due to language barriers, stigma around discussing women's genital health in Islamic communities, and cultural preferences for treatment (e.g. the need to be treated by a female care provider).

Among Aboriginal and Torres Strait Islander women, cultural barriers have been identified as a factor contributing to poor outcomes. For example, research has found that the knowledge, attitudes and beliefs held by Aboriginal and Torres Strait Islander people can have a negative impact on health seeking behaviours, such as engaging in prevention activities and in making decisions around cancer treatment.[94] In some cases, there may be a lack of knowledge around cancer and its causes, as well as feelings of shame around cancer and culturally unsafe health services.[95] A study of the provision of care to Aboriginal and Torres Strait Islanders in Queensland with gynaecological cancers found a pressing need for culturally appropriate, person-centred care.[96] Additionally, a study on the availability of

[91] Suzuki, Y., Ferris, J. S. et al. (2024). Fertility-preserving treatment for stage IA endometrial cancer: a systematic review and meta-analysis. Am J Obstet Gynecol. 2024 Dec;231(6):599-610.e17. doi: 10.1016/j.ajog.2024.07.018. Epub 2024 Jul 19. PMID: 39032722

[92] Islam, N., Patel, S., et al. (2017). Understanding Barriers and Facilitators to Breast and Cervical Cancer Screening among Muslim Women in New York City: Perspectives from Key Informants. SM J Community Med. 2017; 3(1): 1022.

[93] Yeasman, T., Kelaher, M., et al. (2019). Understanding the participation in cervical screening of Muslim women in Victoria, Australia from record-linkage data. Journal of Cancer Policy (22). https://doi.org/10.1016/j.jcpo.2019.100201

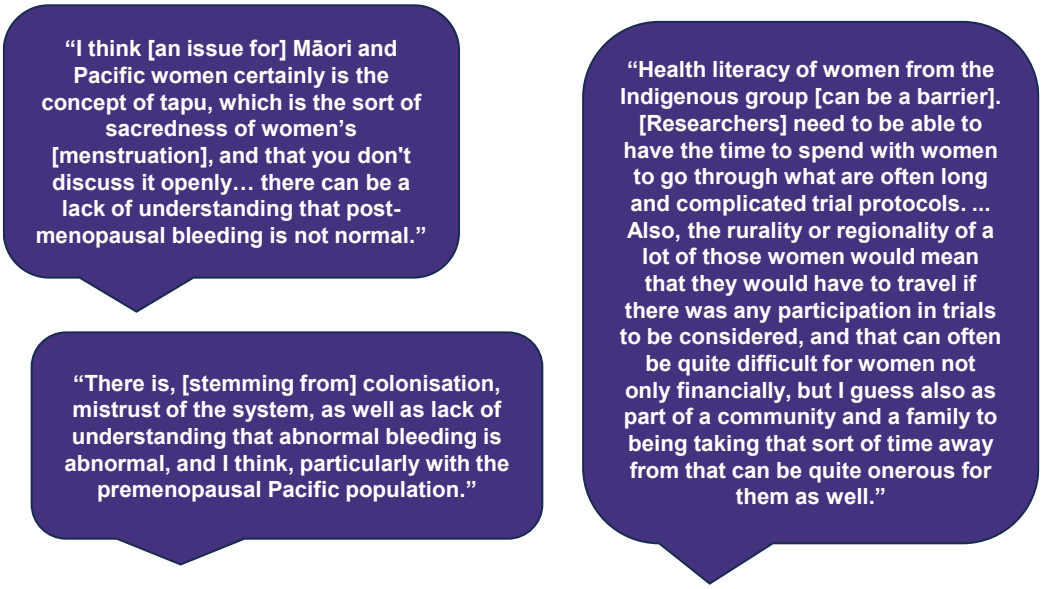
[94] Haigh, M., Burns, J., et al. (2018). Review of cancer among Aboriginal and Torres Strait Islander people. Australian Indigenous HealthBulletin 18(3). https://healthbulletin.org.au/articles/review-of-cancer-2018

[95] DiGiacomo, M., Davidson. P. M., et al. (2012). Cancer in Aboriginal and Torres Strait Islander peoples: a rapid review. Sydney: The Sax Institute.

[96] Marcusson-Rababi, B., Anderson, K., et al. (2019). Does gynaecological cancer care meet the needs of Indigenous Australian women? Qualitative interviews with patients and care providers. BMC Health Services Research. 2019. 19:606. https://doi.org/10.1186/s12913-019-4455-9

resources for gynaecological cancers among Aboriginal and Torres Strait Islander women found only a limited number of resources, most of which were focused on cervical cancer prevention through vaccination and screening.[97] Moreover, there is plausible evidence suggesting Aboriginal and Torres Strait Islanders face systemic barriers preventing participation in clinical trials.[98]

Figure 3.28: Stakeholder perspectives – Barriers to optimal care for First Nations women



Source: Insight Economics stakeholder consultations

In Aotearoa New Zealand, Māori health providers (MHPs) were established in the 1990s, alongside the development of cultural safety education. Under this model MHPs are able to compete with other health providers, while using Māori models of wellbeing, positive Māori development, and Māori philosophical and practical approaches. However, in a 2016 survey conducted on the role of MHPs in cancer care, 50 per cent of respondents cited a lack of cultural safety, and 44 per cent cited a lack of Māori health workers, as a reason for a delay in accessing screening services.[99] Moreover, 48 per cent and 41 per cent cited a lack of cultural safety and no Māori health workers respectively as a reason for a delay in accessing primary care when presenting with symptoms. This indicates there are still substantial cultural barriers that prevent Māori women from accessing the best possible care.

Pacific women are also subject to barriers that prevent culturally sensitive care. Despite comprising eight per cent of the population in Aotearoa New Zealand, Pacific peoples only make up 2.7 per cent of doctors, 2.9 per cent of pharmacists and 4.1 per cent of nurses. This lack of representation makes it difficult for Pacific women to access culturally safe care. Moreover, there is a lack of Pacific-led support groups for cancer, broadly, and uterine cancer, specifically. Groups created by Pacific peoples for Pacific peoples would provide a culturally safe support network for patients and their families.

[97] Kinghorn, M., Garvey, G., & Butler, T. L. (2024). Gynaecological cancer resources for Aboriginal and Torres Strait Islander women: A resource audit. Health promotion journal of Australia. 2024 (Oct). 35(4): pp. 966-976. https://doi.org/10.1002/hpja.822

[98] Cunningham, J. & Garvey, G. (2021). Are there systemic barriers to participation in cancer treatment trials by Aboriginal and Torres Strait Islander cancer patients in Australia? Australian and Aotearoa New Zealand Journal of Public Health. 20021. 45:39–45. https://oi.org 10.1111/1753-6405.13059

[99] Perelini, O. M., Nosa, V. H., et al. (2025). Pacific Peoples' Experiences of Cancer and Its Treatment in Aotearoa Aotearoa New Zealand Through Talanoa: A Qualitative Study of Samoan and Tongan Participants. JCO Global Oncology. 11. https://doi.org/10.1200/GO.24.00133

Women from culturally and linguistically diverse backgrounds, more broadly, are underrepresented in clinical trials, and when they are represented, can face significant barriers preventing accurate collection of data. For example, for domestic trials, patient-reported outcomes mut be completed in English, which poses a challenge to those from non-English speaking households. Furthermore, these women may be discouraged from accessing and engaging with available resources. A recent study to assess the readability of both Australian Government and non-governmental resources on gynaecological cancer found that these resources tend to be difficult to understand, with poor actionability.[100] This makes it more difficult for women from culturally and linguistically diverse background to engage with these resources, and to understand the risks they bear.

These cultural barriers can be combined with geographic and/or financial barriers to prevent women from accessing the care they need. This is particularly pertinent for Aboriginal and Torres Strait Islander women, wāhine Māori and Pacific women, who disproportionately are part of lower SES groups, and live in rural areas.

3.18 Risks of financial toxicity

Out-of-pockets costs and risks of financial toxicity associated with treating any cancer can be substantial, and this holds true for uterine cancer. Women and their families can face out-of-pocket costs associated with consults, specialists, scans, tests, surgery, travel and medicines.

For women being treated in private settings or for women from low-socioeconomic backgrounds and/or from regional areas in particular these barriers can be substantial. For example, women living in regional or remote areas may need to travel for surgery and there is some evidence to show that hospitals and surgeons with higher case volumes tend to have better outcomes (although the magnitude of this effect is generally more modest compared to other high-risk surgeries).[101]

While state and territory governments offer some compensation to regional and rural cancer patients travelling to receive treatment (see Table 3.2 below), support is often limited relative to the costs of accommodation and travel, and there are often delays to reimbursement, which can be challenging for women from low socio-economic backgrounds in particular. For women treated in the private sector, out-of-pocket costs can add up rapidly (Figure 3.29).

In Aotearoa New Zealand, the National Travel Assistance (NTA) scheme is designed to reduce travel-related barriers to accessing specialist care, but its structure can still create financial toxicity for specific women caught in the middle. Eligibility depends on meeting strict distance and frequency thresholds, such as travelling more than 50km one way or accumulating a set number of visits, which means women living just under these thresholds, or requiring shorter but frequent trips, often miss out on support despite facing significant costs.

Even when women do qualify, support is provided as reimbursement rather than up-front assistance. This requires patients to cover the costs of fuel, accommodation and accommodation before receiving any subsidy. For low-income households without savings buffers, fronting the cost of several hundred kilometres of travel or motel stays for cancer treatment cycles can be prohibitive. In practice, this can force families into debt, delay care-seeking, or compel women to accept less timely local options if they cannot afford to travel. While the NTA covers a broad range of transport and accommodation expenses on paper,

[100] DiSipio, T., Scholte, C., & Diaz, A. (2024). Evolution of online-text-based information resources of gynaecological cancer symptoms. Cancer medicine. May 2024. 13(9):e7167. https://doi.org/10.1002/cam4.7167

[101] Wright JD. (2021). The value of volume. J Gynecol Oncol. 2021 Nov;33(1):e17. 10.3802/jgo.2022.33.e17; and Boria, Felix et al. (2024). Exploring the influence of volume center on surgical outcomes in the management of early-stage endometrial cancer: a subanalysis of the SENECA study International Journal of Gynecological Cancer, Volume 34, A29 - A30

the reimbursement-only model and strict criteria mean that many women remain exposed to cash-flow pressures and financial toxicity during already challenging treatment journeys.

Figure 3.29: Stakeholder perspectives – Risks of financial toxicity

Source: Insight Economics stakeholder consultation

Table 3.2: Summary of Patient Transport Support Schemes

	Scheme	Basic eligibility requirements	Travel subsidy	Accommodation subsidy per approved person	Key additional conditions
NSW	Isolated Patients Travel and Accommodation Assistance Scheme	>100km required travel one way; or >200km within a week	Private vehicle – 40c per km; public transport – full reimbursement; taxi – $20 - $160	Private – $40 per person per night Commercial – $75 per night ($120 per night from day eight)	Support is provided as reimbursement for past payments, rather than up-front
Vic	Victorian Patient Transport Assistance Scheme	>100km required travel one way; or an average of 500km per week for one or more weeks	Private vehicle – 20c per km; public transport – full reimbursement for economy ticket; air travel – economy rate for journey >350km one way.	Commercial only – $41 per night ex. GST	Support is provided as reimbursement for past payments, rather than up-front
Qld	Patient Travel Subsidy Scheme	>50km required travel one way (within Qld)	Private vehicle – 34c per km; commercial – full reimbursement	Private - $10 per person per night Commercial - $70 per person per night	Support is provided as reimbursement for past payments, rather than up-front
SA	Patient Assistant Transport Scheme	>100km required travel one way	Private vehicle – 32.8c per km; commercial – full reimbursement	Commercial only – $44 per night inc. GST	Concession card required for first night of accommodation subsidy. Support for non-indigenous is provided as reimbursement for past payments, rather than up-front
WA	Patient Assisted Travel Scheme	>70km required travel one way	70-100km – $20 flat rate; >100km – 26c per km >350km – Economy fare	Commercial – up to $110, plus $15 for approved support person Private - $20 per night	Support is provided as reimbursement for past payments, rather than up-front
Tas	Patient Travel Assistance Scheme	>75km required travel to specialised health service, >50km to cancer dialysis centre	Private vehicle – 24c per km; public transport/commercial – full reimbursement	Within Tasmania – up to $76 per night Interstate – up to $98 per night	Apart from concession card holders, you are required to contribute $82.50 for each journey, and the first 2 nights' accommodation

	Scheme	Basic eligibility requirements	Travel subsidy	Accommodation subsidy per approved person	Key additional conditions
ACT	Interstate Patient Travel Assistance Scheme	Current referral for a specialist medical service not available in the ACT	Private vehicle - $40 to $660 (depending on location and vehicle type); public transport - $125 to $390 (depending on location and transport type)	Commercial only – $50 to $210 (depending on age of patient, type of accommodation and number of escorts)	Support is provided as reimbursement for past payments, rather than up-front
NT	Patient Assisted Travel Scheme	>200km required travel one way; or >400km travel per week	Private vehicle – 20c per km; commercial – full reimbursement, $50 for taxis and buses	Up to $60 per night	Support is provided as reimbursement for past payments, rather than up-front
NZ	National Travel Assistance	Distance and frequency criteria, and >50km required travel one way	Full reimbursement for private vehicles, public transport and specialised transport needs	Cost of motel room or allowance when staying with family and friends (usually >100km)	Support is provided as reimbursement for past payments, rather than up-front

Source: Australian State Government Departments of Health, Cancer Council NZ

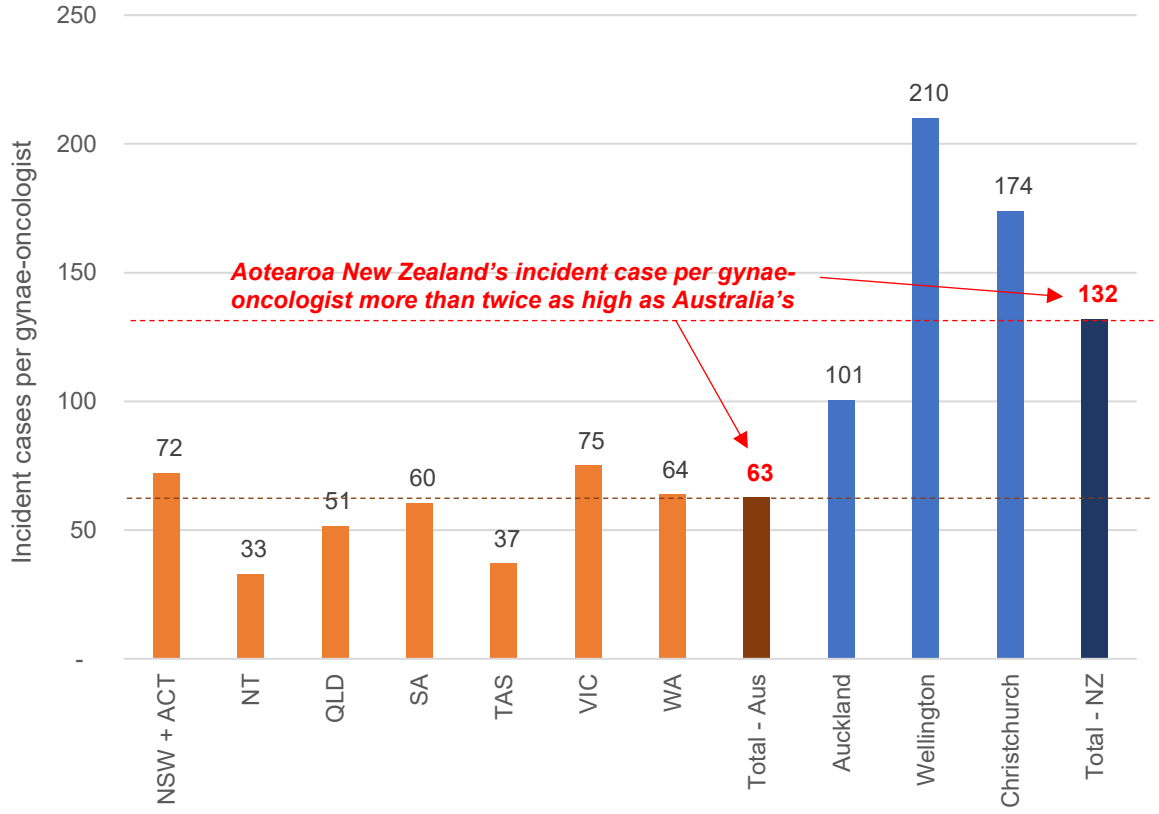
3.19 Significant workforce shortages in Aotearoa New Zealand

Aotearoa New Zealand suffers from workforce shortages in gynaecological oncology, compounded by the higher incidence of uterine cancer, which is double compared to Australia. In 2024, for every 63 women diagnosed with uterine cancer in Australia, there is one gynaecological oncologist available. In contrast, Aotearoa New Zealand had only one gynaecological oncologist for every 132 women diagnosed (Figure 3.30).

This is a concerning disparity that places enormous pressure on the existing workforce. It also impacts the way that services are delivered. In New Zealand, women are triaged using MRI to determine who is referred to a gynaecological oncologist.

The shortage is due, in part, by challenges in recruitment and retention. Regulatory barriers can deter overseas specialists from practising in Aotearoa New Zealand. Even local talent is leaving. Without urgent investment in the gynaecological oncology workforce, including competitive salaries, training pathways, surgical infrastructure (such as access to robotics), and recognition of international qualifications, Aotearoa New Zealand risks falling further behind in its ability to deliver timely, high-quality care for women with uterine cancer.

Figure 3.30: Severe workforce shortages in Aotearoa New Zealand

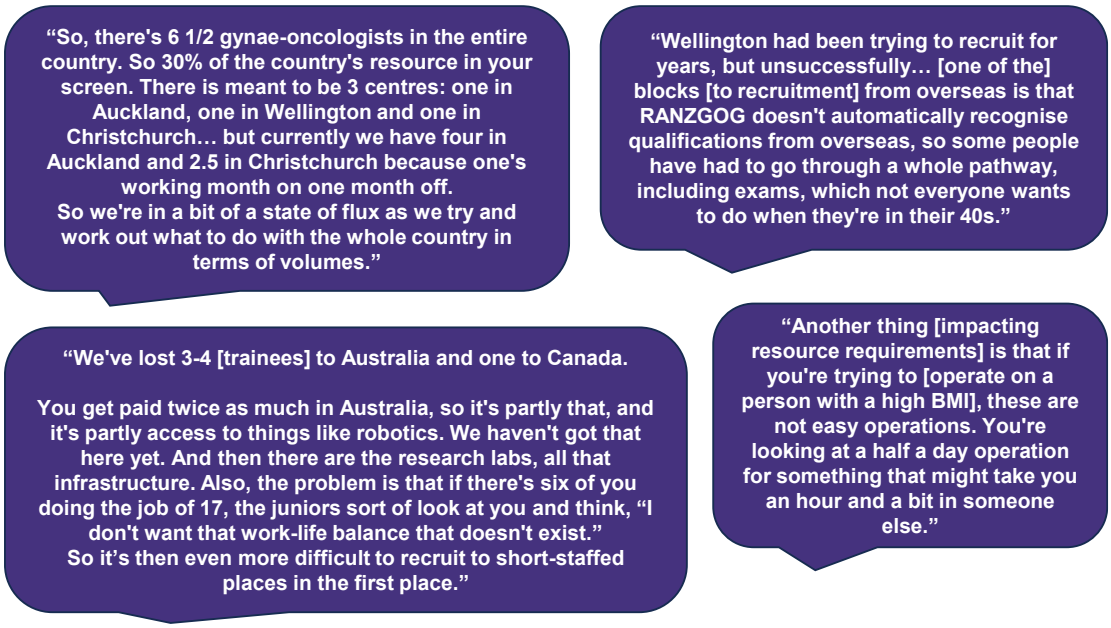


Source: Insight Economics analysis of AHPRA Medical Board Statistics, Dec 2024, Medical Board of Australia - Statistics, Insight Economics incidence modelling see Appendix A, ABS population data Sept 2024 National, state and territory population, September 2024 | Australian Bureau of Statistics, Stats NZ (Tatauranga Aotearoa). population data Dec 2024 Population | Stats NZ and stakeholder reporting on gynae-oncologist workforce numbers as of 2025.

Stakeholders also raised significant concerns about workforce shortages in the Aotearoa New Zealand health system, as can be seen in Figure 3.31. They cited the relatively lower pay in Aotearoa New Zealand compared to Australia and Canada, for instance, as well as a lack of access to research and advanced equipment. Healthcare professionals also

recognised the vicious cycle created by these shortages, as many young doctors are discouraged from a gynae-oncology specialisation because of the work expectations.

Figure 3.31: Aotearoa New Zealand health system in crisis



Source: Insight Economics stakeholder consultations

3.20 Lack of a survivorship model of care

No model of care has been developed for women diagnosed with uterine cancer.

Survivors and clinicians alike expressed frustration around a lack of guidance and clarity following treatment (Figure 3.32). Overall, women found the standard of care post-treatment to be inconsistent, with one woman likening the experience to having a splinter removed. Furthermore, other stakeholders agreed that the provision of survivorship care for uterine cancer patients is woefully inadequate. The few attempts to implement shared care in an endometrial cancer setting have succumbed to a lack of research and funding. Healthcare professionals also noted significant discrepancies in the survivorship support available in the Australian public health sector, compared to a private health setting. Moreover, in Aotearoa New Zealand, a lack of survivorship clinics has been associated with, among other things, poor access to psychological and lymphedema support services.

In order to alleviate these issues among survivors, long-term survivorship models of care for uterine cancers are needed throughout Australia and Aotearoa New Zealand. However, policymakers and caregivers face significant barriers in implementing such a framework across the health sector. Both survivors and other stakeholders indicated there is considerable inertia preventing these models from being more widespread.

Figure 3.32: Stakeholder and consumer perspectives – Lack of survivorship support and evidence for best practice surveillance

Source: Insight Economics stakeholder consultations and consumer roundtables.

3.21 Lack of data to improve clinical practice and research

Improving outcomes for women with uterine cancer depends on access to data: only through data is it possible to identify opportunities to prevention, early detection, treatment and care. Researchers and policy makers require reliable, comprehensive data to conduct the research that helps develop and implement new and effective treatments, while accessible and centralised patient data can help clinicians and medical workers deliver the best care to their patients. Data can drive the discussion for health sector reform and make the case for investment in infrastructure and personnel, ensuring focus is placed in the areas that require the greatest effort. Moreover, a sustained data collection framework can help policymakers establish clinical best practice and monitor achievement against targets.

There are many different types of data that are needed for this work, including:

- Epidemiological data, which are data that help to understand trends in prevalence, distribution among population groups, staging at diagnosis, molecular and histological sub-type and mortality
- Clinical data across all care settings, from primary care to specialist practices, which help to uncover patterns of clinical care and identify clinical best practice
- Genomic data, which can help to identify inform personalised cancer care
- Patient-reported outcomes data, which measure a range of physical, social and emotional outcomes for women
- Patient-reported experience data, which can help to improve women's experience in the healthcare system
- Adverse events/side effects
- Clinical trial data.

Analysis of these different types of data enable researchers, clinicians and policy makers to identify opportunities improve outcomes and quality of life for women.

Unfortunately, Australia and Aotearoa New Zealand do not collect and report these data needed to improve outcomes for women. Even basic data on incidence by stage is not consistently collected and reported, with data collection varying significantly from state to state in Australia. Additionally, the statistics collected by AIHW and Cancer Australia are generated based on the organ of origin, without considering the tissue of origin. This makes even the generation of the report difficult to interpret between rare sarcoma subgroups.

As shown in Table 3.3, while a range of data are collected, these data are often siloed and unable to be accessed and aggregated in such a way to inform research and policy to improve the treatment and care of uterine cancer. There are also major gaps in a number of critical areas of data including:

- Individual risk factors
- Incidence by molecular subtype and for priority populations
- Clinical treatment patterns
- Outcomes data
- Natural history data.

There are also no national datasets available to understand patterns of care in primary care settings; this impedes the potential for improvements in the delivery of primary care. As a result, there are insufficient data collected on women with uterine cancer to fully understand the drivers of incidence, inequity and variation in outcomes that would allow

for informed decisions about policy reform. In the absence of sufficient data, both research and reform are hindered.

This lack of data available on uterine cancer patients and survivors stands in contrast to other chronic diseases, where data are more readily available. In 2017, the Commonwealth Government released its National Strategic Framework for Chronic Conditions, wherein a focus on collecting, linking and sharing consistent, reliable and de-identified data was recognised to be important.[102] Under the current framework for data management, the AIHW plays a key role in analysing and reporting on chronic disease data, while the DoHAC manages the National Notifiable Diseases Surveillance System, which tracks notifiable diseases, including some that can have chronic consequences. In all, this creates a much more data rich environment for researchers and policymakers in the broader space of chronic disease, which is ultimately lacking for uterine cancers.

To try to close some of these gaps in data, the National Gynae-Oncology Registry (NGOR) was established, as first national clinical quality registry dedicated to monitoring and improving the care of patients diagnosed with gynaecological cancers. But NGOR lacks funding and resources to collect sufficient and exhaustive data on uterine cancer patients. Moreover, only endometrial cancer is considered, to the exclusion of uterine sarcomas, and some clinicians are reluctant to participate if they are required to 'enter data twice'.

Both survivors and broader cancer healthcare stakeholders expressed frustration at the current state of data collection. For survivors, they feel dismay at the thought that data on their experiences isn't being collected to better inform future care decisions or to understand unique risk profiles. Stakeholders feel as if their requests for better data collection on gynaecological cancers are not being heard. A lack of data affects both carers' capacity to provide treatment and support to patients, as well as the ability of researchers to discover novel treatments.

Reform efforts are underway at a national level to better coordinate the collection and publication of cancer data, to improve both immediate health outcomes for patients, as well as the capabilities of those working in research and policy development. As part of the Australian Cancer Plan (ACP), the Australian Government has committed to developing a National Cancer Data Framework (NCDF). Under the NCDF, the remit of the Australian Cancer Dataset to collect and publish cancer data will be expanded. The existing data collected by state cancer registries will be integrated with other datasets, such as PROMs and PREMs collected across the cancer care continuum, clinical, administrative data from healthcare providers, the Medicare Benefits Scheme (MBS) and the Pharmaceutical Benefits Scheme (PBS), and Indigenous cancer data collected from Aboriginal and Torres Strait Islander communities. The NCDF will also work to align national data standards, ensuring consistency and comparability across jurisdictions, and to establish governance frameworks to facilitate data access by researchers, clinicians and policymakers. Once established, these frameworks will support secure and ethical data sharing among stakeholders.

These are important, but long-term goals, with the development of the NCDF itself having taken two years to be delivered. Significant work is needed to improve data collection and reporting by Australian cancer registries, the more consistent use of a national patient identifier and to expand data collection across other types of data in both Aotearoa Australia and New Zealand.

[102] Australian Health Ministers' Advisory Council. (2017). National Strategic Framework for Chronic Conditions. Council of Australian Governments. Accessed at: https://www.health.gov.au/sites/default/files/documents/2019/09/national-strategic-framework-for-chronic-conditions.pdf

Table 3.3: Overview of data collected and published in Australia and New Zealand – significant gaps observed

	National datasets					Siloed data						Notes
Data custodian	**DoHAC**	**AIHW**	**ABS**	**ACSQHC**	**Health New Zealand**	**State Govts.**	**NGOR**	**Universities / research**	**GPs / primary care**	**Hospitals**	**Industry**	
Prevention												
Risk factors – population		✓✓	✓✓		✓✓	✓✓		✓✓				Survey data on risk factors collected by national health departments.
Risk factors – priority pop.	✓✓	✓	✓		✓✓	✓✓	✓	✓✓	✓	✓		
Risk factors – individuals							✓	✓✓	✓	✓		
Health interventions pre-diagnosis									✓			
Diagnosis												
Incidence		✓✓✓			✓✓✓	✓✓✓	✓	✓		✓	✓	Incidence data is collected by state and territory cancer registries/NZ Health. Additional diagnostic data is collected by some, but not all, state cancer registries
- by stage						✓	✓	✓		✓	✓	
- by histological sub-type		✓✓				✓	✓	✓		✓	✓	
- by molecular sub-type							✓	✓		✓	✓	
Priority populations					✓	✓	✓	✓		✓		
Treatment												
Clinical data	✓	✓				✓	✓	✓	✓	✓	✓	DoHAC collects clinical data through PBS, MBS and the Private Hospital Data Bureau.
Clinical quality indicators							✓					

	National datasets					Siloed data						Notes
Data custodian	**DoHAC**	**AIHW**	**ABS**	**ACSQHC**	**Health New Zealand**	**State Govts.**	**NGOR**	**Universities / research**	**GPs / primary care**	**Hospitals**	**Industry**	
Outcomes												
Mortality		✓✓			✓✓✓	✓✓✓	✓					Mortality and survival data are collected and published for almost all uterine cancer patients and where mortality and survival are reported, there is often delineation by priority population. But beyond this, data is inconsistently collected and privately held. Clinical trial research and health service records are increasingly collecting these data information, but they are not analysed and reported.
Overall survival		✓✓				✓✓✓	✓	✓	✓	✓	✓	
Progression-free survival							✓	✓	✓	✓	✓	
Adverse events / side effects							✓	✓	✓	✓	✓	
PROMs							✓					
PREMs							✓					
Priority populations					✓✓	✓		✓				
Research												
Natural history data							✓	✓	✓	✓		Research data, especially pharmaceutical-related, is often proprietary and not accessible.
Genomic data							✓	✓		✓	✓	
Clinical trial data						✓	✓	✓		✓	✓	
Legend:	✓: Very limited population coverage, or high barriers to access.					✓✓: Incomplete population coverage, or limited access.				✓✓✓: Near complete population coverage, readily accessible.		

3.22 What are the most critical barriers to address? Patient, carer, clinician and researcher perspectives

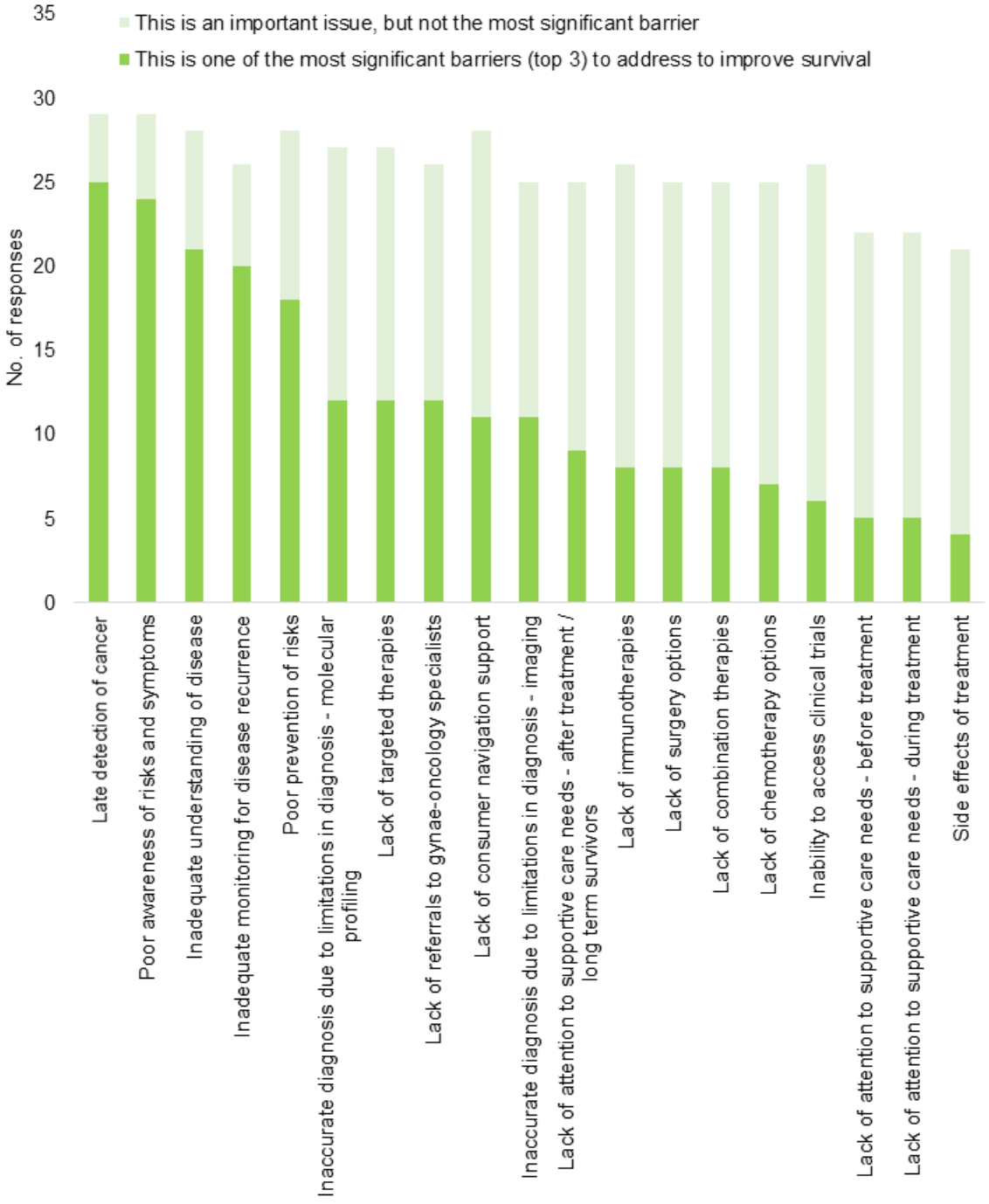
To understand the relative importance of different issues on improving outcomes for women diagnosed with uterine cancers, patients, carers, researchers and clinicians were asked about barriers to improving survival and quality of life. As discussed below, there was common consensus among patients, carers, clinicians and researchers that poor awareness of uterine cancer, late detection and poor screening were among the most significant drivers of poor outcomes in endometrial cancers, while poor understanding of the disease and a lack of treatment options were the primary areas of need among uterine sarcomas. The following sections present further detail on the survey responses.

Patient and carer perspectives on the most important barriers to improved outcomes

In terms of barriers to improving survival, patients and carers identified late detection of cancer as the most important barrier to improved survival. Other barriers most commonly identified included:

- Poor awareness of risks and symptoms (80 per cent)
- Inadequate understanding of disease (70 per cent)
- Inadequate monitoring for disease recurrence (67 per cent)
- Poor prevention of risks (60 per cent).

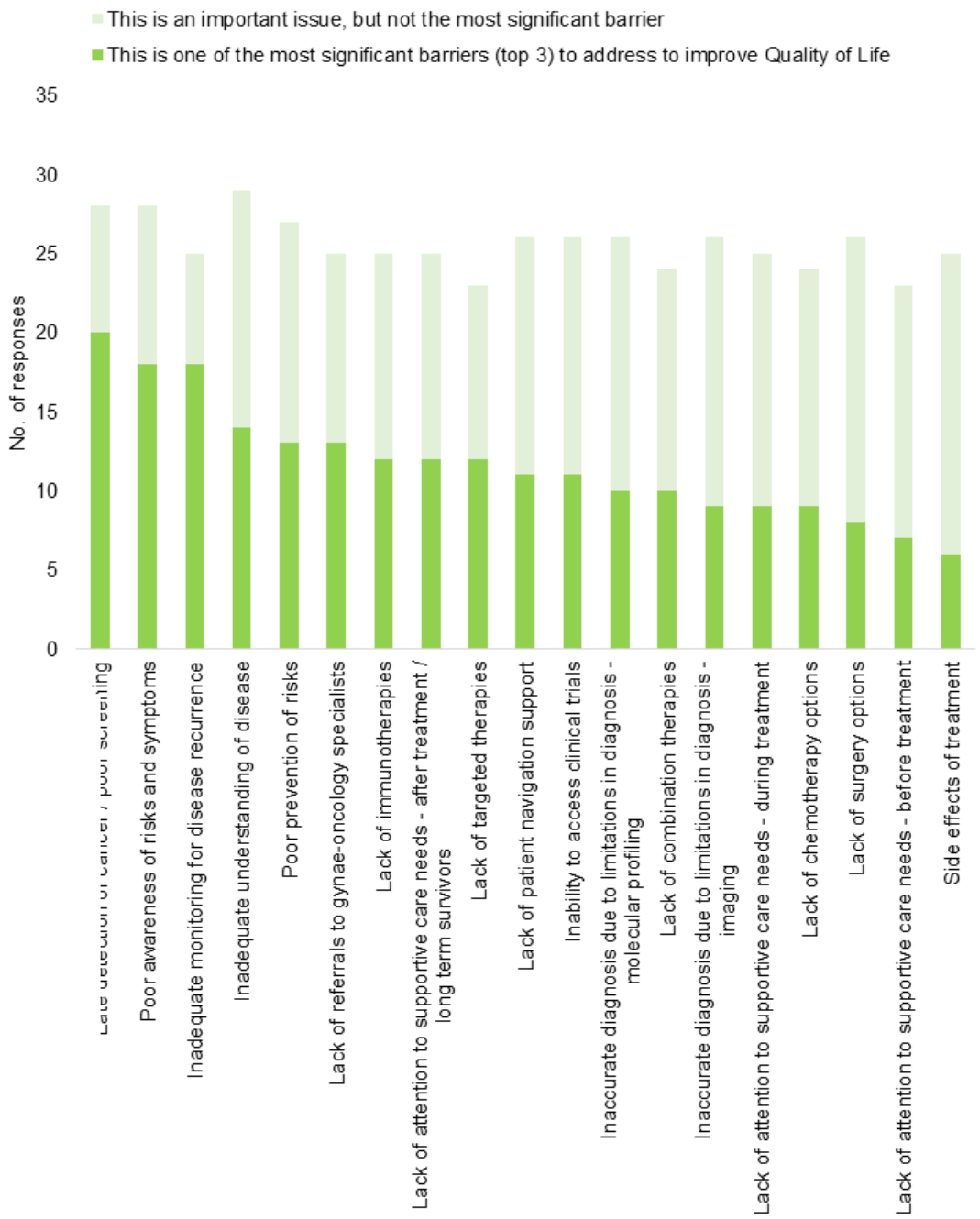
Figure 3.33: Consumer perspectives: Barriers to survival



Source: Survey of Patients and Carers Living with Uterine Cancer

Turning to barriers to quality-of-life improvements, the most commonly identified priority issue identified by consumers was late detection of cancer, with 69 per cent of respondents identifying it as a significant concern. Similarly, poor understanding of disease recurrence and inadequate monitoring for disease recurrence were frequently raised issues impacting on survivors' quality of life, with 60 per cent and 64 per cent agreement among consumers respectively.

Figure 3.34: Consumer perspectives: barriers to improved quality of life



Source: Survey of Patients and Carers Living with Uterine Cancer

Researcher and clinician perspectives on the most important barriers to improved outcomes

Researchers and clinicians were also asked about barriers to improved survival and quality of life for different subtypes of uterine cancer.

For improved survival in *endometrial* cancers, researchers identified:

- Poor awareness of risks and symptoms (96 per cent)

- Inability to access clinical trials (92 per cent)
- Limitations on molecular profiling at diagnosis (88 per cent)
- A lack of targeted therapies (88 per cent).

For improved survival in *uterine sarcomas*, researchers and clinicians identified the most significant barriers to improved survival to be poor understanding of disease biology and treatment options.

In terms of improving quality of life, researchers and clinicians most commonly identified a lack of attention to supportive care a major barrier to quality of life for *endometrial* cancer, with 63 per cent of researchers agreeing it is significant. The next most commonly identified major barrier to quality-of-life improvements was identified to be poor prevention of risks and risk reduction, with 50 per cent agreement from researchers.

For *uterine sarcomas*, researchers and clinicians identified as significant many of the same barriers for quality of life as for survival. This includes:

- A lack of combination therapies (57 per cent)
- A lack of targeted therapies (54 per cent)
- Inability to access clinical trials (54 per cent).

These three barriers, moreover, were also the only issues agreed to be important by all respondents.

Figure 3.35: Clinician and researcher perspectives

Barriers to improved survival (endometrial cancer)

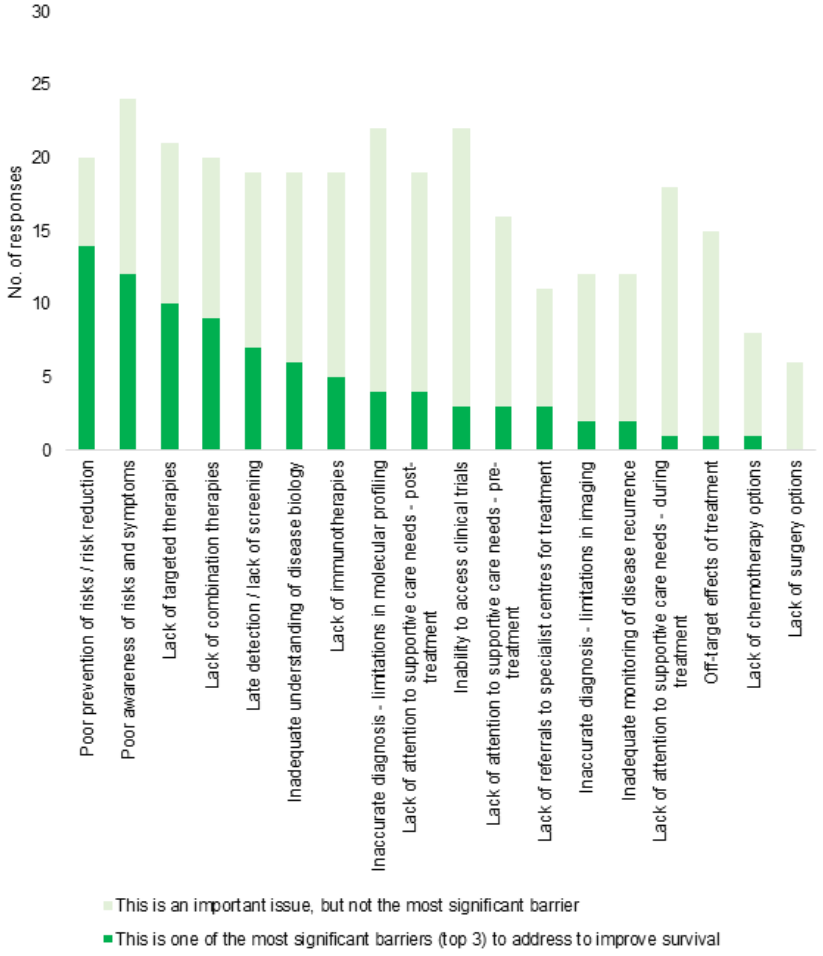
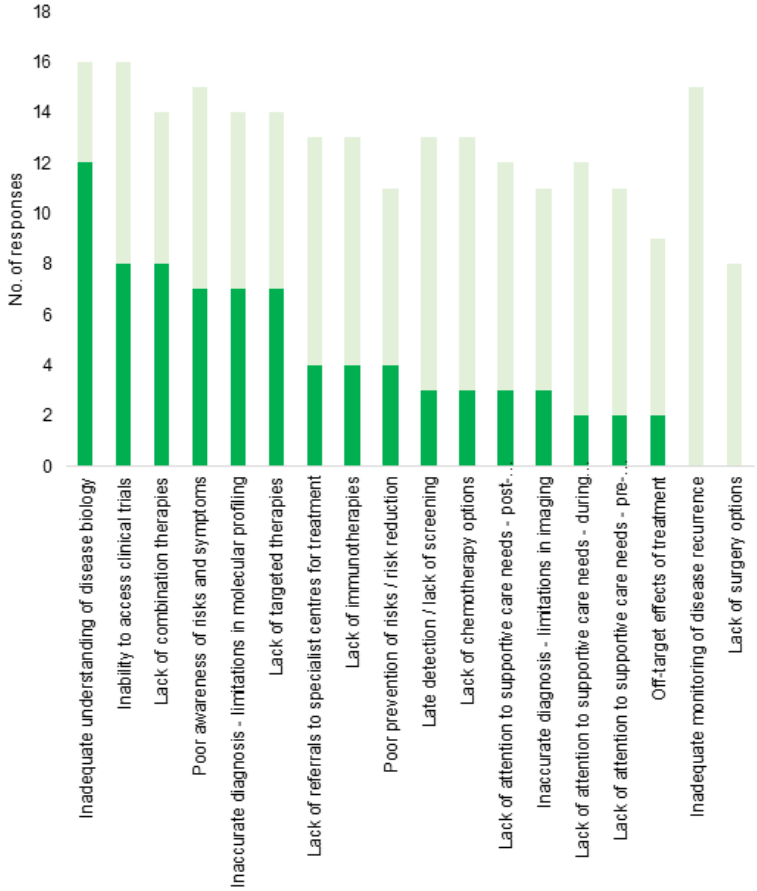


Figure 3.36: Clinician and researcher perspectives

Barriers to improved survival (uterine sarcoma)



Source: Survey of Researchers and Clinicians working in Uterine Cancer

Figure 3.37: Clinician and researcher perspectives

Barriers to improved quality of life (endometrial cancer)

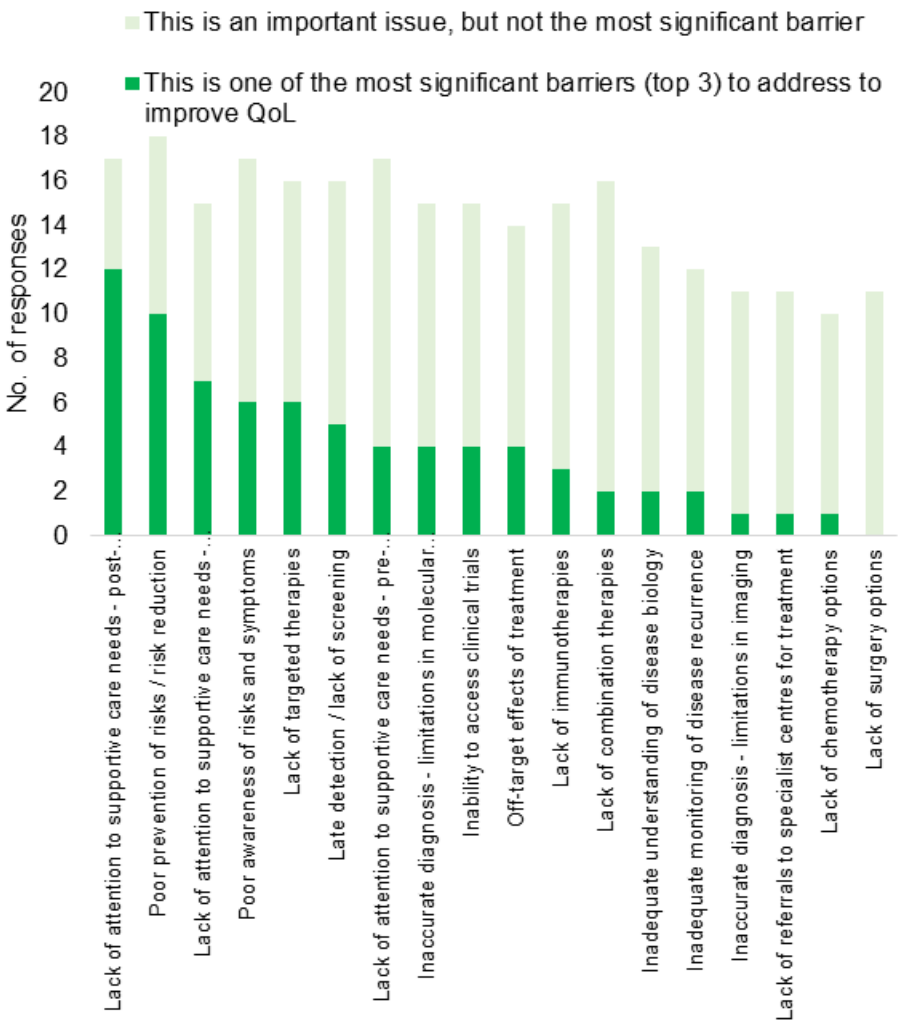
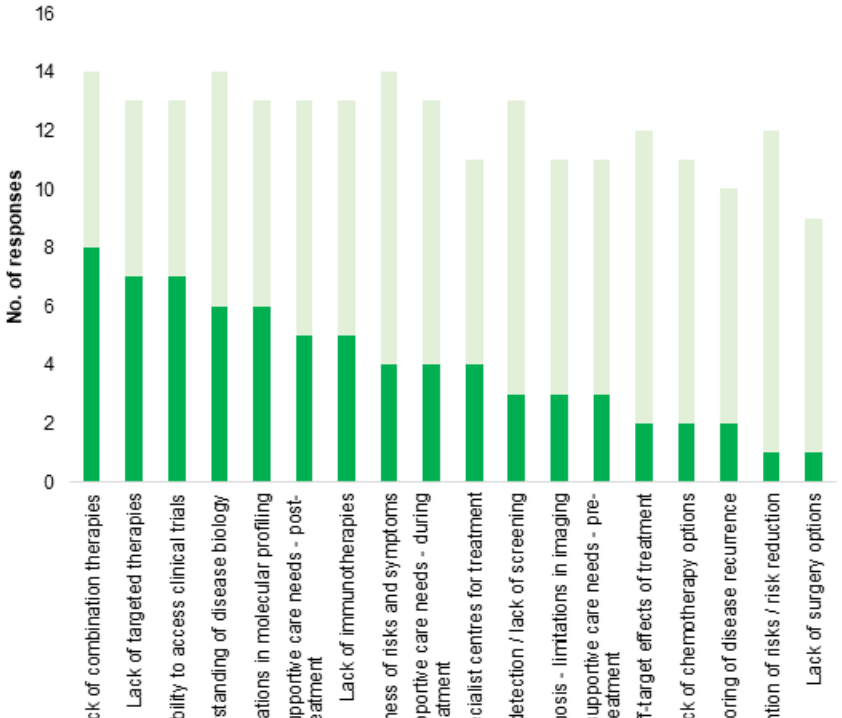


Figure 3.38: Clinician and researcher perspectives

Barriers to improved quality of life (uterine sarcoma)



3.23 Conclusion

This chapter presents a thorough summary of the many barriers that exist to improving survival and quality of life for women impacted by uterine cancers and their families.

It highlights that there is a need for increased investment in research for uterine cancer treatment, to counteract the recent increase in both incidence and mortality. This lack of adequate funding is a result, in part, of the absence of clear and targeted advocacy for uterine cancer patients. Without an organisation that explicitly represents uterine cancer patients—as opposed to one that advocates for all gynaecological cancers, including uterine cancer—the ability to raise awareness of the issues facing women with uterine cancer is hindered. This exacerbates the funding and research discrepancies, leading, ultimately, to worse outcomes for women with uterine cancers.

The next chapter identifies opportunities for future research to improve outcomes for women, and the following chapter identifies opportunities for policy reform and investment by governments to address these barriers and improve outcomes for women and their families.

Chapter 4
Research Priorities in Uterine Cancers

This chapter presents major research advances that have been made globally in the past 15 years, identifies important clinical trials underway, identifies future research questions and priorities and Australia and Aotearoa New Zealand's role to help achieve better survival and quality of life outcomes for women.

4.1 Major advances in uterine cancer research

The last 15 years have seen significant advances in the understanding of uterine cancers and a paradigm shift in the treatment of uterine cancers, with molecular biology and precision medicine leading the way. Across the care pathway, there has been critical evidence development for the improved prevention of uterine cancers, identification of high-risk and early-stage cancers, more personalised and less-invasive treatment options and opportunities to optimise follow-up and support for survivors.

As shown in Figure 4.1, significant improvements have been made in the following domains:

- *Improved understanding of uterine cancer biology* — The Cancer Genome Atlas (TCGA) is a cancer genomics program jointly managed by the National Cancer Institute (NCI) and the National Human Genome Research Institute in the US that has been working to collect samples and molecularly characterise 33 different types of cancers, including uterine cancer. At its most basic level, molecular classification is grouping uterine cancers into subtypes based on differences in DNA and protein patterns. In 2013, the TCGA identified four main molecular subtypes of endometrial cancer:
  - *POLE* ultra-mutated
  - MSI-H (microsatellite instability-high)
  - P53, copy-number low (endometrioid)
  - P53, copy-number high (serous-like)
  - No Specific Molecular Profile (NSMP).[103]

  Building on these TCGA classifications, ProMisE (Proactive Molecular Risk Classifier for Endometrial Cancer) is a classification system that uses pragmatic methods to identify these genomic subgroups. Classification is feasible on formalin-fixed paraffin-embedded (FFPE) material and assigns patients with endometrial cancer to one of four groups, based on a combination of immunohistochemistry for MMR proteins, sequencing for *POLE* mutation and immunohistochemistry for the p53 protein.

[103] Levine, D., (2013). The Cancer Genome Atlas Research Network. Integrated genomic characterization of endometrial carcinoma. Nature 497, 67–73. https://doi.org/10.1038/nature12113

This molecular classification of uterine cancer provides clinicians with important information about a woman's likelihood of survival (called prognostic information) and information to personalise treatment decisions to improve not only her chances of survival but also long-term quality of life. This allows for the potential personalised treatment of more than 60 per cent of all endometrial cancers.

Uterine carcinosarcomas were also included in the TCGA study, which found a range of genetic alterations that could serve as potential therapeutic targets, including mutations in TP53 (91 per cent of all uterine carcinosarcomas) and mutations in PI3K pathway including *PIK3CA* (35 per cent), *PTEN* (19 per cent), or *PIK3R1* (11 per cent), which have sensitivity to PI3K inhibitors like alpelisib, idelalisib, leniolisib, inavolisib and duvelisib.[104]

Additionally, recent Genome Wide Association Studies (GWAS) research has doubled the number of genetic mutations identified as leading to an increased susceptibility to endometrial cancer[105] and confirmed previous studies finding both that higher BMI is causal for endometrial cancer risk and that the later onset of menarche is associated with lower endometrial cancer risk.

[104] Cherniack, Andrew D. Akbani, Rehan et al. (2017). Integrated Molecular Characterization of Uterine Carcinosarcoma, Cancer Cell, Volume 31, Issue 3, 411 – 423, accessed at: https://www.cell.com/cancer-cell/fulltext/S1535-6108(17)30053-3.
[105] O'Mara, T.A., Glubb, D.M., Amant, F. et al. (2018). Identification of nine new susceptibility loci for endometrial cancer. Nat Commun 9, 3166 https://doi.org/10.1038/s41467-018-05427-7

Figure 4.1: Major advances in uterine cancer research

- Four molecular subtypes of endometrial cancer identified to guide precision medicine approaches (The Cancer Genome Atlas)
- Molecular classification of uterine carcinosarcomas identified frequent p53 mutations and mutations along the PI3K pathway
- Genome-wide association studies (GWAS) have identified 17 genetic risks for endometrial cancer

- Diet and lifestyle interventions have been shown to reduce risk
- Identification of biomarkers for early detection.
- Identification of potential minimally-invasive diagnostic methods (e.g. PapSEEK Tao brush, DETECT, WID-Easy)
- Use of AI (ECgMPL) to improve review of histopathological images with 99.26% accuracy
- Surgical innovations (bariatric surgery) shown to reduce risk
- Emergence of a 'precision medicine' paradigm

- Use of biomarkers to support personalised treatment (POLE, MSI-H/dMMR, p53), with trials underway to improve treatment selection (RAINBO, TAPER, PORTEC)
- Use of intrauterine devices (IUDs) for treatment of early endometrial patients (feMMe trial) enabling fertility preservation for younger women, prehab to expand treatment options, treatment options for older women
- Phase III studies show improvements in PFS and OS for dMMR cancers with PD-1 inhibitors (pembrolizumab, dostarlimab)
- Surgical innovations (laparoscopy, robotics)

- Patient-initiated follow-up (PECAN trial) identified as model for follow-up care
- Improved understanding of supportive care needs for survivors
- Survivorship planning tools developed
- Benefits of weight reduction, physical activity demonstrated

Source: Insight Economics, see references for key papers in discussion below.

Research has also identified that there are significant differences between early-onset endometrial cancer and late-onset disease,[106] as well as differences between racial and ethnic groups.[107] Rare and more aggressive uterine cancers have been found to be more common in non-white, older, and less obese patients and associated with higher mortality and recurrence.[108] Other research has also identified variation by race, with women of Black or African American descent having double the mortality of Caucasian American women, and their tumours tend to be of higher grade, especially among younger Black women.[109] No similar work has been completed, yet, however, for Aboriginal and Torres Strait Islander, wāhine Māori or Pacific women.

The continued integration of translational research into clinical trials to further identify other molecular biomarkers and support improved patient stratification remains an important priority for research, building on these initial advances in understanding.

For example, the TransPORTEC trial identified additional prognostic subgroups in addition to the TCGA molecular classifications, with potential therapeutic implications for high-risk endometrial cancers, including *FBXW7* and *FGFR2* mutations (6 per cent of endometrial cancers), alterations in the PI3K-AKT pathway (60 per cent of endometrial cancers) and hormone receptor positivity (45 per cent all endometrial cancers). Other studies have similarly shown high prevalence of these mutations in both endometrial carcinomas and uterine carcinosarcomas of *HER-2* (overexpression and amplification), which occurs in 12-60 per cent of endometrial cancers and 14-80 per cent in uterine carcinosarcomas, and may indicate a role for immunotherapies like trastuzumab and pertuzumab that are used in the treatment of metastatic breast cancer.

ANZGOG's TR-ANZGOG program[110] seeks to increase biospecimen collection and analysis as part of clinical trials in Australia and Aotearoa New Zealand.

- *Improved prevention, including the emergence of a precision prevention paradigm* — Building on the improved understanding of the biology of different uterine cancers, research has identified the need to improve the take-up of risk-reducing strategies (prophylactic surgery) for women with genetic risk, including Lynch syndrome.[111] Obesity management and hormonal contraceptive have also been provide to be modifiable risk factors with preventive potential. For example, studies have shown that behavioural, pharmaceutical and surgical interventions can reduce

[106] Choi, J., Holowatyj, A. N., Du, M., Chen, Z., Wen, W., Schultz, N., Lipworth, L., & Guo, X. (2022). Distinct Genomic Landscapes in Early-Onset and Late-Onset Endometrial Cancer. *JCO precision oncology*, *6*, e2100401. https://doi.org/10.1200/PO.21.00401

[107] Setiawan, V. W., Pike, M. C., Kolonel, L. N., Nomura, A. M., Goodman, M. T., & Henderson, B. E. (2007). Racial/ethnic differences in endometrial cancer risk: the multiethnic cohort study. *American journal of epidemiology*, *165*(3), 262–270. https://doi.org/10.1093/aje/kwk010

[108] Feinberg, J. et al. (2019). Ten-Year Comparison Study of Type 1 and 2 Endometrial Cancers: Risk Factors and Outcomes, Gynecol Obstet Invest (2019) 84 (3): 290–297. https://doi.org/10.1159/000493132

[109] Guttery, D. S., Blighe, K., Polymeros, K., Symonds, R. P., Macip, S., & Moss, E. L. (2018). Racial differences in endometrial cancer molecular portraits in The Cancer Genome Atlas. *Oncotarget*, *9*(24), 17093–17103. https://doi.org/10.18632/oncotarget.24907; and Mukerji, B., Baptiste, C., Chen, L., Tergas, A. I., Hou, J. Y., Ananth, C. V., Neugut, A. I., Hershman, D. L., & Wright, J. D. (2018). Racial disparities in young women with endometrial cancer. *Gynecologic oncology*, *148*(3), 527–534. https://doi.org/10.1016/j.ygyno.2017.12.032

[110] See: ANZGOG, TR-ANZGOG, accessed at: https://www.anzgog.org.au/research/tr-anzgog/

[111] Dominguez-Valentin, M., Seppälä, T. T., Engel, C., Aretz, S., Macrae, F., Winship, I., Capella, G., Thomas, H., Hovig, E., Nielsen, M., Sijmons, R. H., Bertario, L., Bonanni, B., Tibiletti, M. G., Cavestro, G. M., Mints, M., Gluck, N., Katz, L., Heinimann, K., Vaccaro, C. A., … Crosbie, E. J. (2020). Risk-Reducing Gynecological Surgery in Lynch syndrome: Results of an International Survey from the Prospective Lynch syndrome Database. *Journal of clinical medicine*, *9*(7), 2290. https://doi.org/10.3390/jcm9072290

the risks of endometrial cancer.[112] Studies have further shown that there is sufficient evidence to widen eligibility criteria for women with endometrial hyperplasia and a high BMI.[113]

- *Improving early detection and diagnosis* — While there is currently no screening for uterine cancer available today, significant research advances have been made to identify biomarkers and minimally invasive diagnostics to improve the early diagnosis of uterine cancer including among asymptomatic women. For example:
  - Researchers have developed a range of minimally invasive diagnostics that have been shown in early studies to improve early detection. Examples include PapSEEK[114] and DETECT,[115] which are minimally invasive devices that can be used to detect endometrial cancer through cervical samples. For example, in a large retrospective study 93 per cent of endometrial cancers were detected with the Tao brush (this represents the sensitivity of the test), and the Tao brush enjoyed a very high specificity, meaning that zero women tested positive for endometrial cancers that did not have endometrial cancer. The DETECT study sought to identify biomarkers from analysis of tampon specimens.
  - Liquid biopsies and circulating tumour DNA (ctDNA) are under also investigation for real-time monitoring and residual disease detection. A systematic review in 2022 found there were 56 studies of blood-based biomarkers in development and a single study focused on urine samples.[116] More research is needed to reduce the risk of false positives (test specificity) to reduce unnecessary investigations. As such research remains in the discovery phase rather than the validation phase
  - Researchers in Australia have shown the use of AI (ECgMPL) to improve review of histopathological images can improve the accuracy of diagnoses from approximately 80 per cent (78.91–80.93 per cent) when using current clinical practice to more than 99.26 per cent when using the AI system.[117]

  New treatment pathways to preserve fertility and improve surgical outcomes for high-risk and early stage endometrial cancer patients — Research has shown that women at high risk of endometrial cancer or who have been diagnosed with low-risk, early stage endometrial cancer can be treated with a range of lifestyle, pharmaceutical, hormonal and surgical interventions that may potentially completely cure their uterine cancer without the need for major surgery (e.g., a hysterectomy) or can delay the time to major surgery to allow for women to preserve their fertility and potentially conceive a child or improve their outcomes from surgery by accessing prehabilitation services. For example:

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[112] Rundle-Thiele, D., Shrestha, S., and Janda, M., (2022). Prevention of endometrial cancer through lifestyle Interventions: A systematic review and synthesis, Gynecologic Oncology Reports, Volume 39, 2022, https://doi.org/10.1016/j.gore.2021.100900.
[113] Aubrey, C., Black, K., Campbell, S., and Pin, S., (2019). Endometrial cancer and bariatric surgery: A scoping review, Surgery for Obesity and Related Diseases, Volume 15, Issue 3, https://doi.org/10.1016/j.soard.2018.12.003.
[114] Wang, Y., Li, L., Douville, C., Cohen, J. D., Yen, T. T., Kinde, I., Sundfelt, K., Kjær, S. K., Hruban, R. H., Shih, I. M., Wang, T. L., Kurman, R. J., Springer, S., Ptak, J., Popoli, M., Schaefer, J., Silliman, N., Dobbyn, L., Tanner, E. J., Angarita, A., … Papadopoulos, N. (2018). Evaluation of liquid from the Papanicolaou test and other liquid biopsies for the detection of endometrial and ovarian cancers. Science translational medicine, 10(433), eaap8793.
[115] Clarke, Megan et al. (2023). The discovery and evaluation of tests for endometrial cancer in tampons (DETECT) study: A baseline description (2119), Gynecologic Oncology, Volume 176, S208 - S209
[116] Karkia, R., Wali, S., Payne, A., Karteris, E., & Chatterjee, J. (2022). Diagnostic Accuracy of Liquid Biomarkers for the Non-Invasive Diagnosis of Endometrial Cancer: A Systematic Review and Meta-Analysis. *Cancers*, *14*(19), 4666. https://doi.org/10.3390/cancers14194666
[117] Charles Darwin University, 2025, AI diagnoses major cancer with near perfect accuracy, accessed at: https://www.cdu.edu.au/news/ai-diagnoses-major-cancer-near-perfect-accuracy.

The feMMe trial showed disease regression was observed in 82 per cent of women with endometrial hyperplasia with atypia (a common precursor to uterine cancer) in 43 per cent of women with endometrial cancer after treatment for 6 months with a hormonal intrauterine device (an IUD).[118]

Research has also found sufficient evidence to expand access to bariatric surgery for women with a BMI of 30 that have also been diagnosed with endometrial hyperplasia or endometrial cancer.[119]

- *Innovations in surgical treatment* — Minimally invasive surgery (MIS), (laparoscopic or robotic-assisted), is now standard for early-stage disease, reducing morbidity without compromising outcomes. Sentinel lymph node mapping (SLNM) has replaced full lymphadenectomy in many settings, reducing lymphedema risk while maintaining staging accuracy.[120]
- *Improvements in the personalised use of adjuvant treatments* — Adjuvant therapy is increasingly tailored by molecular subtype, not just clinicopathologic features. Trials like PORTEC-3 and GOG-258 clarified roles for radiation and chemotherapy in high-risk groups.
- *Development of targeted therapies, immunotherapies and combination therapies* — Overall, women with endometrial cancer have a good chance of survival, with a 95 per cent five-year survival rate for Stage I disease. However, survival is poor for women with recurrent or late-stage disease. By contrast, women diagnosed with Stages III or IV endometrial cancer have a survival rate of only 19 per cent.[121]

  It may be hard to believe, but prior to 2017, there was no standard of care for women after failing front-line carboplatin and paclitaxel. Then, in May 2017, the FDA approved pembrolizumab in microsatellite instability high (MSI-H)/mismatch repair deficient (dMMR) endometrial cancer patients following failure of systemic chemotherapy.[122]

  This was followed in 2019 with approvals of pembrolizumab and lenvatinib for women who are not MSI-H or are MMR-proficient and later the use of trastuzumab for women that over-express HER2.[123]

  This relatively recent development of novel therapies is ushering in a transition towards precision medicine in uterine cancer, which is critical to improve outcomes for women with rare, recurrent and advanced cancers. But this research is only in its early stages relative to other cancers. A range of trials are now underway to improve treatment selection (See Section 4.2) including the RAINBO and TAPER trials.
- *Improved models of care for surveillance* — Research has also been exploring new approaches to surveillance and follow-up. The development of biomarkers for surveillance remains at a discovery phase but will be important tools over time for monitoring potential disease recurrence. Given limitations for biomarker-based

[118] Helwick, C., (2021). Hormonal Intrauterine Device Under Study for Managing Early Endometrial Cancer, accessed at: https://ascopost.com/issues/may-10-2021/hormonal-intrauterine-device-under-study-for-managing-early-endometrial-cancer/ and Baker, J. et al. (2021). Efficacy of oral or intrauterine device-delivered progestin in patients with complex endometrial hyperplasia with atypia or early endometrial adenocarcinoma: A meta-analysis and systematic review of the literature, Gynecologic Oncology, Volume 125, Issue 1, 263 – 270, 10.1016/j.ygyno.2011.11.043

[119] Aubrey, C., Black, K., Campbell, S., and Pin, S., (2019). Endometrial cancer and bariatric surgery: A scoping review, Surgery for Obesity and Related Diseases, Volume 15, Issue 3, 10.1016/j.soard.2018.12.003.

[120] Darling, Alice et al. (2024). Patterns of adjuvant therapy for endometrial cancer with sentinel lymph node biopsy Gynecologic Oncology, Volume 190, S401 - S402

[121] American Cancer Society, 2025, Survival Rates for Endometrial Cancer, accessed at: https://www.cancer.org/cancer/types/endometrial-cancer/detection-diagnosis-staging/survival-rates.html

[122] Halla K. (2022). Emerging Treatment Options for Advanced or Recurrent Endometrial Cancer. *Journal of the advanced practitioner in oncology*, *13*(1), 45–59. https://doi.org/10.6004/jadpro.2022.13.1.4

[123] Ibid.

surveillance, research remains focused on optimising follow-up protocols of current clinical practice.

No survival benefit has been shown with intensive follow-up; thus, surveillance focuses on risk-based, symptom-driven models of follow-up care and surveillance to minimise the burden on women and the health system. A series of trials have been completed identifying opportunities for less-intensive and patient-led follow up to be adopted as the primary model for follow-up care. Examples include the ENSURE trial in the Netherlands,[124] which found that reduced follow-up did not compromise patient satisfaction or quality-adjusted life years and was more cost-effective. Similarly, a systematic review of patient-initiated follow-up found the model to be acceptable for women with low-risk endometrial cancer.[125]

Other research has explored alternative models for follow-up, such as telephone-based follow-up (TFU) led by specialist gynaecological cancer nurses. These models similarly aim to provide comprehensive follow-up care while reducing the burden on healthcare systems and patients.[126]

- *Improved models of care for survivorship* — Research is also improving the understanding of supportive care, or patient initiated follow up, needs for survivors. There is a growing emphasis on how to improve long-term survivors' quality of life, addressing sexual health, obesity, and comorbidities. Survivorship programs in development now often include psychosocial support, programs to improve weight, physical activity and overall metabolic health, as well as long-term toxicity monitoring and the management of potential side effects from treatment. This includes the development of survivorship clinics, such as those in place in Western Australia and in development in Victoria, as well as new models of care for the delivery of home-based care. A trial in the US found the delivery of home-based strength training was feasible and acceptable, with 75 per cent of women adhering to the exercise prescription and 85 per cent of participants missing fewer than 3 of the workouts over the 10-week program. Forty percent of participants continued workouts during the 5-week follow-up.

  Research conducted for the development of shared care for the delivery of survivorship support. Cancer Australia has endorsed a shared follow-up and survivorship care model for women with low-risk endometrial cancer.[127] This approach involves collaboration between oncology specialists and primary care providers to manage follow-up care, addressing co-morbidities such as hypertension, obesity, and diabetes, which are prevalent among survivors. COSA and Peter MacCallum Cancer Centre have also supported the development of shared care models, emphasising the need for personalised, stratified care pathways that consider individual patient needs, treatment history, and risk of long-term effects.[128]

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[124] Ezendam, N.P.M., et al, (2024). Effect of reduced follow-up care on patient satisfaction with care among patients with endometrial cancer: The ENSURE randomized controlled trial, Gynecologic Oncology, Volume 188, 10.1016/j.ygyno.2024.06.020; and Ezendam, N.P.M., de Rooij, B.H., Kruitwagen, R.F.P.M. *et al.* ENdometrial cancer SURvivors' follow-up carE (ENSURE): Less is more? Evaluating patient satisfaction and cost-effectiveness of a reduced follow-up schedule: study protocol of a randomized controlled trial. *Trials* **19**, 227 (2018). https://doi.org/10.1186/s13063-018-2611-x

[125] Leitch, Megan et al. (2025). Patient-initiated follow-up in low-risk endometrial cancer after surgery: a systematic review, International Journal of Gynecological Cancer, Volume 35, Issue 2, 100037

[126] Collins, A. et al. (2021). Innovative Follow-up Strategies for Endometrial Cancer Clinical Oncology, Volume 33, Issue 9, e383 - e392 10.1016/j.clon.2021.06.001

[127] Cancer Australia, 2020. Shared follow-up and survivorship care for women with low-risk endometrial cancer: summary of evidence https://www.canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/shared-follow-and-survivorship-care-women-low-risk-endometrial-cancer-summary-evidence

[128] Peter MacCallum, (2025).

4.2 Key clinical trials improving treatment and care today

There are also a number of important trials ongoing, including within Australia, that have the potential to further build on the important advances of the past 15 years; these include:

- The RAINBO and TAPER/EN.10 trials
- The feMMe Molecular trial
- The ENDO-3 trial.

The RAINBO and TAPER Trials

The RAINBO program is a platform of four international clinical trials and an overarching research program investigating four molecular class-directed adjuvant treatment strategies following surgical resection to either:

- Increase cure rates through the addition of novel targeted therapies, or
- Safely reduce toxicity and improve quality of life through treatment de-escalation (TAPER).

The four trials are:

- The randomized phase III p53abn-RED trial for women with invasive stage I-III p53abn endometrial cancer compares adjuvant chemoradiation followed by olaparib (PARP inhibitor) for 2 years with adjuvant chemoradiation alone.
- The randomized phase III dMMR-GREEN trial for women with stage II (with lymphovascular space invasion (LVSI)) or stage III mismatch repair-deficient (dMMR) endometrial cancer compares adjuvant radiotherapy with concurrent and adjuvant durvalumab for 1 year to radiotherapy alone.
- The randomized phase III NSMP-ORANGE trial is a treatment de-escalation trial for women with oestrogen receptor positive stage II (with LVSI) or stage III no specific molecular profile (NSMP) endometrial cancer comparing radiotherapy followed by progestin for 2 years to adjuvant chemoradiation.
- The POLEmut-BLUE trial is a phase II trial in which the safety of de-escalation of adjuvant therapy is investigated for women with stage I-III POLEmut endometrial cancer: no adjuvant therapy for lower-risk disease and no adjuvant therapy or radiotherapy alone for higher-risk disease.

The feMMe Molecular trial

As set out in Chapter 1, current standard treatment for uterine cancer involves a total hysterectomy. While highly effective, there are risks and side effects involved for:

- Women with severe medical co-morbidities and/or morbid obesity who are at risk for surgical complications and for whom surgery is unsafe
- Young women who still wish to have children and would lose their fertility by having a hysterectomy.

Against the backdrop of rising early onset of endometrial cancer, particularly low-grade, stage I cancers, improving treatment options for these women is critical.

The feMMe trial explored the use of an intra-uterine device loaded with metformin to treat early-stage endometrial cancer patients as a less invasive treatment that could allow women to undergo pre-habilitation to improve their health in advance of surgery and/or to access fertility treatment prior to surgery.

The trial found this approach was well tolerated and in 50 per cent of patients there was no remaining endometrial cancer found at six months. Unfortunately, we cannot predict yet who will benefit from this treatment. If we can determine who will respond, clinicians could specifically offer this treatment to women who will likely benefit.

In a follow-up trial to the feMMe trial, researchers in the feMMe Molecular trial are evaluating blood and tissue samples collected as part of the feMMe trial to identify predictive biomarkers of LNG-IUD response that indicate whether a patient will or will not benefit from this new treatment. Using the findings, they will develop a personalised decision tool that clinicians and patients can use to decide on the best treatment.

The gains of a successful project will include the reduction of hospital bed days, radical surgery, surgical complications and their associated costs. It will allow an increasing number of women to maintain their fertility and have children.

ENDO3: Optimising SLNB

While many women are cured by a hysterectomy and may experience few side effects, data show that for women with more advanced disease, the risks of side effects can increase with potentially significantly poor outcomes for quality of life.

In particular, lymphadenectomy (the removal of lymph nodes to which the cancer may have metastasised) can be associated with lymphoedema, which is a chronic (ongoing) swelling that occurs as a result of lymphatic fluid being unable to drain due to blockage or damage to the lymphatic system. For women that have completed uterine cancer treatment this lymphoedema can affect their groin and legs.

Sentinel lymph node biopsy (SLNB), which is also referred to Sentinel Lymph Node Dissection (SLND) or sometimes Sentinel lymph node mapping (SLNM), is a common surgical staging approach to detect metastatic disease and has replaced full lymphadenectomy, reducing lymphedema risk while maintaining staging accuracy (FIRES trial, 2017).

There is lack of consensus regarding the role and extent of SLNB/SLND in low-risk patients.[129] The ENDO3trial is developing evidence of best practice surgical treatment in endometrial cancer, comparing Sentinel Lymph Node Dissection (SLND), a commonly performed procedure for the surgical staging of endometrial cancer, to No Node Dissection.

The outcomes from ENDO-3 will provide high-level evidence on the effectiveness, benefit and harm of SLNB/SLND and will determine the value of retaining or discontinuing this procedure in the treatment of apparent early-stage endometrial cancer.[130]

The ENDO-3 trial opened for recruitment in January 2021 at the Royal Brisbane & Women's Hospital and The Wesley Hospital. The first patient was enrolled in February 2021, and the aim is to recruit 760 patients. Currently there are 8 Australian sites collaborating on the ENDO-3 Trial with more in the pipeline, including international sites.

4.3 Key research questions and priorities

These important research advances and trials have laid the foundation to improve outcomes for women diagnosed with uterine cancers.

Due to significant under-funding of uterine cancer research in the modern cancer research era (since 1975), and the very significant increase in incidence, inequity and mortality

[129] Eriksson, A. G. Z., Davidson, B., Bjerre Trent, P., Eyjólfsdóttir, B., Dahl, G. F., Wang, Y., & Staff, A. C. (2021). Update on Sentinel Lymph Node Biopsy in Surgical Staging of Endometrial Carcinoma. Journal of clinical medicine, 10(14), 3094. https://doi.org/10.3390/jcm10143094

[130] University of Queensland, 2025. ENDO-3 Trial. https://gyncan.org/our-research/current-trials/endo-3-trial

expected over the next 20 to 40 years, however, very significant work remains to improve outcomes for women and their families.

Major questions in uterine cancer to be answered by future research are summarised in Figure 4.2. Answering these questions will require investment in a range of research domains, including basic and translational research, clinical trials research, and health implementation science. Key research priorities by domain include:

- *Basic and translational research* — Significant further advances are needed in the understanding of biology, aetiology and treatment of uterine cancer, which is less complete compared to other cancers. While important advances have been made to better understand these areas, more work is needed to be done to identify actionable targets for treatment, particularly for rare and advanced cancers, as well as drivers of disease recurrence and treatment resistance. For example, recent research has uncovered novel treatment methods in uterine cancer and highlighted the need for further research:[131]

  > *Hereditary uterine cancer (UC) is traditionally associated with pathogenic/likely pathogenic germline variants (PGVs) in Lynch syndrome genes or PTEN; however, growing evidence supports a role for other genes that may reveal new clinical management options. Focusing germline testing on Lynch syndrome genes and PTEN and precluding some older women (>50) from accessing testing, may overlook a substantial proportion of UC patients who harbor actionable PGVs. Universal comprehensive genetic testing of UC patients could benefit many patients and at-risk family members, [importantly, preventing some uterine cancers]. Importantly, sixty per cent of PGVs were associated with FDA-approved therapies and 35 per cent with precision therapy clinical trials.*

  Similarly, there remains a poor understanding of the genetic diversity specific to different racial and ethnic groups, which contributes to the gap in survival and quality of life outcomes for Aboriginal and Torres Strait Islander, wāhine Māori, Pacific and Asian women.

- *Improved prevention and early detection* — Consumers, clinicians and researchers alike placed research into the improved prevention and early detection of uterine cancer among the highest priorities for research in the next 15 years.

  The further development and implementation of diagnostic assessment tools that could be deployed in primary practice as well as minimally invasive diagnostics[132] using samples from urine, blood, and/or cervico-vaginal fluids (e.g., samples taken from swabs, Tao brushes or tampons) represent promising and exciting frontiers in uterine cancer care.

  This is particularly important when one considers some of the diagnostic challenges for GPs, with some of the most commonly reported symptoms, such as pain during urination or pelvic pain, representing less than one per cent of the frequency that these symptoms may be reported. It also holds the promise of a significant step change in survival outcomes, with 5-year relative survival for endometrial cancer of

[131] Heald, B. et al. (2022). Unexpected actionable genetic variants revealed by multigene panel testing of patients with uterine cancer, Gynecologic Oncology, Volume 166, Issue 2, https://doi.org/10.1016/j.ygyno.2022.05.023.

[132] See: Crosbie, E. J., Kitson, S. J., McAlpine, J. N., Mukhopadhyay, A., Powell, M. E., & Singh, N. (2022). Endometrial cancer. *The Lancet*, *399*(10333), 1412-1428; Costas, L., Frias-Gomez, J., Guardiola, M., et al 2019. New perspectives on screening and early detection of endometrial cancer. International journal of cancer, 145(12), pp.3194-3206; An, Y., Feng, Q., Jia, L. *et al.* Present progress in biomarker discovery of endometrial cancer by multi-omics approaches. *Clin Proteom* **22**, 15 (2025). https://doi.org/10.1186/s12014-025-09528-6.

at Stage I being 95 per cent, compared to 5-year survival at Stage II of 70 per cent, and only 19 per cent at Stages III and IV.[133]

Research shows that women want to engage with health services to improve their health. The development of new models of care for wellness have the potential to more than halve incidence – but work is needed to develop appropriate and effective, multi-modal and culturally-sensitive models of care.

- *Treatment and supportive care* — As a result of historic underinvestment in research, most genomic variants of uterine cancers lack specific clinical treatments today, and clinical trials are needed to develop evidence of treatment safety and efficacy. In addition, for around 40 per cent of uterine cancer patients today, a specific variant, matching to a treatment, will not be found. While more work is needed to identify additional drug targets, at the same time, many potential drug targets have been identified but require clinical trials to better understand their utility in uterine cancers.

  Uterine cancer needs more small, smart, nimble trials, such as signal-seeking trials, platform trials, basket trials and 'window of opportunity' trials. Signal seeking trials can bring more relevant drugs into Australia, including, in relevant combinations, industry trials and industry support for innovative academic studies. This includes "drug repurposing", which offers the opportunity to significantly expand treatment options for women with uterine cancer, but has had limited funding and success to date.

  Many targeted therapies found to be beneficial in hormone-driven cancers are in early phase I or II trials for uterine cancer, and include immunotherapies, antibody-drug conjugates (ADCs), and targeted agents.

  Added to this, significant health implementation science is needed to improve adherence to clinical best practice along the care pathway, improving consistency in diagnostics, adjuvant therapies, access to supportive care, access to fertility preservation and follow-up care.

  Other opportunities include research to explore the effectiveness and efficiency of new models of care in support, potentially leveraging wider efforts to develop women's health clinics.

[133] American Cancer Society, 2025, Survival Rates for Endometrial Cancer, accessed at: https://www.cancer.org/cancer/types/endometrial-cancer/detection-diagnosis-staging/survival-rates.html

Figure 4.2: Key research questions by domain

What are the exact molecular and genetic drivers of uterine cancer by subtype?
- Identify additional molecular biomarkers
- Racial and ethnic specific risk

What is the role of the immune system in uterine cancer?
- Immune therapies for selected patients
- Role of the tumour microenvironment

How can we better raise awareness of uterine cancer?
- Awareness campaigns
- Education strategies

How can we better prevent uterine cancer?
- Diet and lifestyle interventions
- New models of care to improve wellness

How can we better identify high-risk patients?
- Risk prediction models, scores
- GP protocols for referral of women with abnormal vaginal bleeding
- Identify validated biomarkers to enable screening early detection

What are the best 'precision prevention' interventions for high-risk women?
- Surgical interventions (Bariatric surgery)
- Pharmaceutical interventions (GLP-1)
- Wellness programs
- Programs targeting priority populations

How can we improve early detection?
- Minimally-invasive diagnostic methods
- Screening guidelines
- Awareness campaigns, education strategies

How can we improve survival for women with rare, recurrent and advanced disease?
- Expanding targeted therapy and immuno-therapy options
- Combination therapies

How can we further reduce the toxicity of treatment?
- Precision medicine, selection of adjuvant therapy
- De-escalation
- Predictors of side-effects (lymphoedema)

How can we improve access to clinical best practice?
- Guidelines, improved adherence to guidelines
- Priority population outcomes
- MDT prior to definitive treatment
- Supportive care screening
- Patient support and navigation

How can we maximise quality of life for women during treatment?
- Screening for supportive care, improved adherence to guidelines
- Prehabilitation
- New models of care
- Access to fertility sparing treatment
- Patient support
- Peer support

How can we improve long term surveillance?
- Patient initiated follow-up
- Biomarkers of recurrence

What are the long-term effects of treatment and how can these minimised?
- Impact on quality of life, sexual health, lymphoedema risk, and fertility in survivors
- Survivorship pathway

How can we maximise quality of life and long-term health of survivors?
- New models of care to improve wellness
- Patient support
- Peer support

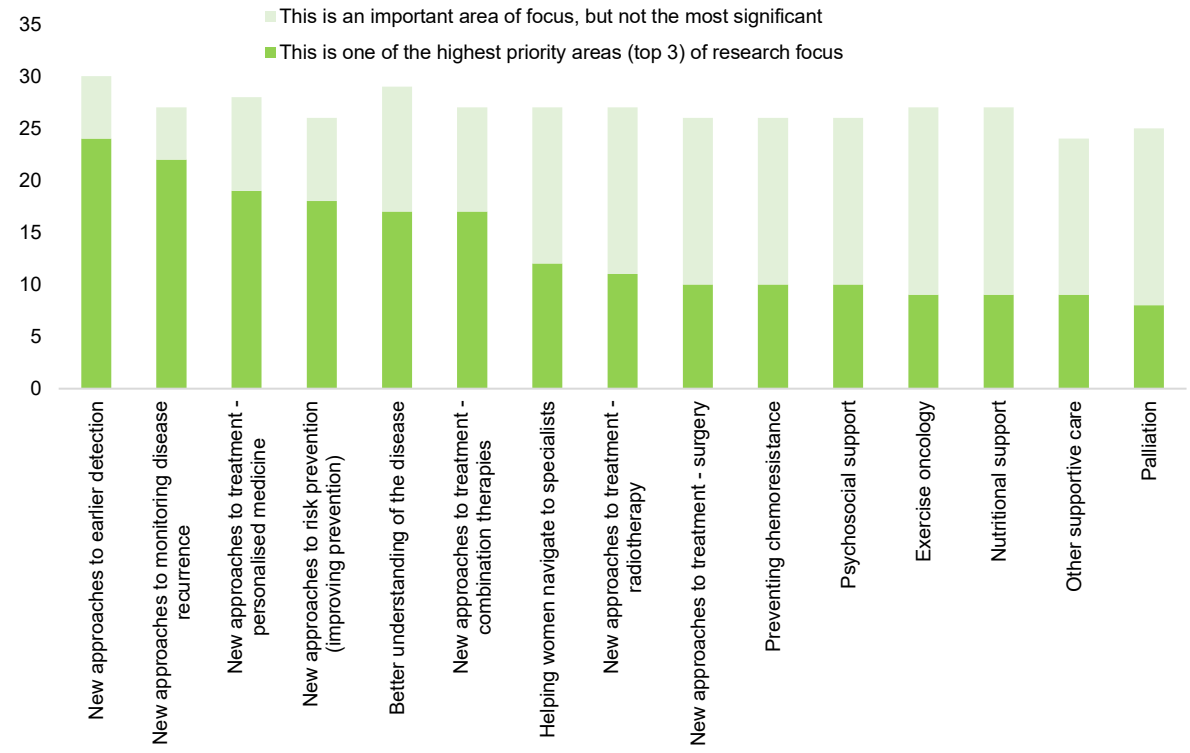
- *Survivorship and surveillance* — Across much of the care pathway there is already strong evidence for what clinical best practice may be, but more work is required to determine how best to *implement* new models of care or adherence to clinical best practice. A good example of this is improvements in surveillance. Research has shown that a risk-based, patient-led approach to follow-up care can be feasible and safe; research is needed to develop guidelines and support implementation of clinical best practice. More research is needed to develop cost-effective models of care for uterine cancer survivors and associated guidelines.

Answering these research questions will work to deliver improvements in survival and quality of life for more than 55,000 women across Australia and Aotearoa New Zealand over the 2025-2035 period.

In terms of research priorities, patients and carers identified new approaches to early detection, new approaches to monitoring disease recurrence and new approaches to personalised medicine as the highest priorities for research to improve outcomes for women (Figure 4.3). This makes intuitive sense: improving early detection would deliver step change improvements in quality of life, with 5-year survival for Stage I diagnoses being 95 per cent compared to 17 per cent for Stages III and Stage IV.

Women are also concerned with expanding treatment options for later stage cancers and minimising the risk of toxicity of treatments based on their own personal risk factors (e.g., molecular subtype).

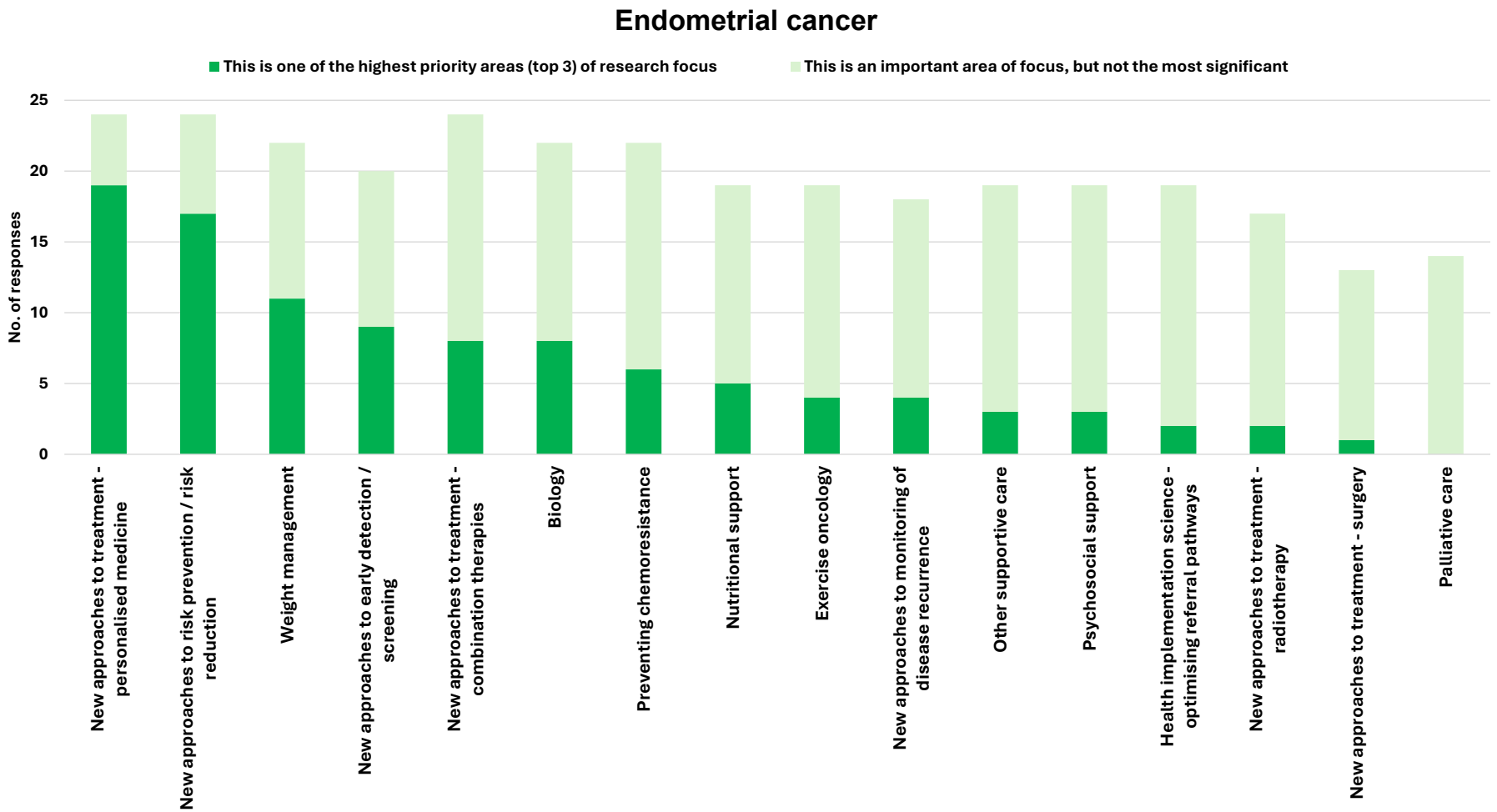
Figure 4.3: Research priorities in uterine cancer research – patient and carer perspective



Source: Survey of Uterine Cancer Patients and Carers.

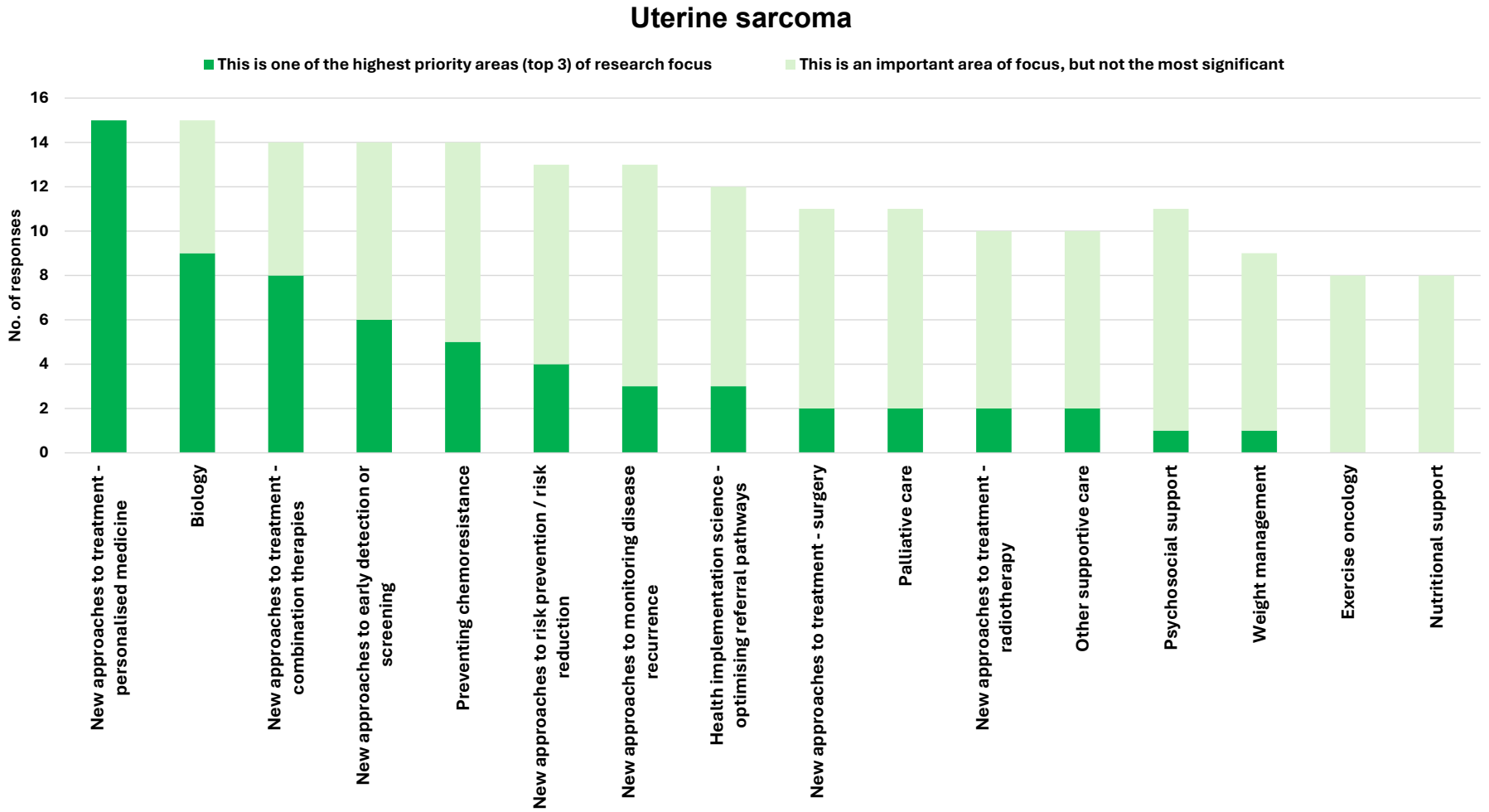
Clinicians and researchers working in the field of uterine cancer were asked a similar question with respect to priorities in research, but some additional information was sought in the clinician and researcher survey (Figures 5.4-5.7).

Figure 4.4: Research priorities to improve survival in endometrial cancer – clinician and researcher perspectives



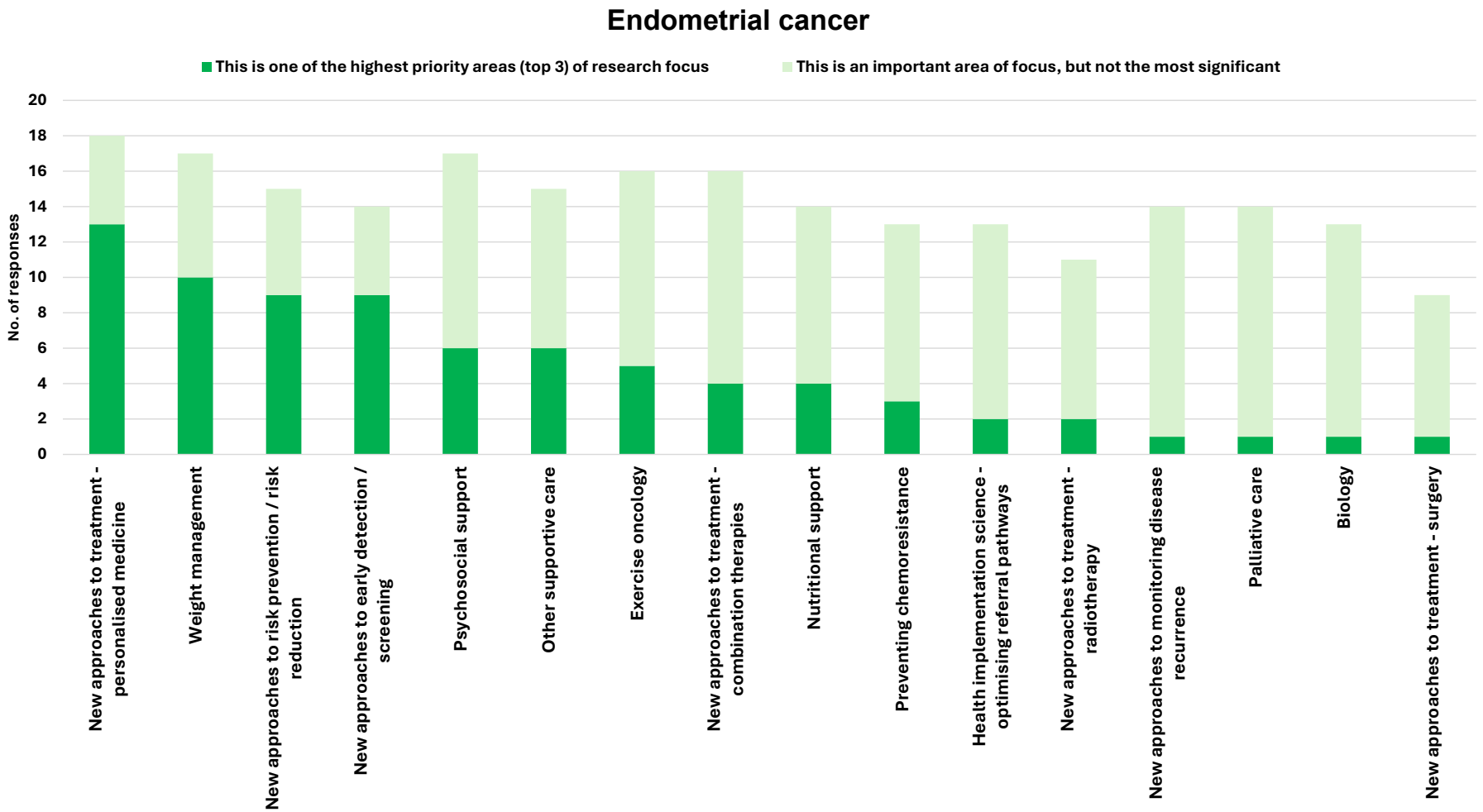
Source: Survey of Uterine Cancer Clinicians and Researchers.

Figure 4.5: Research priorities to improve survival in uterine sarcoma – clinician and researcher perspectives



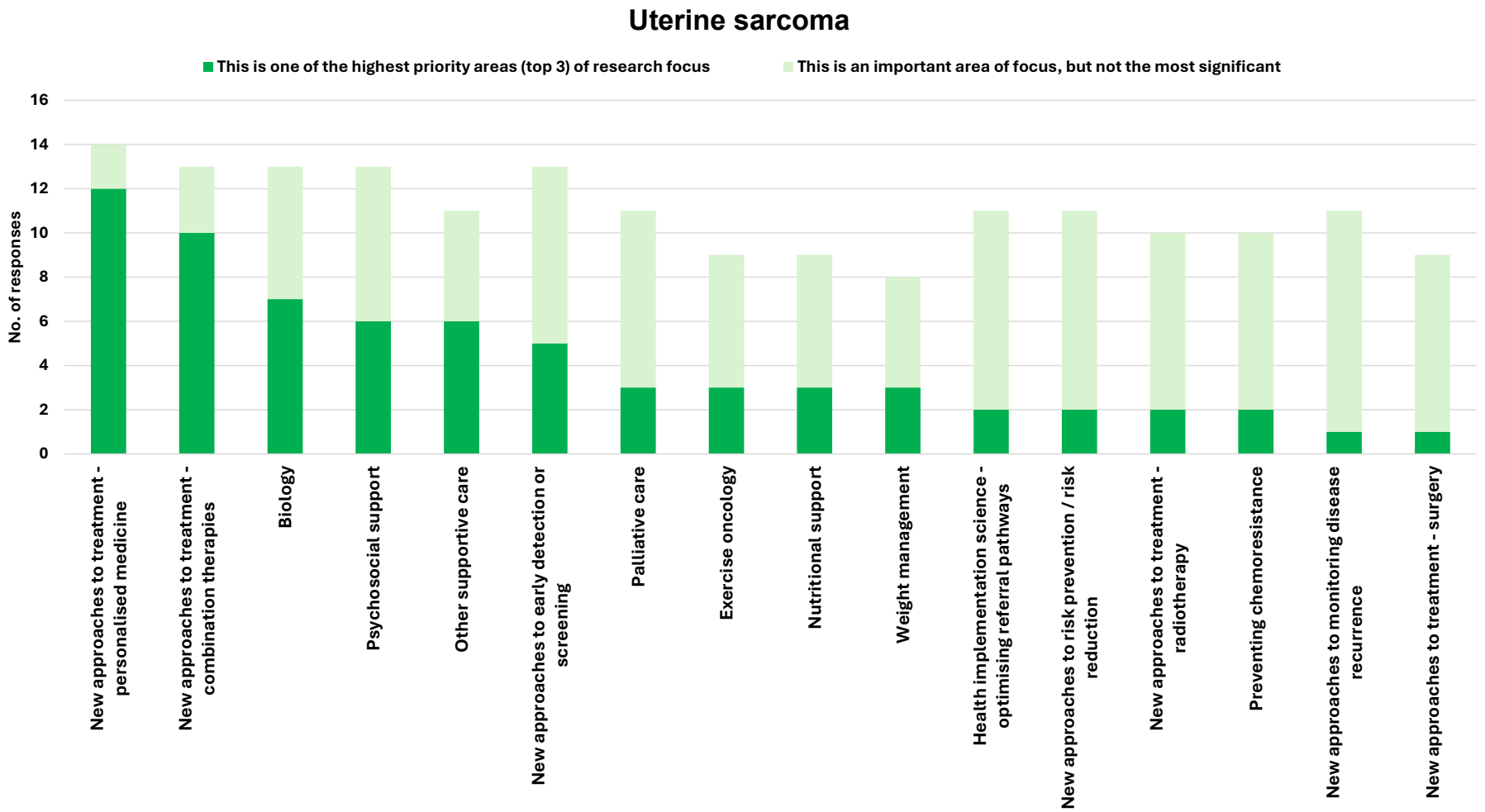
Source: Survey of Uterine Cancer Clinicians and Researchers.

Figure 4.6: Research priorities to improve quality of life in endometrial cancer – clinician and researcher perspectives



Source: Survey of Uterine Cancer Clinicians and Researchers.

Figure 4.7: Research priorities to improve quality of life in uterine sarcoma – clinician and researcher perspectives



Source: Survey of Uterine Cancer Clinicians and Researchers.

Clinicians and researchers were first asked how to improve *survival* for major uterine cancer subtypes (endometrial cancer and uterine sarcomas) and then for research priorities to improve *quality of life*, again for the two major subtypes. Their answers reflect the very different drivers of risk for the two major subtypes and therefore different priorities for rare uterine cancer subtypes which may have fewer treatment options compared to endometrial cancers.

As shown in Figures 5.4-5.7, clinicians and researchers identified identification of precision medicine as the most important research priority to improve survival and quality of life for both endometrial and uterine cancer, which reflects that while many women may be cured with surgery a significant proportion will experience recurrence or be diagnosed with a rare cancer for which there are few treatment options.

For endometrial cancers, however, clinicians and researchers identified improvements to risk prevention, weight management and early detection as the next highest priorities to improve survival and quality of life, similar to patient and carer perspectives, while for uterine sarcomas investment in improved understanding of the disease (biology) and combination therapies were identified as the next highest priorities (followed by earlier detection). This reflects need to significantly expand treatment options for uterine sarcoma as a very rare cancer.

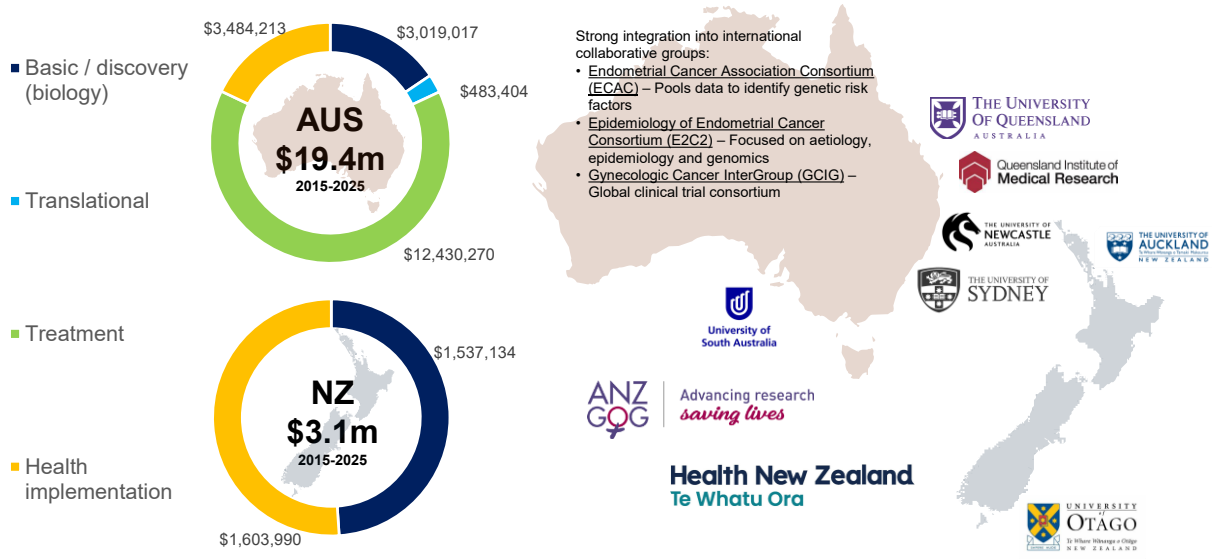
Clinicians and researchers also placed improved access to psychosocial support as an important area for research to improve quality of life for endometrial and uterine sarcoma survivors.

Taken together, the top 5 priorities to improve survival and quality of life identified by patients, carers, clinicians and researchers enjoyed strong alignment, with early detection, precision medicine and prevention identified as key priorities by all stakeholders.

4.4 The uterine cancer research landscape in Australia and Aotearoa New Zealand: areas of comparative advantage and future priorities

Australia and Aotearoa New Zealand's research community have significantly advanced the understanding and management of endometrial cancer and uterine sarcomas and are well placed to address these research priorities and answer these key research questions.

Figure 4.8: Research in uterine cancer in Australia and Aotearoa New Zealand (2015-2025)



Source: Grants Connect and Health Research Council of New Zealand (2025). HRC Research Repository, https://www.hrc.govt.nz/resources/research-repository

As shown in Figure 4.8, the contributions of Australian and Aotearoa New Zealand researchers in the past 10 years have spanned clinical trials, molecular research, and the development of care models, improving outcomes for endometrial cancers and uterine sarcomas. Over the past 10 years total research funding in uterine cancer in Australia has totalled $19.4 million, including $12.4 million in clinical trials research, $3.5 million in basic and translational research and $3.5 million in health implementation science. In Aotearoa New Zealand, $3.1 million has been invested in uterine cancer research, with approximately half this amount being allocated to basic research and the balance being allocated to health implementation science.

The major performers of this research have included the University of Queensland, QIMR, University of Sydney, University of Newcastle, University of South Australia, the University of Auckland, the University of Otago, ANZGOG and Health Aotearoa New Zealand.

These collective efforts by researchers in Australia and Aotearoa New Zealand have significantly advanced the understanding, diagnosis, and treatment of endometrial cancer and uterine sarcomas, contributing to improved patient outcomes and informing global best practices.

Looking forward, Australian and Aotearoa New Zealand researchers have a significant role to play along the whole of the care pathway. In addition to a significant uplift in investment for research, stakeholders also saw a significant opportunity to expand investment into health implementation science in addition to basic, translational and treatment research (Figure 4.9). Moreover, the National Collaborative Research Infrastructure Strategy (NCRIS) provides an avenue for Government to support researchers by investing in infrastructure that can give researchers an edge. As an example, Phenomics Australia, which is supported by NCRIS, will be investing in the development and supply of bespoke organoids for use in treatment for uterine cancer.

Given Australia and Aotearoa New Zealand's areas of comparative advantage and priorities for research, a number of major priorities for Australian and Aotearoa New Zealand research have been identified by ANZGOG and refined with input from stakeholders to this study; these priority projects are summarised in Figure 4.10 and range from projects to improve awareness and develop new models of care for primary and secondary prevention of cancers through to molecular and translational research to identify new biomarkers and treatments for rare, recurrent and advanced cancers as well as studies to validate treatment selection for women based on the molecular profile of their cancer and personal circumstances and treatment goals to maximise quality of life.

To deliver this high impact research program, a comprehensive, nation-wide strategies in Australia and Aotearoa New Zealand are needed with funding for:

- Collection and storage of biospecimens
- Expanded access to comprehensive molecular profiling
- Expanded investment in molecular and translational research
- Growth in clinical trials, including signal seeking trials, basket trials and 'window of opportunity trials'
- Data linkage, analytics, and knowledge curation, powered by AI
- New models of care, including in primary and secondary prevention, supportive care and survivorship care
- Development of living clinical guidelines to drive practice improvements.

Figure 4.9: Stakeholder perspectives on priorities for Australian and Aotearoa New Zealand research

Source: Insight Economics stakeholder consultations and consumer roundtables.

Figure 4.10: Priorities for uterine cancer research in Australia and Aotearoa New Zealand – the EDEN initiative

- Development of change management strategies to improve awareness and education in community and primary care settings
- Regional awareness and education – Pacific Island and Southeast Asia neighbours

- New models of care for wellness leveraging other women's health initiatives
- Precision prevention models of care for high-risk women, including novel screening strategies, especially relevant for young women.
- Develop guidelines and referral pathways for abnormal bleeding in primary care

- Embed access to comprehensive molecular profiling (GCTI) as standard of care
- Expand access to clinical trials and access to novel therapies, esp for rare, recurrent and advanced cancers
- Validation studies of interventions for early endometrial cancer treatments (hormonal therapies, feMMe trial)
- Update and improve adherence to Australian clinical guidelines and OCPs
  - Consistent approach to diagnosis, use of adjuvant therapies
  - Precision-led treatment decisions / stratification

- Identify areas of unmet need for uterine cancer survivors and develop new models of care
- Development of Australian and New Zealand clinical guidelines for risk-based, patient-led surveillance and survivorship care
- Expand access to patient support, peer support

- Development of patient-derived cellular models to advance pre-clinical research in endometrial cancer
- Fund pilot studies to identify new clinical trials opportunities

Source: EDEN Initiative Report (provided by ANZGOG).

This has the potential to deliver step-change improvements in incidence, survival and quality of life.

Unfortunately, Australia's granting systems do not generally support this kind of long term, collaborative program of work. National Health and Medical Research Council (NHMRC) grants, for example, tend to be highly competitive and sometimes put limits on collaboration among researchers. Australia's Medical Research Future Fund (MRFF) can support larger and longer national programs of work through national research missions. Support for uterine cancer research, given the historic underfunding of research, rising incidence and significant equity gaps, through an MRFF Research Mission represents a major opportunity to improve outcomes for women.

Ideally, uterine cancer research strategy could be delivered as part of a broader program of research and practice change that would improve outcomes across gynaecological cancers. ANZGOG has developed such a program, called the Gynaecological Cancer Transformation Initiative, which sets out a detailed plan for research to drive research breakthroughs.[134]

4.5 Conclusion

Uterine cancer research has suffered from historic underfunding relative to disease burden, which will only worsen now that incidence and mortality of uterine cancer are on the rise. As a result, there are fewer treatment options for rare, recurrent and advanced cancers and inadequate models of care to enable precision prevention approaches for high-risk women. Australia and Aotearoa New Zealand have played an important role in uterine cancer research globally, serving as leaders of many international collaborations and undertaking world-leading biology and treatment research. Looking forward, continued basic, translational and clinical research continues to be needed, particularly to expand treatment options for rare, recurrent and advanced cancers which experience poor survival with few treatment options, but more work can also be done in the domain of health implementation science, improving adherence to clinical best practice and developing new models of care for primary and secondary prevention of uterine cancers.

[134] ANZGOG, 2025, A united and urgent call for action: The Gynaecological Cancer Transformation Initiative (GCTI), https://www.anzgog.org.au/gcti/

Chapter 5

Unknown, unsupported, underfunded: Improving outcomes for women

This chapter outlines opportunities to improve outcomes for women impacted by uterine cancers—ranging from awareness and prevention through diagnosis, treatment, and supportive care to long-term survivorship—with the goal of improving outcomes for women in Australia and Aotearoa New Zealand.

5.1 Improving outcomes for women impacted by uterine cancer: overview of major opportunities for research and reform

Improving outcomes for women at risk of and living with uterine cancer requires a coordinated, whole-of-pathway approach that spans the entire continuum of care. From prevention and early detection through diagnosis, treatment, supportive care, and long-term survivorship, each phase of the patient journey presents both unique challenges and critical opportunities for intervention.

Figure 5.1 provides an overview of the major opportunities for improvement, which are discussed in the following sections:

- Invest in research to improve outcomes across the care pathway
- Raise awareness of uterine cancer and embed education into new models of care for women
- Implement consistent screening for Lynch syndrome and other hereditary cancer syndromes associated with uterine cancer risk among patients and families impacted by uterine and other related cancers (e.g., colorectal cancers)
- Develop a new national strategy for wellness and the prevention of chronic disease
- Identify high risk women for targeted screening and preventative treatment
- Improve access to fertility preservation for young women
- Update and improve adherence to clinical guidelines
- Address workforce shortages in Aotearoa New Zealand
- Improve screening for and access to supportive care
- Reform Patient Transport Support Schemes to better meet the needs of low-income patients in regional areas, and harmonise between states and territories
- Invest in data development and linkage
- Expand access to genomics and precision medicine for rare, advanced and recurrent cancers

- Improve access to survivorship care
- Ensure equity of access across the care pathway and expand access to research for priority populations.

These actions were strongly supported as priorities for reform and investment by patients, carers, clinicians and researchers alike.

In surveys completed for this report (Figure 5.2), for example, clinicians and researchers highlighted the need for increased funding for research, improved access to diagnostics—particularly molecular profiling—and strengthened efforts in risk prevention and reduction as among the highest priorities for action.

These priorities were echoed by patients and carers (Figure 5.2), who identified greater investment in research, earlier detection, and improved awareness of risk factors and symptoms as the highest priorities for change. This convergence underscores the importance of a comprehensive, system-wide response that bridges scientific innovation, clinical reform, and public health engagement.

The following sections explore the uterine cancer care pathway in depth. They outline where current systems fall short, identify high-impact areas for reform, and propose integrated solutions that could help deliver better, more equitable outcomes for all women.

Figure 5.1: Improving outcomes for women impacted by uterine cancer – major opportunities for research and reform

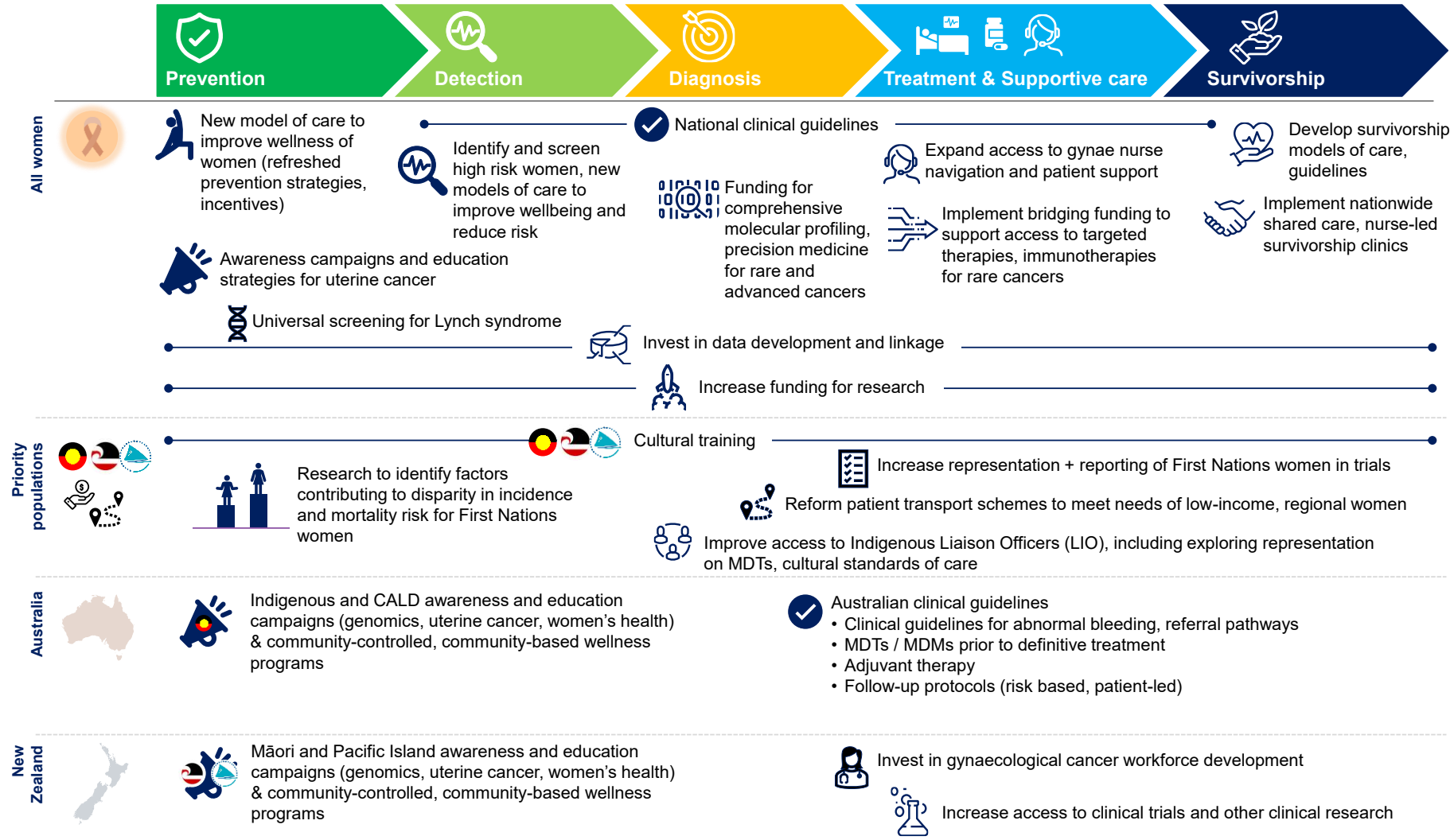
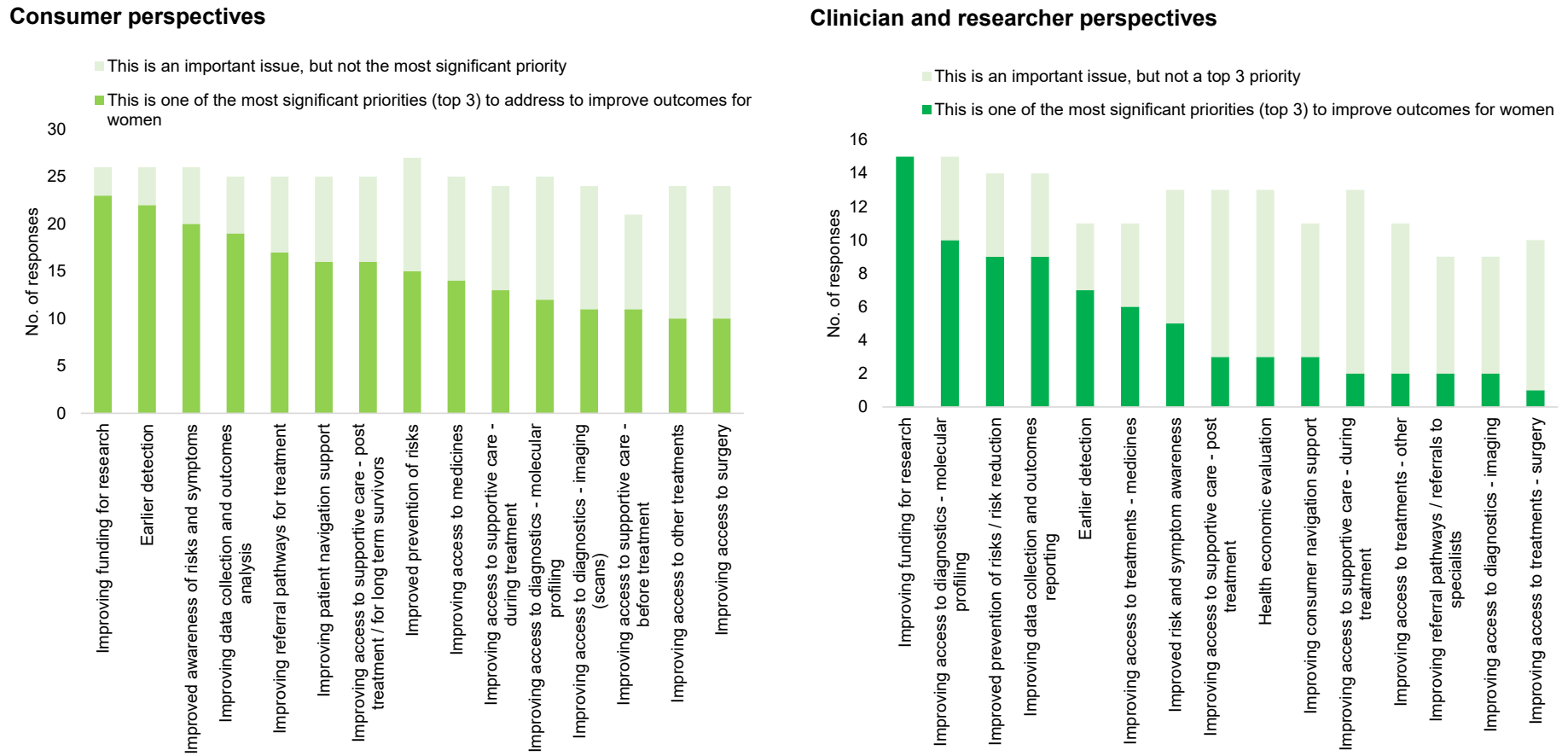


Figure 5.2: Priorities to improve outcomes – survey perspectives



Source: Survey of Uterine Cancer Patients and Carers; Survey of Uterine Cancer Clinicians and Researchers.

5.2 Invest in research to improve outcomes across the care pathway

Patients, carers, clinicians and researchers all identified the top priority for improving outcomes for women and their families was investing in research.

This reflects a clear understanding of the significant underfunding of research that has occurred in the modern cancer research era, leading to a poorer understanding of the disease compared to other cancers, fewer treatment options and underinvestment in new models of care to improve prevention, early detection, treatment, supportive care and survivorship.

There was also strong consensus among patients, carers, clinicians and researchers with regard to the highest priorities for research, discussed in Chapter 4, which include:

- Improving early detection
- Improving access to precision medicine
- Improving prevention
- Improving understanding of the disease (biology)
- Improving access to supportive care, including exercise and weight management as well as psychosocial support.

Improving outcomes against these various domains will require a comprehensive program of work to be completed across all phases of research from basic (or discovery) and translational research through to clinical trials and implementation science to put evidence into policy and practice. For example, improving precision prevention and early detection will require investment in basic and translational research, to identify new and existing biomarkers for early detection, trials to validate new and existing approaches and develop evidence of cost effectiveness and implementation science to support their adoption into clinical practice. Similarly, improving access to precision medicine relies on investment in clinical trials, especially signal seeking trials, as well as improved understanding of the disease, which requires investment in biology and translational research.

Realising these research objectives, in turn, requires strong domestic and international collaborations among uterine cancer research teams and investment in critical enabling infrastructure including tissue collection, comprehensive molecular profiling, data infrastructure, investment in AI systems, supercomputer and analytical capabilities as well as engagement with consumers.

Thus, to transform outcomes for women with uterine cancer, a comprehensive program of work is needed. This would involve expanded investment in:

- Collection and storage of biospecimens
- Expanded access to comprehensive molecular profiling
- Expanded investment in molecular and translational research
- Growth in clinical trials, including signal seeking trials, basket trials and ‘window of opportunity trials’
- Data linkage and analytics, powered by AI
- Knowledge curation
- New models of care, including in primary and secondary prevention, supportive care and survivorship care
- Development of living clinical guidelines to drive practice improvements

- A comprehensive sub-program of work focused on eliminating inequity for priority populations, including understanding specific genetic drivers of disease for Aboriginal women, wāhine Māori, and Pacific women
- Outreach to other Pacific neighbours to support improved awareness, detection and clinic practice improvements.

This should be funded through a research strategy to support a nationally coordinated program of work. This strategy should be led by a national, collaborative taskforce or working group involving ANZGOG, state governments, philanthropy and related non-government organisations.

The benefits that could be unlocked from coordinated uterine cancer research are substantial; as detailed in subsequent sections, research has identified significant health, and economic benefits are possible through improved prevention, detection and treatment that would be enabled by uterine cancer research including:

- Through a focus on lifestyle modification and improved wellness, the number of preventable cases of uterine cancer can be lowered. The preventable share of cancer incidence is estimated to be between 33 per cent to 60 per cent. If all these cases were mitigated, this would benefit between 2,800 to 10,000 women and families over the 2025-2035 horizon, with a potential economic impact in the order of $1.4 billion to $5.0 billion over the 2025-2035 horizon, with full benefits realised by 2040, from improvements for women with uterine cancer alone (see Section 5.5).
- The potential to improve early detection through improved awareness, education and novel surveillance and screening, particularly of high-risk cohorts. Increasing the proportion of Stage I diagnoses to 80 or 90 per cent would benefit between 2,500 to 4,200 women over the 2025-2035 horizon, with a potential economic benefit of between $0.8 billion to $1.2 billion over the 2025-2035 horizon (see Section 5.3).
- Improving the early detection and treatment of women with early stage endometrial cancer and hyperplasia, with a complete response in 43 per cent to 67 per cent of early endometrial cases to IUD implantation and a complete response in 82 per cent women having hyperplasia prior to a uterine cancer diagnosis, potentially benefitting 4,700 to 7,300 women over 2025-2035 period at an economic value of $1.8 billion to $2.6 billion over 2025-2035, with full benefits realised by 2040 (see Section 5.6).
- Expanding access to targeted treatments, immunotherapies and combination therapies for rare, recurrent and advanced cancers, noting that lines of therapy for uterine cancer are significantly limited compared to other cancers due to underinvestment in research. While many women may be cured, nearly 7,000 (based on the number of women that will be diagnosed with Stage II, Stage III or Stage IV cancers) will experience advanced disease with few treatment options (see Section 5.14).
- New models of care for survivorship to potentially benefit more than 50 per cent women of women diagnosed over the 2025-2035 period, which equates to more than 27,800 women that may otherwise struggle with limited support and potentially manageable side effects (see Section 5.15).

Added to this, investment in research is associated with significant economic benefits in its own right, leveraging private sector investment into Australia through investment in clinical trials, improving the efficiency of health services delivery and creating jobs. For example, ANZGOG data show that industry invests $2.30 for every $1 invested by government in

clinical trials and MTPConnect data show that every clinical trial attracted to Australia creates an additional 4.2 jobs.[135]

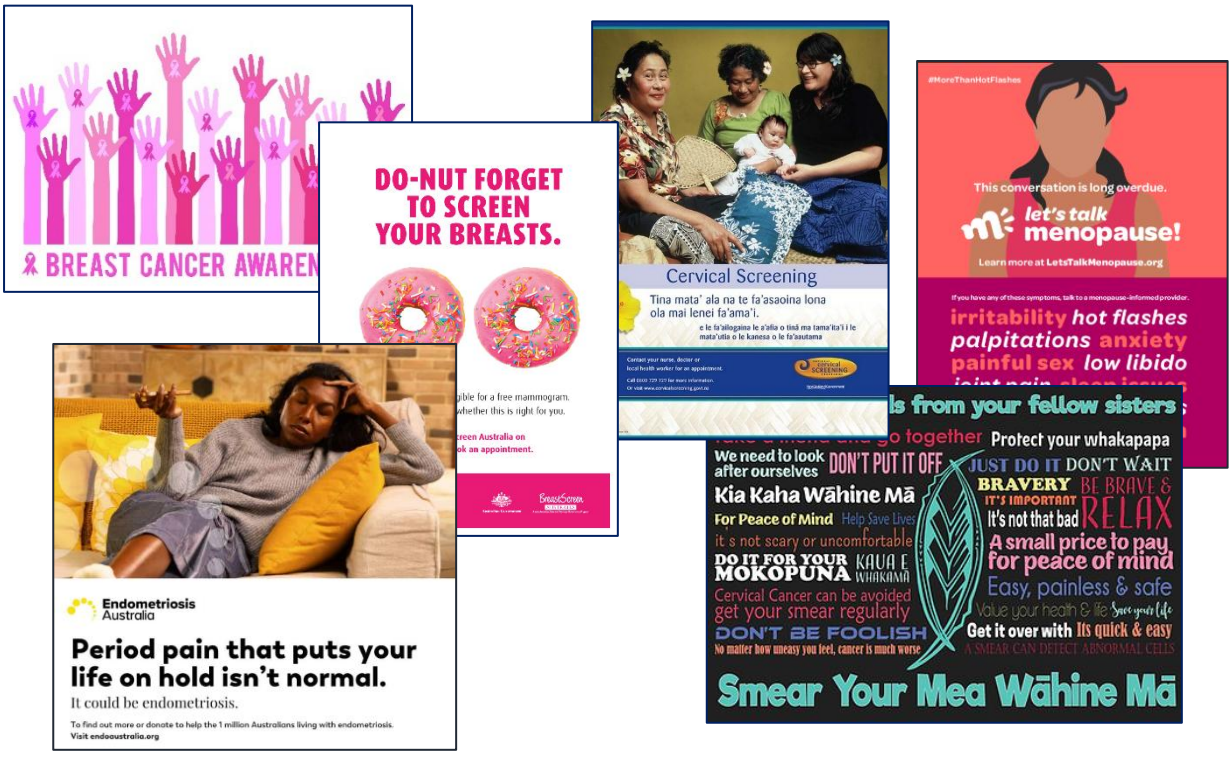
Key improvements in clinical practice in uterine cancer prevention, treatment and care that could be realised over the next five to 10 years through investment in research and policy reform are discussed in turn.

5.3 Raise awareness of uterine cancer and embed education into new models of care for women

Improving outcomes for women with uterine cancer must begin with increased awareness and education as part of a life-course model of care for women. Early detection and prevention depend on women and their healthcare providers recognising early warning signs—particularly postmenopausal bleeding—and understanding the key risk factors associated with the disease.

Awareness campaigns, like those that have been implemented to improve awareness and detection of breast cancer, cervical cancer, menopause and endometriosis (Figure 5.3), can play a powerful role in addressing this gap—not only by improving recognition of symptoms, but also by promoting risk reduction strategies such as maintaining a healthy weight and reinforcing the importance of early detection and screening.

Figure 5.3: Public awareness for uterine cancer needed



Improving public and professional understanding of uterine cancer symptoms was identified in consumer roundtables and in stakeholder consultations as a critical and high-impact opportunity (Figure 5.4).

[135] MTP Connect. (2024). Australia's Clinical Trials Sector Advancing innovative healthcare and powering economic growth, accessed at: https://www.mtpconnect.org.au/images/MTPConnect_2024_AustraliasClinicalTrialsSectorReport.pdf

Figure 5.4: Stakeholder perspectives on the need for an awareness campaign

Source: Insight Economics stakeholder consultations and consumer roundtables.

Education and awareness campaigns might usefully be embedded in wider health service reforms focused on improving women's health as part of a life course model. For example, more structured touchpoints could be built into the health system to promote preventative care, such as publicly funded women's wellness checks at key life stages — 'Well Woman' checks beginning from age 40, which is consistent with Women's Health Strategies that are focused on the implementation of a life course approach and reduction of chronic disease. Improving access to women's health checks through women's health clinics, such as those being piloted in Victoria, could also work to reduce barriers for women with the provision of more gender-sensitive and culturally sensitive, specialist care (Box 5.1). Similarly, expanded access to mobile women's health services to reach underserved and regional populations, building on successful models like Victoria's Women's Health Bus.

Education initiatives should also be extended to clinical settings where high-risk women commonly present, including bariatric, fertility, diabetes, non-gynaecologic cancer and even orthopaedic clinics. These settings offer a unique opportunity to raise awareness and intervene earlier with women who are often navigating multiple health conditions.

These ideas were strongly supported by consumers and clinicians alike (Figure 5.5); research to build on initial pilots to develop cost-effective models of care offers an opportunity to significantly improve awareness, prevention and early detection.

To deliver this impact, further research is needed to identify the most effective models of care and the key barriers and enablers of improved awareness. This includes evaluating the

feasibility of and approaches to women's wellness checks and mobile outreach services and investing in change management programs to support system-wide uptake.

Figure 5.5: Stakeholder perspectives on the need for embedding education about uterine cancer into new approaches for women's health

Source: Insight Economics stakeholder consultations and consumer roundtables.

Box 5.1: New models of care for women: Women's Health Clinics in Victoria, Victoria's Women's Health Bus and Well Woman Clinics

Women's Health Clinics in Victoria – world-leading innovation in women's health

Following an Inquiry into Women's Pain, which identified a range of issues in the delivery of healthcare to women in Victoria, the Victorian Department of Health is leading the delivery of a program of work to change the way women's health issues are treated.

These reforms have included funding for a state-wide network of women's health clinics, including 20 Women's Health Clinics and an Aboriginal-led Women's Health Clinic. These will help women with information, specialist care and services for women's health issues and conditions including endometriosis, pelvic pain, heavy bleeding, prolapse and incontinence, contraception, abortion and menopause.

Women's health clinic services are free to participants and available to girls, women and gender diverse people of all ages, and involve a 'one-stop-shop', multi-disciplinary team approach to improving women's health. Women can access information and services from a range of healthcare teams including gynaecologists, urologists, specialist nursing and allied health professionals.

Women's Health Bus – A Partnership between BreastScreen Victoria and Victorian Government

In rural and regional Victoria, women often face challenges in accessing essential sexual and reproductive healthcare close to home. To address these barriers, the Victorian Department of Health has funded a new Women's Health Mobile Clinic.

Building on BreastScreen Victoria's mobile breast screening service, a 'Nina' van is now equipped to offer a range of additional services. Women can book a free 45-minute appointment with a nurse to discuss sexual and reproductive health, general wellbeing, and get important health checks like cervical and bowel screening. Key services include:

- Contraception, including long-acting options such as IUDs
- Pregnancy options counselling
- Sexually transmitted infections
- Cervical and bowel screening
- Menstruation
- Pelvic pain
- Perimenopause and menopause
- Bladder concerns
- Irregular bleeding
- Any other women's health issue.

This service is available to women of all ages, providing care close to home.

Source: Victorian Government, 2025, Women's Health and Wellbeing Program, https://www.health.vic.gov.au/public-health/womens-health-wellbeing-program; and BreastScreen Victoria, 2025, Better healthcare access for women in rural and regional Victoria.

Importantly, these reforms are well aligned with existing policy commitments. National and regional frameworks—including Australia's National Women's Health Strategy 2020–2030 and National Preventive Health Strategy 2020–2030, as well as Aotearoa New Zealand's Women's Health Strategy 2023 and Preventive Health Strategy 2023—provide a strong foundation for reform.

5.4 Implement consistent screening for Lynch syndrome among women with dMMR

NGOR data suggest the rate of testing for Lynch syndrome among women with uterine cancers is potentially running at roughly half of the ideal rate (see Chapter 3) and there is scope to increase the consistency of screening. Consistent screening for Lynch syndrome among uterine and colorectal cancer patients has been shown to be cost-effective and would bring Australia and Aotearoa New Zealand in line with global best-practice, with screening of all endorsed by global organisations including NICE, NCCN, and ESMO.

Beyond prevention, screening also has important implications for clinical management. A diagnosis of Lynch syndrome can inform both prognostic assessment and treatment planning. In early-stage endometrial cancers, dMMR status may guide decisions around combining chemotherapy with radiotherapy, while in advanced disease, it predicts response

to immunotherapy.[136] Furthermore, expanded access to genetic profiling is likely to pave the way for future targeted treatments.

If effectively implemented, improved screening has the potential to reduce the incidence of cancers attributable to Lynch syndrome. Modelling suggests that reducing the total incidence by 3 per cent could benefit 250 women between 2025 and 2035. Over the same period, this improvement is estimated to generate an economic benefit of $126 million, with benefits beginning to be realised from 2031—starting at 10 per cent and increasing by 10 percentage points each year until being fully realised by 2040.

5.5 Develop a new national strategy for healthy living and the prevention of metabolic and chronic disease

While raising awareness of uterine cancer is important, awareness alone is not enough. Without addressing the broader, systemic drivers of risk—such as obesity, physical inactivity, metabolic syndrome, and other chronic conditions—efforts to improve outcomes will likely be restrained. Uterine cancer is one of the most preventable cancers affecting women, with strong and well-established links to modifiable chronic disease risk factors.

To meaningfully reduce the burden of uterine cancer, prevention strategies must move beyond awareness and address the upstream determinants of chronic disease through coordinated, system-wide action. A tiered and integrated approach to prevention is needed—beginning with universal strategies that promote healthy living for all women. This includes stronger investment in public health and policy levers such as front-of-pack food labelling reforms, restrictions on unhealthy food advertising, sugar-sweetened beverage taxes, improved urban planning, and infrastructure that encourages physical activity.

International examples show promise: the United Kingdom and Mexico have both introduced sugar-sweetened beverage taxes that have led to measurable reductions in sugary drink consumption. However, evidence is mixed as to whether these taxes have led to a reduction in obesity, with evidence from the UK suggesting a measurable improvement in obesity outcomes among year 6 girls[137], while evidence from Mexico is mixed.[138]

As shown in Figure 5.6, Australia and Aotearoa New Zealand's international peers are championing increasingly sophisticated and comprehensive strategies to improve wellness that tackle:

- Policies and taxes to reduce the consumption of sugary beverages
- Commercial determinants of health including marketing to children
- Standards for nutrition in early years of life
- Increased physical activity
- Regulation of front-of-pack labelling
- Nutrition standards for school lunches

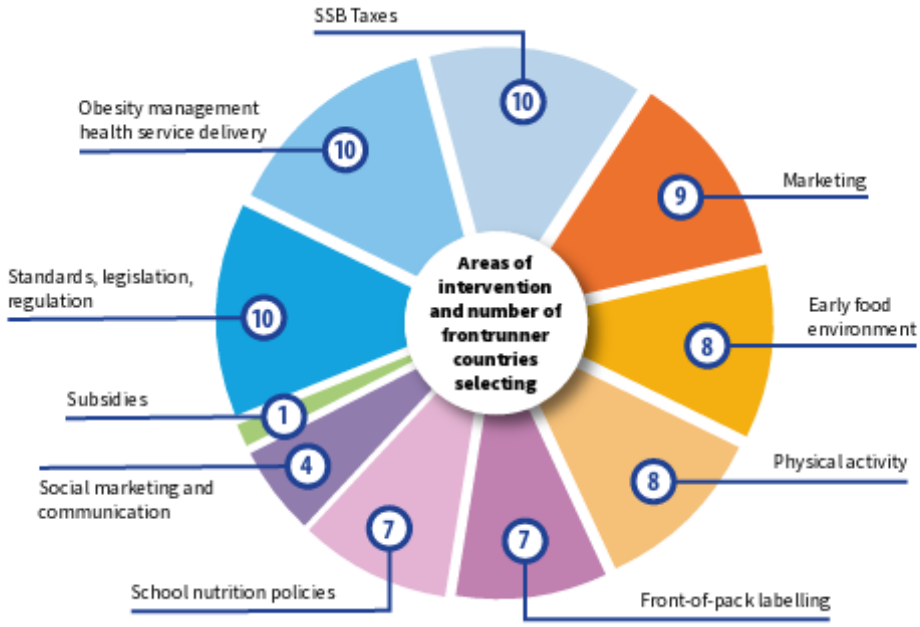
[136] León-Castillo, A., de Boer, S. M., Powell, M. E., et al. (2020). Molecular classification of the PORTEC-3 trial for high-risk endometrial cancer: Impact on prognosis and benefit from adjuvant therapy. *Journal of Clinical Oncology, 38*(29), 3388–3397. https://doi.org/10.1200/JCO.20.00549; Antill, Y. C., Kok, P. S., Robledo, K., et al. (2019). Activity of durvalumab in advanced endometrial cancer (AEC) according to mismatch repair (MMR) status: The phase II PHAEDRA trial. *Journal of Clinical Oncology, 37*(15_suppl), Abstract 5501. https://doi.org/10.1200/JCO.2019.37.15_suppl.5501.

[137] Rogers, N. T., Cummins, S., et al. (2023). Associations between trajectories of obesity prevalence in English primary school children and the UK soft drinks industry levy: An interrupted time series analysis of surveillance data. *PLoS Medicine.* January 2023. 20(1). https://doi.org/10.1371/journal.pmed.1004160.

[138] Aguilar, A., Guitierrez, E., & Seira, E. (2021) The effectiveness of sin food taxes: Evidence from Mexico. Journal of Health Economics. May 2021. 77. https://doi.org/10.1016/j.jhealeco.2021.102455.

- Awareness campaigns
- Subsidies and incentives
- Development of new models of care for obesity management as part of health service delivery.

Figure 5.6: Intervention strategies being implemented by 'frontrunner' countries to improve wellness and reduce risks from higher body weight



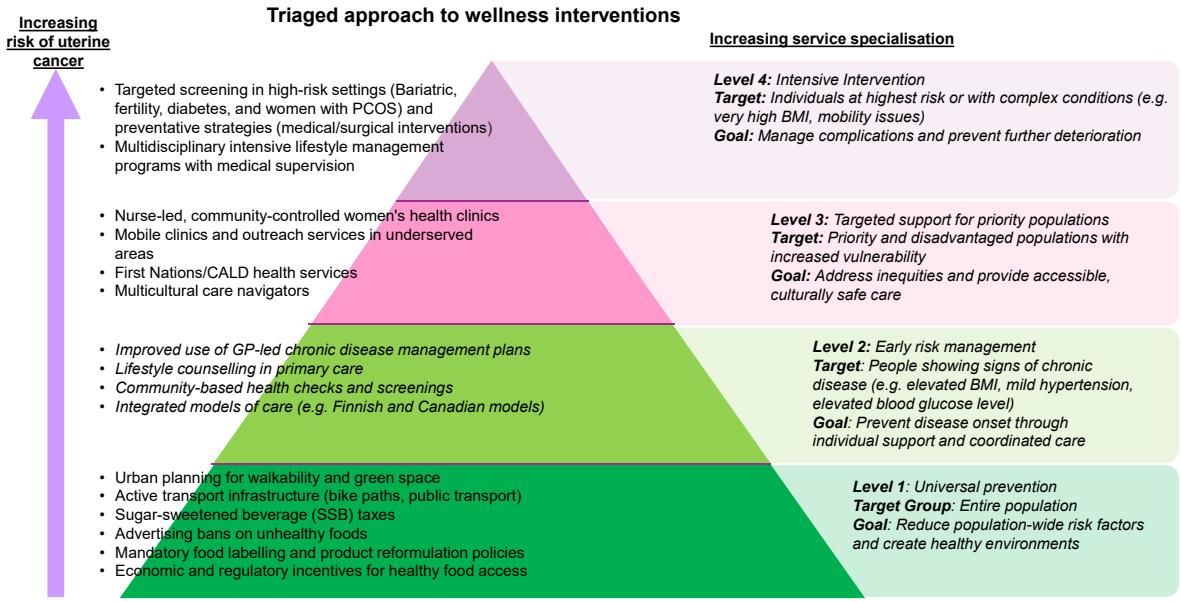
Source: World Health Organisation. (2022). WHO Acceleration Plan to Stop Obesity, accessed at: https://iris.who.int/bitstream/handle/10665/370281/9789240075634-eng.pdf?sequence=1.

In Australia, modelling has shown that a tax on sugar-sweetened beverages could avert 270,000 disability-adjusted life years (DALYs).[139] While pricing policies such as these have demonstrated potential to improve population health, concerns about equity impacts persist. Some studies suggest that such taxes may place a disproportionate financial burden on lower-income households—especially if consumption patterns do not change.[140] However, further analysis indicates that consumption of low-cost unhealthy products may be more closely linked to behaviour (e.g. heavy use) than income alone. Importantly, an Australian modelling study found that although individuals in the most deprived quintiles might pay slightly more per capita under a sugar-sweetened beverage tax, half of the health gains would accrue to these groups—suggesting a neutral to positive equity impact.[141]

Universal population-wide risk prevention strategies should be complemented by increasingly specialised, targeted models of care for women at increasing levels of risk (Figure 5.7).

[139] Monteiro, C. A., Moubarac, J.-C., Cannon, G., Ng, S. W., & Popkin, B. M. (2017). Ultra-processed products are becoming dominant in the global food system. Obesity Reviews, 18(7), 1–13. https://doi.org/10.1111/obr.12107.
[140] Sassi, F., Belloni, A., Mirelman, A. J., Suhrcke, M., Thomas, A., Salti, N., Vellakkal, S., Visaruthvong, C., Popkin, B. M., & Nugent, R. (2018). Equity impacts of price policies to promote healthy behaviours. The Lancet, 391(10134), 2059–2070. https://doi.org/10.1016/S0140-6736(18)30531-2.
[141] Lal, A., Mantilla-Herrera, A. M., Veerman, L., Backholer, K., Sacks, G., Moodie, M., Siahpush, M., Carter, R., & Peeters, A. (2017). Modelled health benefits of a sugar-sweetened beverage tax across different socioeconomic groups in Australia: A cost-effectiveness and equity analysis. PLOS Medicine, 14(6), e1002326. https://doi.org/10.1371/journal.pmed.1002326

Figure 5.7: Tiered intervention model (triage pyramid) for women at varying levels of uterine cancer risk



For example, women at intermediate risk, such as those showing early signs of chronic disease, should have access to GP-managed chronic disease management plans. For women at higher risk, due to factors like obesity, insulin resistance, or clustering of multiple chronic conditions, more intensive, team-based models of care may be required. These could include nurse-practitioner-led services or integrated chronic disease clinics that provide coordinated, preventive care.

Equally important is targeted support for priority populations, which may include nurse-led, community-first clinics focused on women's eHealth; mobile clinics and outreach services in regional and rural areas; culturally appropriate healthcare services for First Nations and CALD communities; and multicultural health navigators—to address inequities and ensure accessible, culturally safe care.

Finally, at the highest level of risk, such as women with extreme obesity or complex metabolic disorders, specific screening protocols should be implemented to detect precancerous changes early. These should be supported by medical and surgical interventions delivered through bariatric, fertility, diabetes, and orthopaedic clinics, alongside multidisciplinary, medically supervised intensive lifestyle management programs. These models are critical to identify those at the greatest risk, as well as to slow down progression before it reaches an advanced stage; this is explored further in the next section.

Figure 5.8: Stakeholder perspectives on the opportunity to improve wellness and the need for new and more specialised models of care for women with higher risk

Source: Insight Economics stakeholder consultations and consumer roundtables.

5.6 Identify high risk women for targeted screening and preventative treatment

Wider systems change for improved wellness and women's health can also lay the foundations for delivering more effective and efficient care to women at high risk of developing uterine cancer.

Identifying high-risk women

More research is needed to support the identification of high-risk women and the development of reliable methods of screening for uterine cancer.

Investment in advanced risk prediction tools that combine genetic, reproductive, metabolic, and lifestyle data could help triage women into low-, medium-, and high-risk groups, allowing for closer monitoring and enabling early intervention. Given the rising numbers of early onset endometrial cancer, this research is particularly important for young, pre-menopausal women and asymptomatic women.

While more work is needed, improvements in clinical practice can also be made today, with research already showing that women with high risk of endometrial cancer are more likely to present to care settings that allow for early detection of endometrial cancer.

For example, research has shown that women referred to bariatric clinics for treatment are at a high risk of developing uterine cancer, with a 2018 study finding that 14 per cent of women referred for bariatric surgery had either endometrial cancer or abnormal hyperplasia.[142] This study recommended all women referred for bariatric surgery should undergo both cervical and endometrial cancer screening.

Stakeholders also indicated that targeted screening could be expanded to other settings where women with higher weight or other fertility issues may present, such as orthopaedic of fertility clinics.

Research has also shown that higher body weight is more predictive of endometrial cancer risk than age,[143] with recommendations that abnormal bleeding in premenopausal women with class III-IV obesity should be taken seriously as a 'red flag' symptom for cancer and investigated on a first exclusion basis.[144] In Australia, current clinical practice guidelines do not make recommendations for referral but Aotearoa New Zealand has recently implemented abnormal bleeding guidelines for primary care that have recommended referral for exclusion of cancer.

To the extent that women's health clinics and/or Well Women screens are more widely implemented (see Section 5.3 above), leveraging the approach that has been taken in Victoria or in Aotearoa New Zealand, these clinics or consults could enable cost-effective identification of women reporting a higher body weight, a history of heavy or abnormal bleeding and other risk factors that contribute to early detection.

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[142] MacKintosh, M.L., Derbyshire, A.E., McVey, R.J., Bolton, J., Nickkho-Amiry, M., Higgins, C.L., Kamieniorz, M., Pemberton, P.W., Kirmani, B.H., Ahmed, B., Syed, A.A., Ammori, B.J., Renehan, A.G., Kitchener, H.C. and Crosbie, E.J. (2019). The impact of obesity and bariatric surgery on circulating and tissue biomarkers of endometrial cancer risk. Int. J. Cancer, 144: 641-650. https://doi.org/10.1002/ijc.31913.

[143] Wise MR, Gill P, Lensen S, et al. (2016). Body mass index trumps age in decision for endometrial biopsy: cohort study of symptomatic premenopausal women. *Am J Obstet Gynecol* 2016; **215**: 598.e1–8.

[144] MacKintosh, M.L., Derbyshire, A.E., McVey, R.J., Bolton, J., Nickkho-Amiry, M., Higgins, C.L., Kamieniorz, M., Pemberton, P.W., Kirmani, B.H., Ahmed, B., Syed, A.A., Ammori, B.J., Renehan, A.G., Kitchener, H.C. and Crosbie, E.J. (2019). The impact of obesity and bariatric surgery on circulating and tissue biomarkers of endometrial cancer risk. Int. J. Cancer, 144: 641-650. https://doi.org/10.1002/ijc.31913.

Over time, as research develops other cost-effective methods for targeted screening, such as lifetime risk prediction models,[145] blood-based biomarkers[146] or minimally invasive tests such as the PapSEEK test[147] or DETECT test[148] (see Chapter 4 for a discussion of future research to improve early detection) targeted screening approaches could be progressively widened.

5.7 Delivering prevention strategies to high-risk women and women with early-stage endometrial cancer

Having identified women at high risk of endometrial cancer, research has shown that a range of interventions can reduce the incidence of uterine cancer, improve their access to minimally invasive treatments and improve survival and quality of life. Research has shown that roughly 33 and 60 per cent of endometrial cancer cases are preventable.[149]

Key interventions to reduce the risk of endometrial cancer include:

- *Physical activity and nutrition to support metabolic health and weight loss* — Obesity is the strongest risk factor for low grade endometrial cancers and its precursor lesion, atypical hyperplasia, with every 5 kg/m^2 increase in body mass index (BMI) conferring a 1.6-fold higher risk of endometrial cancer. As a result, women with a BMI of greater than 40 have an almost tenfold higher lifetime risk of endometrial cancer compared to women of normal weight. For example, research of the impact of lifestyle interventions among post-menopausal women has shown that weight loss can significantly improve a woman's risk: compared with women who had stable weight (± 5 per cent), women with weight loss had nearly 30 per cent lower endometrial cancer risk (HR, 0.71; 95% CI, 0.54 to 0.95).[150] The association was strongest among obese women with intentional weight loss, who experienced a near 60 per cent reduction in risk (HR, 0.44; 95% CI, 0.25 to 0.78).

  Physical activity is also important, with exercise being an important component to improve wellness and reduce risk. A systematic review found significant reductions in disease risk of 15–53 per cent were possible with higher levels of physical activity, but

[145] Kitson, S.J., Evans, D.G., and Crosbie E.J., et al, (2024). Predicting risk of endometrial cancer in asymptomatic women (PRECISION): Model development and external validation. *BJOG*., 131(7): 996–1005. https://doi.org/10.1111/1471-0528.17729; Kitson, S.J., Evans, D.G., and Crosbie E.J. (2017). Identifying High-Risk Women for Endometrial Cancer Prevention Strategies: Proposal of an Endometrial Cancer Risk Prediction Model. *Cancer Prev Res (Phila)* 1 January 2017; 10 (1): 1–13. https://doi.org/10.1158/1940-6207.CAPR-16-0224; Bafligil, C., Thompson, D.J., Lophatananon, A. et al, (2022). Development and evaluation of polygenic risk scores for prediction of endometrial cancer risk in European women, Genetics in Medicine, Volume 24, Issue 9,
https://doi.org/10.1016/j.gim.2022.05.014

[146] An, Y., Feng, Q., Jia, L. *et al.* Present progress in biomarker discovery of endometrial cancer by multi-omics approaches. *Clin Proteom* 22, 15 (2025). https://doi.org/10.1186/s12014-025-09528-6

[147] Wang, Y., Li, L., Douville, C., Cohen, J. D., Yen, T. T., Kinde, I., Sundfelt, K., Kjær, S. K., Hruban, R. H., Shih, I. M., Wang, T. L., Kurman, R. J., Springer, S., Ptak, J., Popoli, M., Schaefer, J., Silliman, N., Dobbyn, L., Tanner, E. J., Angarita, A., … Papadopoulos, N. (2018). Evaluation of liquid from the Papanicolaou test and other liquid biopsies for the detection of endometrial and ovarian cancers. *Science translational medicine*, *10*(433), eaap8793. https://doi.org/10.1126/scitranslmed.aap8793

[148] Clarke, Megan et al. (2023), The discovery and evaluation of tests for endometrial cancer in tampons (DETECT) study: A baseline description (2119), Gynecologic Oncology, Volume 176, S208 - S209.

[149] Wilson, L.F., Antonsson, A., Green, A.C., Jordan, S.J., Kendall, B.J., Nagle, C.M., Neale, R.E., Olsen, C.M., Webb, P.M. and Whiteman, D.C. (2018), How many cancer cases and deaths are potentially preventable? Estimates for Australia in 2013. Int. J. Cancer, 142: 691-701. https://doi.org/10.1002/ijc.31088 Arnold M, Pandeya N, Byrnes G, et al. Global burden of cancer attributable to high body-mass index in 2012: a population-based study. *Lancet Oncol* 2015; 16: 36–46; Kitson, S., Khan, U., & Crosbie, E. (2023). Lay and general practitioner attitudes towards endometrial cancer prevention: a cross-sectional study. *Family practice*. https://doi.org/10.1093/fampra/cmad076; Kabat GC, Matthews CE, Kamensky V, Hollenbeck AR, Rohan TE. (2015). Adherence to cancer prevention guidelines and cancer incidence, cancer mortality, and total mortality: a prospective cohort study. Am J Clin Nutr. 2015;101(3):558–569.

[150] Juhua Luo et al. (2017). Intentional Weight Loss and Endometrial Cancer Risk. *JCO* 35, 1189-1193(2017). DOI:10.1200/JCO.2016.70.5822

with a caveat that these improvements were only observed in the most physically active individuals.[151]

- *Surgical interventions, including bariatric surgery or prophylactic hysterectomies* — Research has shown that bariatric surgery is associated with a 71 per cent reduced risk for uterine malignancy overall, and an 81 per cent reduced risk if normal weight is maintained after surgery.[152]
- *Hormonal therapies, such as the use of IUDs* — For example, the use of IUDs alone in women with early endometrial cancer and abnormal hyperplasia resulted in complete response rates were 43 and 82 per cent, respectively.[153] Complete response was maximised with the addition of weight loss strategies.
- *Other pharmaceutical therapies, including potentially glucagon-like peptide-1 receptor agonists (GLP-1 medicines)* — Recent research has explored the potential of GLP-1, such as semaglutide and liraglutide, in reducing the risk of endometrial cancer, particularly among women with obesity or metabolic disorders. For example, a real-world retrospective study found that combining GLP-1 RAs with IUDs significantly reduced the risk of endometrial cancer by 56 per cent compared to IUD use alone.[154] Other studies, however, have found that prolonged use (over two years) of certain GLP-1 RAs, like exenatide, was associated with an increased risk.[155] Overall, research remains at an early stage with more work needed to be done to inform their use in clinical practice.
- *Combinations of the above therapies, with the addition of support to lose weight and improve metabolic health being associated with significantly improved outcomes* — As noted above, lifestyle interventions improved risk reductions when combined with other interventions. Complete response rates for Stage I endometrial cancers rose to 67 per cent for the IUD plus weight loss, compared to 61 per cent for IUDs alone and 57 per cent IUDs plus metformin.[156] Similarly, the study of intentional weight loss among post-menopausal women found risk reduction was maximised among women that had achieved intentional weight-loss combined with the use of oestrogen and progestin.

Moreover, research has also shown that women want to understand and reduce their risks. For example, in a survey of 660 UK women, 96 per cent of women reported they would be willing to be assessed for endometrial cancer risk and more than 80 per cent of respondents indicated they would make lifestyle changes to reduce their endometrial cancer risk,

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[151] Kitson, S.J., et al. (2022). Quantifying the Effect of Physical Activity on Endometrial Cancer Risk. *Cancer Prev Res (Phila)* 1 September 2022; 15 (9): 605–621. https://doi.org/10.1158/1940-6207.CAPR-22-0129

[152] Ward, K. K., Roncancio, A. M., Shah, N. R., Davis, M. A., Saenz, C. C., McHale, M. T., & Plaxe, S. C. (2014). Bariatric surgery decreases the risk of uterine malignancy. *Gynecologic oncology*, *133*(1), 63–66. https://doi.org/10.1016/j.ygyno.2013.11.012

[153] Helwick, C. (2021). Hormonal Intrauterine Device Under Study for Managing Early Endometrial Cancer, accessed at: https://ascopost.com/issues/may-10-2021/hormonal-intrauterine-device-under-study-for-managing-early-endometrial-cancer/?utm_source=chatgpt.com; and Baker, J. et al. (2012), Efficacy of oral or intrauterine device-delivered progestin in patients with complex endometrial hyperplasia with atypia or early endometrial adenocarcinoma: A meta-analysis and systematic review of the literature, Gynecologic Oncology, Volume 125, Issue 1, 263 – 270; Janda, M., Robledo, K.P., Gebski, V. et al, (2021). (2021). Complete pathological response following levonorgestrel intrauterine device in clinically stage 1 endometrial adenocarcinoma: Results of a randomized clinical trial, Gynecologic Oncology, Volume 161, Issue 1, doi.org/10.1016/j.ygyno.2021.01.029

[154] Comparative effects of glucagon-like peptide-1 receptor agonists combined with hormone therapy on endometrial cancer risk among women with benign uterine or endometrial hyperplasia: A United States real-world retrospective study. Paper presented at: Society of Gynecologic Oncology 2025 Annual Meeting on Women's Cancer; March 14-17, 2025; Seattle, WA. Accessed March 11, 2025. https://www.sgo.org/events/annual-meeting/.

[155] Rothman, S.M., Yin, H., Yu, O.H.Y. *et al.* Incretin-Based Drugs and the Incidence of Endometrial Cancer Among People with Type 2 Diabetes: Active Comparator New-User Design. *Drug Saf* (2025). https://doi.org/10.1007/s40264-025-01551-8

[156] Helwick, C. (2021). Hormonal Intrauterine Device Under Study for Managing Early Endometrial Cancer, accessed at: https://ascopost.com/issues/may-10-2021/hormonal-intrauterine-device-under-study-for-managing-early-endometrial-cancer/?utm_source=chatgpt.com.

including the use of contraceptives or hysterectomy for primary prevention. [157] GPs also reported strong interest in supporting women, with 93 per cent indicating they would be willing to offer an endometrial cancer risk assessment, potentially during a Well Woman screen.

5.8 Improve access to fertility preservation for young women

As more young women are diagnosed with abnormal endometrial hyperplasia or early-stage endometrial cancer, there is an increasing need to consistently explore opportunities to bear children. Continued research is needed to optimise treatment planning in these women,[158] but it is also clear that more work could be done to better support women that chose to seek pregnancy prior to surgery to achieve this treatment goal. Many young women with abnormal endometrial hyperplasia or early-stage endometrial cancer also experience polycystic ovarian syndrome (PCOS) and anovulatory infertility, which makes them in need for assisted reproductive technologies to actively get pregnant.[159] But for women with a higher body weight, access to fertility services may be more restricted and less successful.

Expanding access to specialist support to improve wellness and access fertility support offers an important opportunity to improve quality of life for young women impacted by uterine cancer.

5.9 Update clinical guidelines and improve adherence to best practice

Clinical guidelines communicate best practice and high use of clinical guidelines provides a strong proxy for quality and safety in care. The identification and adherence to clinical best practice is associated with significantly improved survival outcomes. For example, a study published in *Cancer* analysed data from a large cohort of women with endometrial cancer and found that adherence to National Comprehensive Cancer Network (NCCN) guidelines was associated with significantly improved survival outcomes. Nonadherence to treatment guidelines was found to be associated with significantly poorer survival compared with adherent care (adjusted hazard ratio [HR], 1.59; 95% CI, 1.52- 1.67).[160]

While there are limited data in Australia, what data are available, along with stakeholder feedback, suggests there is an opportunity to update guidelines and reduce variation in treatment and care for women by geography and priority population group in Australia, with priority areas for improvement including:

- Improved awareness and adherence to existing guideline for abnormal bleeding and referral pathways in primary care settings
- Consistent approaches to diagnostic work-up, including in particular imaging, across Australia
- Consistent use and adherence to MDTs prior to definitive treatment
- Consistent adherence to guidelines for supportive care screening
- Adherence to best practice approaches to fertility preservation for young women

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[157] Kitson, S., Khan, U., & Crosbie, E. (2023). Lay and general practitioner attitudes towards endometrial cancer prevention: a cross-sectional study. *Family practice*. https://doi.org/10.1093/fampra/cmad076.
[158] See feMMe Molecular trial underway.
[159] Yu, J. et al, (2022). Reproductive advance of fertility preservation in patients with early endometrial carcinoma or endometrial atypical hyperplasia: Gynecology and Obstetrics Clinical Medicine, 10.1016/j.gocm.2022.10.005; and Haoula, Z. et al, (2012). Evaluating the association between endometrial cancer and polycystic ovary syndrome, *Human Reproduction*, Volume 27, Issue 5, May 2012, Pages 1327–1331, https://doi.org/10.1093/humrep/des042.
[160] Rodriguez, V. E., LeBrón, A. M. W., Chang, J., & Bristow, R. E. (2021). Guideline-adherent treatment, sociodemographic disparities, and cause-specific survival for endometrial carcinomas. *Cancer*, *127*(14), 2423–2431. https://doi.org/10.1002/cncr.33502.

- Consistent approaches to adjuvant therapy, including in particular radiation therapy
- Consistent approaches to follow-up and surveillance, with potentially a more consistent shift towards patient-led follow-up where appropriate
- Guidelines for survivorship in uterine cancer.

Updating and improving clinical guideline adherence in Australia therefore represents an important opportunity to improve survival and quality of life outcomes for women.

5.10 Address Aotearoa New Zealand's workforce shortages

Chronic workforce shortages in gynae-oncology are complex and require both immediate interventions and long-term system change. A coordinated national workforce strategy, led by Health New Zealand (Te Whatu Ora) in collaboration with the Ministry of Health, MCNZ, and RANZCOG, is essential to ensure sustainable access to specialist care for all Aotearoa New Zealanders. To address Aotearoa New Zealand's chronic workforce shortages in gynae-oncologists, Health New Zealand (Te Whatu Ora) (Te Whatu Ora) should develop a comprehensive, multi-year workforce strategy, backed by investment to ensure its workforce meets surging demand across the country. This would include:

- Conduct a workforce planning review including remuneration requirements to attract and retain staff and opportunities to expand administrative support
- Actively recruit qualified gynae-oncologists from countries with compatible medical standards (e.g., UK, Australia, Canada), offering, where appropriate, relocation incentives, fast-tracked registration with the Medical Council of Aotearoa New Zealand (MCNZ) and streamlined immigration pathways
- Invest in local training capacity and collaborate with RANZCOG (Royal Australian and Aotearoa New Zealand College of Obstetricians and Gynaecologists) to create more sub-specialty training placements
- Ensure Māori and Pacific representation in medical training and gynae-oncology through targeted outreach and scholarship support.

5.11 Improve screening for and access to supportive care

As shown in Chapter 3, screening for supportive care needs is low and more than half of women reported experiencing some side effects from their cancer or its treatment and more than one third of women reported wishing they had been asked about supportive care needs.

Many women also reported that they wished they had been able to access but unable to find support for a range of needs, including nutrition support, exercise support, weight management support, financial counselling and peer support. Research is needed to develop a survivorship model of care and within this, specialist support for exercise, weight management and nutrition support for women with higher body weight. This will not only improve outcomes in uterine cancer, but also other chronic health conditions such as diabetes and cardiovascular disease.

Research is also needed to improve the understanding of women's unmet psychosocial needs and to expand access to psychosocial support. For example, OCA stakeholders noted there was evidence of patient need for support that was not available:

> *'We do hear through our services that women with other gynaecological cancers are left feeling that they have limited supports to assist them. It is heartbreaking to turn away women who have the same issues and are having the same treatment because their cancer doesn't meet the definition of 'ovarian cancer'.'*

Supporting expanded access to patient support for uterine cancers, including the development of peer support networks and psychosocial support services represents an important opportunity to improve uterine cancer survivors' quality of life.

In particular, extending OCA's Psychosocial Support Service to women with high unmet needs could substantially improve psychosocial outcomes for women with advanced cancers. Modifying the severity of depression and anxiety could deliver significant benefits for these women. For example, in the Global Burden of Disease study the disability weight for a woman with severe major depression is 0.658 compared to 0.396 for a woman with moderate major depression or 0.145 for a mild major depression. Similarly, the disability weight for a woman with severe anxiety is 0.523 compared to 0.133 for a woman with moderate anxiety or 0.03 for a woman with mild anxiety.[161] If, in line with the *Clinical Practice Guidelines for the Psychosocial Care of Adults,* there was a 12 per cent in emotional symptoms, this could produce a benefit of at least $4,886 per woman with severe depression supported and a benefit of at least $3,883 per woman with severe anxiety supported. Because women would likely experience more years of severe distress without help, these values are more likely to be in the order of $9,771 to $14,657 per woman with severe depression and $7,766 to $11,650 per woman with severe anxiety.

5.12 Reform Patient Transport Support Schemes to better meet the needs of low-income patients in regional areas

Enhanced support is also needed to help regional and low-income women access quality care. As shown in Chapter 2, women from low-socioeconomic status and regional areas were more likely to be diagnosed with a uterine cancer and more likely to die from their cancer. Removing barriers to care for women from regional areas and low-income backgrounds is an important part of improving outcomes and reducing inequity for priority populations.

More could be done to improve the levels and consistency of support for low-income women, potentially through increased means-testing of programs, including:

- Continual review of the threshold for distances patients must travel before qualifying for assistance to ensure people from outer regional and rural women are not disadvantaged
- Simplified reimbursement process for travel-related expenses including streamlining application procedures and paperwork, ensuring timely processing to minimise administrative hurdles and make it easier for patients to claim and receive support.
- Rates that reflect the true cost of accommodation and transport and are regularly adjusted for inflation, with potentially higher rates of coverage for women falling below a means-tested threshold.
- Developing a coordinated approach to ensuring affordable access to accommodation, which is close to a hospital where a patient is receiving treatment.

5.13 Invest in data development and linkage and streamline researcher access

A major enabler of better prevention, detection and treatment outcomes lies in the quality of data available to clinicians, researchers, and policymakers. The barriers to improving the quality and availability of data are particularly pernicious in Australia by virtue of its federated health model, which has resulted in siloed datasets, as well as limited investment in data governance outside of Victoria and Queensland.

[161] World Health Organisation. (2019). Global Burden of Disease sequelae, health states and disability weights

Important progress is being made to develop better quality national datasets in Australia, particularly through the development of a National Cancer Data Ecosystem as part of the implementation of the Australian Cancer Plan and the continued development of the AIHW's National Health Data Hub, which links key hospital, PBS and MBS data. Ideally, implementation of the National Cancer Data Ecosystem will see increased use of a common patient identifier to facilitate more efficient data integration and linkage.

Alongside the development of the National Cancer Data Ecosystem, however, key data gaps in uterine cancer need to be addressed with some urgency. At a minimum, all state cancer registries should collect and report at a minimum staging data, ideally by molecular diagnosis and incorporating key patient characteristics such as First Nations status. This is a major and unacceptable gap that is out of synch with international best practice and Australian best practice, with cancer data statistics by stage for example routinely reported for breast, prostate and colorectal cancers.

Investment is also needed in data capture from primary healthcare settings, data linkage across care settings and clinical quality registries such as NGOR. Investment in data linkage to support knowledge curation, potentially powered by AI-advances, are needed to support improvements in clinical practice, allow for benchmarking, and enable more adaptive and responsive health services. Systems must also incentivise timely and complete documentation by healthcare providers and facilitate streamlined, secure access to data for research purposes.

Additionally, government should work to streamline access to data for researchers so that analysis and recommendations can be made in a timelier manner.

Like research, access to data is a fundamental enabler of wider systems improvements, and can support improved prevention, detection and treatment across the care pathway. This is consistent with analyses of a range of other cost benefit analyses, which have found investment in cancer data and clinical quality registries can deliver benefit-cost ratios of between 4:1 and 12:1, depending on the dataset.[162]

5.14 Expand access to genomics and precision medicine for rare, advanced and recurrent cancers

Equally critical is ensuring equitable access to cutting-edge treatments, including genomics and precision medicine. For women with rare, advanced, or recurrent uterine cancers, access to molecular testing, targeted therapies, and investigator-initiated clinical trials can make a significant difference in survival and quality of life and may be strategic in planning adjuvant therapies.

Expanding access to comprehensive molecular profiling in clinical practice is essential, with the potential to improve the personalisation of treatment through either the avoidance of aggressive adjuvant therapies or the capacity to access novel therapies.

In addition, regulatory pathways are needed to support rapid access to novel therapies for rare and uncommon cancer subtypes where market incentives to expand indications may be muted. Implementing the recommendations of the HTA Review[163]—particularly those relating to bridging funding for new therapies—would be a vital step forward in delivering more equitable and personalised care. While implementation of the HTA Review recommendations is ongoing, over time there will be opportunities for ANZGOG and the wider uterine cancer community to come together to:

[162] Insight Economics. (2022). State of the Nation in Upper Gastrointestinal Cancers in Australia. Pancare Foundation.
[163] HTA Review. (2024). Health Technology Assessment Policy and Methods Review, https://www.health.gov.au/our-work/hta-review#:~:text=The%20HTA%20Review%20examined%20Australia%E2%80%99s%20approach%20to%20HTA,health%20technologies%20in%20an%20equitable%20and%20timely%20way.

- Identify a shortlist of High Unmet Need therapies and engage with government to obtain a case manager to navigate potential pathways for access for uterine cancer treatments
- Engage with government on real world evidence data frameworks, data standards, and evidence requirements
- Engage with government in horizon scanning and the development of criteria for identification of areas of therapeutic needs.

Funding research to drive the adoption of precision medicine approaches in clinical practice and identify new biomarker targets is also needed. As discussed in Chapter 4, this can be delivered as a MRFF Research Mission in Uterine Cancer, ideally as part of a larger program of work through the Gynaecological Cancer Transformation Initiative that would deliver outreach to clinicians and promote adherence to molecular profiling as the standard of care for advanced and rare gynaecological cancers.

In Aotearoa New Zealand there should be a review of PHARMAC's regulatory and procurement policies to support more rapid access to novel therapies for women with uterine cancer. This is essential given the very high rates of incidence and poor outcomes for wāhine Māori and Pacific women, to prevent the continued and growing inequity in uterine cancer outcomes in New Zealand.

5.15 Improve access to survivorship care

Survivorship, while often overlooked in uterine cancer treatment, is a distinct and critical stage of the care pathway. Women who have completed treatment often require dedicated long-term support, including surveillance for recurrence, management of late effects, and psychosocial care.

Shared-care models and nurse-led survivorship clinics could help bridge current gaps in follow-up care, offering personalised, coordinated support over the long term. It is important to distinguish survivorship from supportive care during treatment—while both benefit from similar models, survivorship requires a separate focus on the longer trajectory of recovery, wellbeing, and life beyond cancer.

Nurse-led clinics—anchored in multidisciplinary teams (MDTs)—are increasingly being piloted to play a larger role in coordinating care and delivering tailored support, particularly for women with complex needs. Box 5.2 highlights a range of pilot programs and clinical trials underway to develop new models of care to improve access for survivors.

Research to support expanded access to survivorship clinics, such as the Western Australian Gynaecologic Cancer Service (WAGCS) Survivorship Clinic, offers an important opportunity to improve quality of life and survival for long term survivors.

Box 5.2: Case studies in shared care in breast and gynaecological cancers – opportunities for uterine cancer

Western Australian Gynaecologic Cancer Service (WAGCS) Survivorship Clinic

Cancer Australia's Principles of Cancer Survivorship recommends that people affected by cancer receive holistic, patient-centred care that is coordinated and integrated across treatment modalities, providers and health settings. Nevertheless, there currently is no comprehensive gynaecologic cancer survivorship clinic in Australia.

The Western Australian Gynaecological Cancer Service (WAGCS) has identified a gap in the provision of coordinated service delivery and implemented the first such clinic in Australia in July 2024 for uterine cancer survivors with high unmet needs.

Women referred to the clinic will include those that have had multimodal treatment (surgery, radiation and chemotherapy) with curative intent but also have high unmet supportive care needs

including potentially bowel and bladder function, sexual health (loss of sexual function or dysfunction, sex and intimacy issues), surgical menopause, loss of fertility, chronic pain and lymphoedema. The service will be led by a multidisciplinary team including gynae-oncologist, specialist nurse, physiotherapist, clinical psychologist, dietician, palliative care and liaison GP.

Mater Statewide Cancer Survivorship Service

A new survivorship centre has been established in Queensland to support women diagnosed with breast and gynaecological cancers: the Mater Statewide Cancer Survivorship Service. More than 100 women recovering from breast and gynaecological cancers have so far been referred to the new Mater Statewide Cancer Survivorship Service, which has been established with funding from the Mater Foundation and Tour de Cure.

The South Brisbane-based service is the first of its kind in Queensland and provides specialised psychological, medical and peer support for public and private patients following the end of their active cancer treatment. Support is delivered by multi-disciplinary teams involving doctors, senior nurses, psychologists, pelvic health physiotherapists, exercise physiologists, dieticians and occupational therapists.

Nurse-led survivorship clinic pilot in Western and Central Melbourne Integrated Cancer Services Region

Western and Central Melbourne Integrated Cancer Services (WCMICS) has been undertaking a pilot to embed a standardised approach to survivorship within nurse-led clinics, utilising a needs assessment (supportive care screening tool) to guide the development of tailored survivorship care plan (SCP) as part of routine discharge planning

Based on recent VAED and VCR data, the number of cancer survivors has increased 48 per cent over the past 30 years. Nurse-led clinics are well positioned to integrate cancer survivorship care into existing workflows and resourcing.

Implementing a survivorship model of care within such clinics can support these patients transition to the community and reduce repeated hospital admissions from long-term effects of cancer treatment.

To date, WCMICS has 5 health services across 7 tumours streams participating in this pilot project.

Nurse-led shared care for early breast cancer

The EMINENT trial was a single-centre Phase II pilot of a shared care model in breast cancer that demonstrated that nurse-enabled, shared-care arrangements for women with early-stage breast cancer was feasible and as safe as specialist-led model of care. It may provide a more sustainable model of care in a longer term. The trial showed that GPs can meet the survivorship care needs identified breast cancer survivors. This trial can inform a large, pragmatic, hybrid effectiveness-implementation trial.

Evaluation of the program goals indicated that all of the top three goals were exercise (n = 23), diet (n = 12) and mental well-being (n = 11) we able to be supported by GPs and there were no differences between groups for health-related quality of life and the other effectiveness outcomes measures listed above at all timepoints (P > 0.05 for all). The trial found, however, that there were significantly fewer average post-treatment radiation oncology appointments per patient in the intervention group and the unplanned hospital presentations at 24-months were low across both intervention (n = 7) and control (n = 4) groups. Overall, this has laid the foundation for a larger trial (the IBIS trial, now recruiting) and points to the potential to expand access to such a model in other cancers like endometrial cancers.

Source: Ayres. C., (2024). The Western Australian Gynaecologic Cancer Service (WAGCS) Survivorship Clinic, Medical Forum, accessed at: https://mforum.com.au/the-western-australian-gynaecologic-cancer-service-wagcs-survivorship-clinic/#:~:text=There%20currently%20is%20no%20comprehensive%20gynaecologic%20cancer%20survivorship,such%20clinic%20in%20Australia%20in%20July%20this%20year.; Western Australian Government (2025). Western Australian Gynaecologic Cancer Service (WAGCS), https://www.kemh.health.wa.gov.au/For-Health-Professionals/Cancer/Gynaecologic-cancer; Mater. (2025). New Mater service supports Queensland cancer survivors https://www.mater.org.au/about-us/news/mater-news/2025/august/new-mater-service-supports-queensland-cancer-survivors;; Victorian Integrated Cancer Service. (2025). Advancing survivorship across the WCMICS region, accessed at: https://vics.org.au/projects/nurse-led-survivorship#:~:text=WCMICS%20has%20been%20undertaking%20a%20pilot%20to%20embed,plan%20%28SCP%29%20as%20part%20of%20routine%20discharge%20planning; Chan RJ, Crawford-Williams F, Koczwara B, et al. (2025)..Implementation and effectiveness of a nurse-enabled, shared-care follow-up model for early breast cancer survivors (The IBIS-Survivorship Study): protocol for a stepped-wedge cluster randomised trial BMJ Open 2025;15:e103341. Doi: 10.1136/bmjopen-2025-103341

5.16 Ensure equity of access across the pathway and expand participation in research by priority populations

At the heart of all these reforms lies the need for equity. The disparities in uterine cancer incidence and outcomes between different population groups are stark and unacceptable.

Priority populations—such as Aboriginal and Torres Strait Islander women in Australia, wāhine Māori and Pacific women in Aotearoa New Zealand, culturally and linguistically diverse (CALD) communities, women of lower socioeconomic status, and those living in rural and remote areas—must be placed at the centre of reform. Culturally appropriate education campaigns, community-led wellness initiatives, and targeted models of care must be developed and funded. Efforts should include investing in research to understand the drivers of disparities, improving trial representation, reforming patient transport schemes, and ensuring that First Nations care coordinators are represented on MDTs. Standards of care from diagnosis through to survivorship must reflect cultural safety and inclusivity.

Research on uterine cancer (endometrial cancer) is ongoing, and several key questions remain to be addressed to improve prevention, diagnosis, treatment, and outcomes for patients. The key research questions in uterine cancer focus on understanding the molecular drivers of the disease, improving early detection and screening, developing more effective treatments, and addressing disparities in care. Advances in genomics, immunotherapy, and personalized medicine hold promise for improving outcomes, while studies on prevention and survivorship care are crucial for enhancing the quality of life for patients.

5.17 Conclusion

Ultimately, improving outcomes for women with uterine cancer requires a whole-of-system response—anchored in data, driven by equity, and implemented through integrated reforms across the entire care pathway. Only by addressing each phase of the pathway—from prevention through to survivorship—can we deliver the sustained improvements in care, outcomes, and quality of life that women deserve.

Chapter 6

A critical national priority: Reversing the rise of uterine cancers

This chapter sets out a vision and plan for action to reverse the rise of uterine cancers in our communities and ensure that every woman receives the personalised treatment and supportive care she needs to live well.

6.1 Vision for uterine cancer: Eliminating preventable incidence and inequity, and ensuring precision care and support for every woman

Uterine cancers are unknown, underfunded and unsupported*:*

- *Unknown and unspoken*— While uterine cancers are the most common and fastest rising gynaecological cancer impacting women in Australia and Aotearoa New Zealand today, 94 per cent of women reported they were unaware of uterine cancer. Poor awareness is not limited to women but includes the wider community and health professionals who reported poor awareness of risk factors and symptoms, particularly in perimenopausal women, which contributes to late detection of these cancers.
- *Underfunded* — Limited awareness of uterine cancer contributes to issues being overlooked by policy makers and research being underfunded. Uterine cancers are the poorest funded cancer in terms of research funding, both in absolute terms and in terms of disease burden. Only $18 million was invested over the 2003-2020 period; this compares to more than $442 million for breast cancer research or $185 million for prostate cancer research over the same period. This highlights the *severe* disparity and levels of underfunding that contribute to limited treatment options and poor outcomes for women and their families.
- *Unsupported* — Uterine cancers are the only gynaecological cancer without a national, specialist patient support organisation, with significantly limited access to specialist nurses with only three gynaecological cancer nurse consultants to be funded across the whole of Australia, covering not only uterine but also the needs of ovarian, vaginal, vulval and cervical cancer.

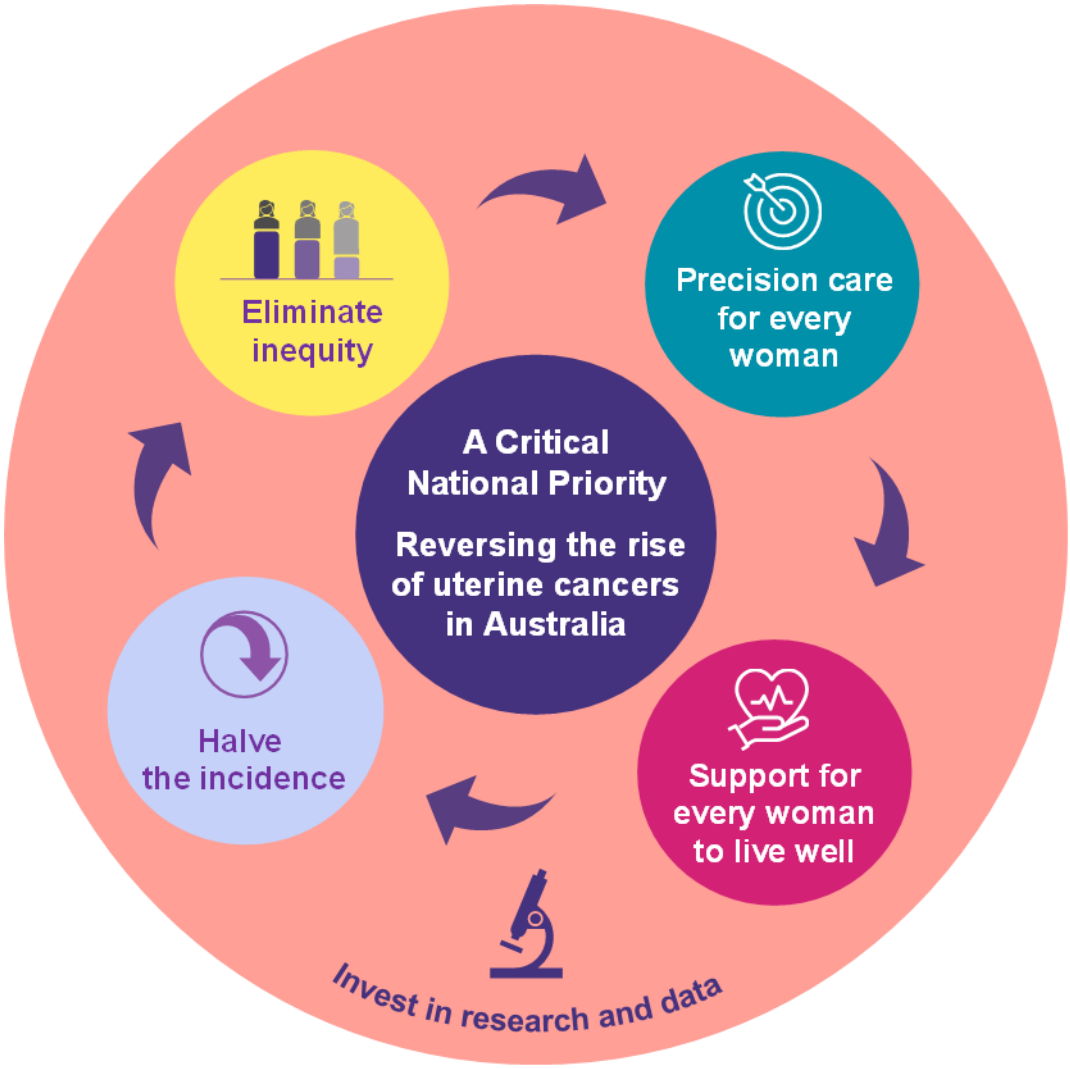
Moreover, there is a history of complacency by governments with respect to women's wellness; obesity and metabolic disease to increase at an unchecked rate, impacting our most vulnerable populations disproportionately. Halting the rise of chronic disease and helping people to live well should be a major community priority, not only for us but for our children. But investments to stem the rise of obesity plaguing our communities remain limited and tokenistic.

ANZGOG aspires to put a stop to the rise and impact of uterine cancers in partnership with Australian and Aotearoa New Zealand governments, relevant partner organisations, and communities.

Through investment in research, improved awareness leading to early detection, community-driven prevention, and streamlined pathways to care, we will reverse the trend,

transforming uterine cancer from a growing threat into a model of how science, policy, and inclusion can change the course of a disease.

Figure 6.1: Vision and goals for uterine cancer



Source: Insight Economics

Driving improvements across these strategic priorities will require sustained partnerships for change across governments, relevant organisations, researchers, clinicians, patients and the broader community. The following sections outline key priority actions for change and key partners for implementation.

6.2 Invest in research and data: key actions and partnerships

The highest priority for action to improve outcomes for women identified by patients, carers, clinicians and consumers alike was to invest in research. This reflected a strong understanding of the relationship between research investment and improved outcomes for cancer survivors. It also reflects a concern for the limited treatment options available to women with rare, recurrent and advanced cancers and an incomplete understanding of the underlying drivers of inequity for priority populations.

To correct the very significant underfunding of uterine cancer against a backdrop of rising incidence and mortality, it is recommended government prioritise and fund uterine cancer research.

Action is also needed to address the significant data gaps that exist for uterine cancer that impede an understanding of outcomes across Australian and Aotearoa New Zealand health systems. While important action is being taken at a national level in cancer data, improvements are needed in cancer registry data collection and reporting, and continued investment will be needed in data linkage to support consistent implementation of clinical best practice and research.

Implementing change in these areas will require partnerships between governments, the research community and clinicians.

Action 1.1	**Fund a Uterine Cancer Research Strategy**
What change is needed	Correct historic underinvestment in uterine cancer research through investment in long-term research strategy focused on expanding treatment options, improving access to precision medicine, the development of new models of care and improvements in clinical practice. The research strategy should invest in expanded biospecimen collection, comprehensive molecular profiling of all rare, recurrent and advanced tumours, a molecular and translational research program, clinical trials and health implementation science to support development of updated clinical guidelines and improved adherence to best practice. The research strategy should also identify opportunities to better identify women at high-risk of endometrial cancer in selected settings including bariatric clinics, fertility clinics, gynaecology centres and orthopaedic clinics with implementation of specialist preventative strategies to improve wellness including potentially exercise and nutritional support, pharmaceutical support and/or surgical interventions. This would include further development of emerging predictors of uterine cancer risk, including the development of biomarkers and polygenic risk scoring tools as well as minimally invasive diagnostics. It should also include an explicit focus on improved outcomes for priority populations with an emphasis on improving outcomes for Pacific women, wāhine Māori, and Aboriginal and Torres Strait Islander women: • Specific genomic risks for Aboriginal, Māori and Pacific women

Action 1.1	**Fund a Uterine Cancer Research Strategy**
	• New models of care to improve wellness among Aboriginal, Māori and Pacific women • Improved understanding of the contributing factors to increased incidence and mortality • Improved models of supportive care • Survivorship and surveillance models of care for First Nations women • Opportunities to improve outcomes for women in neighbouring Pacific nations. In addition to research to improve outcomes for Indigenous women, there should also be tailored research to understand risk factors to improve outcomes for women from low income and regional areas, including the development of targeted public health initiatives, co-designed with these communities, to raise awareness, promote early diagnosis, and improve access to treatment.
Partners for change	MRFF, Cancer Australia, Cancer Control Agency (New Zealand), Department of Health and Aged Care (Australia), Health New Zealand (Te Whatu Ora), State and territory governments, District Health Boards (New Zealand), NACCHO, ANZGOG, Ovarian Cancer Australia, Rare Cancers Australia, Zero Dash, NGOR, COSA, CNSA, Cancer Councils, Counterpart, Obesity Australia, GP organisations, Primary health networks, Cancer registries, Health Research Council of New Zealand

Action 1.2	**Improve data collection and reporting by state cancer registries in uterine cancer**
What change is needed	State and territory cancer registries should set a target to implement improvements in the quality and coverage of reporting for uterine cancers including at a minimum staging data, data on priority populations and molecular diagnosis.
Partners for change	COSA, CNSA, Cancer Councils, Counterpart, Cancer Control Agency (New Zealand) Obesity Australia, GP organisations - Primary health networks, Cancer registries

Action 1.3	**Invest in data linkage in uterine cancer to drive quality improvements in clinical practice and enable research breakthroughs**
What change is needed	Fund research to understand current patterns of clinical practice and opportunities for practice improvements. This includes resourcing for NGOR to collect data and report nationally and funding for data linkage projects in primary care where significant data gaps exist, such

	as through analysis of data assets collected by the University of Melbourne (PATRON) and PHNs
Partners for change	Cancer Australia, Department of Health and Aged Care (Australia), State and territory governments, Health New Zealand (Te Whatu Ora), NGOR, AIHW, University of Melbourne (PATRON dataset), PHNs, NACCHO, ANZGOG, MRFF

6.3 Halve the incidence: key actions and partnerships

Research has shown that up to 60 per cent of endometrial cancer incidence is preventable. Improving prevention to reduce the incidence of endometrial cancer is crucial due to its rising rates and the significant health burden it poses. Prevention strategies like promoting healthy lifestyles, managing chronic conditions, and increasing awareness can lead to earlier detection and intervention, improving outcomes and reducing healthcare costs. Ultimately, prioritising prevention supports not only individual well-being but also public health and health equity.

Action 2.1	**Develop an awareness campaign for uterine cancer**
What change is needed	Fund a national, multi-modal awareness campaign in Australia and Aotearoa New Zealand to improve awareness of uterine cancer, risk factors and opportunities to reduce risk
Partners for change	Cancer Australia, Cancer Control Agency (New Zealand), Department of Health and Aged Care (Australia), Health New Zealand (Te Whatu Ora), State and territory governments, ANZGOG, RACGP, Ovarian Cancer Australia, Rare Cancers Australia, Cancer Councils

Action 2.2	**Expand education of risk factors for uterine cancer, potentially as part of the introduction of government-funded Women's Wellness Checks, women's health clinics and other high-risk settings (e.g., bariatric clinics)**
What change is needed	Fund research to explore the cost-effectiveness of expanding education of uterine cancer risk factors and symptoms by GPs or women's clinics at key phases of a woman's life as part of a wider strategy to improve women's health
Partners for change	National Women's Health Advisory Council, State Governments, Cancer Australia, Cancer Control Agency (New Zealand) Department of Health and Aged Care (Australia), Health New Zealand (Te Whatu Ora), State and territory governments, ANZGOG, RACGP, Cancer Council Australia, Ovarian Cancer Australia, RANZCOG, Primary Health Networks

Action 2.3	**Invest in New National Healthy Living Strategies**
What change is needed	Australian and Aotearoa New Zealand governments should uplift investment in chronic disease prevention, pursuing a multifaceted strategy to reduce the incidence of chronic disease, with funding at least in line with OECD benchmarks for chronic disease prevention (2 per cent of GDP). These strategies should include: • Development of new models of care for obesity management as part of health service delivery, with increasing levels of support and preventative strategies implemented for increasing health risk and funding to reduce wait times to bariatric clinics • Exploration of novel subsidies and incentives for wellness • Improvements to urban planning and built environment • Policies and taxes to reduce the consumption of sugary beverages • Commercial determinants of health including marketing to children • Standards for nutrition in early years of life • Policies and programs to promote increased physical activity • Regulations of front-of-pack labelling • Nutrition standards for school lunches • Awareness and education campaigns • Allow appropriate reimbursement of full medical assessment at GP level
Partners for change	Department of Prime Minister & Cabinet (Australia), Department of Prime Minister & Cabinet (New Zealand), Treasury (Australia) Treasury (New Zealand), Department of Health and Aged Care (Australia), Health New Zealand (Te Whatu Ora), Cancer Australia, Cancer Control Agency (New Zealand), State and territory governments, District health boards (New Zealand), ANZGOG, RACGP, Cancer Australia, Ovarian Cancer Australia, Rare Cancers Australia, Heart Foundation, Diabetes Australia, Kidney Foundation, Lung Foundation, Liver Foundation, Stroke Foundation, Dementia Australia, Business Council of Australia and Consumer Health Forum

Action 2.4	**Pilot targeted screening high-risk women in selected care settings and develop models of care for prevention**
What change is needed	Pilot targeted screening of women in selected settings including bariatric clinics, fertility clinics, orthopaedic clinics with implementation of specialist preventative strategies to improve wellness including potentially exercise and nutritional support, pharmaceutical support and/or surgical interventions.
Partners for change	Department of Health and Aged Care (Australia), Health New Zealand (Te Whatu Ora), Cancer Australia, Cancer Control Agency (New

	Zealand), State and territory governments, District health boards (New Zealand), ANZGOG, RACS, RANZCOG

Action 2.6	**Increased germline screening for hereditary risk among women with uterine cancer**
What change is needed	Increased consistency of germline genetic testing for Lynch syndrome for women found to have a dMMR uterine cancer. Consistency around screening for hereditary screening for uterine sarcomas Development of novel options such as PRS to further evaluate hereditary risk
Partners for change	COSA, HGSA, Department of Health and Aged Care (Australia), Health New Zealand (Te Whatu Ora), Cancer Australia, Cancer Control Agency (New Zealand), ANZGOG, RACGP

6.4 Eliminate inequity: key actions and partnerships

Reducing disparities in the risk of and mortality from uterine cancer for women living in regional areas together with those from low socioeconomic backgrounds. Development of specific and culturally appropriate care pathways for women with Aboriginal, Torres Strait Islander, wāhine Māori and Pacific women, in Australia and Aotearoa New Zealand is a matter of health equity and social justice as well as core to the improvement of cancer outcomes. Addressing inequity is at the heart of the Australian Cancer Plan.

Key actions include investment in culturally tailored research to understand risk factors and barriers to care specific to these populations, and the development of targeted public health initiatives, co-designed with these communities, to raise awareness, promote early diagnosis, and improve access to treatment. Policy reforms could support the expansion of mobile and community-based health services, equitable access to gynae-oncology specialists, and the integration of Indigenous leadership and community voices in cancer care planning as well as the inclusion of Indigenous Liaison Officers or Indigenous nurse navigators (which is the model in Aotearoa New Zealand) to support culturally appropriate treatment planning and care. Enhanced funding for sovereign data collection and reporting, alongside workforce development that includes training and recruitment of First Nation health professionals.

For women from low income and regional areas, reforms to Patient Transport Schemes offer a major opportunity to reduce the risk of financial toxicity. Policy reforms could support the expansion of mobile and community-based health services and equitable access to gynae-oncology specialists also present opportunities to improve outcomes for women from low-income and regional areas.

Through committed research and policy action, Australia and Aotearoa New Zealand can move toward eliminating these preventable health inequities.

Action 3.1	**Fund awareness and education campaigns specifically targeting Aboriginal, Māori and Pacific women, co-designed in partnership with women**
What change is needed	Co-design, in collaboration with Aboriginal, wāhine Māori and Pacific women culturally appropriate, multi-modal awareness campaigns in Australia and Aotearoa New Zealand to improve awareness of uterine cancer, risk factors and opportunities to reduce risk in First Nations communities
Partners for change	NACCHO, Cancer Control Agency (New Zealand) Health New Zealand (Te Whatu Ora), Cancer Australia, Department of Health and Aged Care (Australia), State and territory governments, ANZGOG, RACGP, Cancer Council Australia, Ovarian Cancer Australia, MRFF

Action 3.2	**Develop community-controlled models of care to improve wellness among Aboriginal, wāhine Māori and Pacific women, co-designed in partnership with women**
What change is needed	Co-design, in collaboration with Aboriginal, wāhine Māori and Pacific women culturally appropriate models of care to improve wellness and prevent chronic disease among First Nations women
Partners for change	NACCHO, Cancer Control Agency (New Zealand), Health New Zealand (Te Whatu Ora), Cancer Australia, Department of Health and Aged Care (Australia), Te Rau Ora, National Pacific Health Senate Fatu Fono Ola, Hauora Māori Advisory Committee, State and territory governments, ANZGOG, MRFF

Action 3.3	**Invest in cultural training and improve expand access to Indigenous Liaison Officers (ILOs)**
What change is needed	Invest in the training and development of Indigenous clinicians where possible and expand investments in cultural training and key roles, such as community liaison officers that can potentially participate in MDTs where treatment at a specialist centre is needed.
Partners for change	NACCHO, Cancer Control Agency (New Zealand), Health New Zealand (Te Whatu Ora), Cancer Australia, Department of Health and Aged Care (Australia), State and territory governments, ANZGOG, Cancer Council Australia, Ovarian Cancer Australia

Action 3.4	**Develop and fund standards for improved equity in clinical trials**
What change is needed	Require reporting of First Nations enrolment in clinical trials and fund outreach to support increased recruitment of First Nations women to clinical trials

	The development of Participant Information and Consent Form and other trial information that are language appropriate for women with low health literacy Enabling novel trial design to allow telehealth follow up and or to receive investigational agents at local centres to enable women in regional and remote areas access to novel therapy opportunity
Partners for change	NACCHO, Health New Zealand (Te Whatu Ora), Cancer Australia, Department of Health and Aged Care (Australia), State and territory governments, ANZGOG, Cancer Australia, Ovarian Cancer Australia

Action 3.5	**Reform Patient Transport Support Schemes to better meet needs of low-income women**
What change is needed	Review opportunities to means test programs to increase support for low-income women and streamline access to support, as well as invest in patient hospitals for low-income women
Partners for change	State and territory governments, Health New Zealand (Te Whatu Ora), Cancer Control Agency, Cancer Australia, Department of Health and Aged Care (Australia)

6.5 Precision cancer care for every woman: key actions and partnerships

Implementing comprehensive molecular profiling for all rare, recurrent, and advanced uterine cancers is essential to improving patient outcomes and advancing equity in cancer care. traditional 'one-size-fits-all' approaches have largely failed to deliver significant survival gains. Molecular profiling enables a precision medicine approach by identifying specific genetic and molecular alterations that can guide targeted therapies, predict treatment response, and avoid unnecessary toxicity.

This should be implemented as part of a wider uterine cancer research strategy. A robust research program is needed incorporating biomarker discovery to guide clinical trial design. This is strongly aligned with the National Framework for Genomics in Cancer Control, and would not only improve outcomes for individuals with rare, recurrent and advanced uterine cancers, but also help close the gap in treatment quality and access between high- and low-resource settings, ensuring that all patients—regardless of cancer subtype or geographic location—can benefit from the latest advances in cancer science.

In addition to access to molecular profiling, governments should also commit to ensuring clinical guidelines are updated and maintained to reduce variation in care and ensure access to best practice.

Action 4.1	**Fund comprehensive molecular profiling and access to precision medicine in uterine cancers**
What change is needed	Services to promote education and awareness of precision medicine in uterine cancer care and to ensure consistent access to comprehensive molecular profiling of all rare, recurrent and advanced

	cancers. Optimise access to precision medicine through funding for clinical trials and knowledge curation in a uterine cancer data portal that brings together patient history, genomic, treatment and outcome data from disparate datasets to identify new biomarkers and improved treatment selection.
Partners for change	MRFF, ANZGOG, Cancer Australia, Department of Health and Aged Care (Australia), ARC Portal, Omico, Pharmaceutical Industry partners, MOGA, Health Research Council of New Zealand

Action 4.2	**Update and improve implementation of clinical guidelines**
What change is needed	Update clinical practice guidelines in Australia for uterine cancer to improve consistency of practice along the care pathway but particularly in the investigation of and referral pathways for symptoms associated with uterine cancer, including diagnostic work-up, use of adjuvant therapies, treatment selection, surveillance and survivorship.
Partners for change	Cancer Council Australia, Cancer Control Agency (New Zealand), ANZGOG, RACGP, RANZGOG, Cancer Australia, ASGO

Action 4.3	**Identify therapies and diagnostic tests for funding support through Bridging Funding as part of the implementation of the Australian government's HTA reforms**
What change is needed	ANZGOG should establish a working group to: • Identify a shortlist of High Unmet Need therapies and diagnostic tests and engage with government to obtain funding for them • Engage with government on real world evidence data frameworks, data standards, and evidence requirements • Engage with government in horizon scanning and the development of criteria for identification of areas of therapeutic needs
Partners for change	ANZGOG, Rare Cancers Australia, Omico, Ovarian Cancer Australia, Cancer Australia, Bridging Funding Coalition, MOGA, MSAC, Health Research Council of New Zealand

6.6 Support for every woman: key actions and partnerships

Uterine cancer is the most commonly diagnosed gynaecological cancer but is distinguished by a lack of patient support. Unlike other gynaecological cancers, there is no patient support organisation raising awareness and championing policy reforms that will improve outcomes for women. Screening for supportive care remains inconsistent and many women struggle to find appropriate supportive care services as long term survivors.

Action 5.1	**Ensure adherence to clinical best practice – screening for supportive care**
What change is needed	Implement quality care standard for cancer care that requires screening for supportive care and invest in resourcing to meet standard
Partners for change	State and territory governments, District health boards (New Zealand), Department of Health and Aged Care (Australia), Health New Zealand (Te Whatu Ora), ACQSHC, Cancer Australia, Cancer Control Agency (New Zealand), ANZGOG

Action 5.2	**Support delivery of patient support, peer support and psychological support services for women with uterine cancer by Ovarian Cancer Australia**
What change is needed	Fund expanded access to patient support, peer support and psychosocial services for women with uterine cancer by Ovarian Cancer Australia, progressively expanding on its Teal Nurse Support program
Partners for change	OCA, Counterpart, Cancer Australia, Cancer Control Agency (New Zealand), Department of Health and Aged Care (Australia), Health New Zealand (Te Whatu Ora), McGrath Foundation, Cancer Council Australia, COSA

Action 5.3	**Fund research to develop a model of care for uterine cancer survivorship**
What change is needed	Invest in research to develop an optimised model of care for uterine cancer survivors, building on the findings of the Western Australia Gynaecological Cancer Survivorship Clinic, other women's health and cancer survivorship clinics in Victoria, and trials for shared care underway in early breast cancer care (e.g., IBIS trial)
Partners for change	Department of Health and Aged Care (Australia), Health New Zealand (Te Whatu Ora), Cancer Australia, Cancer Control Agency (New Zealand), ANZGOG, OCA, COSA, Cancer Council Australia, McGrath Foundation, Australian Survivorship Centres

Appendix A: Economic impacts of Uterine Cancers in Australia and Aotearoa New Zealand

This appendix outlines the key assumptions and data informing epidemiological projections and economic cost modelling of uterine cancer in Australia and Aotearoa New Zealand. It also summarises the projected incidence and mortality and the total estimated economic costs in Australia and Aotearoa New Zealand.

A.1 Epidemiological projections

Research have demonstrated a significant link between obesity and increased uterine cancer risk[164]. We employed a Generalised Linear Model (GLM) to account for the influence of obesity and other relevant risk factors on future cancer incidence. In our modelling, we specifically account for obesity as the risk factor for uterine cancer. Poisson GLMs were fitted. The model can be expressed by:

$$lnI_{ij} = lnN_{ij} + \alpha Age_i + \beta Period_j + \gamma Cohort_k + \delta Risk_{ij-L}$$

where δ is the coefficient for the risk factor component, $Risk_{ij-L}$, which denotes the risk factor for age group i in period j$-L$, lagged by L periods to account for delayed effects of risk exposure from obesity.

AIHW data[165] on uterine cancer incidence is available from 1982 to 2024. Data up to 2020 is actual observed data, while the data from 2021 to 2024 consists of projected values from AIHW. A data request was made to the Ministry of Health NZ for Aotearoa New Zealand data.[166] Data available is from 1995 to 2020. These data were then used to fit the GLM models. For Australian population data, historical data from ABS[167] up to 2021 was used, and for population projections from 2022 to 2035, ABS's medium series projections were used.[168] For Aotearoa New Zealand population data, historical data from Stats NZ up to 2023 was used,[169] and for population projections from 2024 to 2035, Stats NZ's medium series projections were used as well.[170]

Australian obesity data was constructed from the available ABS National Health Surveys conducted in 1990, 1995, 2001, 2005, 2008, 2012, 2015, 2018, and 2022.[171] Aotearoa New Zealand obesity data was constructed from the available NZ National Health Survey conducted in 2012-2024 (excl. 2022).[172] To estimate obesity rates for the years between the surveys, we filled in the gaps by assuming a constant annual percentage change. For 2023

[164] Onstad, M. A., Schmandt, R. E., & Lu, K. H. (2016). Addressing the Role of Obesity in Endometrial Cancer Risk, Prevention, and Treatment. Journal of clinical oncology: official journal of the American Society of Clinical Oncology, 34(35), 4225–4230
[165] AIHW CDIA 2024: Book 1a – Cancer incidence (age-standardised rates and 5-year age groups), 1982-2020 (Observed), 2021-2024 (Projected).
[166] Health Aotearoa New Zealand (Te Whatu Ora). Insight Economics data request.
[167] ABS Historical Population, 2021.
[168] ABS Population Projections, Australia, 2022 (base) – 2071, Medium series.
[169] Stats NZ (Tatauranga Aotearoa). Estimated resident population (2023-base): On 30 June 2023
[170] Stats NZ (Tatauranga Aotearoa). National population projections: 2024 (base) – 2078, Medium series.
[171] ABS National Health Surveys, 1990, 1995, 2001, 2005, 2008, 2012, 2015, 2018 and 2022.
[172] Health Aotearoa New Zealand (Te Whatu Ora). Aotearoa New Zealand Health Surveys, 2012–2021 and 2023–2024.

and 2024, we assumed that obesity rates would remain the same as those in 2022 for Australia. We then used a linear regression model to predict obesity rates from 2025 to 2035, based on the filled-in data from 1995 to 2024.

With the projected population data for 2025-2035 and obesity rates for the same period, we used the fitted GLM models to predict the incidence rates and crude incidence for uterine cancer. These models incorporated the population projections and obesity data to generate forecasts of cancer incidence over the 2025-2035 period.

We then used these fitted models to project cancer incidence from 2025 to 2035 for the different gynaecological cancers. The projected incidence for each cancer type, including uterine cancer, served as the foundation for estimating the associated economic costs.

A.2 Economic cost estimation

Inflation, exchange rate, and discount rate

All costs are presented in 2025 Australian dollars, with an annual discount rate of 7% applied. The AUD:NZD exchange rate used is 1.1028 as of 11/03/2025, 2pm AEST.[173]

Health service costs are adjusted for inflation using the Consumer Price Index (CPI) for health services data reported by ABS and Stats NZ in Australia and Aotearoa New Zealand,[174,175] while wages are adjusted for wage inflation using the Wage Price Index data reported by ABS and Stats NZ, respectively.[176,177] For the period from 2025 onwards to 2035, the Health CPI and Wage Price Index are assumed to grow at the CAGR observed over the past 10 years, from FY2015 (September 2014) to FY2025 (September 2024).

Cancer stage-at-diagnosis proportions

The stage-at-diagnosis (localised, regional, and advanced) proportions for uterine cancer in Australia were derived from the NSW Cancer Portal's Incidence and Mortality Dashboard (2017–2021) and are assumed to remain constant over the next 10 years for modelling purposes.[178] For Aotearoa New Zealand, the proportions were derived from the Ministry of Health NZ data recorded over the 1994-2011 period.[179]

The proportions of stage at diagnosis for uterine cancer are 64%, 23% and 13% for localised, regional and advanced stage in Australia, respectively. For Aotearoa New Zealand, the proportions are 68%, 23%, and 9%, respectively.

[173] Yahoo Finance. AUD/NZD (AUDNZD=X) live rate, chart and news. Retrieved 11/3/2025, from https://au.finance.yahoo.com/quote/AUDNZD=X/
[174] ABS CPI: Groups, Weighted Average of Eight Capital Cities, Index Numbers and Percentage Changes, September 2024 release.
[175] Stats NZ (Tatauranga Aoteoroa). Consumers price index: December 2024 quarter
[176] ABS WPI: Total hourly rates of pay excluding bonuses: sector, original, seasonally adjusted and trend, September 2024 release.
[177] Stats NZ (Tatauranga Aoteoroa). Labour market statistics: December 2024 quarter
[178] Cancer Institute NSW. Cancer Statistics NSW. Retrieved from www.cancer.nsw.gov.au/cancer-types-data-nsw on 14/12/2024
[179] Ministry of Health (Manatū Hauora). (2015, April 14). *Cancer Patient Survival: 1994 to 2011* (Revised May 1, 2015). Retrieved August 28, 2025, from https://www.health.govt.nz/system/files/2015-04/cancer-patient-survival-1994-2011-apr15-v2.pdf

10-year survival and cohorts

We based our economic cost estimation on 10-year survival data from the AIHW and Ministry of Health NZ for uterine cancer.[180,181] The survival data in our analysis represent overall survival rates over a 10-year period from diagnosis for all patients, as no stage-specific survival data were available.

As a result, while we acknowledge and consider variations in patient experience and treatment costs by cancer stage (e.g., localised vs. regional vs. late), our final calculations had to be based on assumptions that are weighted averages across all stages due to the lack of stage-specific survival data. These stage-based variations are still considered, but for consistency in our cost estimation, they are captured within this weighted average, allowing us to estimate the overall economic impact using the available data.

For benefit assessments conducted, we used different survival rates compared to the Australian or Aotearoa New Zealand national survival data. Specifically, we applied Queensland survival data, then selecting the better rate of the two to represent improved 'best practice' survival outcomes, with the national survival rates serving as the 'base' survival outcomes.

Economic cost modelling was conducted using rolling 10-year cohorts for each year from 2025 to 2035 calculated based on the corresponding 10-year survival rates.

Variations in patient experience by cancer stage and treatment phase

Cancer progression is categorised into three stages: localised (Stage 1), regional (Stages 2 and 3), and distant (Stage 4). Treatment is typically divided into three phases: the initial phase (the first year after diagnosis), the continued phase (ongoing treatment), and the terminal phase (the final year of treatment before death).

Patients' experiences vary significantly based on the stage of cancer at diagnosis and the treatment phase they are in, which necessitates different assumptions for economic cost estimation. For instance, healthcare costs differ depending on the stage at diagnosis and the treatment phase. In burden of disease calculations, disability weights are adjusted to reflect both the stage and phase of treatment. Similarly, workforce participation impacts and the effects of maternal or partner loss are also estimated based on these variations in patient experience by cancer stage and treatment phase.

Health service costs

Ovarian cancer health service costs reported in the 2023 study by Goldsbury et al.[182] were used for our modelling for uterine cancer hospital costs in Australia. These costs were structured into three treatment phases: initial, continued, and terminal, with variations depending on the cancer stage at each phase. There were no such studies for uterine cancer, and we had to use an AIHW report[183] for the hospital costs of uterine cancer by holding the relativities constant with those reported for ovarian cancer. Annual total hospital costs and the total number of hospitalisations for uterine cancer, as reported by AIHW, were then used to calculate the average cost per hospitalisation for uterine cancer. We then determined the cost ratios ovarian and uterine cancer. These ratios were applied to scale the ovarian cancer

[180] AIHW CDIA 2024: Book 9c1, 9c2 – Cancer survival by ICD-10 4-character subsite (10-year age groups).
[181] Ministry of Health (Manatū Hauora). (2015, April 14). *Cancer Patient Survival: 1994 to 2011* (Revised May 1, 2015). Retrieved August 28, 2025, from https://www.health.govt.nz/system/files/2015-04/cancer-patient-survival-1994-2011-apr15-v2.pdf
[182] Goldsbury, D. E., Vassallo, A., Weber, M. F., et al. (2023). Health services costs for ovarian cancer in Australia: Estimates from the 45 and Up Study. PloS One, 18(4), e0282851. https://doi.org/10.1371/journal.pone.0282851
[183] AIHW Disease expenditure in Australia 2019-20.

health service costs from the 2023 study to estimate costs by different stages and treatment phases for uterine cancer in Australia. The costs are

For Aotearoa New Zealand costs, we used the uterine cancer health service costs reported in the 2015 study by Blakely et al.[184]

The 2025 uterine cancer health service costs in Australia and Aotearoa New Zealand are as follows.

Table A.1: Uterine cancer health service costs in Australia and Aotearoa New Zealand by stage at diagnosis and treatment phase

	Localised	Regional	Distant
Australia – Initial phase	$24,511	$24,511	$35,963
Australia – Continued phase	$3,151	$3,151	$10,280
Australia – Terminal phase	$43,394	$43,394	$36,984
Aotearoa New Zealand – Initial phase	$28,634	$28,634	$28,634
Aotearoa New Zealand – Continued phase	$2,481	$2,481	$2,481
Aotearoa New Zealand – Terminal phase	$49,110	$49,110	$49,110

Source: Goldsbury et al. (2023) and Blakely et al. (2015).

Burden of disease

Burden of disease calculations are based on two key components: Years of Life Lost (YLL) and Years Lived with Disability (YLD), which together form Disability-Adjusted Life Years (DALYs). DALYs represent the total burden of disease by combining the impact of premature death (YLL) and the time spent living with the condition (YLD). The value of a statistical life year (VSLY) is estimated at A$61,574[185] in 2025 dollars, adjusted for inflation, and is used to value DALYs to estimate the total economic cost of the disease burden.

Disability weights, sourced from the Global Burden of Disease (GBD) study,[186] are applied to YLD to account for the severity of the condition at different stages of cancer and phases of treatment. This approach ensures that the quality-of-life impacts are accurately captured. Variations in cancer stage at diagnosis and treatment phase are incorporated to provide a comprehensive estimate of the loss of well-being and the associated economic impacts.

For YLL calculations, the overall age at death from uterine cancer in Australia is calculated as a weighted average using 2024 mortality data from the AIHW.[187] For Aotearoa New Zealand, the mortality data from the Ministry of Health NZ is used.[188]

The average life expectancy at birth for an Australian female is 85.1 years, based on ABS life expectancy data for the 2021-2023 period,[189] while the average life expectancy at birth for a

[184] Blakely, T., Atkinson, J., Kvizhinadze, G., Wilson, N., Davies, A., & Clarke, P. (2015). Patterns of cancer care costs in a country with detailed individual data. *Medical care*, *53*(4), 302–309. https://doi.org/10.1097/MLR.0000000000000330
[185] Taylor, C., & Jan, S. (2017). Economic evaluation of medicines. *Australian Prescriber*, 40, 76–78. https://doi.org/10.18773/austprescr.2017.014
[186] Global Burden of Disease Collaborative Network. (2022). *Global Burden of Disease Study 2021 (GBD 2021) results*. Institute for Health Metrics and Evaluation (IHME).
[187] AIHW CDIA 2024: Book 2a – Cancer mortality (age-standardised rates and 5-year age groups).
[188] Health Aotearoa New Zealand (Te Whatu Ora). Insight Economics data request.
[189] ABS. Life expectancy, 2021-2023.

Aotearoa New Zealand female is 83.5 years based on Stats NZ life expectancy data for the 2017-2021 period.[190] The average Years of Life Lost (YLL) due to premature death is then calculated by subtracting the weighted average age at death from the assumed life expectancy.

The specific disability weights assumed and average YLL for uterine cancer calculated are detailed below.

Table A.2: Disability weights for uterine cancer by stage at diagnosis and treatment phase

	Localised	Regional	Distant
Initial phase	0.2875	0.4514	0.4514
Continued phase	0.0490	0.0490	0.5396
Terminal phase	0.5396	0.5396	0.5396

Source: Global Burden of Disease Study 2021.

Table A.3: Average age at death and years of life lost from uterine cancer in Australia and Aotearoa New Zealand

	Average age at death	Average years of life lost
Australia	68.29	16.71
Aotearoa New Zealand	71.60	11.90

Source: AIHW and Health NZ data.

Workforce participation

The average Australian and Aotearoa New Zealand weekly earnings, sourced from ABS and Stats NZ data, are set at $1,923.40 and $1497.10, respectively, with a full-time work week defined as 38 hours.[191,192] This translates to an hourly wage of $50.62 or $38.60.

It is assumed that patients in their first and last year of treatment following diagnosis (i.e., the initial and terminal treatment phases) will not participate in the workforce. During the ongoing treatment phase, patients are expected to return to work at a reduced participation rate, varying by cancer stage, reflecting absenteeism.[193] For those remaining in the workforce, it is also assumed that they will work reduced hours,[194] with presenteeism affecting the productivity of the hours worked.[195]

[190] Stats NZ. National and subnational period life tables: 2022–2024.
[191] ABS Average weekly earnings, Australia (dollars) - seasonally adjusted, May 2024 release
[192] Stats NZ (Tatauranga Aotearoa), Labour market statistics (income): December 2024 quarter
[193] Thandrayen, J., Joshy, G., Stubbs, J., et al. (2022). Workforce participation in relation to cancer diagnosis, type and stage: Australian population-based study of 163,556 middle-aged people. *Journal of cancer survivorship: research and practice*, *16*(2), 461–473. https://doi.org/10.1007/s11764-021-01041-7
[194] Thandrayen, J., Joshy, G., Stubbs, J., et al. (2022). Workforce participation in relation to cancer diagnosis, type and stage: Australian population-based study of 163,556 middle-aged people. *Journal of cancer survivorship: research and practice*, *16*(2), 461–473. https://doi.org/10.1007/s11764-021-01041-7
[195] So, S. C. Y., Ng, D. W. L., Liao, Q., et al. (2022). Return to work and work productivity during the first year after cancer treatment. *Frontiers in Psychology, 13*. https://doi.org/10.3389/fpsyg.2022.866346

Additionally, around 30% of women living with a gynaecological cancer are assumed to require a carer,[196] typically a close family member, who also experiences reduced work hours[197] and presenteeism at work.[198]

The specific assumptions are detailed below.

Table A.4: Workforce participation assumptions of uterine cancer patients and carers by stage at diagnosis and treatment phase

	Localised	Regional	Distant
Workforce withdrawal (absenteeism) – Initial phase / Terminal phase			
% of women with gynaecological cancer out of workforce	100%	100%	100%
% of all women out of workforce	33%	33%	33%
% of women out of workforce because of gynaecological cancer	63%	63%	63%
Hours of work per week lost per women	38	38	38
Workforce withdrawal (absenteeism) – Continued phase			
% of women with gynaecological cancer out of workforce	48%	51%	51%
% of all women out of workforce	33%	33%	33%
% of women out of workforce because of gynaecological cancer	15%	18%	18%
Hours of work per week lost per women	38	38	38
Workforce withdrawal (absenteeism) – Continued phase			

[196] Australian Cancer Plan. (n.d.). *People living with disability*. Australian Cancer Plan. Retrieved on 14/12/2024, from https://www.australiancancerplan.gov.au/populations/people-living-with-disability

[197] Kamal, K. M., Covvey, J. R., Dashputre, A., et al. (2017). A Systematic Review of the Effect of Cancer Treatment on Work Productivity of Patients and Caregivers. *Journal of managed care & specialty pharmacy*, *23*(2), 136–162. https://doi.org/10.18553/jmcp.2017.23.2.136

[198] Kamal, K. M., Covvey, J. R., Dashputre, A., et al. (2017). A Systematic Review of the Effect of Cancer Treatment on Work Productivity of Patients and Caregivers. *Journal of managed care & specialty pharmacy*, *23*(2), 136–162. https://doi.org/10.18553/jmcp.2017.23.2.136

	Localised	Regional	Distant
% of women with gynaecological cancer out of workforce	48%	51%	51%
% of all women out of workforce	33%	33%	33%
% of women out of workforce because of gynaecological cancer	15%	18%	18%
Hours of work per week lost per women	38	38	38
Reduced working hours (Partial workforce participation) – Initial phase / Terminal phase			
% of women remaining in workforce	0%	0%	0%
Hours of work per week lost	6.26	10.26	10.26
Reduced working hours (Partial workforce participation) – Continued phase			
% of women remaining in workforce	52%	49%	49%
Hours of work per week lost	6.26	10.26	10.26
Presenteeism (Reduced productivity at work) – Initial phase / Terminal phase			
Hours worked per week	31.74	27.74	27.74
Presenteeism due to cancer	17%	17%	17%
Presenteeism (Reduced productivity at work) – Continued phase			
Hours worked per week	31.74	27.74	27.74
Presenteeism due to cancer	17%	17%	17%

	Localised	Regional	Distant
Carer reduced working hours – Initial phase / Terminal phase			
% of women with gynaecological cancer requiring carers	30%	30%	30%
% of carers in workforce	67%	67%	67%
Hours of work per week lost	3.31	3.31	3.31
Carer reduced working hours – Continued phase			
% of women with gynaecological cancer requiring carers	30%	30%	30%
% of carers in workforce	67%	67%	67%
Hours of work per week lost	3.31	3.31	3.31
Carer presenteeism (Reduced productivity at work) – Initial phase / Terminal phase			
Hours worked per week	34.69	34.69	34.69
Presenteeism due to psychosocial impacts	21%	21%	21%
Carer presenteeism (Reduced productivity at work) – Continued phase			
Hours worked per week	34.69	34.69	34.69
Presenteeism due to psychosocial impacts	21%	21%	21%

Source: ABS, Stats NZ data and literature review.

Mother and partner loss

The percentage of Australian women aged 15 and above with children, the average number of children, and the percentage of women with a partner, sourced from ABS data, are assumed

to be 77%, 1.955, and 57%, respectively.[199,200,201] The percentage of Aotearoa New Zealand women aged 15 and above with children, the average number of children, and the percentage of women with a partner, sourced from Stats NZ data, are assumed to be 65%, 2.469, and 45%, respectively.[202] Children and partners are impacted differently by the loss of their mother or partner, with distinct effects on young children, adult children, and partners. Depression is assumed to affect 23.90% of young children,[203] 30.20% of adult children,[204] and 34.90% of partners.[205] The average maternal age is 31.3 years in Australia[206] and 31.5 years in Aotearoa New Zealand,[207] and based on this, we determine whether a woman's children are likely to be young or adults at the time of her diagnosis or passing.

The total impact of a cancer diagnosis, before the death of the mother or partner, is treated similarly to a YLD calculation, as it captures the loss of well-being experienced by the children and partners of women living with gynaecological cancer. Depression severity weights are sourced from the GBD study, reflecting varying levels of depression, from mild to severe.

The total impact of maternal or partner loss at the time of death is projected over the 10 years following the woman's death. This impact is modelled similarly to an YLL calculation, capturing the long-term loss of well-being experienced by children and partners due to depression over the following decade.

Depression severity is assumed to vary by cancer stage at diagnosis, while post-death depression for all children and partners is considered to all be of moderate severity. The specific assumptions are detailed below.

Table A.5: Assumptions on maternal and partner loss from uterine cancer

	Localised	Regional	Distant
Depression prevalence			
Young children (<18 years)	23.90%	23.90%	23.90%
Adult children (≥ 18 years)	30.20%	30.20%	30.20%
Partners	34.90%	34.90%	34.90%

[199] Australian Bureau of Statistics. (2018, May 10). *Australia's fertility rate: Trends and insights*. Australian Bureau of Statistics. Retrieved from https://www.abs.gov.au/ausstats/abs@.nsf/mediareleasesbyCatalogue/168BFDA0C45F98A8CA258288001A58C5?OpenDocument on 14/12/2024

[200] Australian Institute of Family Studies. (2022, March). *Births in Australia: Facts and figures*. Australian Institute of Family Studies. Retrieved from https://aifs.gov.au/research/facts-and-figures/births-in-australia on 14/12/2024

[201] ABS Census of Population and Housing: General Community Profile DataPack, Australia, 2021

[202] Stats NZ (Tatauranga Aotearoa), 2023 Census.

[203] Pham, S., Porta, G., Biernesser, C., et al. (2018). The Burden of Bereavement: Early-Onset Depression and Impairment in Youths Bereaved by Sudden Parental Death in a 7-Year Prospective Study. *The American journal of psychiatry*, *175*(9), 887–896. https://doi.org/10.1176/appi.ajp.2018.17070792

[204] Rheingold, A. A., Williams, J. L., & Bottomley, J. S. (2024). Prevalence and co-occurrence of psychiatric conditions among bereaved adults. *JAMA Network Open, 7*(6), e2415325. https://doi.org/10.1001/jamanetworkopen.2024.15325

[205] Australian Institute of Health and Welfare. (2024, December 13). *Australia's mothers and babies: Maternal age*. Australian Institute of Health and Welfare. Retrieved from https://www.aihw.gov.au/reports/mothers-babies/australias-mothers-babies/contents/overview-and-demographics/maternal-age on 14/12/2024

[206] AIHW. (2025, July 31). *Maternal age* (in *Australia's mothers and babies*). Retrieved August 28, 2025, from https://www.aihw.gov.au/reports/mothers-babies/australias-mothers-babies/contents/overview-and-demographics/maternal-age

[207] Stats NZ (Tatauranga Aotearoa) (2025, February 18). *Women giving birth are older than ever recorded*. Retrieved August 28, 2025, from https://www.stats.govt.nz/news/women-giving-birth-are-older-than-ever-recorded/

	Localised	Regional	Distant
Disability weights following cancer diagnosis			
Initial phase	0.1454	0.3962	0.6583
Continued phase	0.3962	0.6583	0.6583
Terminal phase	0.6583	0.6583	0.6583
Disability following maternal/partner loss			
Initial phase	0.3962	0.3962	0.3962
Continued phase	0.3962	0.3962	0.3962
Terminal phase	0.3962	0.3962	0.3962

Source: Literature review.

A.3 Results

Incidence and mortality projections

Over the 2025-2035 period, it is projected that over 55,600 women in Australia and Aotearoa New Zealand will be diagnosed with uterine cancer, with over 11,800 women expected to die from the disease.

For each cohort of newly diagnosed women, we track their mortality over the following 10 years using AIHW and Stats NZ survival rates. The total mortality for each year is calculated by summing the deaths within that year from the current cohort, as well as from cohorts diagnosed in the past 10 years. The projections for incidence and mortality from 2025 to 2035 are presented below.

Table A.6: Projected incidence of uterine cancer in Australia and Aotearoa New Zealand, 2025–2035

	2025	2026	2027	2028	2029	2030	2031	2032	2033	2034	2035
Australia	**3,507**	**3,609**	**3,709**	**3,809**	**3,908**	**4,005**	**4,100**	**4,193**	**4,289**	**4,390**	**4,493**
Localised	2,244	2,310	2,374	2,438	2,501	2,563	2,624	2,683	2,745	2,810	2,876
Regional	807	830	853	876	899	921	943	964	986	1,010	1,033
Advanced	456	469	482	495	508	521	533	545	558	571	584
Aotearoa New Zealand	**858**	**895**	**933**	**972**	**1,012**	**1,053**	**1,093**	**1,135**	**1,178**	**1,223**	**1,269**
Localised	582	607	633	659	687	714	741	770	799	829	861

	2025	2026	2027	2028	2029	2030	2031	2032	2033	2034	2035
Regional	197	206	215	224	233	242	251	261	271	281	292
Advanced	79	82	86	89	93	97	101	104	108	112	117
Total	**4,365**	**4,504**	**4,643**	**4,782**	**4,920**	**5,057**	**5,193**	**5,328**	**5,467**	**5,613**	**5,763**

Source: Insight Economics modelling based on AIHW and Health NZ data.

Table A.7: Projected mortality of uterine cancer in Australia and Aotearoa New Zealand, 2025–2035

	2025	2026	2027	2028	2029	2030	2031	2032	2033	2034	2035
Australia	**709**	**731**	**748**	**769**	**789**	**810**	**831**	**852**	**872**	**893**	**914**
Localised	454	466	479	492	505	519	532	545	558	571	585
Regional	163	168	172	177	182	186	191	196	201	205	210
Advanced	92	98	97	100	103	105	108	111	113	116	119
Aotearoa New Zealand	**214**	**223**	**232**	**242**	**252**	**262**	**272**	**283**	**294**	**305**	**317**
Localised	145	151	157	164	171	178	185	192	199	207	215
Regional	49	51	53	56	58	60	63	65	68	70	73
Advanced	20	21	21	22	23	24	25	26	27	28	29
Total	**922**	**954**	**980**	**1,011**	**1,041**	**1,073**	**1,104**	**1,135**	**1,166**	**1,198**	**1,231**

Source: Insight Economics modelling based on AIHW and Health NZ data.

Economic costs

Over the 2025-2035 period, the total economic cost is projected to amount to $32 billion in $NPV_{7\%}$ terms.

Table A.8: Projected economic cost of uterine cancer in Australia and Aotearoa New Zealand, 2025–2035

	2025	2026	2027	2028	2029	2030	2031	2032	2033	2034	2035
Australia	**$2.44**	**$2.42**	**$2.41**	**$2.39**	**$2.36**	**$2.35**	**$2.33**	**$2.31**	**$2.28**	**$2.26**	**$2.23**
Localised	$1.34	$1.33	$1.32	$1.31	$1.30	$1.29	$1.28	$1.27	$1.26	$1.24	$1.23
Regional	$0.70	$0.70	$0.69	$0.69	$0.68	$0.67	$0.67	$0.66	$0.66	$0.65	$0.64
Advanced	$0.40	$0.39	$0.39	$0.39	$0.38	$0.38	$0.38	$0.37	$0.37	$0.37	$0.36

Aotearoa New Zealand	**$0.54**	**$0.54**	**$0.54**	**$0.54**	**$0.54**	**$0.54**	**$0.54**	**$0.54**	**$0.53**	**$0.53**	**$0.53**
Localised	$0.33	$0.33	$0.33	$0.33	$0.33	$0.33	$0.33	$0.33	$0.33	$0.32	$0.32
Regional	$0.15	$0.15	$0.15	$0.15	$0.15	$0.15	$0.15	$0.15	$0.15	$0.15	$0.15
Advanced	$0.06	$0.06	$0.06	$0.06	$0.06	$0.06	$0.06	$0.06	$0.06	$0.06	$0.06
Total	**$2.99**	**$2.97**	**$2.95**	**$2.93**	**$2.91**	**$2.89**	**$2.87**	**$2.84**	**$2.81**	**$2.79**	**$2.76**

Source: Insight Economics modelling.

Table A.9: Economic cost breakdown of uterine cancer in Australia and Aotearoa New Zealand, 2025

	Australia	Aotearoa New Zealand	Total
5-year prevalence	14,471	3,233	17,703
Hospital costs (A$ billion)	**$0.18**	**$0.04**	**$0.22**
Reduced productivity (A$ billion)	**$0.81**	**$0.14**	**$0.95**
Patient YLD	3,341	693	4,033
YLD (A$ billion)	**$0.21**	**$0.04**	**$0.25**
YLL	11,844	3,247	15,091
YLL (A$ billion)	**$0.73**	**$0.20**	**$0.93**
Burden of disease (A$ billion)	**$0.93**	**$0.25**	**$1.18**
Mother and partner loss (A$ billion)	**$0.52**	**$0.12**	**$0.64**
Total costs (A$ billion)	**$2.44**	**$0.55**	**$2.99**

Source: Insight Economics modelling.

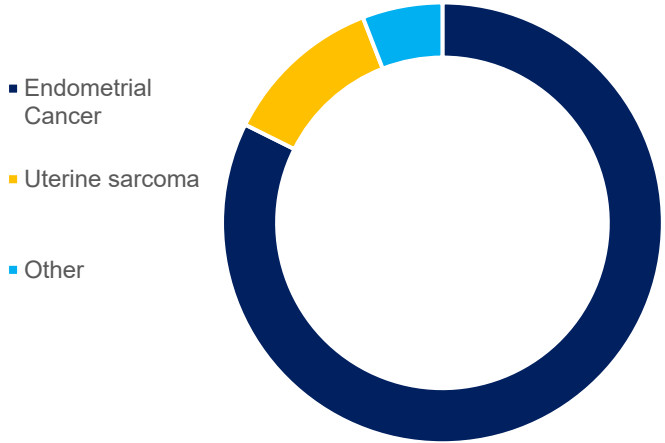
Appendix B: Surveys of Consumers, Clinicians and Researchers

This appendix outlines the respondents to the survey of patients and carers impacted by uterine cancer and the survey of uterine cancer clinicians and researchers.

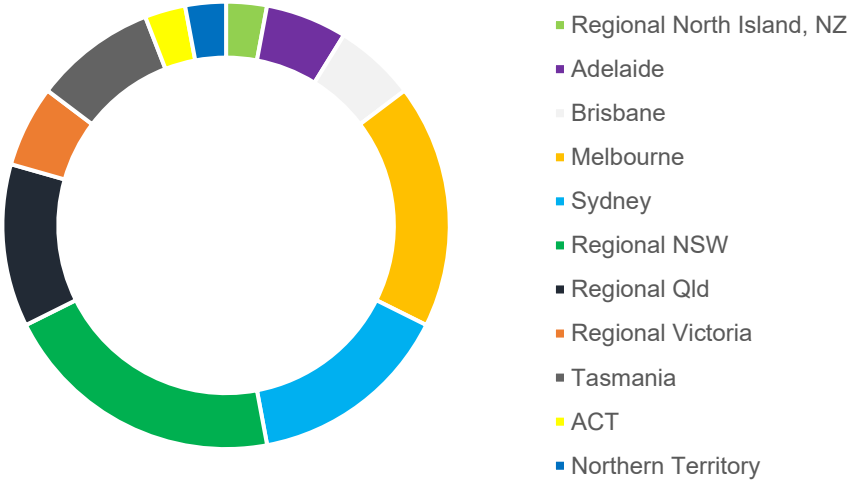
Consumer survey results

- 34 completed response responses (for reference, Vic Optimal Care summit received 10 responses, open for 7 weeks)
- Strong representation from by sub-type, geopgraphy and across income levels, but only one NZ response and only one non-Caucasian response (Asian cultural background).

Responses by uterine cancer sub-type



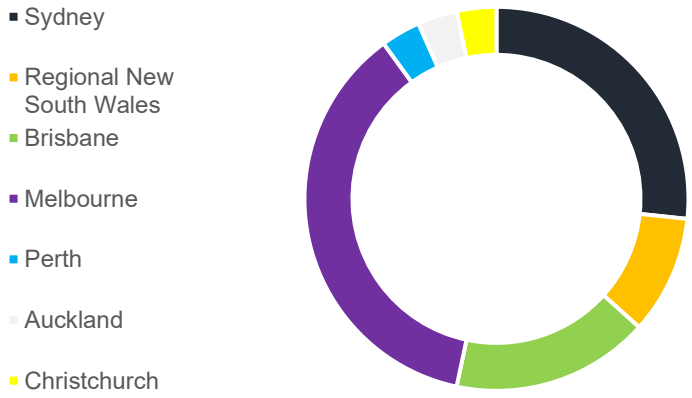
Responses by geography



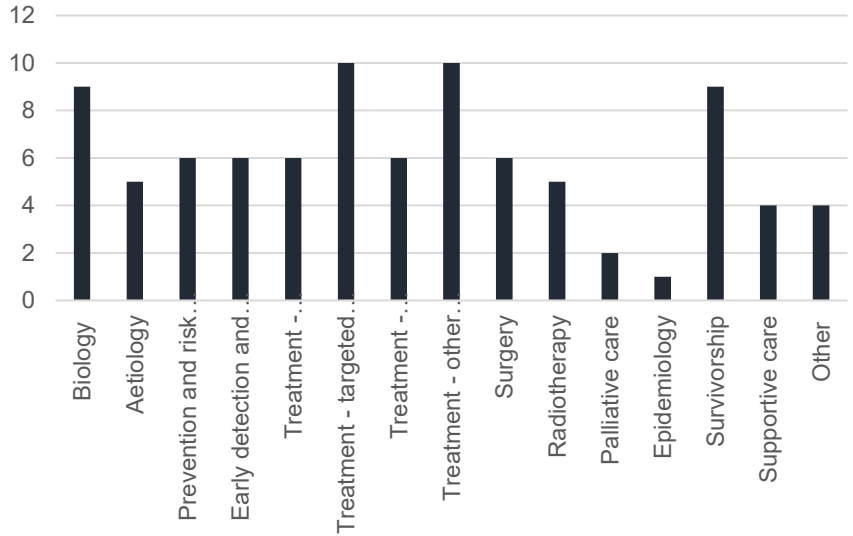
Clinician and researcher survey results

- 31 responses with 78% completion rate
- Strong representation from across geographies, clinical and research backgrounds and areas of research focus

Responses by geography



Responses by research focus



Appendix C: Consumer Roundtable Summary

This appendix outlines outcomes from two consumer roundtables held in May 2025.

State of the Nation in Uterine Cancer

Consumer Roundtables Summary Report

28 April 2025

Insight Economics
Public Policy Corporate Strategy

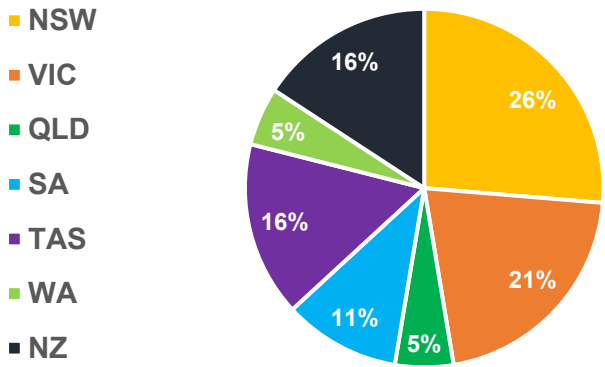
State of the Nation in Uterine Cancer: Consumer Roundtables Summary Report

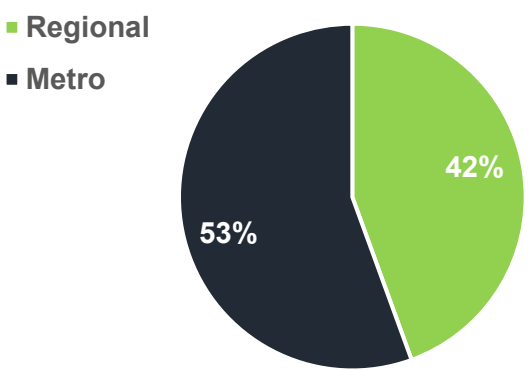
Table of Contents

Overview and key themes

Overview of participation

- Nineteen (19) women and carers from across Australia and New Zealand were interviewed across two roundtable discussions and a series of follow-up interviews with those that could not attend.
- There was strong participation from women and carers of different geographical areas, ages and cancer experience.





Key themes

- The roundtables involved a structured conversation facilitated by Prof Sanchia Aranda, covering three key domains of discussion:
  - Prevention and early detection
  - Treatment and survivorship
  - Research.
- Across the three discussions, concerns for the very poor awareness of uterine cancer at its most basic level as well as very poor awareness and understanding of symptoms of uterine cancer were seen to be to contributing to poor outcomes for women and their families in prevention, early detection and diagnosis. Improving awareness of uterine cancer and its symptoms was raised in all three roundtable discussions.
- The following slides present an overview of key themes discussed in each roundtable by domain. The following sections then present direct stakeholder feedback from each discussion from across the two roundtables and follow-up interviews.

Key themes: Prevention and early detection

- Even among women with increased awareness of cancer risk generally, the risk of uterine cancer was not well known. Many women noted they had never heard of this cancer until they were diagnosed with it.
- Women with genetic risks typically reported they were unaware of this risk prior to diagnosis.
- The issue of weight emerged early in both roundtable discussions. It was noted to be a highly sensitive issue, with women noting that a poor experience with a health care provider could see them avoid the health system altogether: “And I never went back to that person.” Conversely, another participant lamented that it “was never raised because people didn’t want to ‘go there’” and as a result she had to find ways to manage her weight without support. The need for sensitive and supporting conversations and programs to improve outcomes for women in weight management and activity levels was seen as a high priority.

Key themes: Prevention and early detection (cont'd)

- While understanding risk factors was seen to be important, many women noted they would not have been classified as 'high risk' and that improved symptom awareness was paramount, by not only women and their families, but the health system as well.
- Dismissal of women presenting with symptoms and slow investigation of those symptoms were identified as a serious and consistent barrier to safe and quality care in each roundtable and follow-up interview.
- As for opportunities to improve outcomes, participants were strongly focused on the need for advertising campaigns including in doctor's offices and in the community, with high profile ambassadors to be involved if possible.
- There was also strong support for a review of key opportunities to educate women about symptoms, such as through a specific health-check at age 40 or leveraging other programs into communities such breast screening programs.
- There was a strong consensus that uterine cancer would benefit from partnerships in wider advocacy efforts for women.

Key themes: Treatment and survivorship

- Across all conversations poor discussion of side effects and options for the management of side effects were identified to be a major barrier to optimal care and quality of life. Women identified a range of significant side effects, with the most frequently identified side effects identified in conversation including lymphoedema, bone loss, and psychosocial / emotional effects, including anxiety. There were consistent concerns that the potential for side effects were not raised and there was little to no support for women in the event of a side effect occurring.
- A lack of screening for supportive care needs was consistently identified as a major barrier to quality care for women, and access to supportive care services was particularly poor for women being treated in private settings, living in regional areas and living in New Zealand.
- Very significant barriers to accessing consistent, quality services were identified for women living in New Zealand, with a serious lack of specialist capabilities outside of Auckland identified.

Key themes: Treatment and survivorship (cont'd)

- Women and carers identified strong needs for investment in gynae-oncology nurse support, with these services helping women and their families to 'ask the right questions' and navigate to the right service providers to improve their quality of life and outcomes. These roles were identified to be strongly under-supplied in both Australia and New Zealand.
- Improving access to patient support and peer support was also identified as a high priority, with women noting that 'they didn't know where to go' when they had issues and the value of speaking to other women that had been through a similar experience.
- Improving access to exercise for uterine cancer survivors was also identified to be an opportunity and a gap in current care.
- Expanding access to telehealth services was also identified to be important, particularly for women in regional areas.

Key themes: Research

- Investment research to improve health systems to better identify women at risk and to proactively engage with these women to reduce their risks and for any cancer to be detected earlier was identified as a major priority across each roundtable and interview.
- Women identified that there was a need for better data collection to identify and understand a range of risk factors and inform better approaches to prevention and early detection.
- Improving access to personalised medicine was also identified as a high priority across the roundtable discussions. This involved not only improving access to novel therapies but also determining in advance whether chemo was required and how much (e.g.,four weeks vs six weeks) to minimise the adverse effects of treatment. There was a strong consensus that significant investment in the development of new treatments was needed.
- Improved, streamlined access to clinical trials was identified as a high priority and a major area of need for women living in New Zealand.

Key themes: Research (cont'd)

- A major area of focus identified in all roundtables was the need for evidence development for optimal follow-up of women that have completed treatment. Inconsistencies in approaches was reported to be a significant issue and cause of anxiety for women and their families.
- Improved collection of data was identified as an important enabler for research and a current gap to be addressed.

What we heard: Issues and opportunities in prevention and early detection

Questions for discussion

- Is there good **awareness of the risks** of uterine cancer among women? Among primary health care professionals? Among the wider community?
- What are the major **opportunities to improve prevention**? What more should governments and communities be doing?
- What are the major **barriers to early detection** in your view?
- Is there good **awareness of the symptoms** of uterine cancer?
- What needs to be done to **improve early detection**? Are there specific approaches that are needed for women of **different ages or backgrounds**?

What we heard: poor awareness of uterine cancer

"We had a family history of bowel cancer, and we all knew we were at increased risk for that. And so we were just really focused on that, but gynaecological cancer was just not on my radar."

"I had no idea this was a thing until I was diagnosed with it."

"No one told me that I need a check-up every year as tamoxifen increases my risk for uterine cancer."

"My symptoms were really vague. I was so tired, but then I thought, 'Well, I'm a nurse and I work nightshifts and I have three young sons. What do I expect?' Later, I had a cousin that discovered he had Lynch syndrome and we all started putting the pieces together… and I found out I had a genetic risk (Lynch syndrome)."

"Post-menopausal women need to be educated about the fact that they must go see a GP right away. GPs also need to be educated about how to take women's health more seriously."

What we heard: poor understanding of symptoms

"I had no idea of the risk factors at all and I had been bleeding for 12 months and I told the doctor and she put me on HRT. There are clinical guidelines to have an ultrasound, but I didn't question the doctor, I didn't know."

"I didn't fit into any of risk factor boxes, and I didn't have a relationship with any GP. You can feel bad taking your peri-menopause symptoms [to the GP], so you take a wait and see approach. …
But then I had a 20cm undiagnosed pelvic mass and no-one had seen me."

"Women look after themselves last."

"I didn't fit into any risks. It is really important to communicate on a population but also that you may not fit in, and you need to listen to your body and your symptoms. Awareness for women of what's happening in our bodies."

"I had none of the risk factors. We also need to make sure that people understand you can get it even without risk factors – symptoms are really important."

"What slipped through the cracks for me is that I don't have a lasting relationship with my GP, never got to talk about my peri-menopausal symptoms. I knew all of them, but still was late when got diagnosed. [When I was finally seen] I was Stage 4, advanced cancer. But [even then] no one triaged me, gynae wasn't urgent either, only when I got gynae oncologist it got urgent, in hindsight would be better if I get to have someone to go to follow up on my peri-menopausal symptoms."

What we heard: sensitivity of weight management (and lack of sensitivity by doctors to women's feelings) is a barrier to optimal care

"I can't help thinking that a lot of the things that are driving things today are diet.

I am diabetic and very overweight and going through the diagnosis there were so many opportunities for people to talk to me about lifestyle or diet... I went through 20 [appointments] and it never got a mention.

Everyone was too scared to "go there" [to talk about weight management]. Twenty (20) contacts and nobody raised anything about what can I do to prevent my risks of this coming back. I am still fat and overweight, I have risks of heart disease… you've taken my uterus out, but you haven't addressed any of those underlying issues.

Now I've researched ketogenic diets on my own, lost some weight, but I can't believe no one brought this up."

"About six months after my mum was diagnosed, my sister and I got full ultrasounds.
And then GP said, "You're too fat to have an operation at this hospital, anyway."

And of course, I never went back to him.

What we heard: dismissal of women's concerns

"GPs need to be educated about how to take women's health seriously."

"A lot of doctors nowadays don't have experience examining women or experience issues full stop."

"It's always put down to something else. It's menopause, it's emotions… this leads to delays in diagnosis."

"I had a client in Sydney who died because she had been post-menopausal bleeding for years, and her GP had told her it's normal. If you're a woman, everything's either blamed on your menstrual cycle or your weight."

"I found a lot of doctors are so unaware of the symptoms. A lot of doctors put this down to hormonal symptoms and put it down to things like this and they don't investigate things when it could be diagnosed earlier."

"GP need to take post-menopausal bleeding serious from the get-go."

"We need health professionals to be educated and listening to women. Our health system needs to teach them to do this."

"GPs have to be better, they have to be all over [the risks and symptoms and best practice]. They're the first line of defence. And to think that I could see three women [who dismissed the symptoms]. I knew it wasn't right, and I was obviously agitated, anxious and concerned. And I was fobbed off until I saw the gynaecologist. This took more than five months. I went to the doctor five times in five months [before someone took me seriously]. So I think the GPs are really, really important."

What we heard: stigma and embarrassment prevent women from talking about uterine cancer, seeking advice

"We're too embarrarssed. This is very true, I think particularly for Māori and Pacific women."

"When I was having a check-up, I was standing beside a lady who has a chaperone beside her, this lady was not allowed to have an internal ultrasound because her husband wouldn't allow her."

"I'm talking about my vaginal discharge, you know, at the table. And [I guess my sons] are probably sick of hearing about my vaginal discharge, you know…

But I also have to go into hospital every three months now [to deal with side effects on my body from the radiation]. I absolutely hate it. This is not desirable. It's not my choice. And so, I also think, 'How can we improve any of this stuff if it's not talked about?'"

"Talking about women's health needs to be destigmatised."

What we heard: opportunities to improve awareness

“I used to go to the GP when there was something wrong with me, but maybe we could get GPs to approach it differently like: "You’re going into this decade of your life [40s], here are things to look for.” You could raise awareness that way.”

“A lot of oncologists can be focused on treatment rather than seeing people. We need to take more time to give people an explanation of their risks. No information was given to me about genetic risk.”

“We need women of all ages to stand up because I think when it is the actual person and not an actor, you can't really take away that pain and anguish of what their situation is. And they don't want that to happen to anyone else. So maybe that could be a meaningful thing.

Or the other thing of course, is to get high profile people who've actually had a gynaecological cancer, like with the McGrath Foundation. That has got a huge amount of traction. It's obviously those sort of high-profile people that grab the headlines.”

“It would be good to have a big person get involved [in a campaign to raise awareness, like Olivia Newton John or Fran Drescher]. People will see that person and it will bring attention. We don’t hear anything about these cancers. Very few get diagnosed at Stage 1… if we could it that little bit earlier we would save so many lives.”

What we heard: opportunities to improve awareness (cont'd)

"We've had the success in breast cancer because women are aware. Everywhere you look there's pink cricket, football games, every year.

Advertising is important… and thinking about say partnering with a group, like, say, Bonds that make period underwear that that targets women's needs to help get awareness about symptoms."

"[Here in New Zealand, we have the] Love Luna pants. There could be a campaign: "Is your luna time normal?"

"We need to see this as a women's issue more broadly to get it on the agenda."

"What would the bus say? … It would say: 'You know your body, you know what's normal for you. And you know if something is not normal. Trust yourself and ask.'"

"In Wellington, there are big posters for breast cancer, for ovarian cancer, what about me?"

"In NZ, the risks for the Pacific population are even more significant... We need signs up, getting people aware and getting people talking. Yes, it's a bit embarrassing, we need to get this out into the open and having it out there. "

"Even like in doctor's surgeries, you know how they've got the ads for shingles or stuff like that.

You know, if there were posters that were, like: "Any vaginal discharge in a post-menopausal woman is cancer until proven otherwise. Is this you?'"

What we heard: opportunities to improve early detection

"BreastScreen buses [potentially provide a platform] for a wider women's health agenda. You're dealing with the same demographics. It would provide an opportunity to reach more women – it could target Indigenous women and Māori women in the community. And also, you're also educating the community. It's the ripple effect through the community: you educate not just one woman but 10."

"The RFDS runs an outreach dental service for remote Tasmania. Why don't we have remote nurse practitioners going with them to promote women's health?"

"My diagnosis took 6 weeks. There was no urgency at all. A lot of GPs don't take things seriously. We need campaigns to improve GP awareness."

What we heard: Issues and opportunities in treatment and survivorship

Questions for discussion: treatment and supportive care

- Do you think women generally have a **good understanding of their diagnosis, the optimal care pathway and their treatment options**? If not, why not?
- Do women need more **help to navigate the health system**?
- Are there important elements of treatment and/or supportive care that often aren't discussed with women that should be? For example, **do women receive enough information about fertility treatments, nutritional support, exercise or emotional support**? What else could improve outcomes, including **quality of life**, for women in treatment?
- Does more need to be done to **support family and carers**?

Questions for discussion: survivors

- Once treatment is completed, do women receive enough information for how to **maximise their wellbeing**? Are there things that could be done to **improve quality of life for women** following treatment?

- Are there any **issues or opportunities to improve long run surveillance** of potential disease recurrence?

- Are there things that should be done to **better engage survivors to advocate for investment and health systems change**? Are there barriers to engagement that need to be addressed, or opportunities to improve how women are engaged?

What we heard: Inconsistent discussion of treatment options and potential side effects, barriers to understanding

"There were weeks and weeks of radio silence, then I was simply told I needed to go to Wellington for a surgery. I was told it was recommended I get a lymph node dissection, all without keeping me informed."

"Health literacy was the biggest issue for my mum. What was the oncologist saying and did she understand it? All these terms, hormone therapy, chemo, immunotherapy… to her, she was like "Isn't it just chemo?" She had good education, but the terminology was just too much. I went with her so that she could understand the terms. I think sometimes the first meeting with the oncologist needs to be about 'what does the patient understand'."

"I was surprised about there were a lot of decisions to be made about my treatment. I thought it would be *fait accompli* about what would happen. But I did get presented with options and the doctors had different opinions… So I had to make that decision, or the family did."

"I just found those little graphic images so helpful [the diagram of treatment by stage]. [If you're at Stage I], you have surgery and radiation. And then in my case, it was in my cervix as well, so then you have surgery, radiation and chemo. It was really easy to understand and one of simplest, best things I've seen since I've been on this whole sorry journey.

[Other booklets I have received] were more complicated than that [and the text can be a lot]."

"My gynae-oncologist led an MDT, so I didn't have to repeat a lot of things. I trusted them because they told me the process they were going to follow. I just wanted to get better. [I just want the team to] tell me what will happen, what the side effects are and how I can manage it."

What we heard: Inconsistent discussion potential side effects and options for management a serious concern for women (cont'd)

"The big issue we have got is a lot of women with uterine cancer are older women, and they don't have the networks younger women could possibly access. They're not educated enough on what gynaecological cancer is all about. Unless somebody sits down and tells you what you can access, you don't know what options are available to you."

"My thing is that nobody talked about sexual relations after hysterectomy. It's a huge issue for couples. It has become a difficult thing to talk about, but it's an important part of your relationship. And a huge part of your relationship is gone. It needs to be talked about much more."

"My only source of information was a booklet."

"Just being aware of where services are is one thing. One thing that was not made clear to me was that you could get incisional hernias. I thought I had abdominal cancers.

There was no information thinking that this may be a possibility."

"I wasn't given much information about what to expect. I was told to come back every six months for five years. People need to know what to look out for, we need to help give women a bit of autonomy."

What we heard: Inconsistent discussion potential side effects and options for management a serious concern for women

"One GP said, 'Its oedema, just raise your legs.' But my oncologist said, 'Let's get a scan' and recognised it was an issue.

I don't expect oncologist to hold my hand through lymphedema journey, but it would be good for them to tell me what to do [to manage it]."

"I feel sorry for women [dealing with uterine cancer and its treatment] and the side effects that women have. If you have lymphoedema, for example. It affects a woman's self esteem. It affects women in a big way and there is no help for them."

"Lymphoedema, it got diagnosed very late for me. I have had to travel to get very expensive treatment. And then it cost $3,000 for the pump and I got only $128 dollars back from my fund. If I couldn't afford it, I would have been [in pain]. I got the pump, and I spend $700 for stockings every six months. Lymphoedema therapies cost $500 [per service]. I did get plastic surgery for lympohedema; it was the best decision I ever made."

"They talk to you, and they do try to give you time and everything, but re all that follow-up stuff, I had this false expectation that towards the end of my treatment, you know, they would say: 'This is like the exercise physiologist or the psychologist or dietitian,' whatever, all that sort of thing. But none of that, absolutely none of that happened.

For me it was kind of like: 'you finished the treatment and that's it, you're finished.' … But as it's turned out, the radiation has caused me long term grief."

What we heard: Limited screening for supportive care needs

"You need to investigate each woman's level of support. I had had lots of support but there are women that are single or living alone, and they don't have any support. We need to help women to buddy-up."

"After my wife had completed her treatments, we had to wait for six months for chemicals to be out of her body. I found that a really hard period. No phone calls, no one contacted us. I could see in my wife that she wasn't good. I tried to talk to her and keep her spirits up… We didn't have access to a gynae-oncology nurse."

"It's interesting that you use word anxiety. I was so tuned into 'not being that person' that I probably downplayed those symptoms. We need to be careful not to shame women into presenting a particular persona so that we don't downplay potential issues."

"It's not just physical, it's emotional. I was in a lymphedema clinic. And I thought I was all over it and coping, and then I burst into tears, and I realised I wasn't coping. I didn't realise how much I was holding in. A social worker referred me to help, and I got better.

No one is screened for supportive care needs."

What we heard: Barriers to accessing supportive care

"I don't see why a GP service can't help patients access services like the Wellness Centre at Lifehouse."

"People forget that as a carer you're living everything with them.

During COVID, it was like a prison and that was hard because you can't support them. She had to stay [in the hospital] for four weeks. And no one could visit her. When I got her back, you could see a change in her. You're their only support and no one is there to support you. I was her therapist trying to keep her positive.

Carer should be seen as part of the team."

"Basically, the line is: 'Exercise is good for you.' But nobody has information on what to do because it's not their area of expertise. Nobody can really tell you, you know. I've got six specialists but everyone just 'stays in their lane'. So in the end, I just had to fumble along and slowly but surely dragged myself into some sort of, you know, physical capacity.

But I feel like for many people that would be really hard because I was very weakened by the end. I'd finished treatment, but then about 3 weeks later I had terrible shingles, which that did literally finish me. Up until then, I'd still been doing what kind of exercise that I could, but then I just because I had terrible nerve pain, I got an eyelid infection, which they needed to surgically remove. And I had my routine PET scan when I finished treatment, and it just showed that my renal system was pretty well wrecked so I wound up at stage four or five for renal failure. I'd had terrible back pain and nerve pain, and all that, but I didn't have any other symptoms. I thought, 'Well, I've just been through surgery, radiation and chemo." I didn't know what was 'normal' or how I should be feeling."

What we heard: Patients in private settings lack access to supportive care

"She goes to [a large public tertiary specialist hospital], and they have everything she needed was there. In a large centre, she could get access to those [supportive care] resources. Long waiting lists, but they are there."

"There's one cancer consultant nurse - only one in all of Tasmania, for everyone. And she's for like the public patients. But if you're private system like me, there is nothing."

"In private [care settings], you don't get [any supportive care], especially for regional people."

"You get so much more support through the public system."

"As for my journey, my GP referred me to a gynaecologist, and then I got referred to gynae-oncologist, and I didn't get any choice. And there was a real disconnect between the private and public settings. I ended up with septicaemia and there was no connection to private hospital. I felt really stranded."

What we heard: Significant access issues in New Zealand, regional Australia

"In New Zealand, there needs to be more money put into the treatment of gynaecological cancers.

Wellington does not have a permanent gyaneoncologist. One comes from Napier, but no one is permanent.

My next check-up that was supporsed to happen in June is now going to happen in Sept. And this isn't the first time, it is constantly being pushed back. There is just no one here permanently. No options, no second opinions. It is a small country thing.

I find with the meetings that I walk away quite angry and frustrated, and it feels like we're the poorer cousin to Australia."

"In New Zealand, we're having trouble with GPs and specialists and no one has any continuity of care. That was my experience, getting passed like a potato."

"For me, after treatment for my follow up it was a five hour bus trip – it would have been good to have follow-up appointments by telehealth. Need to be more sensitivity to country people."

"In Tasmania, there is only one surgeon and that means travelling. I was just referred to him. There were no options, and he referred me back into the public system. In Tasmania, there is only one, part-time gynae-oncologist who works for the whole state… then there was all this argy bargy about funding and I think now she only works in the South."

What we heard: More patient support to navigate health system, manage side effects is needed

"All those ancillary services I had to source myself and you know have and paid for my myself, you know. So there was nothing available.

I just asked lots of people, and often you'd wind up in the wrong. They give you the wrong information."

"I found I had to become my own expert because my cancer is so rare, and there was no where for me to turn. No one was there to help me. In New Zealand, I can't access the Rare Cancers Portal. The only place for me to look was really heavy medical literature. I had a specialist who didn't want to talk to me about it. We really need some kind of shared portal of information or guidelines – there was no where for me to turn."

"My gynae-oncologist had good information. I looked him up, but no other information for what to do… what to do before surgery."

"I realised afterwards that I was not aware of my options. But I was so overwhelmed anyhow.

I would have liked to have someone to help me navigate [because I didn't understand my options and felt overwhelmed], even with a nursing background."

"I've been so focused on living that I have been lucky in terms of side effects and every time I've had something my doctors have been amazing at getting me support and help.

But not everyone has capacity to navigate system to get their needs met."

What we heard: More patient support to navigate health system, manage side effects is needed

"[Even though I was being treated in the private system], I got to see the [public gynae nurse due to the severity of my side effects] and I found her really, really lovely and helpful. She actually got me onto the Survivors Teaching Students for ANZGOG as well. I wouldn't have heard of that except for her. So she's really, really good.

She started to kind of give me clues about how to find people that were, you know, to do with *cancer*, not just physios, but, you know, *pelvic physios* and stuff like that. So that was really helpful.

She's got a really, really important role and they need to be more of her because you can't just get this from your specialists, they just haven't got the time. They're not interested, you know, so it's those people that are the next level down, but they've got a highly trained, skilled and experienced.

"If you don't have chemo, you're not classed as having cancer, you're classed as having surgery. Even to get a psychologist, my anxiety was through the roof. I couldn't get access, and my oncologist didn't tell me that I could access one. I just felt so stranded."

"Tasmania has only one gynae-oncology nurse. She coordinates allied health services. If she hadn't been there, I wouldn't have known what's going on. Having a gynae-oncology nurse is crucial. To have that person with whom you can have an intensely personal conversation is very important. We don't have enough infrastructure to deal with the number of patients with gynaecological cancer."

What we heard: Opportunities to improve outcomes beyond specialist nurse support: peer support, telehealth

"For my mum's experience, we have used telehealth as much as possible. Usually, they are around just getting results. Otherwise, we would be going three times a week. It's much better."

"One aspect that can help people is getting to know other people in the same situation as you. When I was in Melbourne having my therapy, I met a woman doing the same therapy as me and we chatted for hours."

"I am still in contact with my gynae-oncology nurse and my gynae-oncologist. I have that link available, so I can flip them a quick email or message. But for other people, you come out the other end of treatment, and then you're free, and that's it."

What we heard: Issues and opportunities in research

Questions for discussion: research priorities

- What do you think are the most important areas of need in **research to improve survival**?
- What do you think are the most important areas of need in **research to improve quality of life** for women in treatment? For survivors?
- Are there **barriers to women participating in research**? Is more needed to be done to support women to participate in **different kinds of research**?
- Are there particularly important **research priorities for different groups of women**, say of different ages or different demographic, racial and/or cultural backgrounds?

What we heard: Improved access to trials and novel, personalised medicine identified as a high priority

"Molecular testing at diagnosis is so important. To identify the molecular subtype is so important. Matching that to an applicable therapy is so vitally important. We can do more, and we should better. To enable precision medicine and clinical trials. To convince the Americans to give us the drugs and attracting the trials to Australia. The most information we can have, the more we can do."

"Nuancing of treatments for each person would be wonderful."

"We need better diagnostics. Molecular testing will be the way of the future. Research must be done to determine to identify treatments for uterine cancer."

"We need more research into treatment. We don't know whether six weeks of chemotherapy, for example, is better than four weeks, or not.

More research is required to ensure treatment is limited to what is absolutely necessary."

"One thing that concerns me is that when treatments stop, I was hoping they would do scans more regularly.

For us, when they finally came back the oncologist said, 'I'm so sorry that it has exploded. We can put you on a drug. It has a 5% chance of success.' It was going to cost us $60k per session because it wasn't on the PBS. But what about people that can't afford it? We have to go through so much red tape and people have to spend 100s of thousands of dollars."

What we heard: Improved access to trials and novel, personalised medicine identified as a high priority (cont'd)

"Targeted therapies are important so that we can target the right treatment and therapy to the woman. Otherwise you will be given chemo, but because of the tumour type, it may not be effective. For women with Lynch syndrome immunotherapies area really effective."

"ANZGOG, they send an e-mail and I read it and they were saying there was a clinical trial. So I took it to my gynaecological oncologist to ask: 'Could that be a thing [I could participate in]?' Because I've read about it in the newsletter. And he just said, "Oh, no."
I guess they're aware of the trials and they already know the women that are suitable for those trials. So I kind of went, 'Fair enough'. … Nobody's ever approached me about one and I don't know what the trials are."

"Clinical trials – they are a torturous process. Going through all that testing to work out eligibility for the trial and whether you will be able to access. It was a 9-week-plus process going through testing and waiting for testing to find out that I was being allocated to control group and wasn't getting access to drug anyhow. Can we have all that testing done and be ready to go so we can streamline that process as well?"

"It is difficult for trials to happen in our small country (NZ). It's a tricky situation and ANZGOG is great, but there are things that are funded by the Australian govt that we can't collaborate on or participate in."

"Women with breast cancer are very educated about the trials that are going on. We need to have that."

What we heard: Improved evidence for best-practice surveillance

"Coming from personal perspective, that intervening period between treatment hysterectomy and a metastatic diagnosis, what are standards of care? This is done very inconsistently. I had this test, that test, and then I didn't have any scan, but I did have appointments. But what are right intervals and ensuring that treatments can happen more quickly? Potentially a blood test for might have made a difference, but I wasn't classed as a high-risk person, but obviously there was a problem. What are the most effective surveillance approaches and does that intervention improve the outcomes?"

"I'd like to echo as someone that survived uterine cancer that could recur. At 10 -years, my gynae-oncologist left it up to me: "Do you want to come back?" She left it up to me? I wanted the journey to stop, I guess. I don't want to think about cancer every day. I think that's the gap that's missing for me. My anxiety comes from not really knowing, I'm waiting for something to happen."

"There really isn't any guidance or evidence about what is best practice. For me, it was like I had had a splinter removed. No guidance at all on any follow-up."

"CA125 is what we have to give us an indication of whether the treatment is working. Early detection blood test for uterine cancer rather than having to scan patients 3, 6 monthly. That is blue sky."

What we heard: Health implementation science to improve primary risk prevention, awareness and identification of high risk women is a high priority

"I think cancers are becoming more and more common and in young people. Rather than focusing on tip of iceberg, we need to get into the deeper drivers. I want diet and mitochondria in there [as key areas for future research to be answered]."

"Research around health literacy risk factors and symptoms for what they understand as treatments for cancer. If you want to work with the community, you need to understand what they're thinking – where the deficits are and where the positives are."

"For me, it probably will always come back to diagnosis like the earlier the detection, the better and I don't know, I've hopefully down the track. There'll be something like blood tests or whatever that show that you have a predisposition towards it in the 1st place, so that you, you know it can be headed off at the pass. So as to speak."

"There needs to be more genetic testing being done."

"Overall, getting the public and men as well better educated around uterine cancer is what we really need because it will be their mothers, their wives, the mothers of their children… it can't not affect you just because you're a man. Really. I think that's everyone, not just women. Women firstly, but I think men need to be included, too."

"We should focus on somehow measuring the social cost of gynaecological cancers on women and their families."

What we heard: Improved models of care

"I'd like to see something about the timing of when you first see a gynae-oncologist, as opposed to if your care is under a gynaecologist. We need greater involvement from gynae-oncologists."

"I am really hung up on the journey and public-private side. I'm more on the patient journey and health system research as a priority."

"No one has ever asked me about my pregnancies across my whole journey. It seems that this is a huge missed opportunity [to collect data to better understand risk]."

"I would like it if data on my experience was collected so that they can learn from that and no one else has to through what I have gone through."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Appendix D: Stakeholder engagement

This appendix lists stakeholders interviewed.

A/Prof Yoland Antill	ANZGOG Director and Deputy Chair, ANZGOG Research Advisory Committee and member of the ANZGOG EDEN Research Initiative Steering Committee; Medical Oncologist and Cancer Genetics Specialist – Cabrini Health, Peninsula Health, Royal Melbourne Hospital. Adjunct Clinical Associate Professor, Faculty of Medicine, Dentistry and Health Sciences, Monash University
Prof Linda Mileshkin	Chair of the ANZGOG EDEN Research Initiative Steering Committee; Director of Medical Oncology, Peter MacCallum Centre. Clinical Trials Lead for Gynae-Oncology, Parkville Cancer Clinical Trials Unit
Alex Neville	Patient and carer experience and perspectives
Ali Crawford	Patient and carer experience and perspectives
Prof Andreas Obermair	Director, Queensland Centre for Gynaecological Cancer Research (QCGC Research), University of Queensland
Anne Johnson	Patient and carer experience and perspectives
Anne Mellon	Clinical Nurse Consultant in Gynaecological Oncology, Hunter New England Centre for Gynaecological Cancer. President and Board Chair, Cancer Nurses Society of Australia. Co-Chair, NSW Agency for Clinical Innovation Gynaecological Oncology Network. Co-Chair, International Gynaecologic Cancer Society Nursing Work Group
Bridget Bradhurst	Acting Chief, Support and Advocacy, Ovarian Cancer Australia
Bronwyn Jennings	Gynaecology Oncology Clinical Nurse Consultant, Mater Health
Dr Bryony Simcock	University of Otago Christchurch; Clinical Director of the South Island and Wellington Regional Gynaecological Oncology Service; Gynaecological Oncologist - Christchurch Women's Hospital; Oxford Women's Heath
Carol Chisholm	Patient and carer experience and perspectives
Prof Clare Scott	Chair of ANZGOG, Medical Oncologist, Peter MacCallum Cancer Centre, the Royal Melbourne, and Royal Women's Hospital. Joint Head, Clinical Discovery and Translation and Laboratory Head, Walter and Eliza Hall Institute of Medical Research. Professor of Gynaecological Cancer, University of Melbourne
Dr Claire Henry	Lecturer in the Department of Surgery and Anaesthesia, University of Otago Wellington Aoteoroa New Zealand. Group Lead at the Translational Gynaecology Research Group, Wellington Hospital

Prof David Thomas	Founder and Chief Science and Strategy Officer, Omico. Director of the Centre for Molecular Oncology, University of New South Wales
Debbie Shiell	CEO, Ovarian Cancer Australia
Ella Gillis	Patient and carer experience and perspectives
A/Prof Emma Allanson	Head of the Department of Gynaecological Oncology, King Edward Memorial Hospital
Georgina McPherson	Women's Health Nurse Practitioner, Waitemata District Health Board, Health New Zealand
Helena Rodi	Optimal Care Summits Program Manager, VICS Optimal Care Summits
Jane Snarskis	Patient and carer experience and perspectives
Jennifer Cummings	Patient and carer experience and perspectives
Jill Butty	Director, Women's Health & Population Wellbeing, Victorian Department of Health
John Andrews	Manager of Research Programs and Pipeline, ANZGOG
Prof John Zalcberg	NGOR Academic Lead and Medical Oncologist, Alfred Health
Prof Jon Emery	Herman Professor of Primary Care Researcher, University of Melbourne
Julie Robinson	Patient and carer experience and perspectives
Dr Justine Clarke	Postdoctoral Research Fellow, The Kids Research Institute Australia
Karen Livingstone	Patient and carer experience and perspectives
Kathryn Cornthwaite	Patient and carer experience and perspectives
Kirsten Mulley	Patient and carer experience and perspectives
Dr Kurt Lacovic	CEO, Cancer Trials Australia
Kym Arthur	Executive Director, Population & Women's Health, Victorian Department of Health
Laura Galletta	Patient and carer experience and perspectives
Dr Lois Eva	Clinical Director of Gynaecological Oncology, National Women's Health, Te Toka Tumai, Auckland. Honorary Senior Lecturer, University of Auckland
Mark Nevin	Immediate past CEO, Cancer Council Australia
Maureen Turner	CEO, Biogrid
Dr Michael Burling	Gynaecological Oncologist, St George Private Hospital
Dr Michelle Wilson	Medical Oncologist, Auckland City Hospital
Prof Monika Janda	NHMRC Leadership Fellow. Director, Centre for Health Services Research. Professor in Behavioural Science, Faculty of Health, Medicine & Behavioural Science, University of Queensland
Prof Pamela Pollock	Professor, Faculty of Health, School of Biomedical Science, Queensland University of Technology

Prof Penny Webb	Group Leader, QIMR Berghofer Medical Research Institute
Ronny Verdiesen (bereaved)	Patient and carer experience and perspectives
Dr Rosemary McBain	Gynaecological Oncologist, Royal Women's Hospital and Co-Chair of the Endometrial cancer expert advisory group for the VICS Optimal Care Summit
Ruth Carter	Patient and carer experience and perspectives
Prof Sandi Hayes	Director of Research, The Viertel Cancer Research Centre, Cancer Council Queensland
Dr Sathana Ponnampalam	Senior Medical Officer in Women's Health, Te Toka Tumai
Dr Shaoke Li	Research Fellow in Cancer Services & Data Science, Department of General Practice and Primary Care, University of Melbourne
Dr Sharnel Perera	Program Manager, National Gynae-Oncology Registry (NGOR)
Shirley Kent	Patient and carer experience and perspectives
A/Prof Simon Hyde	Director of Gynaecological Oncology, Mercy Hospital for Women in Melbourne, Co-Chair of the Endometrial cancer expert advisory group for the VICS Optimal Care Summit
Prof Sue Matthews	CEO, Royal Women's Hospital. Member of the Victorian Women's Health Advisory Council. Co-Chair of the Victorian Inquiry into Women's Pain. Member of the National Women's Health Advisory Committee and the National Women's Health Advisory Committee Research Sub-Committee.
Prof Susan Jordan	Professor of Epidemiology and NHMRC Leadership Fellow, School of Public Health, University of Queensland
Dr Tamara Butler	NHMRC Emerging Research Fellow, School of Public Health, University of Queensland
Tracey Page	Patient and carer experience and perspectives
Dr Viet Do	Director, Liverpool Cancer Therapy Centre, South Western Sydney Local Health District
Prof Vivienne Milch	Medical Director, Cancer Australia
Vicki Purnell	Patient and carer experience and perspectives
Victoria Donoghue	Manager, Cancer Alliance Queensland
Virginia MacEwan	Patient and carer experience and perspectives
Wanda Lawson	Patient and carer experience and perspectives
Prof Zoe Wainer	Deputy Secretary for Public Health, Department of Health, Victorian Government

Appendix E: Summary of policy landscape in Australia and Aotearoa New Zealand

This appendix outlines key cancer and health policies implemented at a federal and state level in Australia and Aotearoa New Zealand.

E.1 Overview of policy landscape

There is a large number of policies that can impact women who are patients and/or survivors of uterine cancer, both nationally across Australia and Aotearoa New Zealand, and within the states themselves. In order to collect an exhaustive list of cancer policies, the team began with previous Insight Economics analysis, identifying many of the major Australian state and federal cancer policies (as at 2022). Where policies were out of date, a more current policy was included. Moreover, a scan of available literature found additional policies beyond those already included. For Aotearoa New Zealand, a bottom-up identification of all applicable policies was required.

Across cancer policies throughout Australia and Aotearoa New Zealand, a few key trends have emerged. There is little to no direct focus on uterine cancer; rather, policies are targeted at cancers at-large, or healthcare more broadly, and only affect uterine cancer patients through these broader policies. Furthermore, while a cross-cutting theme of these cancer policies is a focus on priority populations, none of these policies are directly targeted at women diagnosed with uterine cancer.

More recently, there has been significant investment from Australian governments in reforms to cancer policy, with an emergent focus on genomics and molecular profiling. Although, in spite of a more focused effort in recent years, Australian cancer and health policy frameworks are still woefully ill-equipped to manage the unique needs of women with uterine cancers, especially those with rarer uterine sarcomas.

While Aotearoa New Zealand has a strong and well-managed method of accounting for inequity in health outcomes among priority populations (wāhine Māori and Pacific women), there remains significant under-investment in some areas of cancer care, especially in prevention and early detection.

Across both Australia and Aotearoa New Zealand, there is long-standing underinvestment in uterine cancer research, which hinders progress in achieving better outcomes for women with uterine cancer. Moreover, both countries do not provide enough funding for elements of cancer care beyond immediate treatment, with prevention and detection being underfunded on the pre-cancer side of the ledger, while chronic disease management and quality-of-life survivorship fail to attract sufficient support as key parts of post-cancer care.

Table E.1: Summary of cancer policies – Aotearoa New Zealand

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
Aotearoa New Zealand Cancer Action Plan 2019-2029	The plan is guided by four overarching principles: • equity-led • knowledge-driven • outcomes-focused • person and whānau-centred. The plan enables the Cancer Control Agency, the Ministry of Health, the sector and all those affected by cancer to work collaboratively to prevent cancer and improve detection, diagnosis, treatment and care after treatment. Outcomes • Outcome 1: *Aotearoa New Zealanders have a system that delivers consistent and modern cancer care*. Aotearoa New Zealanders should expect to receive high-quality cancer care services now and in the future. To make our health care systems future-proof, we need an approach that involves strong governance, accountability and stewardship. To continue to lift our performance in cancer care, we need to ensure we have strong national leadership, a skilled and sustainable workforce and the right information to make the best decisions possible. • Outcome 2: *Aotearoa New Zealanders experience equitable cancer outcomes.* All Aotearoa New Zealanders should experience the best treatment and care, regardless of where they live or who they are. This is critical to ensure we achieve equitable cancer outcomes for all our people. We will develop service models that better support Māori and Pacific peoples to improve their outcomes. We will partner with different population groups and support our workforce to carry out culturally responsive care and enable an equal chance of success. Essential to this is increasing the number of Māori and Pacific people in the cancer health workforce, as well as developing cultural safety across the wider workforce. A key action from this outcome is the development of a mātauranga Māori framework for delivering this plan. • Outcome 3: *Aotearoa New Zealanders have fewer cancers*. Investment in the prevention of cancer will ultimately make the largest contribution to reducing the burden of cancer in Aotearoa New Zealand and to achieving equity in outcomes. As a country, we must place renewed value and importance on preventing cancer. We must develop a more supportive environment to enable Aotearoa New Zealanders to thrive 12 Aotearoa New Zealand Cancer Action Plan 2019–2029 and enhance their health and wellbeing. We want to develop policies to support an environment where Aotearoa New Zealanders can make healthy choices. Outcome 4: *Aotearoa New Zealanders have better cancer survival, supportive care and end-of-life care*. Surviving many cancers is dependent on early diagnosis and a cancer care system that is well coordinated, information-rich, focused on improving outcomes and can respond in a timely, effective and appropriate way. By ensuring Aotearoa New Zealanders receive timely, high-quality person- or whānau-centred cancer care, we can lift our survival rates and achieve our specific equity goals. Ensuring person- or whānau-centred care for supportive, palliative and end-of-life care will enable optimal wellbeing for people affected by cancer and their whānau. We need a cultural shift in the way we deliver health services to all Aotearoa New Zealanders, particularly for Māori, Pacific people and other priority populations, to better reflect the needs and values of our communities. We need to continue to strive to deliver modern and consistent care. It is essential to address the	• No policies directly related to uterine cancer. • Outcome 2 (Aotearoa New Zealanders experience equitable cancer outcomes) is in line with improving outcomes for Aboriginal and Torres Strait Islander people, who are disproportionately affected by uterine cancer. • Outcome 3 (Aotearoa New Zealanders have fewer cancers) is of particular importance to uterine cancer, as targeting risk factors for prevention is an integral part of reducing the prevalence of uterine cancer.	• Under outcome 1 (Aotearoa New Zealanders have a system that delivers consistent and modern cancer care) and outcome 4 (Aotearoa New Zealanders have better cancer survival, supportive care and end-of-life care), there is scope to specifically include treatment options that benefit women with uterine cancer, such as genetic testing. • Under outcome 2 (Aotearoa New Zealanders experience equitable cancer outcomes) there is scope to work with Māori and Pacific communities to ensure equitable cancer outcomes for uterine cancer, acknowledging any specific barriers faced by women in these communities.

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
	socio-economic and environmental factors that influence cancer awareness among our whānau and communities, to ensure they make the best decisions they can about their health.		
Pae Tū: Hauora Māori Strategy 2023	Pae Tū is a key part of the Government's health system reforms required by the Pae Ora (Healthy Futures) Act 2022. The development of Pae Tū has been a joint initiative between Manatū Hauora (the Ministry of Health) and Te Aka Whai Ora (the Māori Health Authority). Pae Tū reinforces the vision of pae ora – healthy futures for Māori, and the four outcomes set out in Whakamaua: 1. Whānau, hapū, iwi and Māori communities can exercise their authority to improve their health and wellbeing 2. The health system is fair and sustainable, and delivers more equitable outcomes for Māori 3. The health system addresses racism and discrimination in all its forms 4. The inclusion and protection of mātauranga throughout the health system Pae Tū sets out five strategic priorities that build on the health reforms and will accelerate through innovation: 1. Enabling whānau, hapū, iwi and Māori community leadership, decision-making and governance at all levels 2. Strengthening whole-of-government commitment to Māori health 3. Growing the Māori health workforce and sector to match community needs 4. Enabling culturally-safe whānau-centred and preventative primary health care 5. Ensuring accountability for system performance for Māori health Pae Tū is an interim step, ahead of a full review and refresh of He Korowai Oranga to be completed later this year.	• No policies directly related to uterine cancer. • As Māori women are disproportionately impacted by uterine cancer, a health strategy prioritising Māori health outcomes is important in reducing incidences of uterine cancer among priority populations. •	Through Pae Tū, there is scope to work with Māori communities to ensure equitable cancer outcomes for uterine cancer, acknowledging any specific barriers faced by women in these communities.
Whakamaua: Māori Health Action Plan 2020-2025	Since 2002, He Korowai Oranga: Māori Health Strategy (He Korowai Oranga) has set the strategic direction for Māori health development (Ministry of Health 2002). The Māori health action plans have guided the health and disability system to implement the aims of He Korowai Oranga. The overall aim of He Korowai Oranga and the action plans is to ensure that Māori enjoy high standards of health and wellbeing. Refreshed in 2014, the overall aim of He Korowai Oranga is pae ora: healthy futures for Māori. Supplementing the overall aim of pae ora the Plan outlines the aims of: • Whānau ora: Healthy families • Mauri ora: Healthy individuals • Wai ora: Healthy environment Outcomes 1. Iwi, hapū, whānau and Māori communities can exercise their authority to improve their health and wellbeing.	• No policies directly related to uterine cancer. • The focus on cultural sensitivity in the healthcare system is important in improving uterine cancer outcomes and further encourage screening within the Māori community. •	• Under objective 2 (shift cultural and social norms), efforts can be taken to target the stigma faced by women seeking diagnosis of gynaecological cancers such as uterine cancer. Access to services such as genetic testing could help achieve objective 3 (reduce

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
	2. The health and disability system is fair and sustainable and delivers more equitable outcomes for Māori. 3. The health and disability system addresses racism and discrimination in all its forms. 4. The inclusion and protection of mātauranga Māori throughout the health and disability system. Objectives 1. Accelerate and spread the delivery of kaupapa Māori and whānau-centred services 2. Shift cultural and social norms 3. Reduce health inequities and health loss for Māori 4. Strengthen system accountability settings Priority areas for action • Māori-Crown partnerships • Māori leadership • Māori health and disability workforce • Māori health sector development • Cross-sector action • Quality and safety • Insights and evidence Performance and accountability		health inequities and health loss for Māori).
Te Mana Ola: The Pacific Health Strategy	Te Mana Ola was developed with the guidance and support of the Advisory Group and informed by an extensive community and public health sector engagement process. Pacific perspectives of health are holistic, encompassing the physical, mental, spiritual, social and economic wellbeing of the collective. Health inequities for Pacific peoples and whānau are well-documented across the life course. The five key priority areas of Te Mana Ola focus on and embrace the interconnection between: 1. Population health, by working with communities to build, maintain and enable strong foundations for Pacific health and well-being 2. Prioritising disease prevention, health promotion and good health and wellbeing throughout the life course 3. Better understanding the needs of Pacific peoples and communities and enabling them to exercise authority over their health and wellbeing 4. Ensuring that timely, high-quality services are reaching Pacific peoples, wherever they live 5. Growing and supporting strong Pacific health leadership and a resilient health workforce that reflects the population it serves	• No policies directly related to uterine cancer. • As Pacific women are disproportionately impacted by uterine cancer, a health strategy prioritising Pacific health outcomes is important in reducing incidences of uterine cancer among priority populations. •	Through Te Mana Ola, there is scope to work with Pacific communities to ensure equitable cancer outcomes for uterine cancer, acknowledging any specific barriers faced by women in these communities.

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
	Implementing Te Mana Ola includes setting short-term priorities for the Government Policy Statement that links to strategic objectives.		
Aotearoa New Zealand Health Strategy	The strategy sets a long-term vision that is focused on achieving pae ora | healthy futures for all. This vision comprises the many factors that influence people's health and wellbeing. The Aotearoa New Zealand Health Strategy's vision of pae ora is underpinned by two long-term goals. These are: • To achieve health equity for our diverse communities, and especially for Māori, Pacific, disabled and other groups who currently have poorer outcomes • To improve health outcomes for all Aotearoa New Zealanders The strategy sets out six priority areas for change to work towards the two long-term goals. These priority areas are: • Voice at the heart of the system: Giving people, whānau and communities greater control and influence over decisions about their health and the design of their health services and embedding their voices in system planning, delivery and reporting on health care • Flexible, appropriate care: Developing services that adapt to people's health needs and expectations, are focused on preventing ill health, are delivered closer to our homes and communities and support access for all • Valuing our workforce: Recognising our health workforce as our most valuable asset and supporting the development of sustainable, diverse, skilled and confident workers for the future • A learning culture: Creating a culture of continuous learning and quality improvement, supported by research, evaluation and innovation • A resilient and sustainable system: Ensuring our health system is prepared for future shocks and we make the best use of resources to manage demand and affordability over the long term Partnerships for health and wellbeing: Building cross-sector and cross-government relationships to drive collaborative actions on health and wellbeing and the factors that determine health outcomes.	• No policies directly related to uterine cancer. • The commitment to giving people greater control and influence over decisions about their health is in-line with the need for person-centred care in uterine cancer, where so many cases are of rare cancers, requiring individualised and informed treatment plans.	The priority area of a learning culture could be supported by a concerted effort toward genetic testing and other services that both further the outcomes for patients and improve treatments for all future cases.
Health of Disabled People Strategy	The Health of Disabled People Strategy sets out the long-term priorities for the health system, towards achieving equity in disabled people's health and wellbeing outcomes between 2023 and 2033. The Strategy outlines five key priorities, in-line with Aotearoa New Zealand's broader pae ora strategy: • Embed self-determination of disabled people and their whānau as the foundation of a person and whānau-centred health system • Ensure the health system is designed by and accessible for disabled people and their whānau, and provides models of care that suit their needs	• No policies directly related to uterine cancer. Uterine cancer survivors sometimes sustain a disability either during or after their cancer recovery. A	Because many uterine cancer survivors live with a disability, there is scope to ensure the care framework developed by the strategy is fit-for-

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
	• Ensure the health system is part of a coherent cross-government system that addresses broader drivers of poor health and wellbeing • Build health workforce capacity and capability to meet the needs of disabled people and their whānau. Increase the visibility of disabled people in health data, research and evidence.	strategy for supporting the health of disabled people can improve the lives of uterine cancer survivors.	purpose for uterine cancer survivors.
Rare Disorders Strategy	The Aotearoa New Zealand Rare Disorders Strategy sets out the direction for the health system by providing a framework and long-term priorities that will guide health entities in improving health and wellbeing outcomes for people living with rare disorders and their families. This strategy is part of the broader Pae Ora collection of strategies. Sharing in the collective vision on these strategies means people living with rare disorders: • Are part of healthy and inclusive communities • Live in environments that enhance quality of life and promote health and wellbeing • Have the support of an equitable and accessible health system. Achieving this vision requires working with people living with rare disorders, iwi, hapū and other Māori communities; Pacific communities; and other communities our health system serves. It requires the collective efforts across health entities and different groups of workers, and the wider organisations and agencies that contribute to the health and wellbeing of people living with rare disorders. The strategy has highlighted five priorities for achievement: • Gearing the system for quality and timely care • Learning and sustaining progress • Equipping the health workforce for quality rare disorders care • Giving voice to people and their families living with rare disorders Joining up internationally to achieve more	• No policies directly related to uterine cancer. • As there are many rare uterine cancers that affect Kiwi women, a strategy on combatting rare disorders can assist those who are diagnosed with these rare cancers. • The commitment to working with both the Māori and Pacific communities can help to improve equity of access to treatment, as well as treatment outcomes.	Because many uterine cancers are rare cancers, there is scope to include genetic testing and other services that benefit uterine cancer survivors as part of the broader rare disorders strategy.
Rural Health Strategy	Rural communities' health needs are often under-served, particularly in relation to accessing health services. Remote communities and rural Māori feel this even more acutely. Access to health care within their community or being supported to access care from outside their community, were key issues for rural communities. To improve access and rural health outcomes, we need to better value the rural health workforce and have frameworks that support them to meet the broader needs in rural communities. The strategy's vision is for people living in rural communities to live long and healthy lives, supported by a health system that meets the varied needs of these communities and draws on the strengths and knowledge of rural communities to achieve pae ora.	• No policies directly related to uterine cancer. • As rural women are at greater risk of developing uterine cancer, a strategy focused on improving health outcomes in rural communities can	As part of a broader strategy of support for rural communities, there is scope to promote screening and early detection for uterine cancer, which is currently overlooked.

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
	The strategy identifies five priorities that will give effect to this vision • Considering rural communities as a priority group: Health policies and planning are designed to meet the specific needs of rural communities – rather than expecting rural communities to fit into funding approaches and ways of offering care in urban settings • Prevention: paving the path to a healthier future: Rural communities have building blocks in place to support healthier futures – stable jobs, good pay, quality housing, digital connectivity and resilience to climate change. Preventive health interventions (such as screening) and promoting and protecting people's health and wellbeing are key areas of focus. • Services are available closer to home for rural communities: A wider range of service options are available in the home or in the community, including from outreach options (such as mobile outpatients' clinics and digital solutions). • Rural communities are supported to access services at a distance: Where it is not possible to access health services locally, coordinated support is available to help rural people travel or use digital technology to receive care. A valued and flexible workforce: The rural health workforce is developed and supported to deliver the care that rural communities need – including through kaupapa Māori approaches and extended health care roles and rural specialisations.	improve the equity of health outcomes. A focus on prevention, as well as treatment, can empower more women to understand the risk factors of uterine cancer, and implement lifestyle changes to reduce their risk.	
Women's Health Strategy	The Women's Health Strategy focuses on health needs and experiences that are different for, or specific to, women. This strategy sits alongside the other pae ora strategies, which set the direction for the health system that will make improvements for populations of women. The Women's Health Strategy sets out the following goals to guide health entities in their work to achieve the vision for women's health and wellbeing. • The government and health system protect the indigenous rights of wāhine Māori, who are able to exercise tino rangatiratanga | self-determination and mana motuhake over their health and wellbeing. Kaupapa Māori services are accessible to all wāhine Māori who wish to access them. • Women are leaders within the health system, including wāhine Māori and diverse groups of women. • The health system recognises and meets the needs and aspirations of all women and their whānau who will experience equitable health outcomes. All women and their whānau will: o feel welcomed and valued by the health system o not experience gender bias, racism, or other discrimination within health care o be empowered to have ownership over their health o receive high quality, evidence-based care and support that is appropriate to their gender, culture, context, age, and life stage o have more options, including access to kaupapa Māori services for wāhine Māori	• No policies directly related to uterine cancer. • A commitment to ensuring all women feel welcomed and valued by the system, are empowered to have ownership over their health, and avoid gender bias, racism or other discrimination, is an important component of ensuring women's issues are taken seriously by the health system, and	There are opportunities to promote destigmatisation of women's pain and gynaecological issues.

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
	Four strategic priority areas set a clear direction on the changes needed in the next 10 years: • A health system that works for women is our overarching priority which sets out our ambitions for system change: Achieving a health system that works for all women requires us to address gender bias, racism, and other forms of discrimination and bias, including how these influence the design and operation of the health system and women's experience within it. These are the necessary enablers to achieving the ambitions in priority areas 2, 3 and 4, which focus on specific issues women face within the health system. • Improving health care for issues specific to women: Women told us about how barriers like stigma and gaps in service availability and information make it hard to access some forms of health care. Priority area 2 includes a focus on sexual and reproductive health, pelvic and menstrual health. Priority area 2 also includes women's gynaecological cancers. • Better outcomes for mothers, whānau and future generations: We also heard that pregnant women and people are not always able to access pregnancy care that meets their needs. This includes lack of access to early and ongoing support and a lack of continuity between pregnancy and early years care. Inequities in access and perinatal outcomes have been shown to be worse for some groups of women, including wāhine Māori and Pacific women. This informed priority area 3, which focuses on what needs to change to improve the health and wellbeing of mothers and young children and ensure the health of future generations. Living well and ageing well: Women also told us that they want to live longer in good health, in environments that support good health, and with better support for conditions and life stages that affect women's health. Priority area 4 focuses on prevention and early intervention to better manage conditions and life stages, like menopause, as well as how the health system can better respond to the determinants of women's health.	that these women are given the highest quality of care and support. • The priority area of improving health care for issues specific to women may yield positive results for uterine cancer treatment, stigma and gaps in service may drive some women to avoid engaging with the health system, in spite of potential warning signs.	

Table E.2: Summary of cancer policies – Australia

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
Australian Cancer Plan 2023–2033	Launched in 2023, the Australian Cancer Plan outlines six strategic objectives: 1. Maximising Cancer Prevention and Early Detection – A cancer control system that works to eliminate racism, proactively reduces cancer risk and supports all Australians to access personalised, evidence-based cancer prevention and early detection strategies 2. Enhanced Consumer Experience – People affected by cancer are partners in culturally safe, equitable and responsive cancer care, and health services and systems are trusted and supported for optimal experience, quality of life and cancer outcomes.	• No policies directly related to uterine cancer. • The strategic objective of maximising cancer prevention and early detection (strategic	• Under strategic objective 1, there is scope for targeted awareness campaigns of uterine cancer risk, as well as efforts to destigmatise

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
	3. World Class Health Systems for Optimal Care – Integrated, coordinated, data-driven, high-quality health service systems that consistently deliver optimal cancer care and excellence in outcomes 4. Strong and Dynamic Foundations – A modern, fit for purpose cancer control infrastructure, advanced by the innovative application of technology, research and data to improve Australia's cancer outcomes 5. Workforce to Transform the Delivery of Cancer Care – An engaged, capable and future, focused cancer workforce that is culturally safe and responsive, well-equipped, well-supported and driven by collaboration, continuous improvement and diversity to enable to best care for all Australians affected by cancer 6. Achieving Equity in Cancer Outcomes for Aboriginal and Torres Strait Islander People – Supporting Aboriginal and Torres Strait Islander knowledge, strength and sovereignty in a health system that achieves equity for Aboriginal and Torres Strait Islander people affected by cancer The Australian Cancer Plan highlights the achievement of equity in healthcare outcomes, especially among the following groups: • Aboriginal and Torres Strait Islander People • People living in rural and remote areas • Lesbian, gay, bisexual, transgender, intersex, queer and asexual (LGBTQIA+ people) • People from culturally and linguistically diverse (CALD) backgrounds • People living with disability • People in lower socioeconomic groups • People living with a mental illness • Older Australians • Adolescents and young adults • Children Optimal care pathways outline best care recommendations across seven steps along the cancer continuum. There is close alignment of the OCP steps across the care continuum with the scope of the Plan's Strategic Objectives. • Prevention and early detection • Presentation, initial investigations and referrals • Diagnosis, staging and treatment planning • Treatment • Care after initial treatment and recovery • Managing recurrent, residual or metastatic disease End-of-life care	objective 1) is highly impactful on uterine cancer, as early detection remains an area of focus for uterine cancer prevention. The strategic objective of achieving equity in cancer outcomes for Aboriginal and Torres Strait Islander people (strategic objective 6) is in line with improving outcomes for Aboriginal and Torres Strait Islander people, as well as rural women, who are disproportionately affected by uterine cancer.	and facilitate screening. • Under strategic objective 2, guidance can be provided to clinicians and patients on how to ensure treatment options are well understood and decisions are made with consent and clarity.

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
National Health Reform Agreement 2020-25	The National Health Reform Agreement is the instrument through which the Federal Government provides funding to states and territories for health and hospital services. It also sets out the architecture to deliver major structural reforms required to establish the foundations of Australia's future health system to improve health outcomes for all Australians and ensure the sustainability of the Australian health system, with jurisdictions operating in partnership. The 2020-25 National Health Reform Agreement, signed by states and territories and the Federal Government in May 2020 following initial Heads of Agreement in 2018, continues the existing agreement on funding determination and provides additional funding guarantees to public hospitals over five years from 2020-21. Changes to the National Health Reform Agreement, the New Addendum, took place from 1 July 2020 and have impacted the claiming of Medicare benefits for private health services provided within public hospitals. Compliance with the National Health Reform Agreement is required of public health facilities that seek to access Medicare rebates for private health services provided within those facilities.	• No policies directly related to uterine cancer.	
National Service Improvement Framework for Chronic Conditions	The National Strategic Framework for Chronic Conditions (the Framework) is the overarching policy document for chronic conditions that sets the directions and outcomes to achieve its Vision that "all Australians live healthier lives through effective prevention and management of chronic conditions." The Framework provides guidance for the development and implementation of policies, strategies, actions and services to reduce the impact of chronic conditions in Australia, including cancer. The Framework moves away from a disease-specific approach and provides national direction applicable to a broad range of chronic conditions by recognising that there are often similar underlying principles for the prevention and management of many chronic conditions. It supersedes the National Chronic Disease Strategy 2005 and associated National Service Improvement Frameworks, including the 2006 National Service Improvement Framework for Cancer. The Framework was developed through the Australian Health Ministers' Advisory Council, in partnership with states and territories, and endorsed by all Health Ministers, through the Council of Australian Government (CoAG) Health Council, in 2017. The Framework is directed at decision and policy makers at national, state and local levels. Vision All Australians live healthier lives through effective prevention and management of chronic conditions. Objectives The Vision is supported by the following three objectives: 1. Focus on prevention for a healthier Australia	• No policies directly related to uterine cancer. • Cancer survivors, including uterine cancer survivors, often live with chronic conditions, even after their cancer is gone. This framework assists cancer survivors in living longer and more fulfilling lives. • The focus on equity in access to cancer prevention, treatment and supportive care is in line with improving outcomes for Aboriginal and Torres Strait Islander people, who are	• Many uterine cancer survivors live with chronic conditions, treatment for which may differ from other chronic conditions. There is scope for engagement by representative bodies and uterine cancer representatives to establish the extent to which this framework is fit-for-purpose for uterine cancer survivors.

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
	2. Provide efficient, effective and appropriate care to support people with chronic conditions to optimise quality of life 3. Target priority populations The Framework identifies eight guiding principles to inform the planning, design and implementation of policies, strategies, actions and services aimed at preventing and/or managing all chronic conditions. The principles are: • Equity – all Australians receive safe, high-quality health care, irrespective of background or personal circumstance. • Collaboration and partnerships – identify linkages and act upon opportunities to cooperate and partner responsibly to achieve greater impacts than can occur in isolation. • Access – high standard, appropriate support and services are available, accessible, equitable and affordable for all Australians. • Evidence-based – rigorous, relevant and current evidence informs best practice and strengthens the knowledge base to effectively prevent and manage chronic conditions. • Person-centred approaches – the health system is shaped to recognise and value the needs of individuals, their carers and their families, to provide holistic care and support • Sustainability – strategic planning and responsible management of resources delivers long-term improved health outcomes • Accountability and transparency – decisions and responsibilities are clear and accountable, and achieve best value with public resources • Shared responsibility – all parties understand, accept, and fulfil their roles and responsibilities to ensure enhanced health outcomes for all Australians. The Framework identifies seven specific Enablers, the appropriate use of which will give effect to successful policies, strategies, actions and services that will support people with, or at risk of developing, chronic conditions. The Enablers comprise: • Governance and leadership – supports evidence-based shared decision-making and encourages collaboration to enhance health system performance. • Health workforce – a suitably trained, resourced and distributed workforce is supported to work to its full scope of practice and is responsive to change. • Health literacy – people are supported to understand information about health and health care, to apply that information to their lives and to use it to make decisions and take actions relating to their health. • Research – quality health research accompanied by the translation of research into practice and knowledge exchange strengthens the evidence base and improves health outcomes. • Data and Information – the use of consistent, quality data and real-life data sharing enables monitoring and quality improvement to achieve better health outcomes.	disproportionately affected by uterine cancer. • The principle of access is important for uterine cancer patients, as many women in rural and remote areas are unable to access the same treatment options as women in metropolitan areas, adversely affecting outcomes.	

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
	• Technology – supports more effective and accessible prevention and management strategies and offers avenues for new and improved technologically driven initiatives Resources – adequate allocation, appropriate distribution and efficient use of resources, including funding, to address identified health needs over the long term.		
National Framework for Genomics in Cancer Control	The Australian Cancer Plan (the Plan) is designed to improve cancer outcomes for all Australians, and particularly for those groups whose health outcomes are poorest. Achieving equity in cancer outcomes will be a fundamental measure of success for the Plan and will align Australia with global calls to improve cancer outcomes for all people. The National Framework for Genomics in Cancer Control (the Framework) has been developed under the Plan's Strategic Objective to deliver Maximised Cancer Prevention & Early Detection. However, the Framework applies across the entire cancer care continuum and to all the Plan's Strategic Objectives. The Framework shares the vision of world-class cancer outcomes and experiences for all Australians, as well as the Plan's guiding principles. • Person-centred: the Plan is designed with, and for, all people affected by cancer. This includes people at risk of cancer, people diagnosed with cancer, and their families and carers. • Equity-focused: the need for equity in cancer outcomes and experience is at the centre of the Plan. If the Plan does not 'shift the dial' for people whose outcomes are poorest, it will not be successful. • Future-focused: the Plan addresses both current and future cancer and health trends and challenges, so Australia can take advantage of emerging opportunities to improve cancer outcomes. • Strengths-based: the Plan adopts a strengths-based approach which identifies gaps and issues in the system, and builds on the strengths, opportunities, and the diversity of Australia's population groups and our cancer care system. • Evidence- and data-driven: the Plan is evidence-informed, and promotes better, ongoing use of data to drive, understand, and evaluate the performance of Australia's cancer care system. • All cancers: the Plan addresses issues relevant to all cancer types, with a focus on addressing disparity of experience and outcome. • Encompassing the cancer control continuum: the Plan addresses the whole continuum of cancer care – spanning prevention and early detection, diagnosis, treatment, survivorship care, end-of-life care, and supportive care. • Collaborative: the implementation of the Plan, as with its development, will encourage and involve system-wide, cross-sector, inter-jurisdictional, and national collaboration.	• No policies directly related to uterine cancer. • The principle of person-centredness is particularly relevant for uterine cancer, where so many cases are of rare cancers, requiring individualised and informed treatment plans. • The principle of equity in access to cancer prevention, treatment and supportive care is in line with improving outcomes for Aboriginal and Torres Strait Islander people, who are disproportionately affected by uterine cancer.	• Because of the high impact of genetic testing in diagnosing, treating and researching uterine cancers, there is opportunity to expand genetic testing for women with uterine cancers, and make available the resulting data for researchers.
National Women's Health	The National Women's Health Strategy is an overarching document designed to complement and align with other health-related policies and strategies. It is designed to provide a gender-specific approach to activities already	• No policies directly related to uterine cancer.	• The principle of taking a life course approach to health can be developed

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
Strategy 2020-2030	underway and to guide the development of new and innovative policies and approaches aimed at addressing the specific health needs of women and girls in Australia. The Strategy works in tandem with the National Men's Health Strategy 2020-2030. The aim of these strategies is to acknowledge the different biological and societal factors that impact women's and men's health and wellbeing, and to strengthen and improve national approaches for both. The strategy recognises five key principles, with associated objectives, that underpin the strategic direction of women's health reform. Principle 1: Gender equity *Objective:* Highlight the significance of gender as a key determinant of women's health and wellbeing, to strengthen gender-equity and to enhance women's and girls' engagement with the health system Principle 2: Health equity between women *Objective:* Recognise the different health needs of priority populations, address gaps in services and target those women's population groups where the worst health outcomes are experienced Principle 3: A life course approach to health *Objective:* Develop health initiatives that focus on improving health and target risk factors and critical intervention points for women across the life course Principle 4: A focus on prevention *Objective:* Invest in positive prevention and early intervention from childhood, with a focus on the social and gendered drivers of health and holistic person-centred care Principle 5: A strong and emerging evidence base *Objective:* Support effective and collaborative research, data collection, monitoring, evaluation and knowledge transfer to advance the evidence base on women's health	• The principle of health equity between women is in line with improving outcomes for Aboriginal and Torres Strait Islander people, who are disproportionately affected by uterine cancer.	specifically for uterine cancer to encourage prevention and detection activities, as well as to reduce the stigma faced by women in understanding their symptoms.
Optimal Care Pathways	OCPs are national guides to best practice cancer care for eighteen specific tumour types. There is also an OCP focused on Aboriginal and Torres Strait Islander people with cancer. The OCPs describe the treatment journey from diagnosis through treatment and supportive care with guidance for appropriate expectations for information, treatment and supportive care at each phase. These OCPs do not incorporate clinical guidelines.	An OCP has been developed for women with endometrial cancer; however, women with rare uterine cancers lack an OCP.	• With more data collection on rare uterine cancers, there is an opportunity to develop OCPs for these rarer cancers.

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
Principles of Cancer Survivorship	The Principles of Cancer Survivorship provide a national framework to cancer policy, planning and health system responses to cancer survivorship, focusing on the health and wellbeing of people living with and beyond cancer. The principles are supported by intended outcomes and underpinned by elements to achieve personalised care, opportunities for self-management, an emphasis on recognising and incorporating patient experiences, and a focus on the ongoing management, recovery, health and wellbeing during and after cancer treatment. Principle 1: Consumer involvement in person-centred care Principle 2: Support for living well Principle 3: Evidence-based care pathways Principle 4: Coordinated and integrated care Principle 5: Data driven improvements and investment in research	• No policies directly related to uterine cancer. The principle of customer involvement in person-centred care is particularly relevant for uterine cancer, where so many cases are of rare cancers, requiring individualised and informed treatment plans.	• Because of the relatively low mortality rate of uterine cancers, there are many survivors of uterine cancer. Under principle 1 (consumer involvement in person-centred care) and principle 3 (evidence-based care pathways), genetic testing could be included as part of survivorship recommendations for uterine cancer, to test for hereditary genetic links, as well as to personalise a care and survivorship program for that individual.
Primary Health Networks	On 1 July 2015, the Australian Government established 31 PHNs as independent primary health care organisations located throughout Australia. PHNs have two key objectives: • To improve the efficiency and effectiveness of medical services for patients, particularly those at risk of poor health outcomes. • To improve the coordinated of care to ensure patients receive the right care, in the right place, at the right time. They do this by working to connect different elements of Australia's health system so that patients are more likely to receive the right care, in the right place, at the right time. PHNs develop partnerships that bring together different health providers and state and territory-based health authorities to create a more holistic system of care.	• No policies directly related to uterine cancer. The focus on those at risk of poor health outcomes aligns with many of the groups with a high risk of uterine cancer, such as poorer, more rural or Aboriginal and Torres Strait Islander women.	• The PHN system could be leveraged to be ensure more uniform treatment standards, particularly among rare uterine cancers.

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
National Medical Workforce Strategy 2021-2031	The Strategy stems from three rounds of consultations with individuals and organisations and synthesises the prioritised solutions into five priorities for action and three intersecting themes. Vision Work together, using data and evidence, to ensure that the medical workforce sustainably meets the changing health needs of Australian communities Themes • Growing the Aboriginal and Torres Strait Islander medical workforce and improving cultural safety • Adapt to and better support new models of care • Improving doctor wellbeing Priorities • Priority One: Collaborate on planning and design • Priority Two: Rebalance supply and distribution • Priority Three: Reform the training pathways • Priority Four: Build the generalist capability of the medical workforce Priority Five: Build a flexible and responsive medical workforce	• No policies directly related to uterine cancer.	• With one of the themes being growing the Aboriginal and Torres Strait Islander medical workforce and improving cultural safety, this can work to include Aboriginal and Torres Strait Islander input into how to encourage prophylactic activity, early screening and proactive engagement with healthcare services among Aboriginal and Torres Strait Islander Australians.
Health Pathways	• The Health Pathways is a web-based health information technology platform that builds relationships with GPs, other primary health care providers, specialists and hospital services. It is a single source of evidence-based clinical and referral information that is developed, agreed and maintained locally to provide support for primary health care services providers at the point of care.	• No policies directly related to uterine cancer. • The platform allows clinicians to remotely access expert knowledge to assist in diagnosing rare uterine cancers.	• There is an opportunity to use novel methods such as genetic testing to expand the information available on Health Pathways about uterine cancer, especially rare cancers.
National Palliative Care Strategy 2018	The WHO in 2017 reported that only 14 per cent of people who need palliative care receive the care they need. The National Palliative Care Strategy represents the commitment of the Commonwealth, state and territory governments to ensuring the highest possible level of palliative care is available to all people. It builds on the previous strategies and on a legacy of investment into research, education and training, workforce and service development, and community awareness and engagement.	• No policies directly related to uterine cancer. • While the mortality rate in uterine cancer is lower than many other common	• There is scope for representative bodies or advocates on behalf of uterine cancer survivors to advocate for palliative care needs specific to

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
	This National Palliative Care Strategy provides an overarching vision for palliative care in Australia: that people affected by life-limiting illnesses get the care they need to live well. Six guiding principles are identified as fundamental to ensure that all people experience the palliative care they need: • Palliative care is person-centred care • Death is a part of life • Carers are valued and receive the care they need • Care is accessible • Everyone has a role to play in palliative care • Care is high-quality and evidence-based The Strategy sets out objectives to achieve the vision for the strategy. This includes: • Goal 1: Understanding – People understand the benefits of palliative care, know where and how to access services, and are involved in decisions about their own care. • Goal 2: Capability – Knowledge and practice of palliative care is embedded in care settings. • Goal 3: Access and choice – People affected by life-limiting illnesses receive care that matches their needs and preferences. • Goal 4: Collaboration – Everyone works together to create a consistent experience of palliative care across care settings. • Goal 5: Investment – A skilled workforce and systems are in place to deliver palliative care in any setting. • Goal 6: Data and evidence – Robust national data and a strong research agenda strengthen and improve palliative care. • Goal 7: Accountability – National governance of this Strategy drives action. An Implementation Plan has been developed in consultation with states and territories. It is intended to be used by all Australian Governments. A Monitoring and Evaluation Plan will be developed to identify how progress on the priorities in the National Strategy will be measured and reported. Data collection should contribute to annual monitoring and reporting as well as to longitudinal evaluation of achievements over the five-year timeframe for the Implementation Plan.	cancers, palliative care is still an important component of care for women with uterine cancer nearing end of life.	uterine cancer patients.
National Aboriginal and Torres Strait Islander	The Framework provides guidance for individuals, communities, organisations and governments along seven priority areas for action: • Improving knowledge and attitudes about cancer • Focusing prevention activities • Increasing participation in screening and immunisation	• No policies directly related to uterine cancer. Encouraging Aboriginal and Torres Strait Islander women to	• There is scope to encourage greater participation in screening for uterine cancer among Aboriginal and Torres

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
Cancer Framework	• Ensuring early diagnosis • Delivering optimal and culturally appropriate treatment and care • Involving, informing and supporting families and carers • Strengthening the capacity of cancer related services to meet the needs of indigenous people	increase preventative activities and participate in screening for uterine cancer addresses a large risk factor.	Strait Islander women.
Aboriginal and Torres Strait Islander Cancer Plan	This vision for the Aboriginal and Torres Strait Islander Cancer Plan must be sufficient to sustain effort across all components of the Australian health care system. It must meet the needs of all Aboriginal and Torres Strait Islander peoples, including intersectional groups such as people with a disability or other chronic conditions and people who identify as lesbian, gay, bisexual, transgender, intersex, queer, asexual and other sexually or gender diverse identities (LGBTQIA+). This ensures equitable, culturally safe, holistic and evidence-based cancer prevention, screening, treatment and supportive care can be accessed by all Aboriginal and Torres Strait Islander peoples. The Plan outlines five focus areas, each of which bring with them strategic outcomes: Focus area 1: Enablers for real change • 1.1: Shared decision-making and partnerships at all levels of the healthcare system and Community • 1.2: Skilled and stable health workforce performing at highest scope of practice and in place proportionate to need • 1.3: Awareness, communication and co-ordination across the cancer continuum • 1.4: Sustainable investment in continuity of care through Aboriginal and Torres Strait Islander community-controlled primary health care services with streamlined funding and reporting processes to reduce inequities • 1.5: Aboriginal and Torres Strait Islander peoples are advocates in their health journey Focus area 2: Cancer prevention • 2.1: 'Whole-of-community', culturally informed, place-based health promotion to change the cancer narrative, raise awareness and create supports for the Community • 2.2: Environmental and individual factors increasing cancer risk are widely known and addressed Focus area 3: Timely cancer screening and early diagnosis • 3.1: High participation rates in cancer screening programs • 3.2: Emerging cancer screening technologies are universally accessible once proven • 3.3: Prompt investigation in a supportive patient-led clinical environment of any sign or symptom suspicious of cancer Focus area 4: Improving the health system at all stages of individual cancer journeys	• No policies directly related to uterine cancer. • Encouraging Aboriginal and Torres Strait Islander women to increase preventative activities and participate in screening for uterine cancer addresses a large risk factor. An emphasis on culturally safe practices within the healthcare system	• There is scope under focus area 2 (cancer prevention) for specific programs targeted at uterine cancer risk factors specifically.

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
	• 4.1: Continuity of care based on high-trust relationships in primary care as first point of entry to the rest of the health system • 4.2: Culturally safe mainstream services • 4.3: Meaningful rapport and relationships between Community members and treating teams to achieve integration and co-ordination of care • 4.4: Holistic approach to navigating cancer services and wrap around care • 4.5: Support for individuals, their carers and treating teams in their communities, including peer support and psycho-oncology • 4.6: Palliative care Focus area 5: Culturally informed evidence base • 5.1: Indigenous Data Sovereignty and timely data sharing across sectors • 5.2: Indigenist research and evaluation methods • 5.3: Sharing stories of lived experience • 5.4: Information systems strengthened, including Patient Information Management Systems, and users supported to access data to identify Community needs 5.5: Safe and relevant cancer clinical trials with high participation rates of Aboriginal and Torres Strait Islander peoples		
National Aboriginal and Torres Strait Islander Health Workforce Strategy 2021-2031	The National Workforce Plan aims for Aboriginal and Torres Strait Islander people to represent 3.43 per cent of the national health workforce by 2031, based on targets of the Aboriginal and Torres Strait Islander working age population. The Strategy has the dual objectives of: • Increase Aboriginal and Torres Strait Islander representation in all health roles and locations across the Australian health system, to improve health, mental health and social and emotional wellbeing of Aboriginal and Torres Strait Islander peoples. • Strengthen the health system to create and sustain its cultural and professional capabilities, increase access to services and improve the attraction, retention and career development of Aboriginal and Torres Strait Islander staff. To achieve these objectives, the Plan highlights six strategic directions: 1. Aboriginal and Torres Strait Islander people are represented and supported across all health disciplines, roles and functions 2. The Aboriginal and Torres Strait Islander health workforce has the necessary skills, capability and leadership across all health disciplines, roles and functions	• No policies directly related to uterine cancer. • The objective of strengthening the health system's cultural and professional capabilities can help care be culturally sensitive for Aboriginal and Torres Strait Islander women. •	• Alongside encouraging Aboriginals and Torres Strait Islanders to enter the health workforce, greater opportunity could be provided to Aboriginals and Torres Strait Islanders to influence broader health policies on prevention, early detection, treatment and supportive care targeted at Aboriginal and Torres Strait Islander communities.

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
	3. Aboriginal and Torres Strait Islander people are employed in culturally safe and responsive workplace environments that are free of racism across health and all related sectors 4. There are sufficient numbers of Aboriginal and Torres Strait Islander students studying and completing health qualifications to meet the future health care needs of Aboriginal and Torres Strait Islander peoples 5. Aboriginal and Torres Strait Islander health students have successful transitions into the workforce and access clear pathway options 6. Information and data are provided and shared across systems to assist health workforce planning, policy development, monitoring and evaluation, and continuous quality improvement In addition, the Plan details the following Closing the Gap priority reforms: • Formal partnerships and shared decision making • Building the community-controlled sector • Transforming Government organisations Shared access to data and information at a regional level		Such policies are likely to be more culturally sensitive and yield more positive results for these communities.
Cultural Respect Framework for Aboriginal and Torres Strait Islander Health 2016-2026	The Cultural Respect Framework (CRF) was developed for the Australian Health Minister's Advisory Council (AHMAC) by the National Aboriginal and Torres Strait Islander Health Standing Committee. The Cultural Respect Framework 2016-2026 is a 10-year framework that commits the Commonwealth Government and all states and territories to embedding cultural respect principles into their health system. The CRF has identified six domains and focus areas that underpin culturally respectful health service delivery: • Whole of organisation approach and commitment • Communication • Workforce development and training • Consumer participation and engagement • Stakeholder partnership and collaboration • Data, planning research and evaluation The primary audience for the CRF is the Australian public health system. This framework should be used in the government health sector, health departments and hospitals, and primary care settings to guide strategies to improve culturally respectful services. Where your work interacts with health service delivery and design, the CRF should be used as a reference to ensure that the health system is accessible, respectful, and safe for Aboriginal and Torres Strait Islanders.	• No policies directly related to uterine cancer. • Ensuring cultural respect and sensitivity in Aboriginal and Torres Strait Islander healthcare is important in improving uterine cancer outcomes among Aboriginal and Torres Strait Islander people.	• There is scope to assess the success of the CRF in driving change within the Aboriginal and Torres Strait Islander community around uterine cancer awareness and proactivity, to contribute updated guidance related to uterine cancer for the subsequent framework.
National Aboriginal and Torres Strait	The National Aboriginal and Torres Strait Islander Health Plan 2021-2031 provides an overarching framework for all programs and policies affecting the health of Aboriginal and Torres Strait Islander peoples. The Health Plan adopts a strengths-based approach that is built on an understanding that Aboriginal and Torres Strait Islander	• No policies directly related to uterine cancer.	• Under this plan, there is an opportunity to partner with Aboriginal and Torres

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
Islander Health Plan 2021-2031	people view health in a holistic context that recognises that physical health includes the social, emotional and cultural wellbeing of individuals, families and communities throughout the entire life course. The Plan outlines 12 priorities across four thematic groups: Enablers for Change • Priority 1: Genuine shared decision making and partnerships • Priority 2: Aboriginal and Torres Strait Islander community controlled comprehensive primary health care • Priority 3: Workforce Focusing on prevention • Priority 4: Health promotion • Priority 5: Early intervention • Priority 6: Social and emotional wellbeing and trauma-aware, healing-informed approaches • Priority 7: Healthy environments, sustainability and preparedness Improving the health system • Priority 8: Identify and eliminate racism • Priority 9: Access to person-centred and family-centred care • Priority 10: Mental health and suicide prevention Culturally informed evidence base • Priority 11: Culturally informed and evidence-based evaluation, research and practice Priority 12: Shared access to data and information at a regional level	• Priority 4 (health promotion) and priority 5 (early intervention) is highly impactful on uterine cancer, as prevention and early detection remain areas of focus for uterine cancer prevention. • Priority 9 (access to person-centred and family-centred care) is particularly relevant for uterine cancer, where so many cases are of rare cancers, requiring individualised and informed treatment plans. •	Strait Islander representatives to determine the care requirements specific to Aboriginal and Torres Strait Islander women with uterine cancer.
National Digital Health Strategy 2023-2028	The National Digital Health Strategy places people at the centre of a modern, connected and digitally enabled healthcare system. It is a strategy inclusive of all who live and receive healthcare in Australia, from Aboriginal and Torres Strait Islanders to people newly arrived on our shores. It works to increase data and digital progress, access and inclusion and also takes into consideration the aims and activities of other plans and strategies, both across governments and the broader digital health ecosystem. The Strategy outlines the following change enablers: • Policy and regulatory settings that cultivate digital health adoption, use and innovation • Secure, fit-for-purpose and connected digital solutions • Digitally ready and enabled health and wellbeing workforce • Informed, confident consumers and carers with strong digital health literacy	• No policies directly related to uterine cancer. • Digital health is important in unifying best practice treatment for rare uterine cancers and improves the ability of researchers to use data from uterine cancer patients.	• Better data collection activities for uterine cancer patients, particularly those with rare uterine cancers, could yield more unified treatment plans for these rarer diseases.

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
	Using these instruments, the Strategy has highlighted the following health outcomes that will be enhanced by digital health: • Digitally enabled: Health and wellbeing services are connected, safe, secure and sustainable • Person-centred: Australians are empowered to look after their health and wellbeing, equipped with the right information and tools • Inclusive: Australians have equitable access to health services when and where they need them Data-driven: Readily available data informs decision making at the individual, community and national levels, contributing to a sustainable health system	• The outcome of person-centred care is particularly relevant for uterine cancer, where so many cases are of rare cancers, requiring individualised and informed treatment plans.	
Carer Gateway	The Carer Gateway is an integrated national services consisting of a website and phone service for carers to access practical information and support. The Gateway provides a range of information that can help carer sin their role, from practical advice and resources to help finding support services in their local area, including: • Help and advice • Phone counselling: one-on-one support with a professional counsellor over the phone for carers who feel stressed or overwhelmed • Carer support • Connect with other carers through an online forum • Self-guided coaching • Skills courses • Taking a break (respite) • Help finding respite care services when carers need a break • Financial help • Information on payments and concessions that are available, including how to access NDIS and aged care support • Real-life stories and tips The Department of Social Services is responsible for the Carer Gateway.	• No policies directly related to uterine cancer. •	• As part of a broader framework of support for carers, there is an opportunity to include family genetic profiling, which can help establish intergenerational uterine cancer risk.
Australian Rare Cancers Portal	The Australian Rare Cancer (ARC) Portal is an online service for doctors to access a network of expert support, guidelines and research for people diagnosed with a rare or less common cancer. The ARC Portal team can help treating cancer specialists and their patients by facilitating: • Specialist advice on diagnosis or management through a network of Australian and International rare cancer experts	• No policies directly related to uterine cancer. • As many uterine cancers are rare cancers, many uterine	• Because of the high degree of effectiveness among uterine cancers, there is scope to include specialists for genetic

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
	• Identification of clinical guidelines or best available evidence • Advice on molecular testing – appropriate tests and interpretation of results • Patient access to rare cancer research and clinical trials. In February 2025, the Government committed to an additional $6.7 million investment in the ARC Portal, to allow for a pilot program in Queensland to service people in remote areas through a partnership with Cancer Alliance Queensland.	cancer patients and survivors benefit from the ARC portal. •	testing for uterine cancer patients in the ARC Portal.
Australian Medical Research and Innovation Strategy 2021-2026	The Medical Research Future Fund (MRFF) is a $20 billion vehicle for investment in health and medical research. It represents The Australian Medical Research and Innovation Strategy 2016-2021 which sets out the vision, aims and objectives for the MRFF. It identifies a series of strategic platforms that, if funded, have the potential for the greatest impact. The Advisory Board, which allocates funding in the order of $1 billion per year, must take into account priorities that are in force at the time, which are summaries in a separate Priorities document that is complementary to the strategy. Vision A health system fully informed by quality health and medical research Aim Transform health and medical research using priority-driven investments that promote collaborative research, research innovation, research translation and impact to improve lives, whilst contributing to health system sustainability, nurturing the next generation of researchers and building the Australian economy. Strategic Objectives To deliver: • Equitable health outcomes through research-informed preventive health and health care across the spectrum from primary to tertiary care. • Health and economic benefits from transformative and innovative research through translation of outcomes into policy and practice, and commercialisation of new diagnostics, therapeutics, and preventive health interventions. • A skilled and sustainable health and medical research workforce with expertise in research translation, innovation, and commercialisation. • A health and medical research sector and health system positioned to respond to emerging and future challenges. Research funded through the MRFF will address:	• No policies directly related to uterine cancer. • The strategic objective of achieving equity in outcomes is in line with improving outcomes for Aboriginal and Torres Strait Islander people, who are disproportionately affected by uterine cancer. • With MRFF research addressing existing areas of unmet health need, uterine cancer research fits into this category.	• It is within the remit of the MRFF to include funding for cutting-edge projects related to uterine cancer detection, treatment and survivorship.

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
	• New or emerging areas of health need with high potential for generating innovative approaches, tools, or technologies to transform health care and practices. • Existing areas of unmet health need, to address underinvestment and support capacity development with a focus on achieving equity in health outcomes, particularly for Aboriginal and Torres Strait Islander people and other priority populations. • Improvement in the efficiency and effectiveness of the health system, by promoting adoption of evidence-based practices, enabling equitable health outcomes, and focussing on the needs of patients, their families, and carers. • Social, environmental, and cultural factors that impact health and wellbeing, including strengths-based approaches that leverage patient/consumer and community knowledge and experience to deliver improvements in population health and wellbeing. • Enhancements to the translation of research outputs to deliver impact through health and economic outcomes, including through commercialisation of research outcomes and implementation of policy changes nationally and globally. • Promotion of capacity and capability in the health and medical research workforce, through investments in priority areas, by fostering collaboration between research groups and across disciplines and addressing gender equity. Encouragement of adaptive approaches to emerging challenges2, supporting rapid response and effective collaboration both nationally and internationally with other public and private sources of health and medical research funding.		
Australian Medical Research and Innovation Priorities 2024-2026	In accordance with the Medical Research Future Fund Act 2015 (the MRFF Act), the independent Australian Medical Research Advisory Board (the Advisory Board) must determine the Australian Medical Research and Innovation Strategy every five years, and the Australian Medical Research and Innovation Priorities (Priorities) every two years. The Australian Medical Research and Innovation Strategy 2021-2026 (the 2021-2026 Strategy) was registered on the Federal Register of Legislation as the Australian Medical Research and Innovation Strategy 2021-2026 Determination 2021 and effective 9 November 2021. The current priorities are: • Consumer-driven research: Research that is driven by meaningful consumer and community involvement and partnerships, to incorporate their diverse priorities, needs, values and experiences to deliver outcomes that are accessible, useful and used by consumers, carers, health care professionals and other end-users. • Research Infrastructure and Capability: Address gaps in the generation of knowledge, in early biomedical and medical technology product development and translational research by supporting access to expertise, capability, and infrastructure, in partnership with industry to drive new research discoveries and accelerate innovation. This includes research facilities, equipment, systems, services, networks, digital infrastructure, integrated data, and biobanks.	• No policies directly related to uterine cancer.	

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
	• Translation and Commercialisation: Provide a focus on research translation, implementation and commercialisation by accelerating and advancing innovation to improve health outcomes and impact, and by supporting the development of biomedical research industries in Australia. Leverage opportunities from novel or emerging tools and technologies that can transform health and medical research, health interventions and care. This includes building the evidence base for improved adoption into health care and policy, as well as increasing collaborations between the research sector, industry, health services, governments, and community. • Effective and High Value Care: Demonstrate the comparative clinical and cost effectiveness of health interventions to identify and improve the delivery of high value care and to minimise unnecessary, ineffective, and harmful health interventions. This includes the generation of a range of evidence, including through innovative clinical trials, health economic evaluation, and analysis of real-world data, to enable ongoing assessment of interventions, care models and health technologies. • Preventative and Public Health Research: Invest in preventive and public health research that can be translated into evidence-based health care, policies and systemic changes to maximise health and wellbeing, reduce the burden of disease, improve health equity and deliver social and economic benefits. • Primary Care Research: Support primary care research with an emphasis on multidisciplinary collaboration, adaptive research methodologies, innovative models of care, and clinician capability. Develop the evidence base about the efficacy and value of different primary care models and health systems. This includes improving primary care intersection with secondary and tertiary care and promoting shared models of care between clinicians and consumers, including self-care interventions, for a more integrated and efficient health care sector. • Health and Medical Researcher Capacity and Capability: Support development of Australian health and medical researcher capability, with a focus on improving the translation and integration of evidence-based research into primary and tertiary care settings, policy and commercial outcomes. Create a funding environment that fosters equity and increases opportunities for researchers with a diversity of backgrounds, career stages, skills and expertise to build research capacity and capability. • Aboriginal and Torres Strait Islander Health and Wellbeing: Improve the health and wellbeing of Aboriginal and Torres Strait Islander people to close the gap in health mortality and morbidity, improve experiences of health care and eliminate discrimination across the health system through Aboriginal and Torres Strait Islander-led priority setting, research leadership and self-determination. Recognise Aboriginal and Torres Strait Islander people's diverse experiences and health needs, including access and engagement across the health sector, including public, private and Aboriginal and Torres Strait Islander community-controlled health, to improve health outcomes. • Priority Populations: Ensure equitable health outcomes for all people living in Australia by funding research to understand specific health needs for diverse individuals and communities and enabling the development of inclusive and targeted approaches to support health and wellbeing for priority populations, including Aboriginal and/or Torres Strait Islander people, people in remote/rural communities, people with a disability (including people with intellectual disability), people from culturally and linguistically diverse communities (including		

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
	people who are immigrants or refugees), LGBTIQ+ people, children and youth, older people experiencing diseases of ageing (e.g. cognitive decline and dementia), people with rare or currently untreatable diseases/conditions • Global Health and Health Security: Build capacity for both proactive and reactive action to address identified, emerging or potential global health threats, including pandemics, zoonotic diseases and antimicrobial resistance (AMR), in alignment with international efforts and capabilities and in consideration of evolving geopolitical environments. • Health Impacts from Environmental Factors: Understand and address the emerging and long-term impact of environmental factors, such as climate change and natural disasters, on physical and mental health and wellbeing. Address the changing burden of communicable and noncommunicable disease linked to environmental causes. Artificial Intelligence and Digital Health: Support for the improved, secure and ethical integration and governance of artificial intelligence and data science approaches, health informatics, and other data-driven digital or technological innovations. This includes data-driven innovations such as quantum technologies, precision medicine, diagnostics, digital health tools and devices. This is critical to realising the benefits of more digitally integrated and effective health care systems to improve health outcomes.		
Living Well After Cancer	The Living Well After Cancer program is delivered by Cancer Council services nationally using trained facilitators who have experienced cancer firsthand. Living Well After Cancer is a free program for people who have finished their cancer treatment. It is a two-hour program that provides practical support and welcomes open discussion. This program is for cancer survivors, carers, family members, friends and even work colleagues. There are also Living Well After Cancer practical information and support guides, as well as the Cancer Council's hotline for support.	• No policies directly related to uterine cancer. This program can help cancer survivors, especially uterine cancer survivors, many of whom survive cancer, albeit with a lower quality of life.	
Chronic Disease Management Plans	Chronic Disease Management Plans funded through the Medicare Benefits Schedule (MBS) enable GPs to plan and coordinate the health care of patients with chronic or terminal medical conditions, including patients who require multidisciplinary, team-based care from a GP and at least two other health or care providers. A chronic medical condition is one that has been (or is likely to be) present for six months or longer, for example asthma, cancer, cardiovascular disease, diabetes, musculoskeletal conditions and stroke. There is no list of eligible conditions, however, the CDM items are designed for patients who require a structured approach, including those requiring ongoing care from a multidisciplinary team.	• No policies directly related to uterine cancer. • Many uterine cancer survivors continue to live with chronic conditions after they have recovered from their cancer. Chronic	• There is scope for additional services useful to survivors of uterine cancers, such as genetic testing, to be provided and funded under the Chronic Disease Management Plans.

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
	Whether a patient is eligible for CDM services is a clinical judgement for the GP, taking into account the patient's medical conditions and care needs, as well as the general guidance set out in the MBS. Patients who have a chronic medical condition and complex care needs and are being managed by their GP under a GP Management Plan (item 721) and Team Care Arrangements (item 723) are eligible for Medicare rebatable allied health services from certain provider groups on referral from their GP.	disease management plans can help these women live longer and more fulfilling lives. •	
Clinical Quality Registry Strategy	The National Clinical Quality Registry Strategy aims to "maximise the considerable potential of Australian Clinical Quality Registries through a strategic, national, coordinated approach" to real world data collection through the development of "high-functioning, mature Clinical Quality Registries". The National Clinical Quality Registry Strategy is a 10-year strategy which sets out national principles, stakeholder roles and responsibilities, strategic objectives, and issue/action streams for achieving the Strategy's vision. The vision of the National Clinical Quality Registry Strategy is that "National Clinical Quality Registries are integrated into Australia's health care information systems and systematically drive patient-centred improvements in the quality and value of health care and patient outcomes, across the national health care system.	• No policies directly related to uterine cancer.	• Under the CQRS framework, there is scope to expand the data collection activities for women with uterine cancer, including genetic testing, which will improve both treatment outcomes for women with uterine cancer as well as the data available for research.

Table E.3: Summary of cancer policies – Australian states and territories

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
The NSW Cancer Plan 2022–2027	The goals of the NSW Cancer Plan are to: • Reduce inequality in cancer outcomes: achieve equitable cancer outcomes for all NSW residents. • Reduce the incidence of cancer: reduce the risk of preventable cancers for people in NSW. • Increase cancer survival • Enhance quality of life and experience for people at risk of and affected by cancer The overriding principles governing the NSW Cancer Plan are:	• No policies directly related to uterine cancer. • Priority 2: Screening and early detection of cancer is highly impactful on uterine cancer, as early	• Priority 1: Prevention of cancers notes prioritising evidence-based prevention efforts in areas with the greatest need and demonstrated impact, highlighting nicotine

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
	• Equity of outcomes: improve cancer outcomes among communities with poorer outcomes, including Aboriginal communities. • Person-centredness: focus on the experiences of people with cancer to ensure they achieve outcomes that are meaningful to them. • Collaboration: work together at the system service and care team levels to achieve the best cancer outcomes. The Plan is focused on the following priorities: 1. Prevention of cancers 2. Screening and early detection of cancers 3. Optimal cancer treatment, care and support 4. Cancer research The following system enablers are targeted by the Plan: • Staff are engaged and well-supported • Innovation and digital advances inform service delivery • The system is managed sustainably Additionally, the Plan is designed to achieve the following target outcomes: • Achieve equitable cancer outcomes for all NSW residents • Reduce the risk of preventable cancers for people in NSW • Increase one- and five-year survival of NSW residents with cancer. • Increase the collection and use of people's reported experience and outcomes to improve care and services. For each of the priority areas, the Plan outlines the actions the to which the Government will commit in order to achieve its stated goals. Clear governance structures have been put in place to support effective, coordinated and collaborative implementation of the NSW Cancer Plan. Overall governance of the Plan is provided by the multi-stakeholder NSW Cancer Plan Governance Committee. The Governance committee: • Provides oversight and advice on implementation, monitoring and reporting • Promotes and facilitates engagement and communication between all stakeholders involved in implementation • Provides oversight and advice through the development and implementation of subsequent cancer plans for NSW • Reflects the diversity of the community in NSW Alongside the NSW Cancer Plan, an implementation plan has been developed. The implementation plan details the activities and initiatives, the responsible collaborators and stakeholders, and the timeframes for delivering these within the life of the NSW Cancer Plan.	detection remains an area of focus for uterine cancer prevention. • Priority 2 also specifically targets increasing uptake of cancer screening among priority populations, including Aboriginal and Torres Strait Islanders (2.4). • Under Priority 3: Optimal cancer treatment, care and support, emphasis is placed on providing patient-led culturally safe care, which aligns with current gaps in care delivery.	consumption, drinking and UV exposure. Alongside these risk factors, obesity could be included as a recognised risk factor for uterine cancer. • Under Priority 4: Cancer research, there is an opportunity to promote genetic testing for women with rare uterine cancers, to tailor a treatment plan to the patient, to test for generational risk factors, and to provide additional data to be used by researchers.

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
Victorian Cancer Plan 2024–2028	The Victorian Cancer Plan provides a framework to improve cancer outcomes for all Victorians and provide a roadmap for investment in necessary infrastructure, systems and workforce. The Plan sets a long-term (2040) goal to: • Halve the proportion of Victorians diagnosed with preventable cancers • Double the improvement of one- and five-year survival • Ensure the best possible experience in treatment and with system • Achieve equitable outcomes for all Victorians. Two major priority areas have emerged from Victoria's health outcomes data: • The need to drive greater equity in access to cancer prevention, treatment and supportive care. This will help achieve improvements in survival rates for priority groups to enable comparable outcomes across the Victorian population. • The need for a renewed focus on cancer screening and early detection to improve participation rates to detect early signs of disease, either before a cancer has developed or in its early stages before any symptoms occur, when early interventions can be most successful. Underpinning the Plan's ultimate goals are five pillars that inform the actions and policies the Government will enforce. 1. Consumers are active partners in their health and wellbeing 2. Empowering Victorians to prevent cancer 3. Optimal access and care across the cancer pathway 4. A workforce that can deliver now and into the future 5. System design and delivery driven by research, data and intelligence. The pillars frame the Victorian Government's collective efforts to improve cancer care over the Plan's period. These five pillars reflect the shared system-level priorities across the cancer pathway, where the biggest impact on cancer outcomes can be made. For each pillar, the Government has outlined priority goals to act as markers of success. Under pillar one, the Government's goal is to ensure Victorians have the best possible experience within the cancer treatment and care system. This will be done through the promotion of accessible information for consumers, collection and monitoring of consumer feedback, and improving access to appropriate services and care for priority populations, including Aboriginal people. For pillar two, the Government aims to halve the population of Victorians diagnosed with potentially preventable cancers, to eliminate hepatitis B and C as public health concerns, and to eliminate cervical cancer as a public health problem in Victoria by 2035.	• No policies directly related to uterine cancer. • The focus on equity in access to cancer prevention, treatment and supportive care is in line with improving outcomes for Aboriginal and Torres Strait Islander people, who are disproportionately affected by uterine cancer. • The five pillars underpinning the Plan are broadly aligned with some key risks posed by uterine cancer, particularly pillar 1 (consumers are active partners in their health and wellbeing) and pillar 3 (optimal care and access across the cancer pathway).	• Under pillar two (empowering Victorians to prevent cancer), the Victorian Government could also commit to reducing obesity, increasing activity and improving the diet of Victorians, reducing the risk of uterine cancer. • Under pillar five (system design and delivery driven by research, data and intelligence), a commitment to genetic profiling as part of both treatment delivery for uterine cancer and research for developing effective novel treatments.

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
	Pillar three outlines the priority goals of achieving equitable outcomes for all Victorians, increasing the proportion of women who rescreen for breast cancer within 27 months to more than 75 per cent, and to increase to 90 per cent the proportion of patients who die from cancer and received palliative care. Pillar four brings with it no specific priority goals; however, the Government has highlighted its desire to build a strong cancer workforce, with a focus on workforce gaps (including regional and rural areas, and Aboriginal Victorians), to strengthen capability within the healthcare workforce, and to enhance relationships between clinical, academic and research institutions. The priority goal for pillar five is to increase the number of new clinical trial enrolments in rural and regional areas in Victoria by 30 per cent.		
Queensland Cancer Strategy 2024	The Queensland Cancer Strategy is designed to advance a more connected and networked cancer care system, driving research, education and innovation across Queensland. The Strategy will facilitate an expansion of the network of cancer services across the state, and ensure all Queenslanders have access to world-leading cancer prevention, early detection, treatment and support services. Success is defined as improving equity outcomes, reducing cancer risk factors, increasing access, improving cancer treatment and support for survivors. The Strategy outlines six focus areas: • Coordinated care: coordinated and integrated care across the cancer care continuum. • Aboriginal and Torres Strait Islander equity: provide quality, accessible and culturally safe cancer care for Aboriginal and Torres Strait Islander Queenslanders. • Screening, prevention and early detection: better understanding of cancer prevention in the community and reduction of risk factors. • Services and treatment: better cancer services and treatment through redesign, growth and innovation. • Health, wellbeing and survivorship: holistic support for people to live well with, through and beyond cancer. • Research and education: better care for consumers through empowering clinicians to undertake research, drive innovation and develop skills. In order to support these focus areas, Queensland has identified three overarching principles that govern policymaking. These are: • Equity: a focus on equity and inclusion for populations with specific cancer care needs • Quality care: improving quality of care in all aspects along the cancer care continuum. • Implementation: support for each focus area through detailed strategic planning. The Strategy also considers the role of certain cancer services in optimal care pathways, including: • Cancer care for adolescents and young adults • Cellular therapy	• No policies directly related to uterine cancer. • The focus on equity in access to cancer prevention, treatment and supportive care is in line with improving outcomes for Aboriginal and Torres Strait Islander people, who are disproportionately affected by uterine cancer. • One of the six focus areas is screening and early detection of cancer, which is highly impactful on uterine cancer, as early detection remains an area of focus for uterine cancer prevention.	• The focus on screening, prevention and early detection could be expanded to include efforts at destigmatisation of uterine cancer screening, especially among older women. • Under the focus on coordinated care, funding could be provided for genetic testing for women with uterine cancer, which can help clinicians better tailor treatment plans to individuals.

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
	• Haematology • Interventional oncology • Palliative care • Radiation oncology • Surgical oncology • Theranostics • Systemic therapy (which includes chemotherapy, immunotherapy and new targeted drugs). Multidisciplinary teams will plan and deliver care aligned to the national Optimal Care Pathways. Statewide networked service arrangements for all cancer clinical streams will enable more local access to safe, quality cancer services that can be delivered broadly and provide highly specialised services and cancer expertise. Complementary to inpatient care, the Government is supporting an increased presence of community-based care through new technologies that enable remote monitoring, in-home care and telehealth. The Queensland Government has also contributed $1.25 billion towards building the Queensland Cancer Centre to enhance the broader network of existing public cancer services by providing cutting-edge cancer treatments like cellular therapy, theranostics and a new statewide proton beam therapy service. Additionally, the new Alliance for Cancer Care in Queensland is designed to bring together stakeholders from across the cancer sector to transform the Queensland cancer care system. The three focuses of the Alliance are: • World-leading, equitable clinical care • Research and innovation translated into better patient outcomes • Education and training to grow the workforce Through the Alliance, Queensland's service delivery and cancer research networks will be connected to the Australian Comprehensive Cancer Network nationally, and to cancer care leaders globally.	• The consideration of a wide range of cancer services in optimal care pathways, including cellular therapy, is particularly important in treating rare uterine cancers.	
SA Cancer Plan 2025–2029	The SA Cancer Plan has a vision of leading the way to cancer prevention and control with personalised care, with the goals of enhancing prevention of cancer and reducing unnecessary deaths through early diagnosis, improving the cancer experience for those diagnosed with cancer and their families/carers, and improving quality of survivorship. The Plan has stated its overriding principles to be: • Equity of access: equity of access to prevention and care across cancer types and population groups. • Evidence and research: translational, meaningful, impactful research focused on patient outcomes and/or experiences. • Person-centred: care that is respectful of and responsive to the preferences, needs and values of the patients.	• No policies directly related to uterine cancer. • The principle of equity in access to cancer prevention, treatment and supportive care (as well as priority area 6) is in line with improving outcomes	• Under Priority 2 (Maximise cancer prevention and early detection), there is scope to include policy targeted at awareness of uterine cancer risk factors, and promotion of screening for uterine cancer, particularly

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
	• Integrated care: care that is connected and coordinated within and between services so that the person receiving care is not tasked with holding the system together. • Holistic care: care that recognises and supports all aspects of a person and their life around and beyond cancer. Six priority areas were identified within the Plan to add to the work being done at a national level to improve cancer prevention, care, outcomes and experience: 1. Improve cancer experience 2. Maximise cancer prevention and early detection 3. Enable health systems for optimal care 4. Provide strong and dynamic foundations 5. Enhance the workforce to deliver cancer care into the future 6. Achieve equitable access to cancer healthcare for Aboriginal and Torres Strait Islander South Australians Additionally, four outcomes were highlighted to be realised with the implementation of the Plan • Reduce the risk of preventable cancers for SA residents • Achieve equitable access to cancer care for all people living in SA • Increase the one- and five-year survival of people in SA with cancer • Measure and improve the experience of people with cancer in SA from pre-diagnosis to survivorship and end of life.	for Aboriginal and Torres Strait Islander people, who are disproportionately affected by uterine cancer. • The principle of person-centredness is particularly relevant for uterine cancer, where so many cases are of rare cancers, requiring individualised and informed treatment plans. • Priority area 2 on prevention and early detection of cancer is highly impactful on uterine cancer, as early detection remains an area of focus for uterine cancer prevention.	in priority populations. • Under priority area 3 (Enable health systems for optimal care), there is scope to include genetic testing for women with uterine cancer, which can have a large impact on the quality of treatment and survivorship for these women.
WA Cancer Plan 2020–2025	The WA Cancer Plan provides high-level direction to guide the optimal delivery of cancer control and research to meet the needs of Western Australians impacted by cancer. The plan outlines priority areas to strengthen existing partnerships and develop new ones to achieve cancer control suitable to all people affected by cancer. The goals of the WA cancer plan are: 1. To reduce the impact of cancer, 2. To ensure consumers have the best experience of cancer control, 3. To drive cancer control that is based on data and research. There are five priorities Priority 1: Reduce the cancer burden for Western Australians. • Reduce exposure to risk factors for preventable cancers. • Reduce Aboriginal people's exposure to risk factors for preventable cancers.	• No policies directly related to uterine cancer. • Under priority 1 (reduce the cancer burden for Western Australians), there is a focus on equity in access to cancer prevention, treatment and supportive care is	• Under priority 4 (Western Australia has a globally connected cancer research system), there is scope to include genomic research to help both provide invaluable data to further the scientific

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
	• Raise awareness of cancer signs and symptoms and the need for early intervention in the community. • Increase equitable access to and participation in screening programs. • Enable increased participation of Aboriginal people in screening and early intervention programs by ensuring services are accessible, promoted and delivered in a culturally safe manner. • Advocate for improvements to the quality and analysis of national cancer screening data to improve services. • Improve access to standardised diagnostic pathways with subspecialist assessment where appropriate. • Improve pathways for local early intervention and diagnostic services throughout rural and remote WA. Priority 2: Western Australians receive optimal care. • Implement OCPs to guide the delivery of consistent, safe, high-quality and evidence-based care. • Collaborate with ACCHOs to ensure the OCP for Aboriginal and Torres Strait Islander people with cancer is used to complement implementation of cancer pathways in a culturally secure manner. • Ensure each patient's treatment and support options are reviewed and planned by a multidisciplinary team. • Actively engage primary and community care practitioners as key care providers across the cancer pathway. • Ensure each patient's treatment and support options are reviewed and planned by a multidisciplinary team. • Actively engage primary and community care practitioners as key care providers across the cancer pathway. • Improve the timeliness and efficient sharing of relevant patient information with those who need it. • Provide consumers with reliable information about their cancer care, treatment pathway and potential costs. • Improve access to evidence-based cancer control services across regional WA. • Provide coordinated care for people with rare cancers and those at increased risk of inherited cancers. • Develop and implement state-wide genomic sequencing capability to inform treatment. Priority 3: Western Australians with cancer and their families live well • Ensure access to supportive and psychological care for all following a cancer diagnosis. • Enhance provision of culturally secure supportive care, communication and information for Aboriginal people, their family, carers and community across the cancer continuum. • Co-develop and implement Survivorship Care Plans and Treatment Summaries in partnership with cancer survivors. • Empower cancer survivors to access appropriate services to self-manage the long-term effects of cancer and to engage in healthy lifestyle behaviours. • Co-develop and implement Transition Care Plans in partnership with young people, their families and carers. • Ensure appropriate palliative care services and end-of-life care are accessible to all. • Ensure Advance Care Planning and Goals of Patient Care clinical documents are available to all. • Establish transparent public reporting of patient reported experience and outcomes, and monitoring of systemwide performance indicators.	in line with improving outcomes for Aboriginal and Torres Strait Islander people, who are disproportionately affected by uterine cancer. • Under priority 2, alignment with the OCP on endometrial cancer ensures there are optimal standards care for Western Australians across the state.	understanding of rare uterine cancers, and receive individualised, person-focused care. • Under Priority 1 (reduce the cancer burden for Western Australians), there is scope to specifically carve out programs to increase uterine cancer screening, stigma against which can be a barrier for many women seeking a diagnosis and treatment.

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
	Priority 4: Western Australia has a globally connected cancer research system • Commission research that addresses variations in cancer outcomes. • Develop mechanisms for cancer research to be translated into practice or policy. • Increase and advocate for cancer policy research to be translated into practice or policy. • Enhance opportunities for cancer patients to be part of studies, especially clinical trials. • Build strategic partnerships with the philanthropic and private sectors to leverage cancer research funding. • Streamline access to patient cancer data for researchers. • Provide opportunities for cancer researchers to access innovation and commercialisation initiatives in WA. • Developed targeted strategies to attract and retain an internationally recognised cancer research workforce for the future. Priority 5: Western Australia has a robust, contemporary and sustainable cancer care system • Establish a coordinated approach and clear pathways for addressing state-wide cancer related issues. • Formalise patient referral pathways, based on the principles of OCPs, across the health system. • Establish a fit-for-purpose systemwide information system to share multidisciplinary team treatment recommendations and outcomes. • Facilitate the review and update of policy and legislation to support improvements in cancer data collection. • Provide digital options to deliver and support optimal cancer care closer to home. • Foster collaboration between the WA health system and its partners to facilitate integrated and coordinated cancer care. • Engage in interagency collaboration and cross-sector engagement to improve the broader social determinants of health relevant to cancer control. • Enhance engagement with Aboriginal people, Aboriginal health workers and ACCHOs in the planning, design and delivery of services and research. • Support the wellbeing of the cancer workforce. • Support education and upskilling of the cancer workforce to be responsive to the unique, diverse and emerging needs of the population. • Support growth, strengthening and upskilling of the Aboriginal health workforce. The Plan is designed to address a range of factors that impact cancer control and cancer research. Such factors include processes across the health system that influence the: • Quality of care • Outcomes and experiences of people affected by cancer • Availability of and communication between services and programs • Quality improvement and decision-making processes across the public health system		

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
	The Plan specifies three goals to be achieved by the end of the current reporting period: 1. To reduce the impact of cancer 2. To ensure consumers have the best experience of cancer control 3. To drive cancer control that is based on data and research While the Plan applies to all people affected by cancer in WA, it is recognised that targeted interventions to reduce inequities and assist those in the community who have a higher risk of exposure to cancer risk factors is essential. These priority populations include Aboriginal people and people living in rural and remote areas. As part of the Plan, the WA Government established the Future Health Research and Innovation (FHRI) Fund to provide a long-term secure source of funding for WA researchers. Moreover, the establishment of the WA Health Translation Network in 2017 increased opportunities for networking and coordinating research efforts, especially providing opportunities for research translation in WA.		
Long-Term Plan for Healthcare in Tasmania 2040	Under Tasmania's Long-Term Plan for Healthcare, the Department of Health has committed to commissioning a Cancer Plan, which is due to be completed later this year. The Plan also commits to ensuring access to interstate specialist hospital services not available in Tasmania for rare and complex adult cancers, including uterine cancers. Under the Plan, Tasmania has also adopted a model of GPs with a Special Interest (GPSI) wherein eligible physicians, alongside their core general practice, work on a sessional/part-time basis to deliver specialist health services in hospital outpatient clinics and other health settings, such as district hospitals. Integrated care is also a priority for public cancer services in Tasmania. The Northern Integrated Cancer Service is an example of an integrated service, established as a part of the Stage One reforms to provide and coordinate care across the State's north and north-west. By leveraging the cancer services expertise and infrastructure available across the whole region, people now have access to high-quality, timely cancer care. The establishment of the Northern Integrated Care Centre provided significant improvements in patient safety, access to treatment closer to home, and timeliness of service provision. The Plan also outlines the benefits precision genomic medicine could have on cancer survivors, through its ability to stratify cancers, characterise genetic disease and help provide information about how a person is most likely to respond to treatment. To this end, the Tasmanian Government has committed to establishing a Genomics Clinical Network to provide advice and strategic leadership for harnessing genomic technologies in Tasmania's health system.	• No policies directly related to uterine cancer. • Tasmanian Cancer Plan will provide a statewide cancer strategy, that will yield benefits for uterine cancer treatment. • Northern Integrated Cancer Service allows infrastructure and expertise from across the region to be leveraged to help cancer patients. • Support for precision genomic medicine in Tasmania is useful in developing tailored treatment solutions for rare uterine cancers.	• Through the Northern Integrated Cancer Service, resources could be collected to ensure women diagnosed with uterine cancers (including rare cancers) are provided the best quality care, including by linking with specialists on the mainland, where the expertise in Tasmania does not exist.

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
Cancer Care Strategy 2019-2022	The NT Cancer Care Strategy 2019-2022 was developed by the Northern Territory Cancer Care Network on behalf of NT Health. The Northern Territory Cancer Care Network comprises allied health, cancer care coordinators, cancer nurses, clinical trials committees, GPs, epidemiologists, haematologists, Aboriginal liaison officers, medical oncologists, physicians, radiation oncologists and surgeons, as well as representatives of the NT Primary Health Network, Cancer Council NT, CanTeen and Leukaemia Foundation. The Strategy aims to assist with integration of cancer care service providers across the diverse settings of prevention, cancer screening, primary health care, acute cancer services, survivorship and palliative care. It has specific focus to address the challenges of NT having a small, multicultural population widely dispersed over a large geographical area, such as communication, workforce recruitment and retention and access to specialised services. The key priorities of the Strategy are: • Person-centred care and communication • Governance and leadership • Workforce development • Quality and safety Major enabling infrastructure to support the realisation of the strategy was: • Better education resources for cancer patients • Increasing the use of telehealth • NT Cancer Registry • NT-wide clinical system (Acacia clinical system) and NT electronic health record across hospitals, primary health care and community health services. Evaluation of performance was identified to be important.	• No policies directly related to uterine cancer. • The key priority of person-centredness is particularly relevant for uterine cancer, where so many cases are of rare cancers, requiring individualised and informed treatment plans.	• The NT Cancer Registry collects some data on cancer patients in the NT. This could be expanded to include other datapoints, such as the stage of the cancer at diagnosis. • While the NT has yet to release a revised cancer care strategy, there is scope for representative bodies or advocates on behalf of women with uterine cancer to contribute to a follow-up strategy.
Victorian Cancer Survivorship Program	The Victorian Cancer Survivorship Program (the Program) was established in 2011 to help develop innovative models of follow-up care and to address the needs of survivors following treatment. In its first phase (2011-14) the focus of the Program was on trialling collaborative models of care across acute, and primary and community care sectors. Six pilot projects were funded and evaluated for effectiveness, acceptability, sustainability and transferability. The Program pilot projects sought to improve our understanding of the specific survivorship care needs of different groups, develop resources tailored to survivors' and health professionals' needs and inform future survivorship care in Victoria.	• No policies directly related to uterine cancer. • Support for cancer survivors provides assistance for uterine cancer survivors, especially those	• With the ongoing program working group, there is scope for the statewide directory to include proven survivorship models of care for uterine cancers,

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
	From 2015, three of the pilot projects have been supporting a select number of cancer services across Victoria to implement their models of care. In 2025, a program working group was assembled from across the various Integrated Cancer Services to assist with scaling and spreading established cancer survivorship models of care, to improve patient outcomes. In March, the working group conducted an environmental scan of established cancer survivorship models of care across Victoria, and a review of their responses is underway. The program will develop a statewide directory of proven survivorship models of care (MOCs) that can be adopted, adapted, scaled and spread across Victoria.	cancers where mortality rates are low.	including endometrial cancer, as well as rare uterine cancers, where these models are available.
Queensland Collaborative for Cancer Survivorship	The Queensland Collaborative for Cancer Survivorship is a non-government research collaborative led by Queensland University of Technology, which directs world-class research to improve patient outcomes from the time of diagnosis, and for the remainder of their life. The collaborative comprises research leaders of international repute from the Metro North Hospital and Health Service, Metro South Hospital and Health Service, Queensland University of Technology, University of Queensland, QMIR Berghofer Medical Research Institute, and Youth Cancer Service – Children's Health Queensland. The Collaborative focuses on developing and evaluating health innovations that (1) promote best outcomes for patients; and (2) ensure high-quality, sustainable health services. The objectives of the collaborative are: • Set common goals and deliverables for the collaborative • Enhance cross-disciplinary research and research translation to achieve better patient and system outcomes • Develop a strategic approach to lobby and apply for funding to support research activities • Seek clinical and administrative buy-in to implement best survivorship care and sustainable models of care across diverse clinical contexts including for patients living in regional, rural and remote areas • Involve and collaborate with clinicians in developing research ideas/proposals and dissemination/knowledge transition plans • Maintain a website including a register of research and research translation activities and work to enhance the visibility of the work conducted by the collaborative and their partners • Form collaborative networks with relevant state and national cancer organisations professional bodies, and other centres of excellence in cancer survivorship	• No policies directly related to uterine cancer. • Support for cancer survivors provides assistance for uterine cancer survivors, especially those cancers where mortality rates are low.	• In line with the collaborative's objectives, a program targeted at genetic testing of women with uterine cancers could yield benefits for both researchers and patients.
South Australian Survivorship Framework	SA Cancer Service in collaboration with key stakeholders has developed the South Australian Survivorship Framework and companion resources to support in the delivery of consistent and quality survivorship care across the state. The Framework outlines both a minimum and recommended standard of care for South Australians who have been diagnosed with cancer. This includes the provision of:	• No policies directly related to uterine cancer. • Support for cancer survivors provides assistance for uterine	• Genetic testing could be incorporated into the patient-centred care model for uterine cancers, which could allow clinicians to

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment
	• Cancer Treatment Summary • Survivorship Needs Assessment – Distress Thermometer and Checklist Template, utilised to inform the development of a • Survivorship Care Plan The Framework was developed with the following considerations: • Survivor (patient)-centred care, with the survivor featured at the centre of survivorship care which is tailored to their individual requirements, situations and comorbidities • Overarching and implementation principles • Three key components identified as the minimum standard of care cancer survivors will receive including a documented cancer treatment summary, needs assessment and survivorship care plan • Implementation tools and considerations, including workforce requirements, tools for implementation and data to drive survivorship care delivery • Evaluation and monitoring including key performance indicators and health economic measures to monitor, evaluate and continually improve survivorship care services in SA • Context-specific considerations and factors that may impact on implementation including the unique needs of different population groups. The Framework was developed with support of funding by the National Cancer Expert Reference Group (NCERG).	cancer survivors, especially those cancers where mortality rates are low. • The consideration of person-centredness is particularly relevant for uterine cancer, where so many cases are of rare cancers, requiring individualised and informed treatment plans.	better tailor treatment plans to individuals.
Women's Health and Wellbeing Program	To bridge the gap in women's healthcare, the Department of Health is leading the delivery of the $153.9 million package to change the way women's health issues are treated. This will expand upon the Victorian Government's current investment in women's health promotion services, access to information, sexual and reproductive health services, primary care sentinel practices, public hospital specialist clinics, and initiatives aimed at healthcare recruitment and training. A Victorian Women's Health Advisory Council will advise on the rollout of this investment in women's health to give independent expert advice on the delivery of the program. The delivery of the package will include the following initiatives: • Women's health clinics: The establishment of 20 new women's health clinics over 4 years, and a dedicated Aboriginal-led women's clinic, to overcome some of the barriers to women's medical treatment our community faces. The clinics aim to gradually provide a 'one-stop-shop" experience while enabling women to receive services or advice on issues from contraception to menopause and pelvic pain. The clinics will facilitate access to interdisciplinary care for women, girls, and gender diverse people. • Mobile women's health clinic: Establish a mobile women's health clinic in regional and remote Victoria to improve women's access to health services. The Department of Health has partnered with BreastScreen	• No policies directly related to uterine cancer. • The establishment of women's health clinics might help alleviate the stigma associated with screening for gynaecological cancers. Additionally, a dedicated Aboriginal-led women's clinic can help ensure culturally sensitive screening and treatment is	• Leverage investment in women's health clinics to deliver more specialised services to women at-risk or impacted by uterine cancer. • Mobile women's health clinics have partnered with BreastScreen Victoria to deliver community outreach to rural communities. There is an opportunity to partner with uterine cancer screening

Policy	Description	Relevance to uterine cancer	Gaps/opportunities in uterine cancer treatment

	Victoria to deliver a community outreach service for women's health. The mobile women's health clinic will be available to girls, women and gender diverse people living in regional and rural Victoria.
	• Virtual women's health clinic: The Department of Health has partnered with community health organisation EACH to deliver a virtual women's health clinic offering free, expert medical advice and care via telehealth.
	• Aboriginal women's health clinic: First Peoples' Health and Wellbeing will deliver an Aboriginal women's health clinic providing free, comprehensive and culturally safe care to Aboriginal women. The clinic will provide a range of services to Aboriginal women including screening, diagnosis, and treatment of women's health conditions (including pelvic pain, endometriosis and menopause), long-acting reversible contraception, and termination of pregnancy. Additionally, the clinic will provide education to increase Aboriginal women's understanding of their own bodies, fostering self-determination in health and wellbeing, and promoting Aboriginal women's health literacy.
	• Laparoscopies: An additional 10,800 laparoscopies to help diagnose and treat debilitating endometriosis, which affects one in every 9 girls and women.
	• Sexual and reproductive hubs and primary care sentinel practices: Establish 9 additional sexual and reproductive health hubs, bringing the total number of hubs to 20. All hubs are now operational. The expansion of the hubs improves access to care and provides services such as:
	  ○ long-acting contraception
	  ○ sexually transmissible infection prevention, testing, and treatment
	  ○ medical termination of pregnancy, and support referral for surgical termination.
	• Grants to women's health NGOs: $1.8 million over 4 years is allocated to 13 organisations to establish mental, physical and wellbeing support groups for women to address specific health issues, including chronic disease and menopause. For a list of participating organisations, see Women's Health and wellbeing support groups and programs.
	• Women's health research initiative: Support the creation of a women's health research initiative to identify and treat common health issues (e.g. cardiovascular) and diseases specific to women (e.g. endometriosis). The initiative will establish links with research institutes nationally and internationally, the key health services, researchers and clinicians across metropolitan Melbourne and regional Victoria and drive clinical trials in women's health issues.
	• Inquiry into women's pain: Establish an inquiry into women's pain to examine systemic issues and find solutions that will be the basis for improving patient care. It will enable women and those with living, and lived experience, to inform the design and delivery of initiatives and service improvement relating to pain management services across the state.
	• Research support services: Funding data collection of sex and gender demographics and research projects that explore differences in access to services for diagnostics, treatment, and management of different health conditions. Research findings will inform public health policy and clinical practice.
	• Women's health specialist scholarships: Provide scholarships for extra specialists in women's health. Over 150 scholarships were distributed in 2023-24 to women's health professionals across Victoria.
		provided for Aboriginal Victorians.
		• The establishment of a virtual women's health clinic can help rural women access adequate care and services.
		• Access to laparoscopies to help diagnose endometriosis can help detection of endometrial cancer, due to the link between the two diseases.
		• The Women's Health Research Initiative can help expand the research base for uterine cancers, due to their focus on health issues specifically affecting women.
			service providers to allow these clinics to screen for both breast and uterine cancer.

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Executive Summary Endnotes

[i] See Appendix A for epidemiological and economic impact modelling data, assumptions, method and projections

[ii] See Appendix A for epidemiological and economic impact modelling data, assumptions, method and projections.

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