

# State of the Nation: Uterine Cancers

Australia Country Summary Report

November 2025



Advancing research  
*saving lives*





## **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 in Australia. 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 2025* report is more than data, it provides a window into the lives of Australian women. 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, Australia has 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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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 Mileskin 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

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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

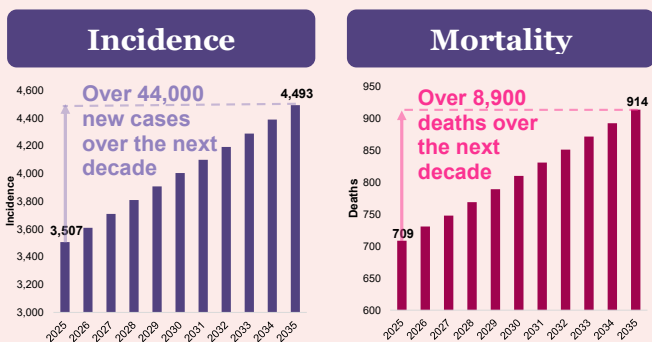
Helena Rodi	Optimal Care Summits Program Manager, VICS Optimal Care Summits
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Dr Kurt Lacovic	CEO, Cancer Trials Australia
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Maureen Turner	CEO, Biogrid
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Prof Pamela Pollock	Professor, Faculty of Health, School of Biomedical Science, Queensland University of Technology
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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.*

# State of the Nation: Uterine Cancers in Australia Summary Report 2025

## A rapidly rising tide of incidence and mortality



## Exacerbating health inequities

- Indigenous women** 1.2x higher mortality rate
- Low Socio-Economic women** 2.1x higher mortality rate
- Regional women** 1.6x higher mortality rate

## Unknown

**94%** Percentage of women do not know about uterine cancer

## Unfunded

**<\$1m** Average amount of research funding invested per annum in uterine cancer in Australia 2003-2020

## Unsupported

**0** Number of national patient support organisations dedicated to uterine cancer

## Missed prevention opportunities

**60%** Percentage of cases that are potentially preventable

**5x** How much more peer nations spend on prevention than Australia

## Barriers to precision cancer care

**0** Funded molecular sequencing to enable classification and treatment consideration

**15%** Percentage of young Australians with cancer that access fertility preservation

## No survivorship model, limited support

**58%** Underperformance relative to state target for supportive care screening

“Nothing about whole-person-care was offered. I had to search for support for the whole-person struggles/issues when I was strong enough.”

## Significant health, economic and social costs to Australia



# State of the Nation: Uterine Cancers in Australia Summary Report 2025

## A CRITICAL NATIONAL PRIORITY: Reversing the rise of uterine cancers in Australia

Priority	Actions	Impact
 <p><b>Invest in research and data</b></p>	<ul style="list-style-type: none"> <li>1.1 Prioritise funding for Uterine Cancer Research and Data</li> <li>1.2 Improve state cancer registry data collection and reporting</li> <li>1.3 Invest in data linkage</li> </ul>	<p><i>Essential enabler to other actions (below).</i></p> <p><i>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.</i></p>
 <p><b>Halve the incidence</b></p>	<ul style="list-style-type: none"> <li>2.1 Awareness campaign</li> <li>2.2 Expand education of risk factors</li> <li>2.3 Invest in new National Healthy Living Strategy</li> </ul>	<p><i>Up to 60 per cent of cases is potentially preventable. Over 2025-2035 this translates into more than 7,800 Australian women and families avoiding a uterine cancer diagnosis (assuming phased implementation of policy reform from 2031), with a potential economic impact in the order of \$4.1 billion over 2025-2035 horizon.</i></p>
 <p><b>Eliminate inequity</b></p>	<ul style="list-style-type: none"> <li>3.1 Indigenous Awareness campaign</li> <li>3.2 Community-led wellness strategy</li> <li>3.3 Expand access to Aboriginal and Torres Strait Islander health officers</li> <li>3.4 Standards for equity in clinical trials</li> <li>3.5 Patient Transport Scheme reform</li> </ul>	<p><i>Achieving equity in survival and incidence for Aboriginal and Torres Strait Islander women and women of low socioeconomic status could benefit up to 20% of cases, representing more than 2,600 Indigenous and low SES women (assuming phased implementation with full benefits realised by 2035).</i></p>
 <p><b>Precision care for every woman</b></p>	<ul style="list-style-type: none"> <li>4.1 Fund comprehensive molecular profiling</li> <li>4.2 Update and improve adherence to clinical guidelines</li> <li>4.3 Accelerate access to diagnostics and medicines through Bridging Fund recommended by HTA review</li> </ul>	<p><i>Precision treatment: More than 15,800 Australian women expected to be diagnosed with advanced or recurrent uterine cancers.</i></p> <p><i>Precision prevention: Early detection and treatment of high-risk women have potential to benefit 3,600 to 5,600 women over 2025-2035 period at an economic value of \$1.4 billion to \$2.0 billion over 2025-2035.</i></p>
 <p><b>Support for every woman to live well</b></p>	<ul style="list-style-type: none"> <li>5.1 Ensure screening for supportive care</li> <li>5.2 Expand access to patient support services nationally</li> <li>5.3 Fund research to develop a model of care for uterine cancer survivorship</li> </ul>	<p><i>Potentially benefit more than 50 per cent of women diagnosed over the next 2025-2035 period, which equates to more than 22,000 women that may otherwise struggle with limited support and potentially manageable side effects.</i></p>

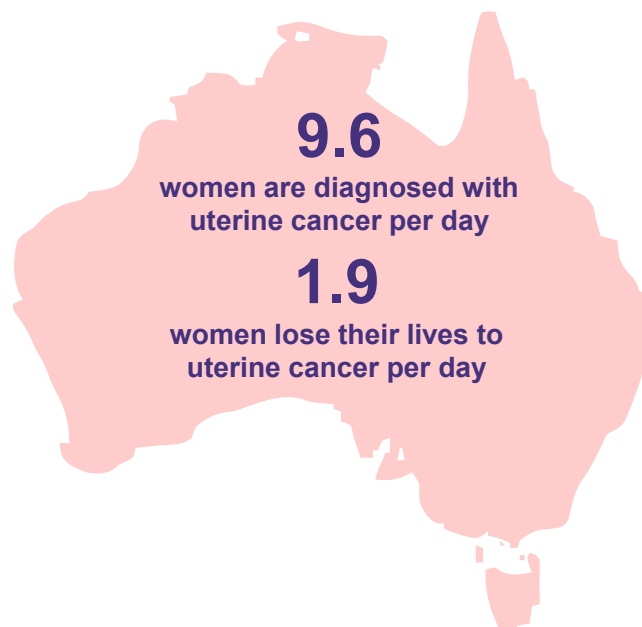
# Understanding uterine cancers

## The most commonly diagnosed gynaecological cancer in Australia

Currently, over 14,400 women in Australia are estimated to be living with a uterine cancer, having received a diagnosis within the last five years.

In 2025 alone, approximately 3,500 Australian women are expected to be diagnosed with uterine cancer, and more than 700 women are expected to lose their lives. This means every day, around 10 Australian women will hear they have uterine cancer, and nearly two women will die from this disease (Figure 1).

**Figure 1: Uterine cancer in Australia – diagnoses and deaths each day**



Source: Insight Economics

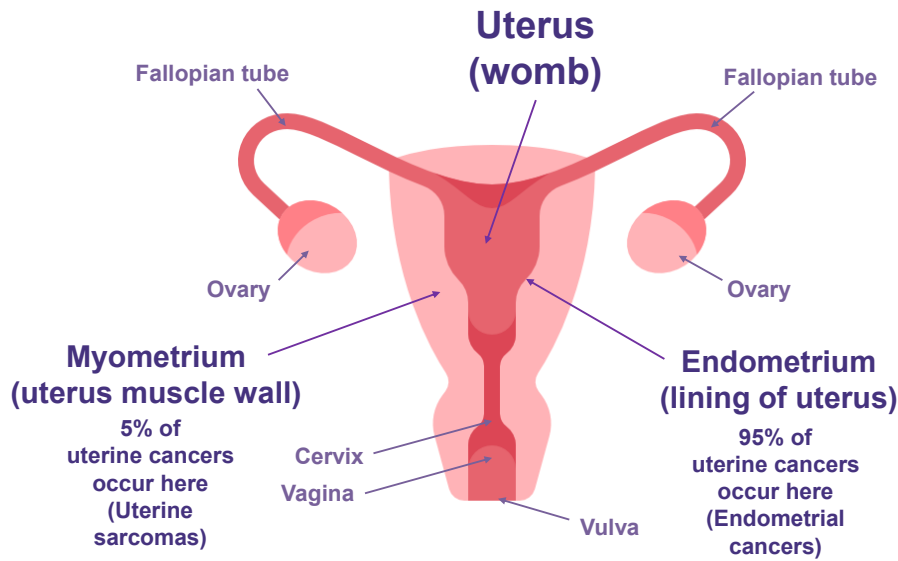
## What is uterine cancer?

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 2: Where do uterine cancers occur?

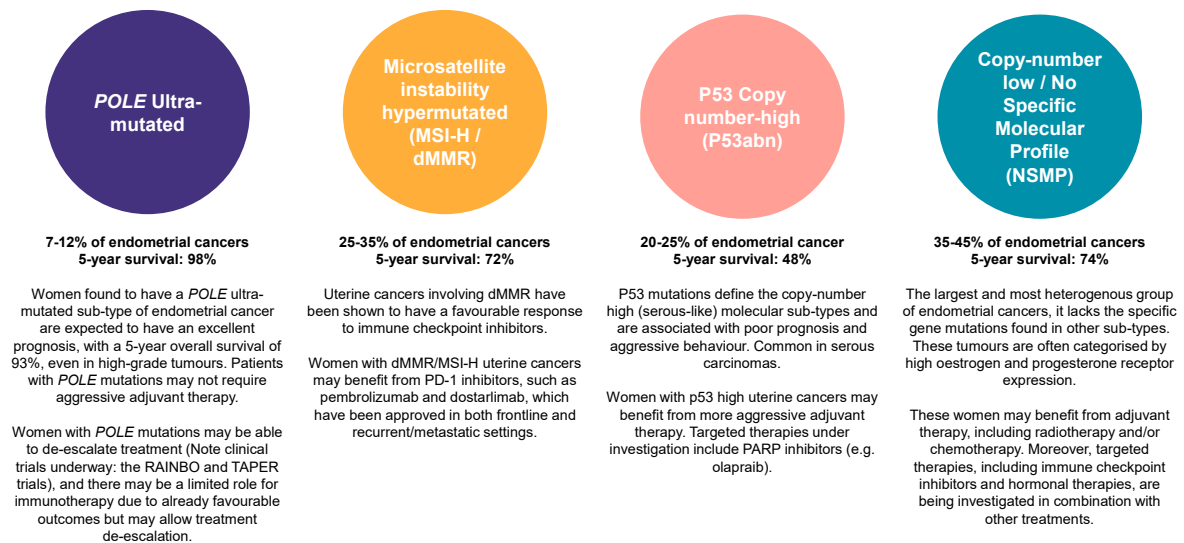


Source: Insight Economics

### In focus: Endometrial Cancer

Historically, endometrial cancers have been divided into two main types: Type 1 and Type 2. These groups were based on the grade and the cell type (histology) that made up most of the cancer. Today, endometrial cancer is divided into four main subtypes based on molecular classification: *POLE* ultra-mutated, microsatellite instability hypermutated (MSI-H), P53 mutations and No Specific Molecular Profile (NSMP). These subtypes have very distinct genetic profiles that have significant impacts for the risk of recurrence of disease in early-stage endometrial cancer and treatment strategies both in early and late-stage disease (Figure 3).

Figure 3: Major subtypes of uterine cancer



Sources: Cancer Genome Atlas Research Network, et. al (2013) and León-Castillo, A., et al, (2020).

Several factors can increase the risk of developing endometrial cancer, many of which

are related to hormonal imbalances between oestrogen and progesterone exposures, which may be driven by a range of reproductive, lifestyle, and medical factors:

- *Reproductive factors*
  - Not reaching menopause until after 55 years
  - Never having had children
  - Starting periods early (before age 12)
- *Genetic factors*
  - Family history of ovarian, uterine, or bowel cancer
  - Having a genetic condition such as Cowden syndrome or Lynch syndrome
  - High polygenic risk
- *Lifestyle and medical history factors*
  - Living with overweight or obesity
  - Type 2 diabetes
  - Polycystic ovary syndrome
  - Using oestrogen only menopause hormone therapy (MHT) previously known as hormone replacement therapy (HRT) or fertility treatment
  - Previous radiation therapy to the pelvis
  - Taking tamoxifen to treat breast cancer
  - Previous sex cord or stromal ovarian tumours.

Many (though not all) of these risk factors are interrelated and influence hormonal balance, with several acting as comorbidities. Women are often exposed to multiple risk factors, 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 endometrial cancer.

### **In focus: Uterine Sarcomas**

A sarcoma is a cancer of the bone, cartilage, fat, muscle, blood vessels, or other connective or supportive tissue in the body. A uterine sarcoma is a rare type of cancer that forms in the muscle or other tissues of the uterus (womb). For most women, this occurs after the onset of menopause, but it can occur at younger ages. There are a number of sub-types of uterine sarcoma:

- *Leiomyosarcomas* — This is the most common form of uterine sarcoma. Leiomyosarcomas develop from the smooth muscle cells of the myometrium. They are often aggressive, often metastasise, and generally have a high recurrence rate. However, leiomyosarcomas can have a good prognosis when caught early.
- *Endometrial stromal sarcoma* — These are rare sarcomas that develop from the connective tissue (or stroma) of the endometrium. These tumours are most often found in pre-menopausal women between the ages of 40-50 years old. These cancers are usually non-aggressive, slow growing, and may have a good prognosis when caught early. A small proportion of these sarcomas are high grade and have a greater risk of recurrence.
- *Undifferentiated uterine sarcoma* — Undifferentiated uterine sarcomas are rare malignancies that can start in either the endometrium or the myometrium. This type

of cancer is often considered to be aggressive, which means they often metastasise and may have high recurrence rates.

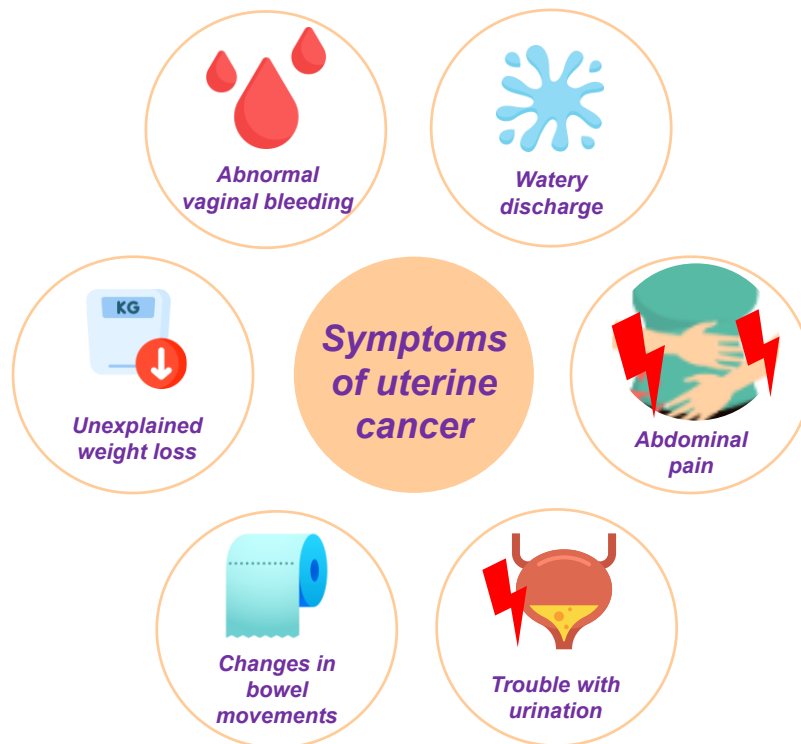
- *Other rare types of Uterine Sarcoma* – Additionally, there are number of other very rare subtypes of uterine sarcoma, including perivascular epithelioid cell tumour (PEComa) and NTRK- rearranged spindle cell sarcoma.

Like endometrial cancers, risk factors for uterine sarcomas include age, living with obesity, diabetes, past treatment with radiotherapy to the pelvis and treatment with tamoxifen for breast cancer, especially for a long time (five years or more). Uterine sarcomas also have a number of genetic risk factors, including hereditary gene changes in TP53, BRCA2 (leiomyosarcoma), Lynch Syndrome (leiomyosarcoma), TSC1/TSC2 (PEComa), FH (leiomyosarcoma) and RB1 (leiomyosarcoma) are all genes associated with uterine sarcomas. A family or personal history of cancers or conditions associated with these genes should be considered.

### What are the signs of uterine cancer?

Recognising early signs of uterine cancer and seeking prompt medical care are critical for early diagnosis and improving outcomes (Figure 4).

Figure 4: Symptoms of uterine cancer



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

Common symptoms experienced by women with uterine cancer include abnormal 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.

Other symptoms can also include unexplained weight loss, difficulty urinating or pain on urination, changes in bowel habits, or persistent abdominal or pelvic pain.

## How is uterine cancer diagnosed?

A doctor typically begins by gathering a thorough medical history and performing a physical and pelvic examination. A doctor may also order a transvaginal ultrasound (TVUS), which is a non-invasive scan that uses soundwaves to evaluate the thickness of the uterine lining (endometrium) and to identify any masses.

If initial tests raise suspicion of uterine cancer, the next crucial step is to obtain a tissue sample to confirm the diagnosis. This will involve an endometrial biopsy, which is the most used diagnostic test for uterine cancer. If the biopsy is inconclusive, or if a more detailed examination is needed, the doctor may recommend a hysteroscopy.

Once the uterine cancer is confirmed, further imaging is also used to determine the extent or stage of the cancer, which may involve an MRI, CT and/or PET scan. MRIs provide a detailed view of the uterus and surrounding issues, while CT scans are used to rule out metastatic disease and PET scans may be used for more advanced cases to detect distant metastases. Clinical best practice also involves the use of comprehensive molecular testing to inform the treatment plan.

Once these initial investigations are completed, uterine cancers can be graded and staged. Grading describes how abnormal the cancer cells appear compared to normal uterine cells. Well-differentiated (Grade 1) tumours tend to grow more slowly and are less likely to spread, while poorly differentiated (Grade 3) tumours are faster-growing and more likely to spread. Staging assesses how far the cancer has spread, both within the uterus and beyond:

- *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 the cancer 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, to other parts of the body such as lungs, bones, or distant lymph nodes in the groin.

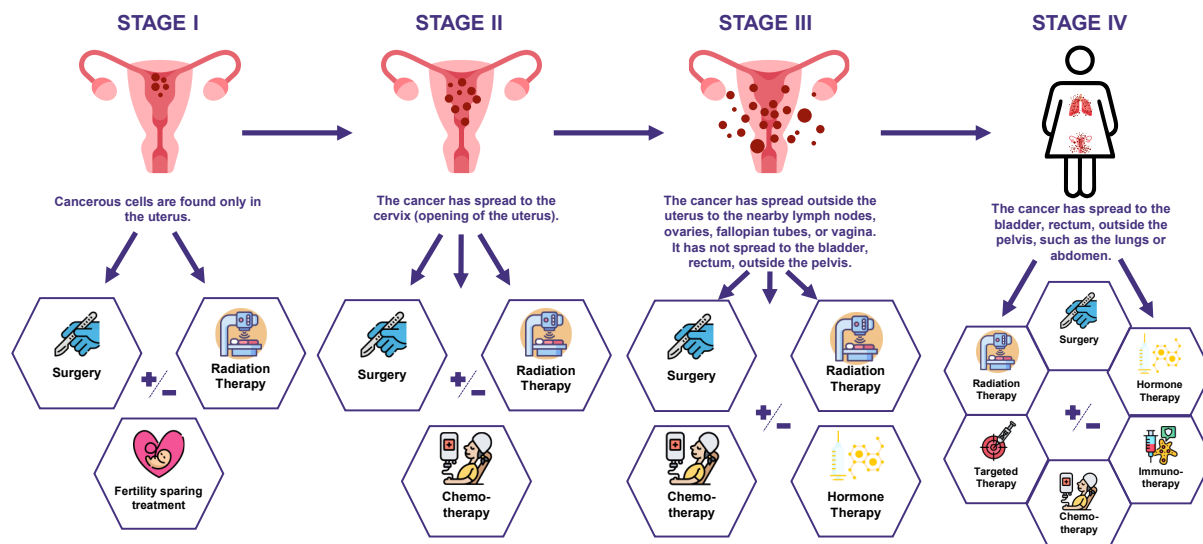
## How are uterine cancers treated?

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

The choice of treatment depends heavily on how far the cancer has spread and the tumour's characteristics (Figure 5). For early-stage (Stage 1) 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 endometrial cancers, surgery alone may be

curative, and no further treatment may be required. This is particularly the case for NSMP and *POLE* endometrial cancers.

Figure 5: Treatment of uterine cancers – a high-level overview



For selected women, particularly younger patients who wish to preserve fertility, or those women who are unable to undergo surgery for other reasons (e.g. they are medically unwell or living with extreme obesity) conservative (non-surgical) management using hormonal therapy may be considered. This would only be recommended for those tumours with oestrogen expression and would not be recommended for those with poorer responses to hormone therapies, such as p53 mutant subtypes. It is also sometimes recommended for women with mismatch repair deficiency (dMMR).

For cancers that have started to spread regionally (Stage 2 or 3), treatment is often more intensive. Surgery is typically followed by radiation therapy, which uses targeted X-rays to destroy remaining cancer cells and reduce the risk of local recurrence. Chemotherapy may also be used, particularly for high-grade or more aggressive tumours and in stage 3 cases.

In cases where cancer is advanced or metastatic (Stage 4), treatment becomes more complex and systemic (affecting the whole body). Hormonal therapy may be used as a first treatment option if the cancer is oestrogen receptor expressing and low grade. In other cases, chemotherapy or chemotherapy with immunotherapy may be used first. Treatments after this will depend on many factors, including the well-being of the patient, whether a targeted treatment option is available, what was used first and how long the cancer responded to the first treatment. Decisions around treatment options are complex, particularly as there are very limited treatment options in the setting of advanced or recurrent uterine cancer.

In addition, women should be assessed for potential supportive care needs from diagnosis, including services to help women improve their physical wellbeing, manage emotional distress and access other financial and practical supports as needed. Quick reference guides are provided at the end of this report with respect to key supportive care services that should be discussed and offered from diagnosis through treatment and into long-term survivorship.

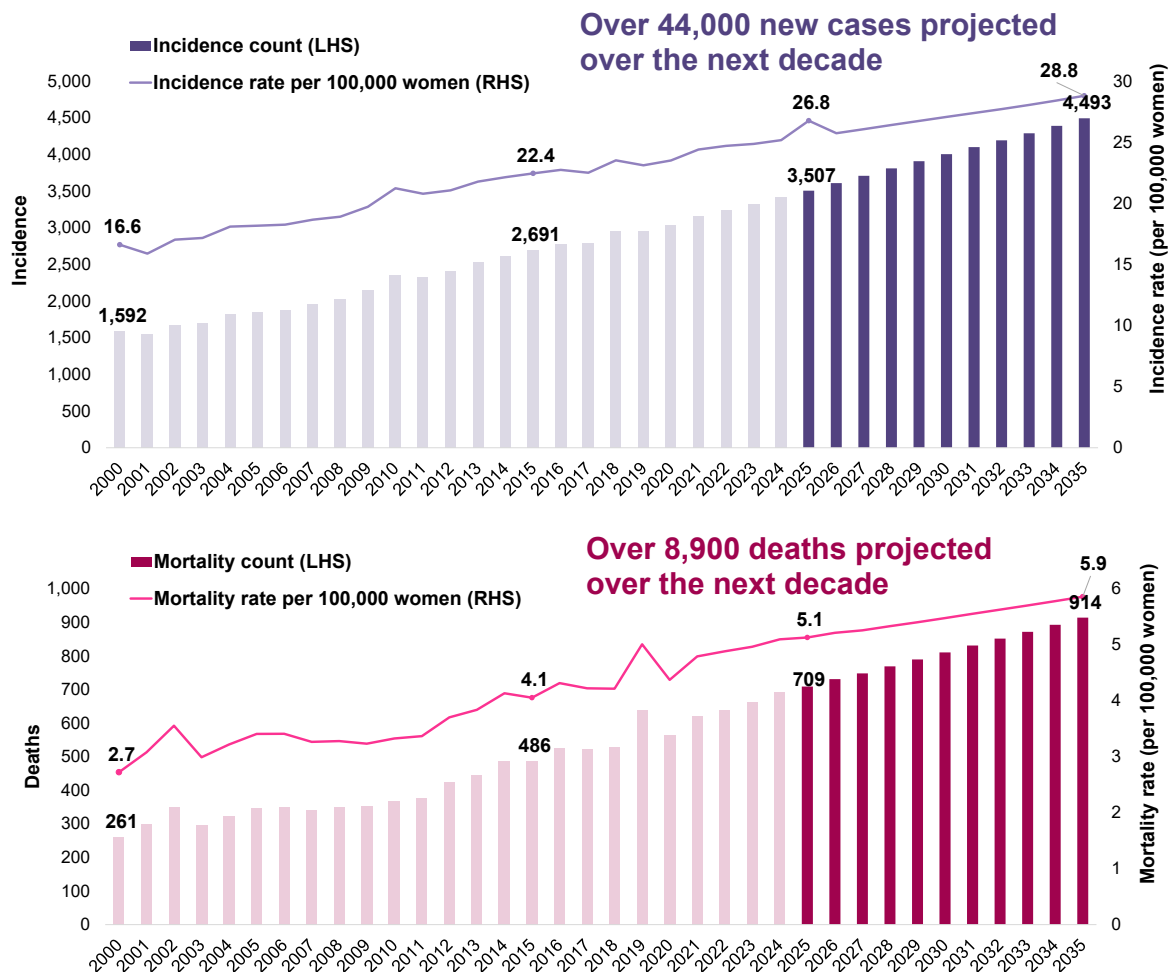
# The rising, inequitable tide of uterine cancers

## Rapid growth in incidence and mortality expected, leading to a health crisis.

Globally, the incidence of uterine cancer has more than doubled and this trend is set to accelerate. Over the past two decades, the global incidence of uterine cancer increased by 132%, and over the next two decades incidence is expected to increase by a further 148%.<sup>i</sup> This means that in one generation, from 2004 to 2044, incidence will have increased 280% globally.

In Australia, similar patterns of growth are anticipated (Figure 6). The number of cases in Australia has grown 16% in the last five years alone. Looking forward, a further 44,000 women are expected to be diagnosed over the 2025-2035 period. The rising incidence of uterine cancer, coupled with more women being diagnosed with advanced stage disease, is expected to lead to an increase in deaths from uterine cancer, with more than 8,900 women projected to lose their lives to the disease over the 2025-2035 period.

Figure 6: Actual and projected uterine cancer incidence and mortality in Australia, 2000-2035

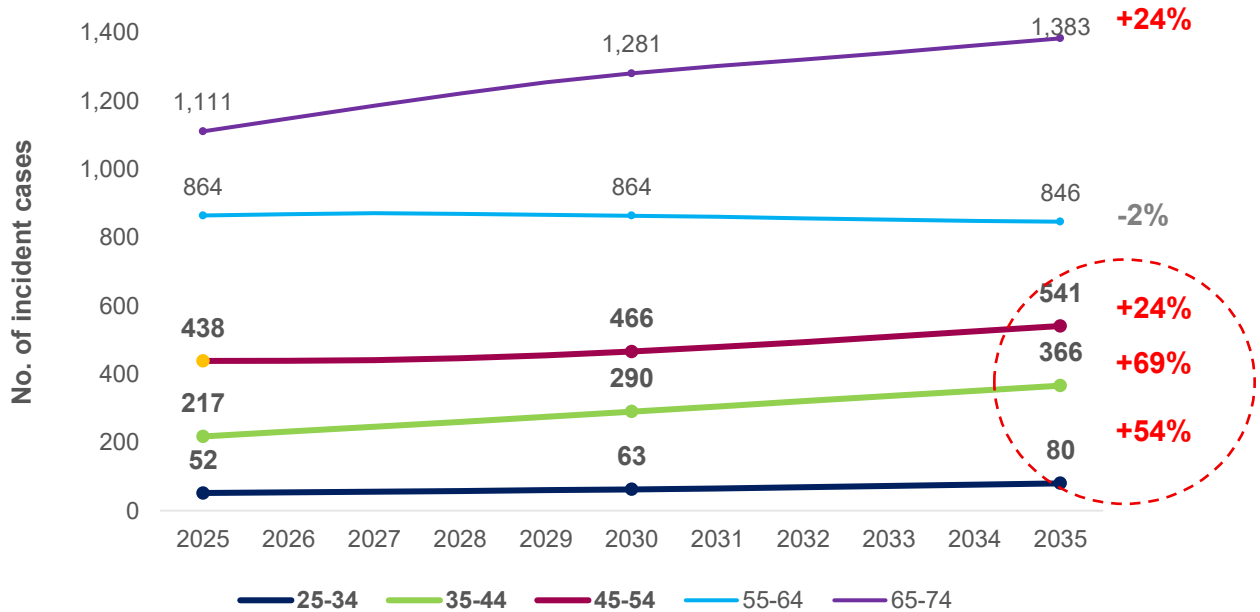


Source: Insight Economics projections. See Appendix A of the Full Report for more details.

### Significant growth in incidence among young women expected

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. Incidence is expected to grow fastest among younger age groups over the 2025-2035 period (Figure 7). For example, among women aged 25-34, cases are projected to rise from 52 in 2025 to 80 in 2035—a 54% increase. In the 35-44 age group, cases are expected to climb from 217 to 366, a 68% increase. For women aged 45-54 and 55-64, more modest growth is projected, with both groups seeing around a 24% increase over the same period.

Figure 7: Projected uterine cancer incidence in Australian women, 2025-2035



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

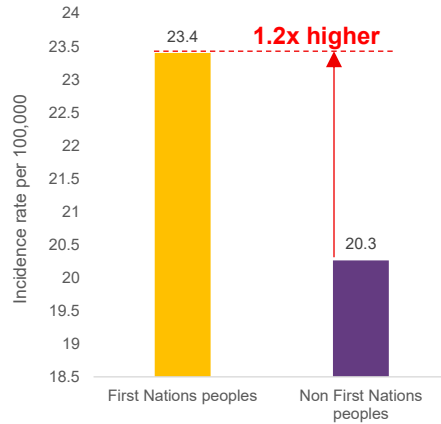
### Uterine cancers disproportionately impact Indigenous and other disadvantaged women, exacerbating health inequity

The rising burden of disease is not shared equally. Priority populations—are at higher risk of uterine cancer, and have poorer outcomes (Figure 8):

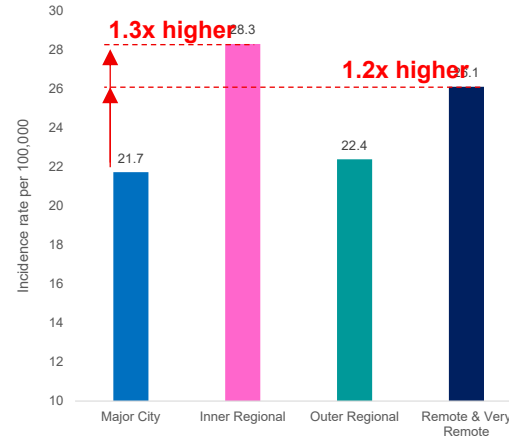
- Aboriginal and Torres Strait Islander women are 1.2 times more likely to be diagnosed with and to lose their life to uterine cancer compared to non-First Nations women
- Women from low socioeconomic status (SES) backgrounds are 1.7 times more likely to be diagnosed with uterine cancer and 2.1 times more likely to lose their life from it compared to women from higher SES backgrounds
- 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 lose their life from it, compared to women living in urban areas.

Figure 8: Increased incidence and mortality in uterine cancer for disadvantaged women

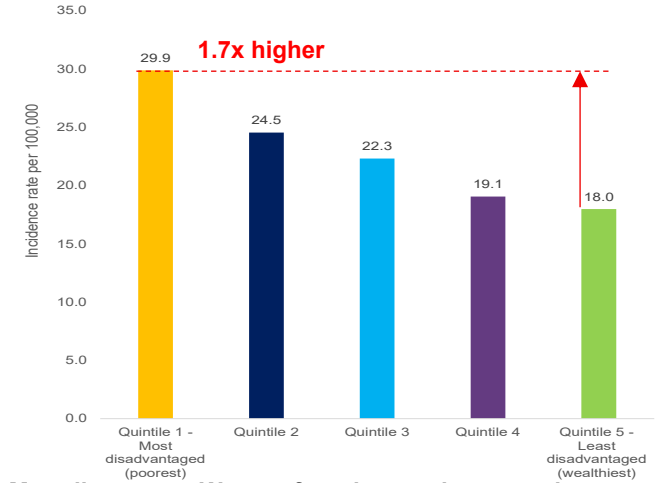
Incidence rates – First Nations women



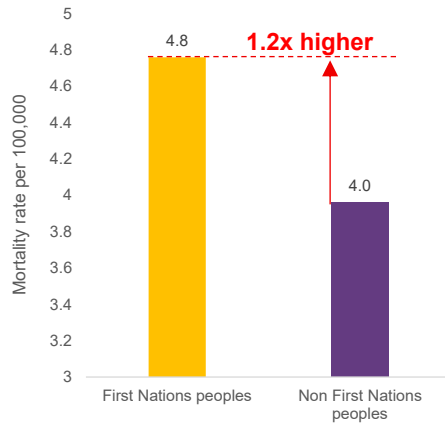
Incidence rates – Women in regional areas



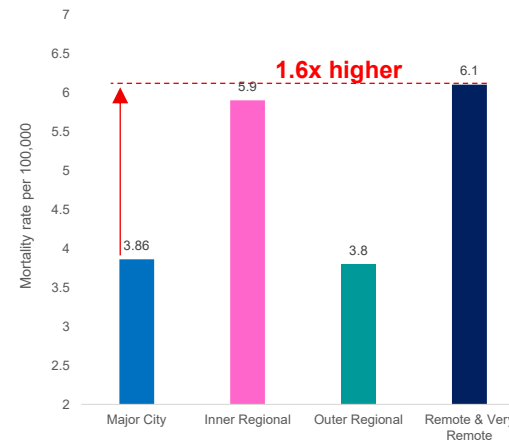
Incidence rates – Women from low socioeconomic areas



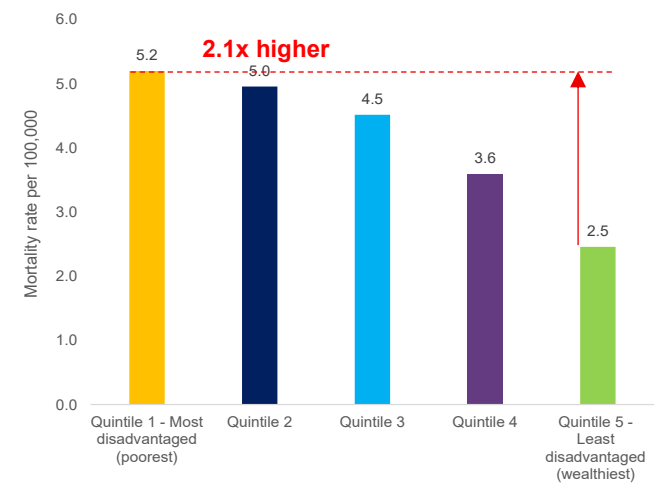
Mortality rates – First Nations women



Mortality rates – Women in regional areas



Mortality rates – Women from low socioeconomic areas

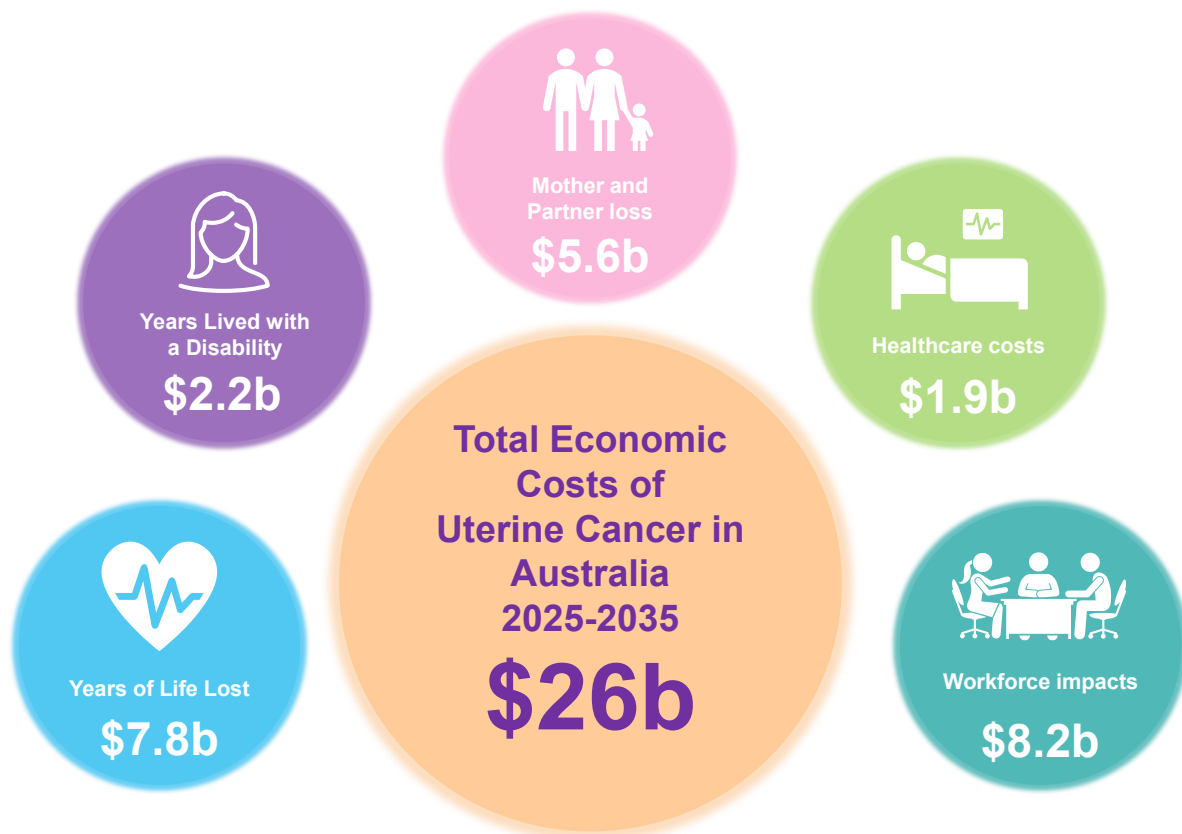


Source: Queensland Health. (2024). OASys.

### Significant health, economic and social costs from uterine cancers

The health and economic costs of increasing incidence and mortality are significant, with an estimated \$26 billion in Net Present Value (NPV)<sub>7%</sub> terms in health and economic costs expected to be incurred over the 2025-2035 period alone. This estimate is comprised of direct health care costs, premature death, years lived with disease, workforce impacts and the impacts on families from mother and partner loss (Figure 9). This is because uterine cancer does not just affect the woman diagnosed; it also touches every part of her family and the wider community.

Figure 9: Economic costs of uterine cancer in Australia



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

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 governments and communities.

# Unknown and unspoken: Poor awareness of uterine cancers

## Part of a broader failure to support women's health over their life course

Despite having a high incidence, being the fifth most commonly diagnosed cancer in women,<sup>ii</sup> uterine cancer remains under-recognised as a major health concern in Australian communities. Most women have never heard of uterine cancers. For example, research shows that 94% of Australian women do not know what uterine sarcomas or endometrial cancers are.<sup>iii</sup>

The silence and stigma surrounding gynaecological cancers works to deter awareness-raising, early presentation, and advocacy. The absence of patient support organisations in uterine cancers with a role to advocate on behalf of women impacted by these cancers is also likely to be one of the major impacts on low community awareness.

Figure 10: Unknown and unspoken – silence around uterine cancer in Australian communities



Source: Insight Economics consumer roundtables. George, M., Abu Asab, N., et al. (2014). Risk Awareness on Uterine Cancer among Australian Women, *Asian Pacific Journal of Cancer Prevention*, 15(23). <http://dx.doi.org/10.7314/APJCP.2014.15.23.10251>.

The consequences of poor awareness for women, their families and the wider community are serious, contributing to growth in preventable disease, delayed diagnoses, inconsistent access to specialist care, inequities in outcomes, and avoidable deaths.

For younger women, this is particularly problematic. 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. 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.

These examples are symptomatic of larger bias in the healthcare system and 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 in healthcare, with 70 per cent of women surveyed reporting the experience of bias in diagnosis and treatment.<sup>iv</sup>

These issues can often be amplified for women from priority populations. Aboriginal and Torres Strait Islander 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.

Additionally, 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 11: Consumer perspectives – stigma and embarrassment prevent women from talking about uterine cancer, seeking advice**



Source: Insight Economics consumer roundtables.

Moreover, while the relationship between obesity and uterine cancer is well recognised, there is no inclusion of this in current guidelines for the investigation of abnormal uterine bleeding, the most common symptom of uterine cancer.<sup>v</sup> Further, obesity is a recognised barrier to accessing healthcare, particularly in relation to gynaecological and pelvic conditions. This relates to feelings of disrespect, being weighed, receiving unsolicited advice, negative attitude of healthcare providers, and equipment being inadequate to enable examination in women with larger body size.<sup>vi</sup>

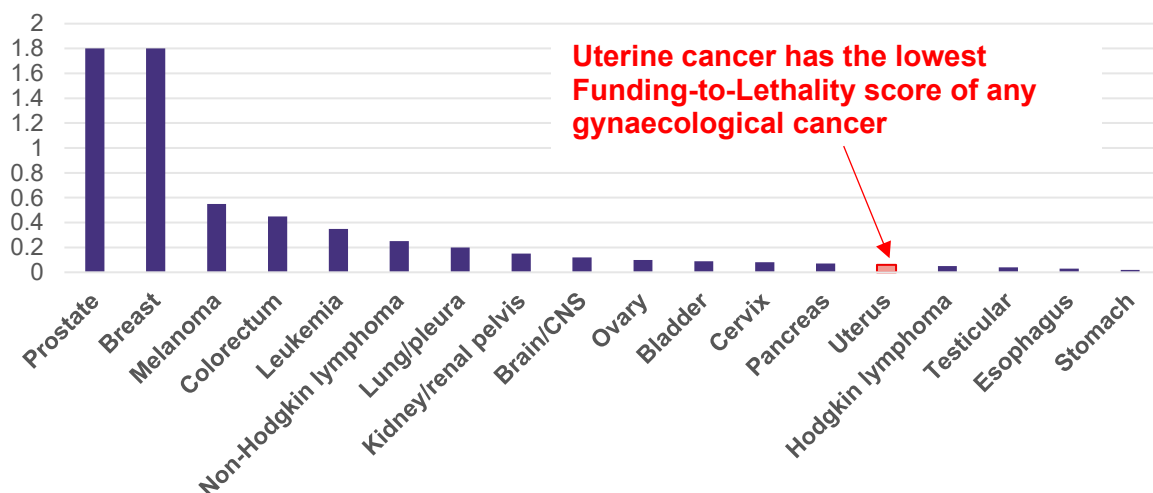
# Underfunded: Lack of investment in research and data

Poor awareness of uterine cancer contributes to complacency and lack of prioritising by policy makers, and in turn underfunding of research and the collection of data to improve clinical practice and inform research breakthroughs.

## Chronic underfunding of research globally and in Australia

Despite the rising and inequitable incidence and mortality patterns observed for uterine cancers, funding by governments and the private sector alike have been historically and recently low. Analysis of funding for research by the United States' National Cancer Institute, for example, shows that funding for uterine cancer has been significantly lower than other cancers. This has been true both historically<sup>vii</sup> and more recently, with a significant disparity in funding allocation in the eight years to 2014.<sup>viii</sup> As a result, uterine cancer has one of the poorest 'Research Funding to Lethality' scores of any cancer (Figure 12).

Figure 12: National Cancer Institute (US) Funding-to-Lethality Scores (2007-2014)

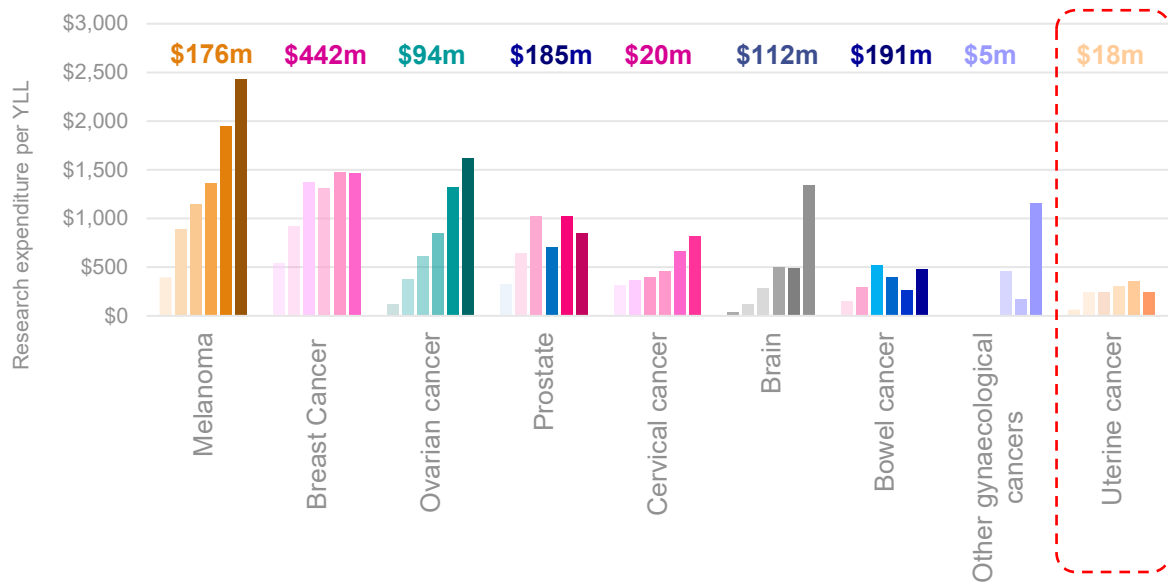


Source: Spencery, R.J. (2019). Disparities in the allocation of research funding to gynaecologic cancers by Funding to Lethality scores, *Gynecologic Oncology*, Volume 152, Issue 1, 106 – 111.

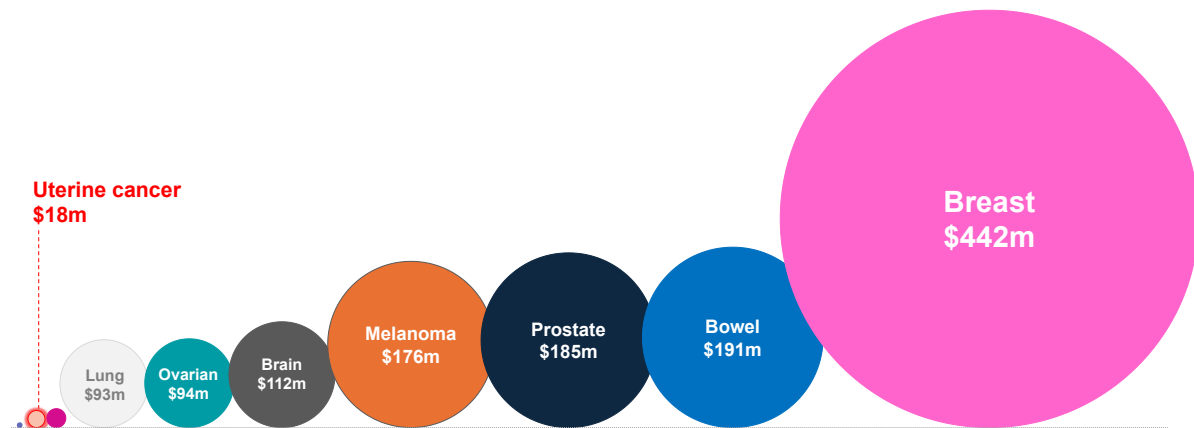
In Australia, uterine cancers are among some of the poorest funded cancers in terms of research funding, both in absolute terms and in terms of disease burden. Cancer Australia's Research Audit, for example, indicated that only \$18 million had been invested over the 2003-2020 period; this translates into less than \$1 million in funding per annum. This contrasts against more than \$442 million for breast cancer research or \$185 million for prostate cancer research over the same period (Figure 13). This severe and persistent disparity in funding has led 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.

**Figure 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

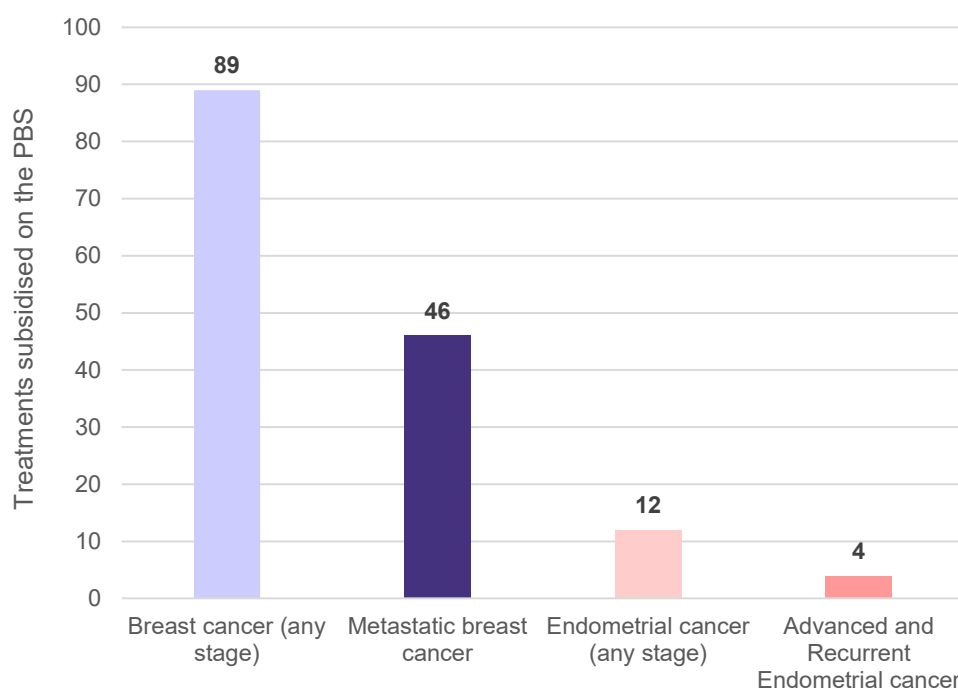


Notes: The columns present a simple ratio of direct research funding reported for each of the following time periods 2003-2005, 2006-2008, 2009-2011, 2012-2014, 2015-2017, 2018-2020, relative to the number of YLLs estimated by the AIHW in 2022 for each cancer. Source: Insight Economics reporting of Cancer 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](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.

Moreover, funding for research and the collection and storage of data on First Nations peoples has been woefully underserved, especially in an Australian context. Aboriginal and Torres Strait Islander women in Australia have been 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. Critically, there is no research on how the genetic makeup of Indigenous women might lead to unique risk factors facing these women, which may further limit future treatment options for these women relative to their non-Indigenous peers.

Limited funding has translated into severely limited treatment options. To put the limited treatment potential into perspective: Australian women with breast cancer have more than seven times as many treatment options as women with endometrial cancer, which accounts for 95% of all uterine cancer diagnoses. Women diagnosed with metastatic breast cancer have 11.5 times the number of treatment options as women with advanced endometrial cancer (Figure 14). Women with rare uterine sarcomas have even fewer options. This is a direct product of significantly more investment in research to identify new therapies for breast cancer relative to uterine cancer.

**Figure 14: Understanding the impact of underfunding of research on treatment options - comparing treatment options for women with breast cancer to treatment options for women with endometrial cancer**



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

Taken together, this points to a need to invest in research, to expand treatment options, attract clinical trials to Australia, 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.

### **A lack of data to support improvements in 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 for improved 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.

Unfortunately, Australia collects and reports minimal data in relation to uterine cancer.

Even basic data on incidence by stage is not understood at a national level, with inconsistently collected and reported data from state to state. Data collected by the AIHW and Cancer Australia are generated based on the organ of origin, without considering the tissue of origin. This makes it impossible to identify sarcoma subgroups and therefore conduct any accurate analysis with regards risks, treatments and outcomes.

Where data are collected, these data are often siloed and cannot be accessed and aggregated in such a way to inform research and policy to improve the treatment and care of uterine cancer (Table 1). There are no national, publicly-available datasets available to understand patterns of care in primary care settings; this impedes improvements in the delivery of primary care. The result is 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.<sup>ix</sup> 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. For uterine cancers this is unavailable.

To try to close some of these data gaps, the National Gynae-Oncology Registry (NGOR) was established as the first national clinical quality registry dedicated to monitoring and improving the care of patients diagnosed with gynaecological cancers.<sup>x</sup> But NGOR lacks the funding and resources to collect sufficient and exhaustive data on uterine cancer patients and therefore currently only information relevant to endometrial cancer is collected and considered. Again, this excludes all uterine sarcomas and other extremely rare cancers of the uterus. Additionally, there are no streamlined mechanisms in place to allow data collection, requiring additional workloads for clinicians for individual patient information.

Both survivors and broader cancer healthcare stakeholders expressed frustration at the current state of data collection. Survivors feel dismay at the thought that data isn't being collected on either the cancer diagnosis or their experiences 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.

While reform efforts are underway at a national level to better coordinate the collection and publication of cancer data, these are long-term strategies that may take a decade or more to deliver on their vision; the development of the National Cancer Data Framework alone has taken two years to be delivered. Significant work is needed in the short-term to improve data collection and reporting by Australian cancer registries, to promote more consistent use of a national patient identifier and to expand data collection across other types of data in Australia.

Table 1: Overview of data collected for uterine cancers in Australia, organised by National Cancer Data Framework domains

Legend: ✓: Very limited population coverage, or high barriers to access. ✓✓: Incomplete population coverage, or limited access. ✓✓✓: Near complete population coverage, readily accessible.											
Data custodian	National datasets				Siloed data						Notes
	DoHAC	AIHW	ABS	ACSQHC	State Govts.	NGOR	Universities / research	GPs / primary care	Hospitals	Industry	
<b>Prevention</b>											
Risk factors – population		✓✓	✓✓		✓✓		✓✓				Survey data on risk factors collected by national health departments.
Risk factors – priority pop.	✓✓	✓	✓		✓✓	✓	✓✓	✓	✓		
Risk factors – individuals						✓	✓✓	✓	✓		
Health interventions pre-diagnosis								✓			
<b>Diagnosis</b>											
Incidence		✓✓✓			✓✓✓	✓	✓		✓	✓	Incidence data is collected by state and territory cancer registries. 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					✓	✓	✓		✓		
<b>Treatment</b>											
Clinical data	✓	✓			✓	✓	✓	✓	✓	✓	

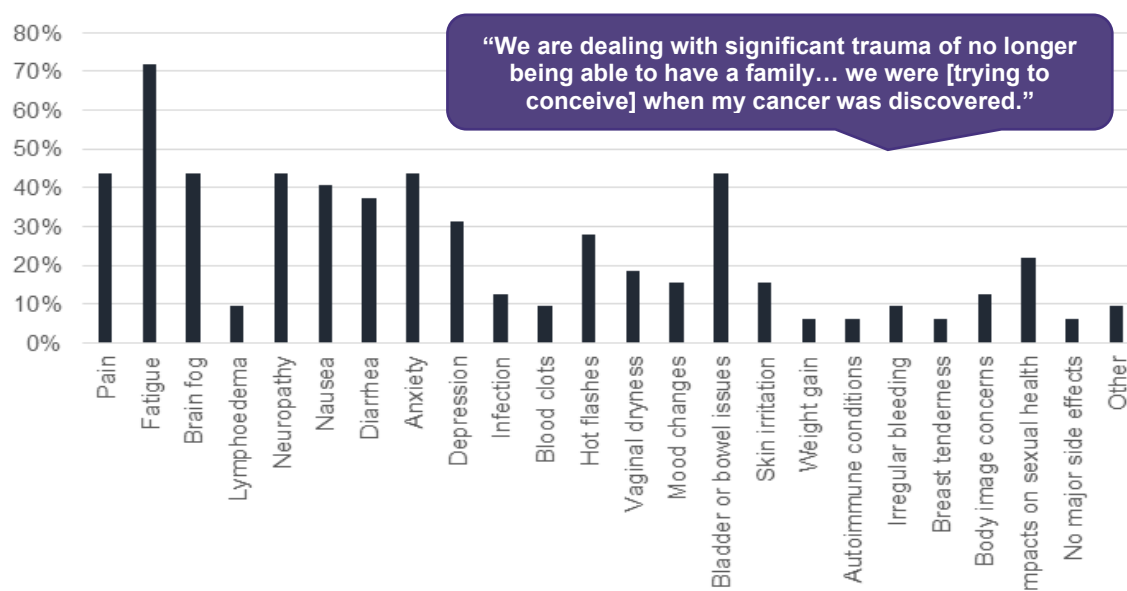
Data custodian	National datasets				Siloed data						Notes	
	DoHAC	AIHW	ABS	ACSQHC	State Govts.	NGOR	Universities / research	GPs / primary care	Hospitals	Industry		
Clinical quality indicators						✓					DoHAC collects clinical data through PBS, MBS and the Private Hospital Data Bureau.	
<b>Outcomes</b>												
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					✓		✓					
<b>Research</b>												
Natural history data						✓	✓	✓	✓		Research data, especially pharmaceutical-related, is often proprietary and not accessible.	
Genomic data						✓	✓		✓	✓		
Clinical trial data					✓	✓	✓		✓	✓		
<b>Legend:</b>	✓: Very limited population coverage, or high barriers to access.				✓✓: Incomplete population coverage, or limited access.				✓✓✓: Near complete population coverage, readily accessible.			

## Unsupported: Inconsistent and inequitable patient support

Access to supportive care, which encompasses all aspects from diagnosis to beyond treatment and aims to improve survivorship and quality of life, is also inconsistent, inadequate and inequitable.

If diagnosed at an early stage, most women will be cured through surgery with a low symptom burden following treatment. But any treatment, and particularly treatments such as radiation and chemotherapy, has the potential for treatment-related side effects. These can be experienced both in the short-term, during treatment, or in the long-term, even years after treatment has been completed.<sup>xi</sup> In a survey for the State of the Nation report (Figure 15), it was found that many women experienced a range prevalence of side effects, with only 6% of uterine cancer patients reporting having experienced no major side effects.

Figure 15: Side effects experienced by women with uterine cancer



Source: Survey of Patients and Carers Living with Uterine Cancer.

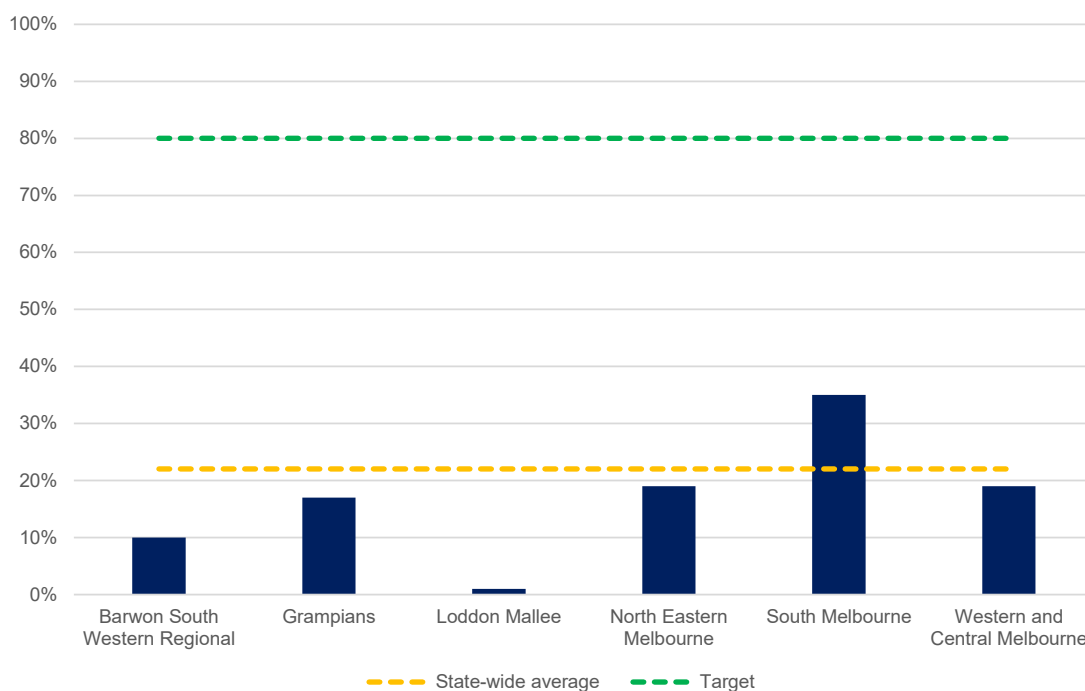
Similarly, an ANZGOG study called EmQuest<sup>xii</sup> indicated that many women treated for endometrial cancer experience a high symptom burden following the completion of treatment.<sup>xiii</sup> For example, among participants in that study:

- 46% reported neuropathy over six months following treatment, with 20% reported this to be moderate to severe
- 25% reported mild-moderate depression
- 29% reported experiencing mild-moderate anxiety
- 3% reported experiencing severe anxiety
- 20% reported moderate to severe insomnia.

Very little data are collected and reported on rates of screening for supportive care needs following a diagnosis of uterine cancer. Victoria stands out as the only jurisdiction reporting

completion rates of supportive care screening, which is undertaken as part of a strategy of the integrated cancer services aimed at improving cancer related outcomes. Data collected showed that rates of supportive care screening fell well below statewide targets of 80% completion in all regions. (Figure 16). Importantly, stakeholders from outside Victoria reported that their own region would have performed similarly or potentially worse than the reported Victorian figures.

**Figure 16: Rates of supportive care screening completed and documented for endometrial cancer patients in Victoria, by region, 2020-22.**



Source: Victorian Integrated Cancer Services.

Additionally, unlike many other cancers impacting women, uterine cancer is distinguished as a cancer that lacks a dedicated, national patient support and advocacy organisation today. While several community support groups exist that might encompass a support role for a patient diagnosed with uterine cancer, such as the Cancer Council and Counterpart, there is no national support organisation focused on advocacy and support for women impacted by uterine cancer. Similarly, while the Australian Government has invested in an Australian Cancer Nursing and Navigation Program to provide general consumer navigation support to cancer survivors, there is no funding for specialist services with these programs for women with uterine cancer as there are for other cancers.

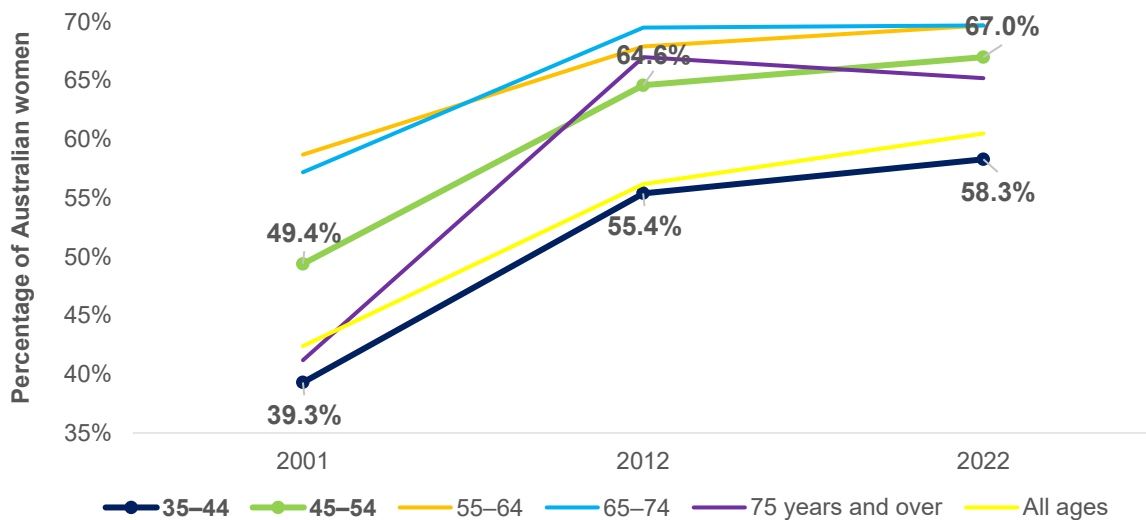
In the absence of a dedicated national patient support organisation, women diagnosed with uterine cancer have not had the same specialised patient support as other major cancers. They have also lacked the ability to come together to raise their voices and awareness of the disease, to advocate for research funding, and to contribute to policy reforms as other cancers. This has likely further contributed to poor awareness of the cancer and very limited policy focus by governments in Australia, with severely low funding for research.

# Missed opportunities for prevention

While there are many recognised risks for uterine cancer, the most significant risk factor is obesity. The rapid rise of endometrial cancer cases observed in Australia is likely the product of the increasing prevalence of higher body weight.

In Australia, the share of adults who are living with a higher body weight has nearly doubled since 1980. Critically, more women are experiencing higher body weight at younger ages. In 2001, 49% of Australian women aged 45-54 were living with overweight or obesity (Figure 17), but by 2022, this rate had increased to 67%. Similar increases are seen in women aged 35-44, suggesting that higher BMI is now being established earlier in life.

Figure 17: Increasing rates of obesity in females by age cohort in Australia (2001-2022)

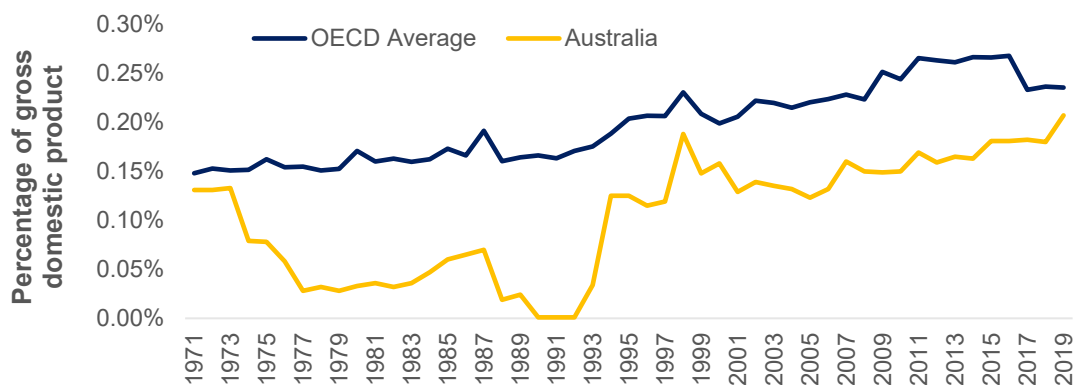


Source: AIHW. (2024). Overweight or obesity tables, 2022 data (latest data); AIHW. (2001). A growing problem: trends and patterns in overweight and obesity among adults in Australia, 1980 to 2001.

As a result, much of the rising incidence of uterine cancer is potentially preventable—potentially up to 60% of incidence<sup>xiv</sup>—but only through investment in policies and programs that promote healthy body weights and health lifestyles, including participation in physical activity in the community.

Australia invests a small amount of budget funding on prevention and improving the wellness of the community. While health expenditure per capita in Australia overall is higher than the OECD average, expenditure on preventive health measures accounts for only 1.3% of total healthcare expenditure, compared to an average of 2.8% in OECD countries — that equates to 54% less investment in prevention than Australia’s developed nation peers. Expressed as a percentage of GDP, Australia spends only 0.13% of GDP on prevention (Figure 18). By contrast, in the EU, spending on preventive healthcare accounted for 0.65% of GDP in 2021.<sup>xv</sup>

**Figure 18: Australian investment in preventative care compared to OECD average, percentage of gross domestic product**



Source: AIHW and OECD data.

This underinvestment in prevention is occurring within a food and built environment that contributes to increasing body weight and rising rates of chronic disease and health inequity (Figure 19). Data show that the food and built environments of Western countries, including Australia, significantly contribute to increasing prevalence of overweight and obesity (obesogenic environments) and, in turn, chronic disease, including cancer.

In Australia, National Health Surveys have shown that Ultra Processed Foods (UPFs) accounted for 42% of total energy intake, while expenditure on UPFs was estimated to have risen by five percentage points from 1989 to 2010.<sup>xvi</sup>

AIHW data also estimated that 78% of adults aged 18-64 were insufficiently physically active and also did not meet the muscle-strengthening component of the physical activity guidelines.

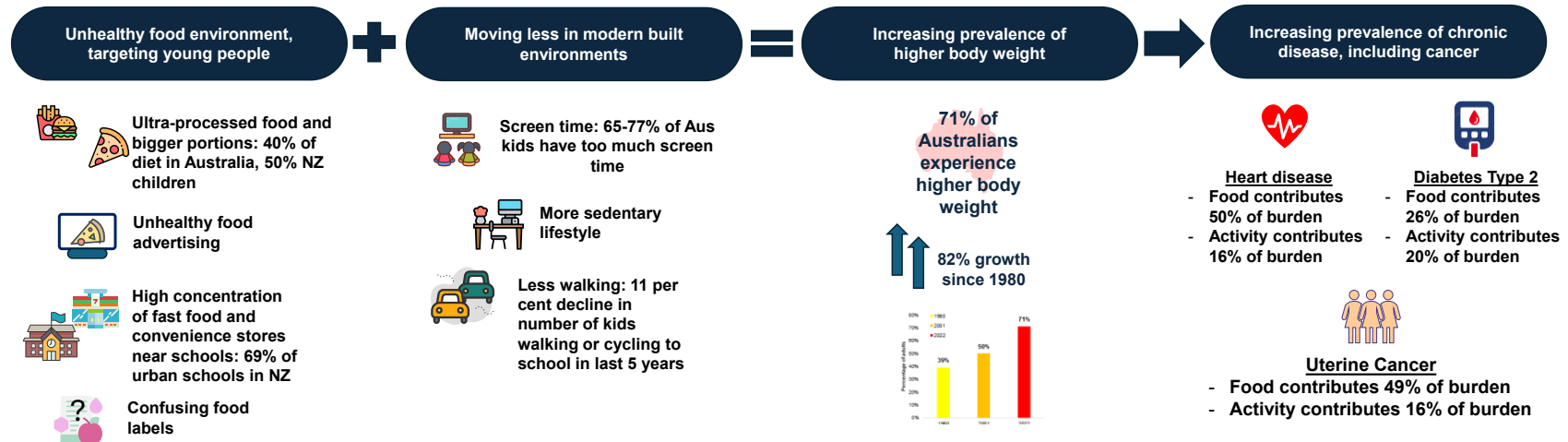
Unhealthy behaviours are often established at a young age, with young people often heavily targeted through advertising and other marketing. Physical activity among Australian children has been found to be low, while screentime has been increasing. Increased screentime among children can contribute to exposure to advertising, which is difficult to avoid, and encourages unhealthy food choices.

Moreover, these unhealthy behaviours significantly contribute to health inequity.

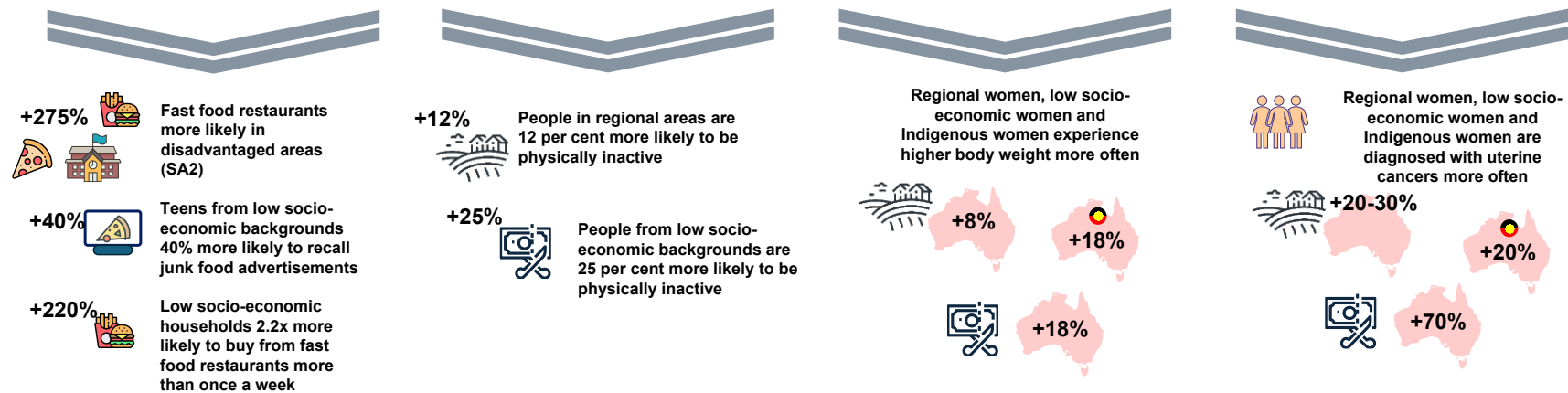
Australian research has shown that low-income earners more frequently consume meals purchased from fast-food outlets.<sup>xvii</sup> Similarly, a Cancer Research UK study demonstrated a link between a child's ability to recall a junk food advertisement and increased caloric consumption, and found that teens from low socioeconomic status communities were 40% more likely to recall a junk food advertisement, compared to teens from better off families. People from outer regional areas were also 12% more likely to be physically inactive, while people from the lowest socioeconomic status group were 25% more likely to be physically inactive than people from the highest socioeconomic status group.<sup>xviii</sup>

Figure 19: The way we live makes it hard to stay healthy – how food and built environments contribute to higher body weight and chronic disease

**Food and built environments contribute to higher body weight and chronic disease, including cancer...**



**... and further exacerbate health inequity, starting at young age**



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

# Barriers to precision cancer care

Contributing to the inequity around the care of patients with uterine cancer are a range of barriers to best practice cancer care, including:

- Lack of funded access to essential genomic tests
- Variation in clinical practice nationally
- Variation in access to fertility preservation
- Delays to Pharmaceutical Benefits Scheme (PBS) funding for medicines available in Australia's developed nation peer countries
- Lack of evidence-based survivorship pathways.

## Lack of funded access to best practice genomic medicine

The recent molecular characterisation of uterine cancers through the work of the Cancer Genome Atlas has ushered in a new and emerging era for precision medicine in uterine cancer, with *POLE* molecular testing recommended as part of international guidelines as part of the pathology work up of endometrial cancers.<sup>xix</sup>

While existing use of immunohistochemistry enables the identification of three of the four molecular subtypes, it does not provide for identification of *POLE* mutations and immunohistochemistry lacks precision in estimating relapse risk. As a biomarker, a *POLE* mutation is likely to outrank all other histological features and molecular markers in terms of risk of relapse.<sup>xx</sup>

Despite the importance of molecular testing, however, this is not currently funded in Australia. MBS funding for immunohistochemistry is available, but data collected by NGOR indicate that while most tumours are assessed for dMMR (98%), testing for other potential precision medicine biomarkers is substantially less. NGOR<sup>xxi</sup> estimates report that oestrogen and progesterone receptor testing is completed in 76% of tumours, p53 testing is completed in only 40% of tumours and *POLE* testing is completed in only 2.7% of tumours. This low level of testing likely reflects the lack of funding for these tests.

*This means that almost no woman diagnosed with a uterine cancer receives a complete diagnosis of her specific uterine cancer molecular sub-type.*

## Variation in clinical practice in cancer diagnosis, treatment and care

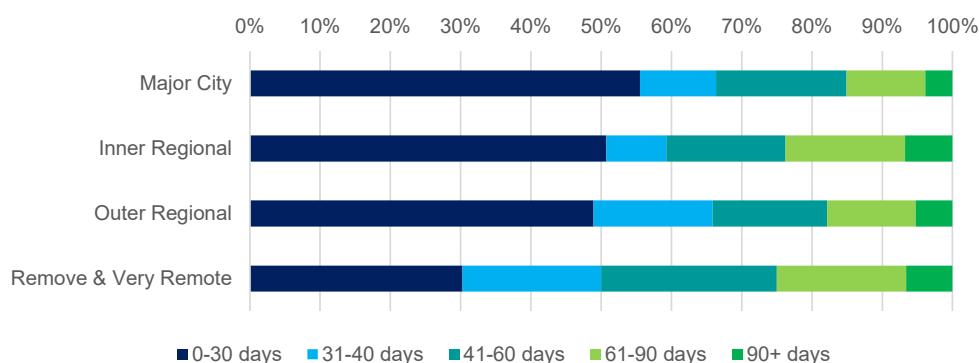
Australia lacks up-to-date clinical guidelines, while data and stakeholder interviews suggest there is substantial variation in clinical practice in Australia along the whole care pathway:

- Stakeholders indicated that there was substantially different practice to diagnostic work-up of patients from state to state, with varying use of imaging and other diagnostic tests ordered from state to state.
- Variation was 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 raised in access to fertility preservation and screening for supportive care. There was also a lack of access to bariatric services that might help women with pre-invasive cancers become fit enough for surgery.

- Stakeholders reported that variation in follow-up care and surveillance was often significant and anxiety producing, necessitating a nationally consistent approach.

There is also significant variation in time to treatment observed nationally. Women living in regional and remote areas experience longer delays to treatment than their metropolitan counterparts (Figure 20).

**Figure 20: Proportion of Queensland uterine cancer patients who receive treatment within a band of time, by remoteness**



Source: Queensland Cancer Data Alliance. (2025). Queensland Uterine Cancer Quality Index 2013-2022.

### Lack of access to fertility preservation services and supportive care

As more young women are diagnosed with atypical endometrial hyperplasia or early-stage endometrial cancer, there is an increasing need to consistently explore opportunities to preserve fertility. Continued research is needed to optimise treatment planning in these women,<sup>xxii</sup> but it is also clear that more work could be done to better support women that choose to seek pregnancy prior to surgery to achieve this treatment goal (Figure 21). Only 15% of young cancer patients in Australia access specialised consultation and undergo fertility preservation before cancer treatment.<sup>xxiii</sup>

For endometrial cancer, treatment with hormonal therapies such as a progesterone implanted IUD has been found to be effective as a primary treatment regimen that also helps young women with low-grade early-stage endometrial cancer to preserve fertility.<sup>xxiv</sup> However, the more advanced the disease, 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.

Many women that follow fertility sparing treatment can also struggle to become pregnant. For example, young women with atypical endometrial hyperplasia or early-stage endometrial cancer often also experience polycystic ovarian syndrome (PCOS) and anovulatory infertility, which makes them in need for assisted reproductive technologies to actively get pregnant.<sup>xxv</sup>

Women with a higher body weight may also require additional specialist supportive care services or surgery to realise her goals for childbearing, but unfortunately, access to fertility services may be restricted and are not always successful. Due to the lower likelihood of a successful pregnancy in women living with obesity, many public fertility services require a patient to have a BMI of under 35 as a criterion for referral, preventing women living with higher body weight from being able to access funded fertility specialist services. This was echoed by our stakeholders who indicated women living 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 assisted pregnancy.

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.

**Figure 21: Stakeholder perspectives on the need to improving access to fertility preservation and support for women to have a baby**



Source: Insight Economics consumer roundtables.

### Delays in access for new medicines compared to Australia's peers

In Australia, drugs like carboplatin and paclitaxel are subsidised through the PBS. These drugs are recognised as the most effective chemotherapies for the treatment of advanced endometrial cancer and have been shown to improve survival among patients.

In recent months, immune checkpoint-inhibitor therapies have been approved 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 is the combination of pembrolizumab with lenvatinib as a second line therapy regardless of dMMR status. This is limited relative to treatment options available in other parts of the developed world. Women with uterine cancer in the US, UK and Canada, for example, have funded access to more targeted therapies.

Ensuring Australian 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 the rest of the world.

### Inconsistent screening for familial cancer risk

The first assessment for hereditary endometrial cancer and Lynch Syndrome is immunohistochemistry assessment for mismatch repair proteins. Based on preliminary clinical data collected by NGOR from 2023, it appears this is performed almost universally, or with a high degree of coverage, but other genetic tests are not performed on all patients.

But, dMMR testing is only the *first* step to determining whether a woman has Lynch syndrome.<sup>xxvi</sup> Immunohistochemistry testing for mismatch repair genes (*MLH1*, *MSH2*, *MSH6*, or *PMS2*) will provide information regarding 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 Lynch syndrome.

Funding for methylation testing is not available through the MBS and is usually completed through familial cancer service budgets. 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, preliminary 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 or long waiting lists. Importantly, this is consistent with previous analysis completed by the Clinical Oncology Society of Australia (COSA), which estimated that improved screening for Lynch syndrome would increase diagnoses by 50%.<sup>xxvii</sup> Similarly, in the PHAEDRA study, a clinical trial assessing the benefit of durvalumab in advanced endometrial cancer, found that, of women with potential hereditary risk, only two thirds of participants reported having had their family history taken and only 35% of women were referred to genetic services.<sup>xxviii</sup>

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 culturally experienced care

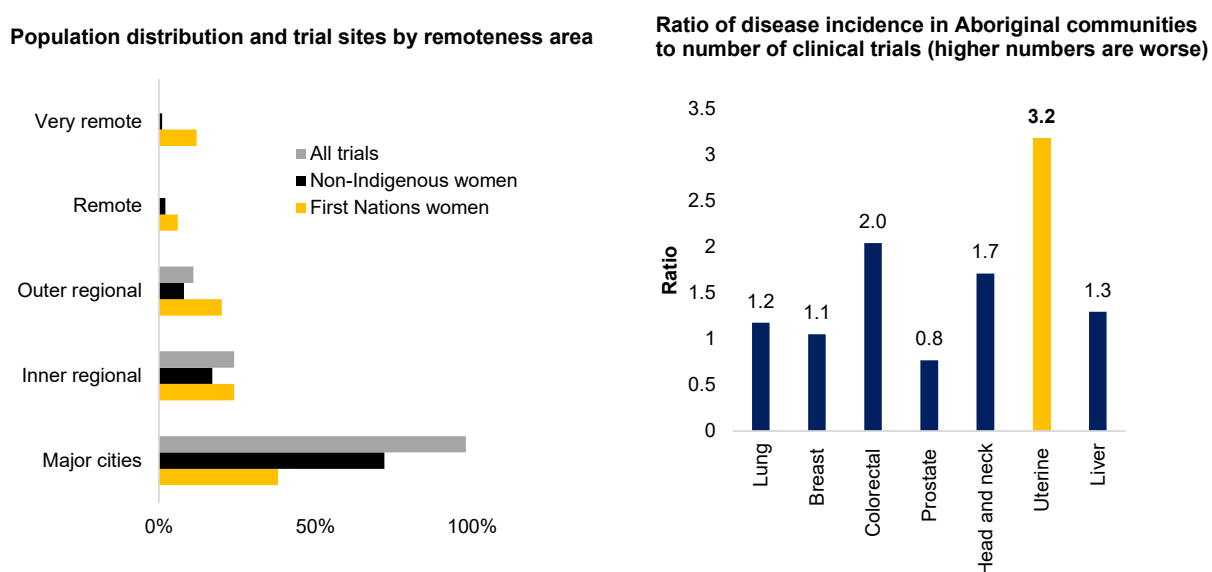
Outcomes for priority populations are consistently worse than for the general population; this is true for health care broadly as well as for uterine cancer specifically. Women from culturally and linguistically diverse groups of people may face a range of barriers, some of which are shared and some of which are unique to their racial or cultural background.

For example, Muslim women throughout the western world<sup>xxix</sup> (including in Australia)<sup>xxx</sup> 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. Research has found that a range of cultural factors can have a negative impact on health seeking behaviours, such as engaging in prevention activities and in making decisions around cancer treatment.<sup>xxxi</sup> 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.<sup>xxxii</sup> 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.<sup>xxxiii</sup> Similarly, a study of the availability of 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.<sup>xxxiv</sup> There is also plausible evidence suggesting Aboriginal and Torres Strait Islanders face systemic barriers which prevent their participation in clinical trials.<sup>xxxv</sup>

Women from Indigenous and culturally and linguistically diverse backgrounds, more broadly, are underrepresented in clinical trials (Figure 22), and when they are represented, can face significant barriers preventing accurate collection of data. For example, for domestic trials, patient-reported outcomes must 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 gynaecological cancer resources found that these resources tend to be difficult to understand, with poor actionability.<sup>xxxvi</sup> This makes it difficult for women from culturally and linguistically diverse backgrounds to engage with these resources, and to understand the risks of treatment.

**Figure 22: Barriers to participation in clinical trials 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.

### Lack of survivorship models of care and guidelines

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

Survivors have expressed frustration around a lack of guidance and clarity following treatment (Figure 23). Overall, women found the standard of care post-treatment to be inconsistent, with one woman likening the experience to “having a splinter removed.” Other stakeholders similarly 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.

**Figure 23: Stakeholder and consumer perspectives – Lack of survivorship support and evidence for best practice surveillance**



Source: Insight Economics stakeholder consultations and consumer roundtables.

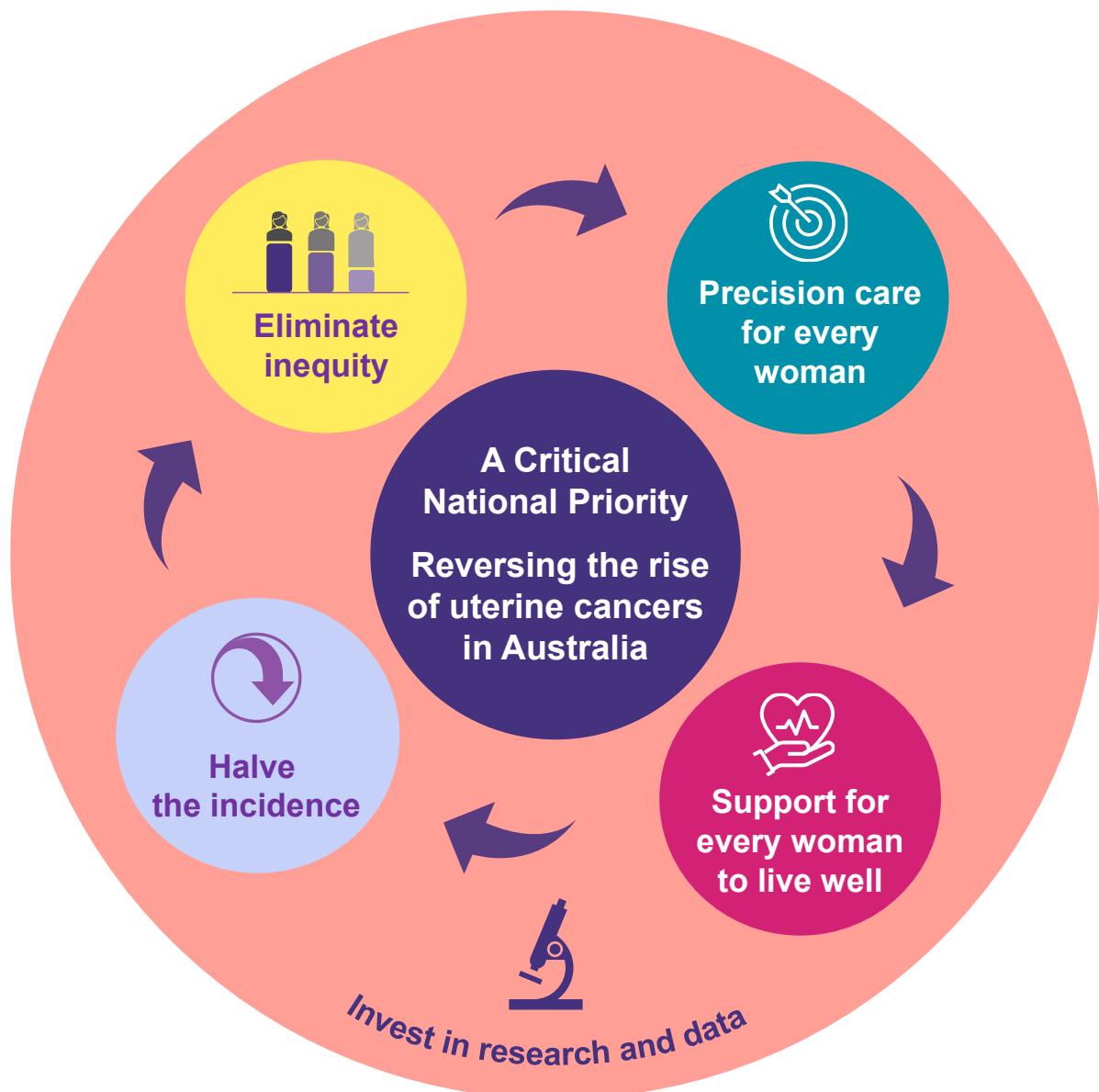
In order to alleviate these issues among survivors, long-term survivorship models of care for uterine cancers are needed throughout Australia. Currently policymakers and caregivers face significant barriers in implementing such a framework across the health sector. Both survivors and other stakeholders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

# A critical national priority: Reversing the rise of uterine cancers in Australia

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

The vision is to transform uterine cancers from a largely unknown and underfunded health crisis to a critical priority for governments and reverse the rise of uterine cancers.

Figure 24: Vision and goals for uterine cancer





## Strategic Priority 1: Invest in research and data

In spite of being the most common gynaecological cancers in Australia, uterine cancers have been notably absent from national health priorities. Unlike other cancers, uterine cancers have not benefited from widespread community awareness, political attention, or coordinated efforts to improve prevention, and overall care. Limited investment in research, the delay in the evolution of guidelines and the inability to utilise precision molecular tools have resulted in significant gaps in access to timely and effective care — especially for women in underserved or higher-risk communities.

Investing in research will work to deliver improvements in survival and quality of life for more than 44,000 Australian women expected to be diagnosed across Australia over the 2025-2035 period and the 18,700 Australian women that will be living with uterine cancer by 2035.

**This was identified to be the highest priority for action by governments by consumers, researchers and clinicians.**

This high prioritisation by the uterine cancer community reflects a strong understanding of the relationship between research investment and improved outcomes for cancer survivors, as well as concern regarding the limited treatment options available to women with rare, recurrent and advanced cancers.

To correct the very significant underfunding of uterine cancers against a backdrop of rising incidence and mortality, it is recommended that Commonwealth Government prioritise funding a national uterine cancer research strategy led by a national, collaborative taskforce or working group involving ANZGOG, state governments, philanthropy and related non-government organisations. The taskforce would develop a national response and funding for the research priorities noted below.

Even with severely limited funding, in the past ten years Australia has made important contributions to advancement of knowledge of uterine cancers, leading a small number of world-leading clinical trials as well as innovative molecular research and the development of care models for patients diagnosed with endometrial cancers and uterine sarcomas.

Looking forward, Australian researchers have a significant role to play along the whole of the care pathway. Stakeholders saw a significant opportunity to expand investment into health implementation science in addition to basic, translational and treatment research. 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.

Given Australia's areas of comparative advantage and global priorities for research, a number of major priorities for Australian research have been identified (Figure 25). These include projects to improve awareness and develop new models of care for primary and secondary prevention of cancers. It also includes molecular and translational research to identify new biomarkers and treatments for rare, recurrent and advanced cancers and 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.

Figure 25: Priorities for uterine cancer research in Australia– 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

To deliver this high impact research program, comprehensive, Australia-wide strategy, led by a national uterine cancer taskforce or working group, is 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 based on the findings of above based research.
- Development of living clinical guidelines to drive practice improvements.

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

Action is also needed to address the significant data gaps that exist for uterine cancer that impede an understanding of outcomes across Australia’s health system; this includes:

- Improving state cancer registry data collection and reporting
- Investing in data linkage (NGOR) and streamlining researcher access to data.

While important action is being taken at a national level to develop a National Cancer Data Ecosystem, alongside this work, investment is needed to accelerate 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.



**Strategic Priority 2: Halve the incidence**

Potentially up to 60% of uterine cancer cases are preventable — but little investment in programs and strategies have been implemented to improve women’s health. If all these cases were prevented, this would benefit nearly 7,800 women and families over 2025-2035 horizon, with a potential economic impact in the order of \$4.1 billion over 2025-2035 horizon (assuming phased implementation with full benefits realised by 2035).

Prevention strategies, such as promoting healthy lifestyles, managing chronic conditions, and increasing awareness, can lead to earlier detection and intervention, which improve outcomes and reduce 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 to improve awareness of uterine cancer, risk factors and prevention
- 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

- A New National Strategy for Healthy Living
- A pilot of targeted screening of high-risk women in selected care settings and develop models of care for prevention
- Consistent screening for Lynch syndrome and development of tools to assess for other familial cancer risk.

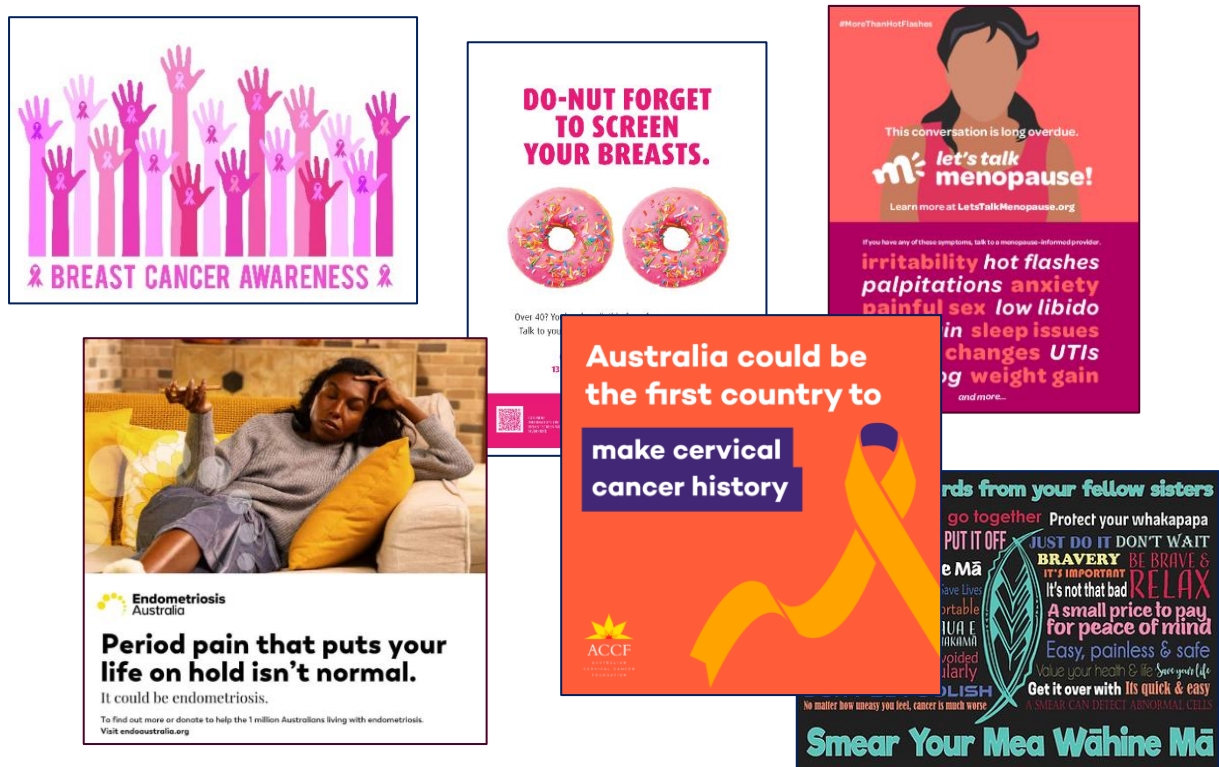
These are discussed in turn.

**National awareness campaigns for uterine cancer**

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 and cervical cancer or non-cancer conditions such as menopause (Figure 26), 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.

Figure 26: 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 27).

Figure 27: Stakeholder perspectives on the need for an awareness campaign



Source: Insight Economics Consumer Roundtables.

### ***Education as part of a wider women's health strategy***

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 (e.g., 'Well Woman' checks beginning from age 40). This is consistent with Women's Health Strategies that focus 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 1). Similarly, successful models which promote mobile women's health services, like the Victoria's Women's Health Bus, could be expanded upon to reach underserved and regional populations.

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

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

**Box 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 and teenagers, 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*, which provide a strong foundation for reform.

### ***A New National Strategy for Healthy Living***

While raising awareness of uterine cancer is important, awareness alone is not enough. Without addressing the broader, systemic drivers of risk—such as the increasing proportion of our population living with obesity and physical inactivity—efforts to improve outcomes will likely be limited. 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.

For example, Australia'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
- Awareness campaigns
- Subsidies and incentives
- Development of new models of care for obesity management as part of health service delivery.

Universal, population-wide risk prevention strategies should be complemented by increasingly specialised, targeted models of care for women at increasing levels of risk (Figure 28).

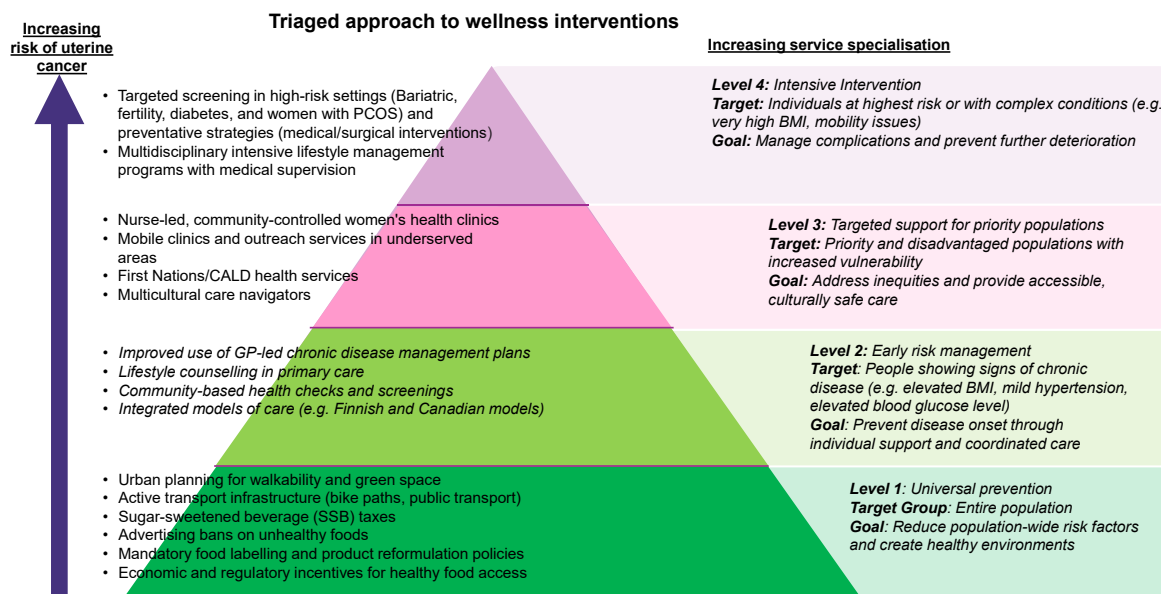
For example, women at intermediate risk, such as those showing early signs of chronic disease, should have consistent access to GP-managed chronic disease management plans. For women at higher risk, due to factors like obesity, insulin resistance, or clustering of multiple chronic conditions, more intensive, 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 developed as part of the wider research strategy to detect precancerous changes early. These should be supported by medical and surgical interventions delivered through bariatric, fertility, diabetes, and PCOS or endometriosis 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 28: Tiered intervention model (triage pyramid) for women at varying levels of uterine cancer risk**



Source: Insight Economics

### ***Pilot targeted screening of high-risk women in selected care settings and develop models of care for prevention***

Substantial research is underway to support the identification of high-risk women and the development of reliable methods of screening for uterine cancer (Box 2). 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.

#### **Box 2: Improving early detection and diagnosis – research developments and future directions**

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**<sup>xxxvii</sup> and **DETECT**,<sup>xxxviii</sup> which are minimally invasive devices that can be used to detect endometrial cancer through cervical samples.
- 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.<sup>xxxix</sup> 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 also shown the use of AI (**ECgMPL**) to review histopathological images can improve the accuracy of diagnoses from approximately 80% (78.91–80.93%) when using current clinical practice to more than 99.26% when using the AI system.<sup>xi</sup>

Early identification of women with a typical hyperplasia or early-stage endometrial cancer opens up greater treatment choice and the potential for prevention and improved survival outcomes.

Source: 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>. 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>; 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; 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; 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>; 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>.

While more work is needed, improvements in clinical practice can also be made today; research shows that women with high risk of endometrial cancer are more likely to present to other healthcare settings, allowing for early detection of endometrial cancer or the precursor lesion atypical hyperplasia. In a small single centre study of 72 women attending a metabolic bariatric surgical clinic 14% were found to have either endometrial cancer or atypical hyperplasia.<sup>xli</sup> This study demonstrated the opportunity for screening in a health service directed to women living with obesity.

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 PCOS, diabetes or even orthopaedic clinics.

Research has shown treatment of women at high risk of endometrial cancer or in early-stage endometrial cancer can realise excellent treatment outcomes. For example:

- *Surgical interventions, including bariatric surgery or prophylactic hysterectomies* — Bariatric surgery was associated with a 71% reduced risk for uterine malignancy overall, and an 81% reduced risk if normal weight is maintained after surgery.<sup>xlii</sup>
- *Hormonal therapies, such as the use of IUDs* — The use of IUDs in women with early endometrial cancer and atypical hyperplasia resulted in complete response rates of 43% and 82%, respectively.<sup>xliii</sup> 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 also 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% compared to IUD use alone.<sup>xliv</sup> It should be noted, however, that other studies have found that prolonged use (over two years) of certain GLP-1 RAs, like exenatide, was associated with an increased risk.<sup>xlv</sup> 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 reduction when combined with other interventions. Complete response rates for Stage I endometrial cancers rose to 67% for IUD plus weight loss, compared to 61% for IUDs alone and 57% for IUDs plus metformin.<sup>xlvi</sup> Similarly, a 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.

Research has also shown that women want to understand and reduce their risks. For example, in a survey of 660 UK women, 96% of women reported they would be willing to be assessed for endometrial cancer risk and more than 80% of respondents indicated they would make lifestyle changes to reduce their endometrial cancer risk, including the use of contraceptives or other primary prevention strategies.<sup>xlviii</sup> GPs also reported strong interest in supporting women, with 93% indicating they would be willing to offer an endometrial cancer risk assessment, potentially during a Well Woman screen.



### Strategic Priority 3: Eliminate inequity

Reducing disparities in the risk of, and mortality from, uterine cancer for Aboriginal and Torres Strait Islander women, women living in regional or remote areas, and those from low socioeconomic backgrounds in Australia 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.

For Aboriginal and Torres Strait Islander women, policy reforms could support the expansion of mobile and community-based health services, more equitable access to gynaecology specialists by Indigenous women, 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 New Zealand) to support culturally appropriate treatment planning and care. Other reforms include enhanced funding for sovereign data collection and reporting, alongside workforce development that includes training and recruitment of First Nation health professionals.

Additionally, for women from remote and regional areas of all backgrounds, reforms to Patient Transport Schemes offer a major opportunity to reduce the risk of financial toxicity, particularly for those with low socioeconomic backgrounds. Access to low- cost or no-cost mobile and community-based health services would also allow women of low socioeconomic background a greater access to gynaecologic specialist care.



## Strategic Priority 4: Precision care for every woman

### ***Improve funded access to best practice genomic medicine***

Implementing and funding molecular profiling for *POLE* for all endometrial cancers is essential to improving patient outcomes and advancing equity in cancer care. These traditional 'one-size-fits-all' approaches have failed to deliver significant survival gains for these women. For women with advanced or recurrent uterine cancers, comprehensive molecular profiling should be implemented for all, not just for those well enough to consider participation in a clinical trial.

Beyond testing for *POLE*, broader 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 mission. 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 each case has access and opportunity for presentation at an MDT meeting prior to definitive treatment recommendation.

### ***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. Identification of 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).<sup>xlviii</sup>

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, 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
- 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.

### ***Improve access to novel treatments***

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<sup>xlix</sup>—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:

- 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 Appendix A of the Full Report, 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.



## **Strategic Priority 5: Support for every woman to live well**

Survivorship, while often overlooked in uterine cancer treatment, is a distinct and critical stage of the care pathway, which begins from diagnosis. Women should be offered supportive care from diagnosis and women who have completed treatment often require dedicated long-term support, including surveillance for recurrence, management of late effects, and psychosocial care.

Unlike other gynaecological cancers, there is no dedicated, national patient support organisation raising awareness and championing policy reforms that will improve outcomes for women with uterine cancers. 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 supportive care needs, expanding access to patient support, peer support and psychosocial services. Alongside more consistent screening, this could involve the expansion of the Teal Nurse Support program run by Ovarian Cancer Australia, as well as funding of research to develop a model of care for uterine cancer survivorship. 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 3 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.

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

**Box 3: 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 a 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.

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.](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>.

# Partners for change

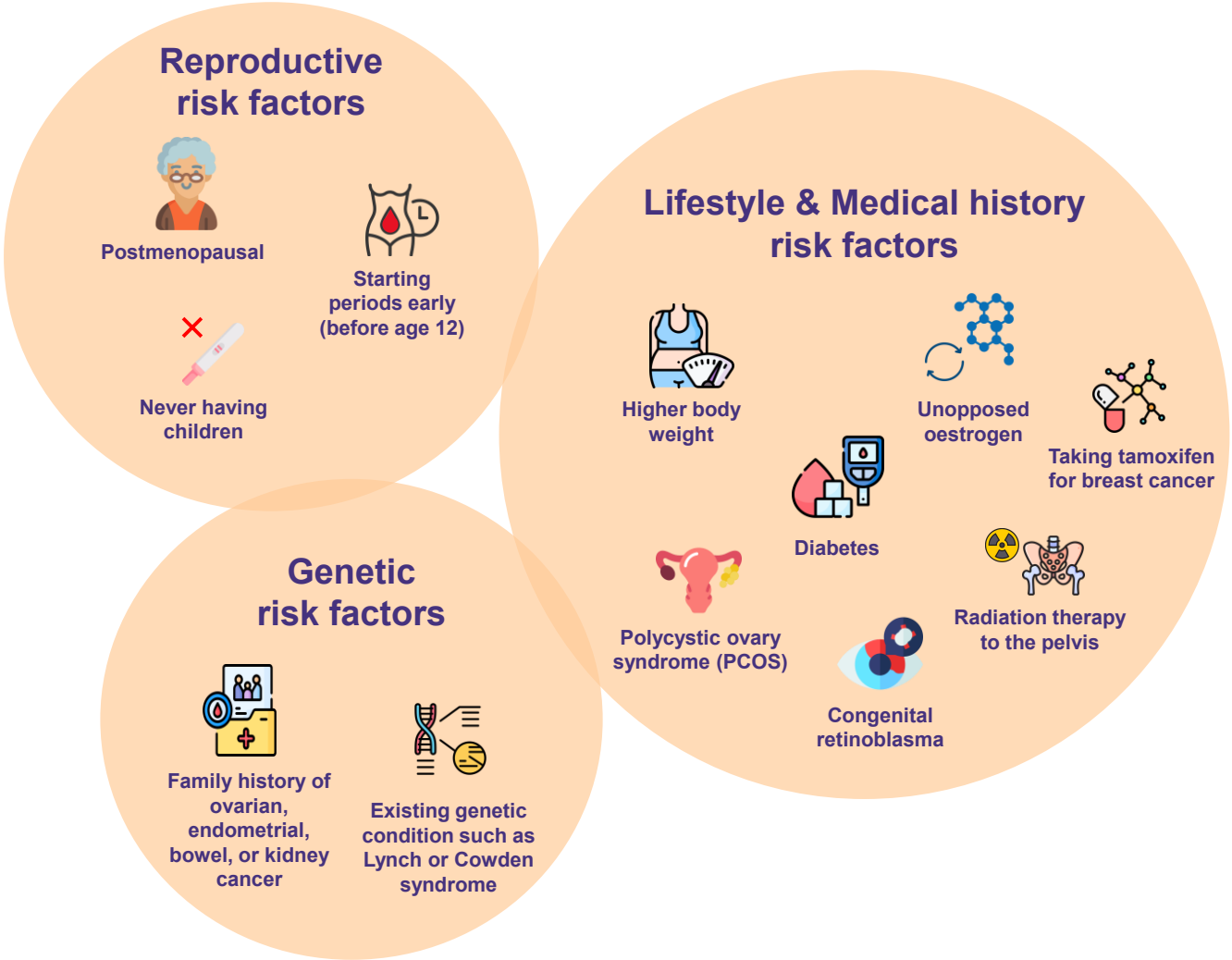
***“Collaboration is the key to reversing the rise and halving the impact of uterine cancers on women, their families and our communities. We welcome opportunities to work with like-minded organisations on this critical priority”***  
***Professor Clare Scott AM, ANZGOG Chair***

Delivering this work will require strong, long-term collaborative partnerships across both the cancer sector and the wider health and social services system. It will also require sustained collaboration from governments, the not-for-profit sector and industry. Organisations with the potential to help improve women’s health and reverse the rise of uterine cancers include:

- Cancer Australia
- Department of Health and Aged Care
- Australian Prime Minister & Cabinet
- Australian Treasury
- National Women’s Health Advisory Council
- State and territory governments
- Primary Health Networks
- Cancer registries
- National Aboriginal Community Controlled Health Organisation
- Federation of Ethnic Communities’ Councils of Australia
- National Health and Medical Research Council
- Australian Research Council
- Medical Research Future Fund
- National Collaborative Research Infrastructure Strategy
- Australian Institute of Health and Welfare
- Australia New Zealand Gynaecological Oncology Group
- Omico
- Zero Dash
- National Gynae-Oncology Registry
- Australian universities and medical research institutes
- Ovarian Cancer Australia (OCA)
- Counterpart
- Rare Cancers Australia
- McGrath Foundation
- Cancer Council Australia
- Cancer Councils
- Australian Survivorship Centres
- Australian Rare Cancers Portal
- Clinical Oncology Society Australia
- Cancer Nurses Society Australia
- Medical Oncology Group of Australia
- Human Genetics Society of Australasia
- Australian Society of Gynaecologic Oncologists
- Royal Australian College of General Practice
- Royal Australian College of Surgeons
- Royal Australian and New Zealand College of Obstetricians & Gynaecologists
- Royal Australian College of Pathologists
- Obesity Australia
- The Obesity Collective
- Heart Foundation
- Diabetes Australia
- Business Council of Australia
- Consumer Health Forum
- Pharmaceutical industry partners.

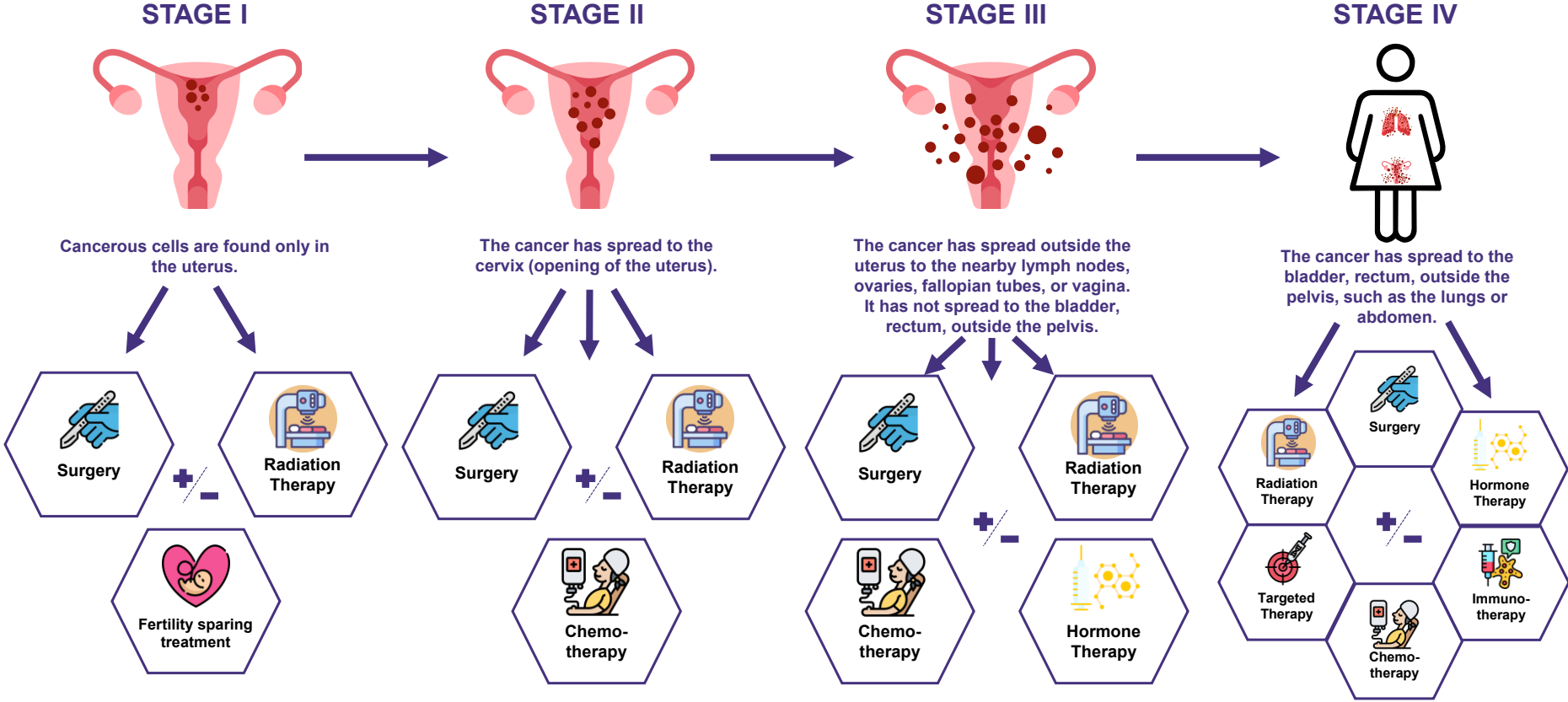
# **Quick Guides to uterine cancer risk factors, treatment, supportive care and research questions**

### Quick Guide to Uterine Cancer Risk Factors










Source: Insight Economics









### Quick Guide to Uterine Cancer Treatment



Source: Insight Economics

### Quick Guide to Supportive Care

Physical Wellbeing		
Exercise support		● ● ●
Nutrition support		● ● ●
Weight management		● ● ●
Pain management		● ● ●
Lymphoedema support		● ● ●
Emotional and Mental Health		
Psychologist support		● ● ●
Peer support		● ● ●
Pastoral care		● ● ●

Practical and Financial Support		
Social worker support		● ● ●
Financial counselling		● ● ●
Return-to-work support		● ● ●
Childcare support		● ● ●
Transport support		● ● ●
Future Planning		
Familial cancer risk		● ● ●
Palliative care		● ● ●
Fertility planning*		● ● ●

● Pre-treatment      ● During treatment      ● Post-treatment

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

Source: Insight Economics

## Quick Guide to Key Research Questions in Uterine Cancer



### What are the exact molecular and genetic drivers of uterine cancer by subtype?

- Identify additional molecular biomarkers
- Racial and ethnic specific risk
- Develop further understanding of hereditary risk (e.g. polygenic risk score)
- To further understand the relationship between risk factors for UC and carcinogenesis (e.g. PCOS, endometriosis, obesity)

### What is the role of the immune system in uterine cancer?

- Immune therapies for selected patients
- Role of the tumour microenvironment
- Further the understanding of treatments response and resistance (innate and acquired)

### Improving disease models

- Develop models to enable novel treatment testing e.g. organoid, PDX
- Develop models to explore ADC applicability e.g. panel testing, proteomics



### 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
- Identify novel biomarkers for screening for atypical hyperplasia and uterine cancers

### 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 be minimised?

- Impact on quality of life, sexual health, lymphoedema risk, and fertility in survivors

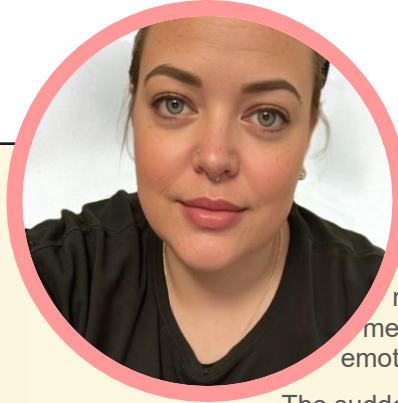
- Survivorship pathway

### How can we maximise quality of life and long-term health of survivors?

- New models of care to improve wellness
- Patient support
- Peer support

# **Australian women perspectives: the stories of uterine cancer survivors**

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.

### Alex's story - 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.

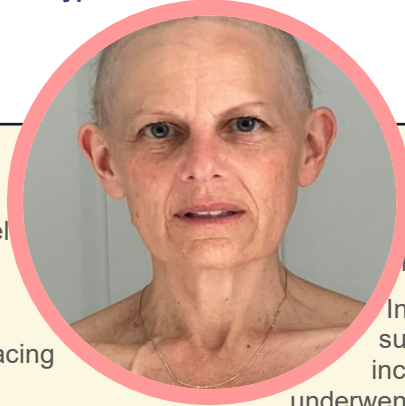
Living in a regional area only made things harder. Long hours of travel, extended wait times, and the emotional strain of being far from home weighed heavily on her. "It shouldn't matter where you live or what type of cancer you have," Alex reflected.

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.*"

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."

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# Endnotes

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