

# Gynaecological Cancer Transformation Initiative

*A \$100 million commitment to deliver breakthroughs and best practice treatment and care for everyone with a lived experience of gynaecological cancers ... your mothers, daughters, sisters and friends.*

**Extended Executive Summary - Updated 25 February 2025**





Advancing research  
*saving lives*



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## Stronger Together

It is time to transform the diagnosis, treatment and care pathway for women with a gynaecological cancer. With devastating low survival rates, treatment resistance, no form of early detection for many, and poor information pathways, these women's cancers are most often diagnosed at later stages, when disease is widespread, and recurrence is the norm.

Women and their families are desperate for change to the diagnosis and management of cancers that have been overlooked for decades, costing lives and heavily impacting families, the community, women's participation and financial wellbeing, and the economy.

Australia is one of the world's recognised leaders in cancer research, and yet there remains a trickle of funding allocated to gynaecological cancers relative to their lethality and impact.

As the leading organisations for gynaecological cancer in Australia, we believe this document provides a compelling case for support that offers effective and attractive solutions where few currently exist.

Government has made great strides with its strategic funding support for programs such as Omico, Zero Children's Cancer, the National Cancer Nursing and Navigation Program, and the Medical Research Future Fund program strategies.

It is now time to put women's gynaecological cancers front and centre in our discussions about women's health, women's disease, and change.

As a major new collaboration, the **Gynaecological Cancer Transformation Initiative's** aim is to connect, coordinate, amplify and leverage existing programs to deliver better outcomes for all those diagnosed with a gynaecological cancer. This initiative engages researchers and clinicians proactively and with greater agility, to provide cohesive diagnosis, treatment and care pathways for women, underscored and enhanced by increased investment in world-class research, data and information.

We encourage you to read this document in full – it will surprise, and likely shock in parts, however, we hope you will see that for the 7,000 women diagnosed with gynaecological cancers every year, this initiative represents a genuine lifeline to greater hope, better outcomes, and improved survival for this generation of women and the next.

Yours sincerely



**Alison Evans - CEO  
ANZGOG**



**Debbie Shiell - CEO  
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**Robin Penty - CEO  
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Developed by  
women with  
gynaecological  
cancer and leaders  
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## Executive Summary

The Gynaecological Cancer Transformation Initiative has been developed in partnership with women with a lived experience of gynaecological cancers and eminent scientists and business leaders who are deeply concerned about poor health outcomes for women and families impacted by gynaecological cancers.

Under the leadership of the Australia New Zealand Gynaecological Oncology Group (ANZGOG) in unity with Ovarian Cancer Australia and the Ovarian Cancer Research Foundation as well as many other collaborators across the sector the GCTI will address gaps in coordination, research, practice and support, and will be delivered in partnership by Australia's leaders in research, molecular profiling and patient support along with the Australian Government.

The Initiative brings together three key and interdependent areas of focus:

- *The patient journey*—equitable access to optimal treatment and improved survival, with an enhanced experience through improved access to personalised, specialist supportive care
- *The clinical team*—delivering timely care that is driven by innovative application of technology, research and data
- *The research community*—a framework for co-ordinating and integrating gynaecological cancers research for rapid translation into new treatment solutions ('bench to bedside').

The goal of the Initiative is to revolutionise research translation, diagnosis, treatment and care in gynaecological cancers. A core pillar of the Initiative is an outreach program focused on expanding the use of molecular profiling and precision medicine maximising the productivity of Australian research infrastructure including access to programs such as Omico and the Australian Rare Cancers Portal. This will ensure that women receive the best possible health outcomes, benefiting them, their families, and the Australian community.

We are asking the Australian Government for a **\$100 million commitment over 4 years including from its strategically aligned Medical Research Future Fund** programs to take advantage of a once-in-a-generation opportunity to revolutionise the diagnosis, treatment and care pathway for women with a gynaecological cancer, saving lives.

The Gynaecological Cancer Transformation Initiative is:

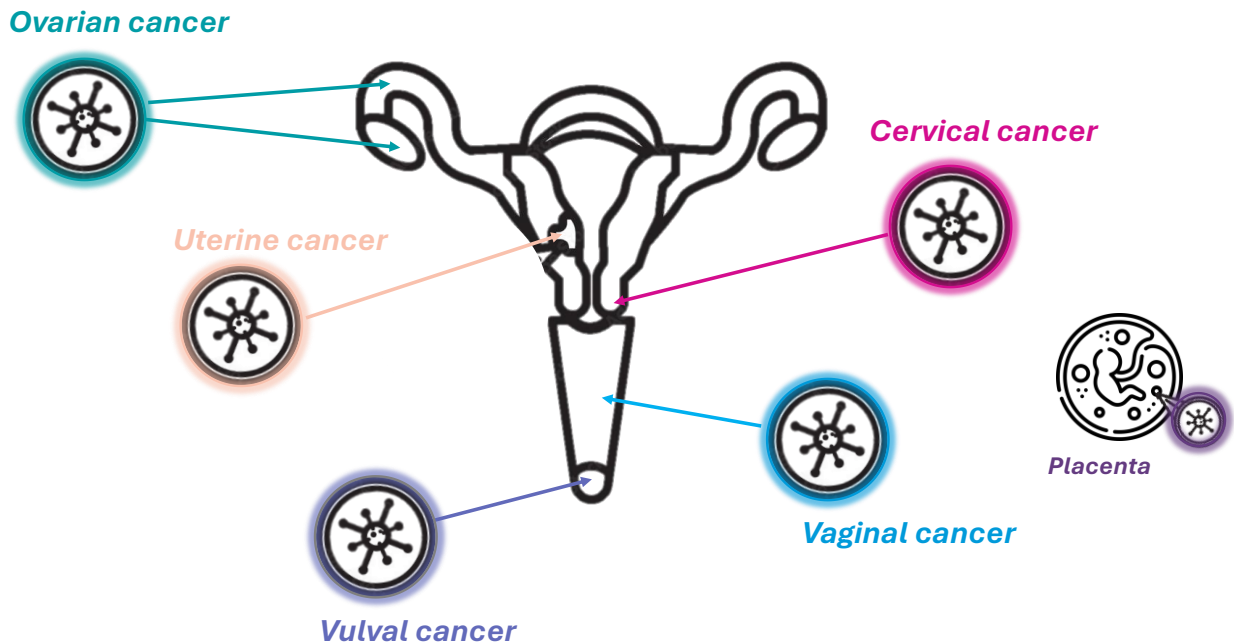
- Driven by women diagnosed with these rare and low survival cancers. We cannot emphasize enough the isolation and difficulties women with a gynaecological cancer experience as part of their diagnosis and care, not only priority populations but due to the quantity of rare subtypes of gynaecological cancer it can be any women diagnosed who cannot find answers or other women with the same disease.
- A powerful partnership of advocacy, funding and research organisations working in the sector utilising service deliverers already funded by government.
- The GCTI will maximise the access for a greater number of women to genomic profiling at diagnosis ensuring a personalised treatment program for each woman informed by clinical knowledge of treatment pathways based on the latest research.
- The GCTI is an implementation partner for government programs such as the Australian Cancer Plan, National Framework for Genomics in Cancer Control and Medical Research Future Fund research priorities including the low survival cancer mission and consumer driven research.
- We are seeking a \$100 million commitment from the government over the next 4 years. Without this we can't begin to make a difference for these many isolated and alone women who have been ignored for too long.
- The ground swell of our community is strong, patient advocates are passionate and have a voice in government. These women feel the time is now for change in the treatment of their cancers.

## Gynaecological cancers

### Rare and low survival cancers with devastating impact

Gynaecological cancers are cancers of the female reproductive system and the third most common subset of cancers affecting women in Australia today. There are five main types of gynaecological cancer: ovarian, uterine (endometrial), vulval, vaginal and cervical. There is also a pregnancy-related cancer (placental cancer).

#### Main types of gynaecological cancer



More than 55 per cent of gynaecological cancers are rare with limited treatment options – vaginal, vulval and placental cancers are rare and too often forgotten by the system. For example, vulval cancers have a 5-year survival rate of approximately 74.7 per cent; however, if discovered at an advanced stage, because of delay in reporting embarrassing symptoms that rate drops to 19 per cent.

Ovarian cancer is the most lethal cancer impacting Australian women today and has the same survival outcome (49 per cent) of all cancers in 1975 – 50 years ago. Further, 67 per cent of ovarian cancers are diagnosed at the advanced stage with a survival outcome of 29 per cent.

There is higher incidence and even higher mortality for Aboriginal and Torres Strait Islander women, regional women and women from socio-economically disadvantaged backgrounds.

More than 26,400 women diagnosed in the last five years currently struggle to live with a gynaecological cancer and everyday a further 19 women are diagnosed. These women often endure significant pain from both the cancer and its treatment. They also experience depression at 10 times the rate of the average Australian and anxiety at five times the rate of the average Australian.

Over the next 10 years, a further 86,000 women will be diagnosed. More than 55 per cent of these women will be diagnosed with a cancer that is untreatable or has only limited treatments available due to its rarity. As a result, more than 28,500 women will lose their lives, with gynaecological cancers being in the top 4 causes of cancer related deaths for women.

Sadly, the loss doesn't stop with the death of the woman, life-altering impacts for her family and community that can endure many lifetimes. In the next 10 years alone, more than 42,900 children will lose their mothers.

Over the next 10 years, the economic impact of gynaecological cancers will be \$72 billion.

## **Urgent need for action**

Gynaecological cancers are not like other chronic diseases, or even other cancers. They often grow silently during the curable stage, so that when detected, the cancer is often advanced and incurable. Women may have symptoms, but these are routinely dismissed by primary healthcare professionals. When the cancer is found, many of them are rare subtypes. Molecular profiling is best undertaken at diagnosis as it informs treatment, and it may be ineffective and too late once a cancer recurs.

Women cannot wait for the National Framework for Genomics in Cancer Control to be implemented. In the time it takes for national reform to begin to work its way through the health system, more than 12,000 women will have died at a cost of \$34 billion to the Australian community. Added to this, more than women with uterine, vaginal, vulval and cervical cancers will go without specialist patient support, enduring their journey alone.

**Accelerating access to comprehensive genomic profiling and precision medicine has the potential to improve survival for women — *today* — and provide the necessary biospecimens and data needed to help realise breakthroughs in research.**

These devastating outcomes are the result of decades of underinvestment in research, the de-prioritisation and dismissal of women leading to late diagnosis, barriers to adoption of life-saving comprehensive molecular profiling and precision medicine approaches, unacceptable inequities in health outcomes and unacceptable gaps in patient support.

## **Barriers to improvement under the status quo**

More than 90 per cent of women diagnosed today will miss out on access to comprehensive molecular profiling and precision medicine that has been shown by Omico and Zero Children's Cancer Program, to save lives. Barriers to the adoption of comprehensive molecular profiling in routine clinical practice include:

- A lack of established guidelines
- Gaps in clinician knowledge for interpreting test results and complex genomic data
- Lack of reimbursement
- A lack of resources and systems, particularly in resource-constrained and regional hospitals.

The continued loss of women to gynaecological cancers is the cumulative product of decades of surely unintended underinvestment and the de-prioritisation of women generally and gynaecological cancers specifically.

Added to this, the rarity and complexity of gynaecological cancers creates market and health system barriers that have contributed to significant underinvestment in research for treatments and cures.

Cancer Australia data show that gynaecological cancers have been among the poorest funded cancers over the 2003-2020 period. Without decisive action, gynaecological cancers will once again be relegated to the back of the line, and survival rates will continue to see little to no improvement.

## United for Change

The Gynaecological Cancer Transformation Initiative will provide the critical linkages to ensure research is translated into clinical practice with equitable access to precision medicine approaches across all states and territories of Australia.

**ANZGOG**, as the peak national gynaecological cancers research organisation in Australia and New Zealand, will serve as the primary implementation partner to drive this transformation, creating an organisational base for operation of the Initiative.

By working through its network of more than 1,450 members representing clinical, allied health and pure research specialities, as well as consumer community, ANZGOG will lead outreach to clinicians for the Initiative and promote adherence to molecular profiling as the standard of care for advanced and rare gynaecological cancers.

The Initiative will be further supported by **Omico**, who will deliver the comprehensive molecular profiling capability, and the **Australian Rare Cancers Portal**, which will deliver expert clinical advice to cancer specialists caring for women with complex rare cancers with which they need assistance.

The **National Gynaecological Oncology Registry (NGOR)** is a key data partner. NGOR measures standard of care provided against the nationally agreed optimal care pathways to identify where unwarranted variation in care may exist and is in a unique position to assist track the progress of the Initiative through their existing infrastructure, to better understand treatment and patient outcomes moving forward.

**Ovarian Cancer Research Foundation (OCRF)** will lead sector discovery for development of a virtual biobank and use of data analytics to inform research priorities including new opportunities to inform early diagnosis. OCRF has long recognised the necessity of biobanking for the advancement ovarian cancer discovery research, having provided longitudinal funding for biobanks in two states. The critical role of biobanking was also reinforced in an extensive national consultation exercise OCRF undertook in 2024. The need for expansion and coordination of existing resources was a consistent theme.

## Impact on specialist patient support

The Gynaecological Cancer Transformation Initiative would also close the gap with respect to specialist patient support services, which currently are available only to ovarian cancer patients.

**Ovarian Cancer Australia** would deliver the model, building on the success with respect to women's support services, which currently include its Helpline, Psychosocial Support Services and Teal Nurse Support Program.

The National Cancer Nursing and Navigation Program members – the McGrath Foundation, Cancer Council Australia, Cancer Nurses Society of Australia, Ovarian Cancer Australia and others – are focused on improving care and information for patients.

The Initiative aims to become a centralised information source of best treatment pathways for gynaecological cancers.

Combined, the Gynaecological Cancer Transformation Initiative programs of work will combine to be greater than the sum of its parts, fundamentally changing the experience and outcomes for all women impacted by a gynaecological cancer and their families.



## Options Analysis and Selected Program for Funding

An in-depth analysis of the benefits, costs and risks of four alternative implementation options was conducted to identify the proposed solution. Refer to Chapter 6 of the Business Case for details of the four alternative options.

Ultimately, Option 3 was selected as the best balance of benefit, cost and risk.

Requirement	Option 1 – ‘Do Nothing’	Option 2 – ‘Do Minimum’ Targeted Strategy for Ovarian Cancers (Do Minimum)	Option 3 – Targeted Strategy for Advanced, Rare or Recurrent Cancers	Option 4 – National Access Strategy for all Women
Benefits (NPV <sub>7%</sub> ) – improved access only	-	\$202.4m	\$352.5m	\$636.3m
Benefits (NPV <sub>7%</sub> ) – improved access and long run research impacts	-	\$267.2m	\$495.0m	\$887.6m
Costs (NPV <sub>7%</sub> )	-	\$62.5m	\$85.1m	\$144.9m
Benefit Cost Ratio – improved access only	-	3.2	4.1	4.4
Benefit Cost Ratio – improved access and long run research impacts	-	4.3	5.8	6.1
Funding requirement over four years	-	\$73.8m	\$100.7m	\$171.7m
Implementation timeframe	-	4 years	4 years	4 years

### Option 3: Targeted National Strategy focused on Advanced, Rare or Recurrent Gynaecological Cancers

Option 3 focuses on improving outcomes for the poorest outcome cancers across all gynaecological cancers, bringing into the scope of the program not just advanced ovarian cancers but also advanced uterine, cervical, vaginal, vulval and other gynaecological cancers. These cancers are among the most poorly funded cancers from a research perspective of any cancer group (See Chapter 2 of Business Case).

The cost of Option 3 is expected to be \$100.7 million in absolute terms; in NPV<sub>7%</sub> terms the costs of this program would be \$85.1 million. The benefits ‘unlocked’ by this option are significant and derive from improved outcomes for women with advanced gynaecological cancers through more systematic access to comprehensive molecular profiling and access to precision medicine approaches as well as more rapid adoption of health technologies, more consistent adherence to clinical best practice, the attraction of clinical trials and investment to Australia and long run improvements to survival arising from a nationally-coordinated approach to research and knowledge curation through the GCTI portal. The expected benefits of this option expected to range from a minimum of \$352.5 million in NPV<sub>7%</sub> terms (which would yield a BCR of 4.1 and would account for only the improvements in survival arising from improved access to comprehensive molecular profiling and precision medicine), to \$495.0 million, which would yield a BCR of 5.8, taking into account improvements in survival that

would be expected in the longer term arising from research advances made possible by a nationally-coordinated approach.

These improved health outcomes would not be limited to the woman but would extend to her family. Over the next 10 years, it was expected 367 fewer women would die, resulting in more than 550 children avoiding the loss of their mum. When also considering the long-term impact of research, there would be up to 686 fewer women to die, with more than 1,030 children avoiding the loss of their mother.

Additionally, the option would also see an expansion in specialist patient support services to women with gynaecological cancers other than ovarian cancer by OCA. An additional 625 women would receive support through an expansion of the Psychosocial Support Service program.

There would also be more clinical trials as a result of the huge expansion in the number of women with access to comprehensive molecular profiling and world-leading data capabilities in the data portal. It was expected between 10 and 20 additional clinical trials would be attracted, bringing leveraged private sector investment, jobs and access to novel therapies for more women.

Against the different policy objectives this option was assessed to perform better than Options 1 and 2 by a significant margin, with the program having substantial coverage of the highest unmet needs across all gynaecological cancers:

- *Better health outcomes* — It was expected that at least 367 deaths would be avoided over the next 10 years, with more than 550 children avoiding the loss of their mum after adjusting for base case improvements from 2030. When considering the long-term impact of research, up to 686 deaths could be avoided, with more than 1,030 children avoiding the loss of their mum. The value of avoided loss of life, mother loss and partner loss over the 2025-2035 horizon was expected to be \$303.9 million in NPV<sub>7%</sub> terms, or up to \$446.4 million in NPV<sub>7%</sub> terms if accounting for the impact of research.

Moreover, it was expected that the women referred to OCA's psychosocial support program would be women with very high unmet needs, from priority populations that would not otherwise have access to support, including First Nations women, regional women and women from low SES backgrounds. To the extent that these women had significant psychosocial morbidity, there could be significant benefits delivered from access to the program. Conservatively, it was expected their emotional wellbeing could improve by 12 per cent, based on Clinical Guidelines for Psychosocial Care in Cancer, with only one year of benefit valued. If access to the program prevented a longer period of distress, this benefit could increase substantially. In NPV<sub>7%</sub> terms, expanded access for women with high unmet needs from priority populations was expected to yield a benefit of at least \$2.3 million over four years, and could be in the order of \$7 million or more depending on the duration of poor health in the counterfactual.

- *Prevention and early detection* — The research program was expected to deliver research focused on the improved prevention and detection of uterine cancer, as well as the elimination of cervical cancer, and helping Australia to meet the 2035 elimination target through better understanding of the areas of need and opportunities for intervention, particularly for women from disadvantaged communities. Additionally, the research program would improve the understanding of the molecular make up of *all* gynaecological cancers, improving opportunities for prevention and early detection.
- *World class health systems* — Option 3 would see over 12,500 women have access to comprehensive molecular profiling and access to clinical best practice in the next four years alone. It would further see the development of a world-leading data asset in gynaecological cancers through the development of a virtual biobanking and data portal. Like Option 2, this would be expected to deliver improvements in streamlining evidence development through the development of real-world data for health technology applications and to inform routine clinical practice, enabling the avoided prescribing of ineffective therapies.

Together this would attract new clinical trials with an addition 960 women expected to gain access to clinical trials in addition to the base case.

- *Achieving equity* — Option 3 would similarly fund education and outreach to drive increased uptake of comprehensive molecular profiling but also to improve access to molecular profiling and clinical best practice by First Nations women, women from regional Australia, women from low socio-economic status backgrounds, women from culturally and linguistically diverse backgrounds and other priority populations. It would also substantially improve information about the numbers of women from disadvantaged backgrounds for inclusion in national datasets. The return from these efforts would be significantly higher, particularly as there are very substantial disparities in risk and outcomes in cervical and uterine cancers for these priority population women.
- *Strong and dynamic foundations* — Option 3 would see significant gains in research impact and translation compared to the base case. The research program would close gaps in understanding of the molecular profile across all gynaecological cancers and enable an expansion in precision medicine treatment options. This research would be consumer driven, informed by the Consumer Reference Panel.
- *Economic growth and health services efficiency* — The attraction of clinical trials would leverage \$24.8 million of private investment into Australia and the creation of 96 new clinical trials jobs and at least 10 new jobs in the further development of data curation and analytics (including AI capabilities) in gynaecological cancer. It was also expected that the data portal and advanced analytics program would enable health system efficiencies across the whole of gynaecological cancers, delivering a further conservative estimate of benefit of \$21.5 million in avoided use of ineffective treatment over the next 10 years.
- *Implementation risk* — This option, too, was considered to be a relatively low risk of implementation option. Even though the number of women to be tested expands, Omico still has the capacity to meet the expected uplift in testing, and similarly, there are proven academic centres able to supplement this with additional tests, including at Peter MacCallum Cancer Centre, Westmead Hospital and other hospitals nationally.

ANZGOG's membership is not limited to ovarian cancer but incorporates all gynaecological cancers and so it similarly has the reach to rapidly implement education and outreach across all gynaecological treating teams. It also has experience in sample coordination for the TR-ANZGOG program.

OCA will build on its expertise in delivery of psychosocial support services for ovarian cancer and will phase the implementation of access to minimise operational risk.

OCRF would be a lead partner in the research program and the Initiative enjoys leadership from some of the world's foremost researchers in gynaecological cancers – bringing the best minds to the research program to deliver the highest impact.

Option 3 sees the Transformation Initiative address gaps and work as a trusted and capable implementation partner in gynaecological cancers.

## The Transformation Initiative Activity Plan

The Gynaecological Cancer Transformation Initiative is a once-in-a-generation opportunity to revolutionise research translation, diagnosis, treatment, and care in gynaecological cancers.

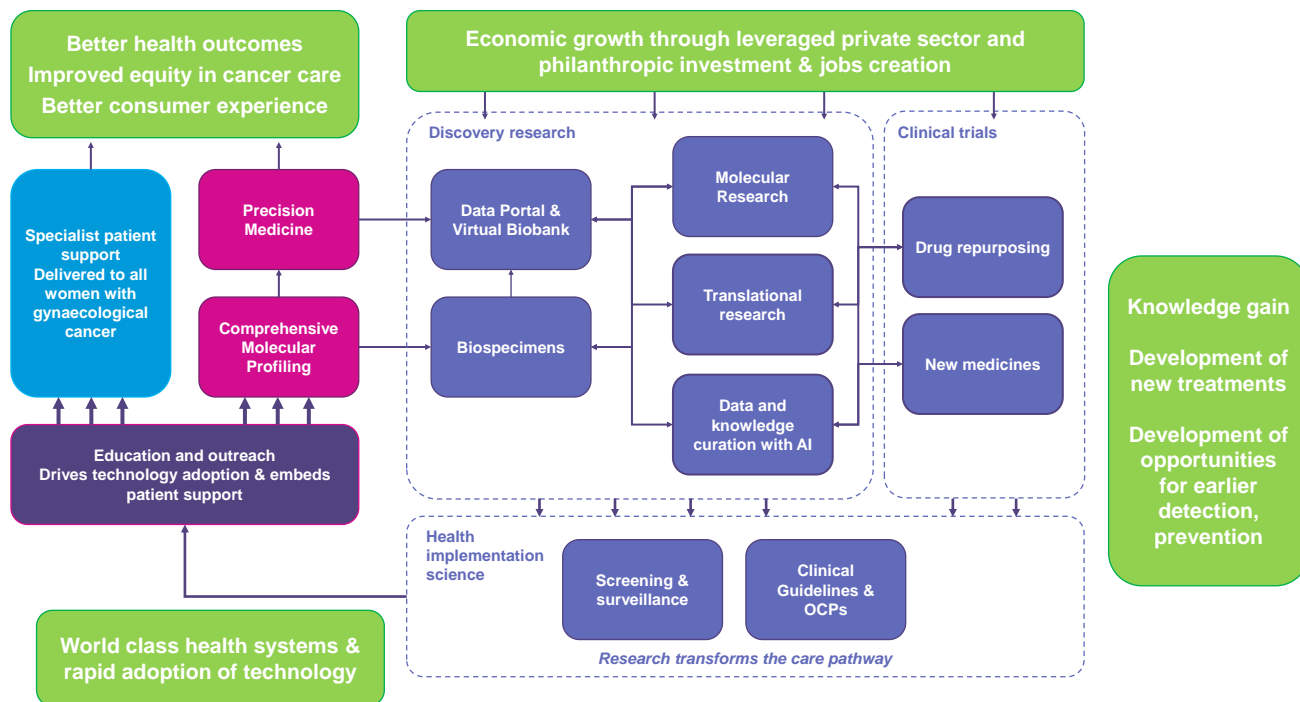
The Initiative will drive the rapid adoption of comprehensive molecular profiling and precision medicine, ensuring that women receive the best possible health outcomes, benefiting them, their families, and the Australian community. The biospecimens and data collected from molecular profiling will be linked into a wider program of research that will address clear knowledge gaps to identify new targets for treatment and transform the care pathway. The initiative will also ensure every woman, regardless of her cancer type, has equitable access to specialist psychosocial support.

The funding sought will deliver complementary and system-reforming activities under the Initiative:

- *Molecular profiling* – A nationally consistent approach taking advantage of a powerful collective delivering the information and resources needed to provide testing for women with rare, recurrent or advanced gynaecological cancers by:
  - Leveraging Omico funded testing capacity, with 3,600 women gaining access to testing from FY2025 – more than 50 per cent of women diagnosed
  - Supplementing Omico testing with further academic lab tests for rare or non-standard tests (approx. 20 per cent of women diagnosed or 712 women per annum)
  - Improving the productivity of Australia’s research infrastructure including greater access to samples and data
  - Enabling more clinical trials of novel treatments to be conducted in Australia with increasing economic benefit and access to more treatments for women.
- *Clinician education and outreach* – Enhanced clinician outreach will facilitate the testing growth across hospitals nationally by:
  - Increasing patients’ access to available molecular profiling through streamlining and support of the consent process particularly in regional and remote areas
  - Overcoming gaps in clinician knowledge for interpreting test results and complex genomic data and a lack of guidelines for all rare cancers
  - Supporting clinicians in treatment decisions to ensure more consistent adherence to clinical best practice for all women.
- *National Gynaecological Cancers data portal and virtual biobank* – Modules for each gynaecological cancer would be developed and a virtual biobank established to address information barriers to research activity and facilitate access to samples nationally.
- *Research* – Material expansion in research capacity and discovery research activity across all gynaecological cancers, requiring a total of \$60 million over the four years of the program. This would include the attraction of increased drug repurposing and clinical trials with innovative trial design lowering costs and time to open trials including pre- screening of all women with advanced cancers in the program.
- *Specialist psychosocial support services* – To close gaps in patient support for women diagnosed with gynaecological cancers other than ovarian cancer, the program provides for an extension of the cost of patient support for women with advanced cancers at the same cost per patient funding provided to ovarian cancer patients.
- *Governance* – To enable coordination of the additional testing, care and research activity, some funding is required for program management and governance.

The Initiative will be the implementation partner of government to realise the vision and priorities of the Australian Cancer Plan, the Women’s Health Strategy, the National Framework for Genomics in Cancer Control and the Australian Government’s Medical Research and Innovation Priorities in gynaecological cancers.

**Key activities and outcomes of the Gynaecological Cancer Transformation Initiative**



**Transforming gynaecological research**

The Gynaecological Cancer Transformation Initiative would see funding set aside for discovery, translational and clinical research. The research program would aim to address identified knowledge gaps, and would be co-ordinated and integrated by Gynaecological Cancer Transformation Initiative across the following key focus areas:

- Molecular research, including understanding cancer biology and drug resistance
- Translational research
- Novel clinical trials
- Drug repurposing
- Epidemiology research and population level data
- Data curation and AI analytics
- Surveillance and screening.

# Budget, implementation and Cost Savings

## Overview of Budget and Plan

The Gynaecological Cancer Transformation Initiative is asking the Australian government to commit \$100 million over 4 years to drive change in diagnosis, treatment and care for women and research into new treatments and understanding of the disease. Further funding will be sought from philanthropy, industry and donors to support the Initiative, much of this dependent on government commitment.

The costs of the Initiative breakdown into two major funding requirements:

- **Program Implementation and Outcomes**, requiring total funding over 4 years of \$40.7 million, with phasing through time of:
  - Year 1: \$9,300,932
  - Year 2: \$10,257,810
  - Year 3: \$10,034,599
  - Year 4: \$11,131,598.
- **Gynaecological Cancers Research Consumer Driven Research Priorities**, requiring total funding over 4 years of \$60.0 million, with phasing through time of:
  - Year 1: \$9,000,000
  - Year 2: \$16,500,000
  - Year 3: \$19,000,000
  - Year 4: \$15,500,000.

## Implementation Plan

The goal of the Gynaecological Cancer Transformation Initiative (GCTI) is to drive excellence and innovation in gynaecological cancers diagnosis, treatment, support, research and its translation, and enable clinical implementation, access and adoption of genomics to deliver better health outcomes for Australian women and their families.

The Transformation Initiative will be the implementation partner of the Australian Government and its agencies, Cancer Australia and Genomics Australia, to drive rapid adoption of best practice precision medicine in gynaecological cancers.

Through the research program, **the Initiative will lift survival outcomes above 50 per cent**, delivering on government objectives for the Low Survival Cancer Research Mission and Australian Innovation and Research Priorities.

To establish the Gynaecological Cancer Transformation Initiative, the following activities will need to be developed, building incrementally upon existing models throughout Australia:

- Establish a governance model for the program
- Build economies of scale from existing testing, clinician outreach and patient support to expand testing coverage to all gynaecological cancers nationally
- Facilitate greater discovery research into rare and low-survival gynaecological cancers through use of greater molecular testing data and establish competitive funding pool for discovery research through MRFF to support access to next generation gynaecological cancer treatments.

The implementation plan reflects this incremental nature of the expansion of existing programs to provide for a national testing programme for all gynaecological cancers under the Gynaecological Cancer Transformation Initiative.

### Governance model

The success of the Gynaecological Cancer Transformation Initiative will depend on the effective of coordination among partners and providers for the successful growth and complementary delivery of their services nationally for all gynaecological cancers.

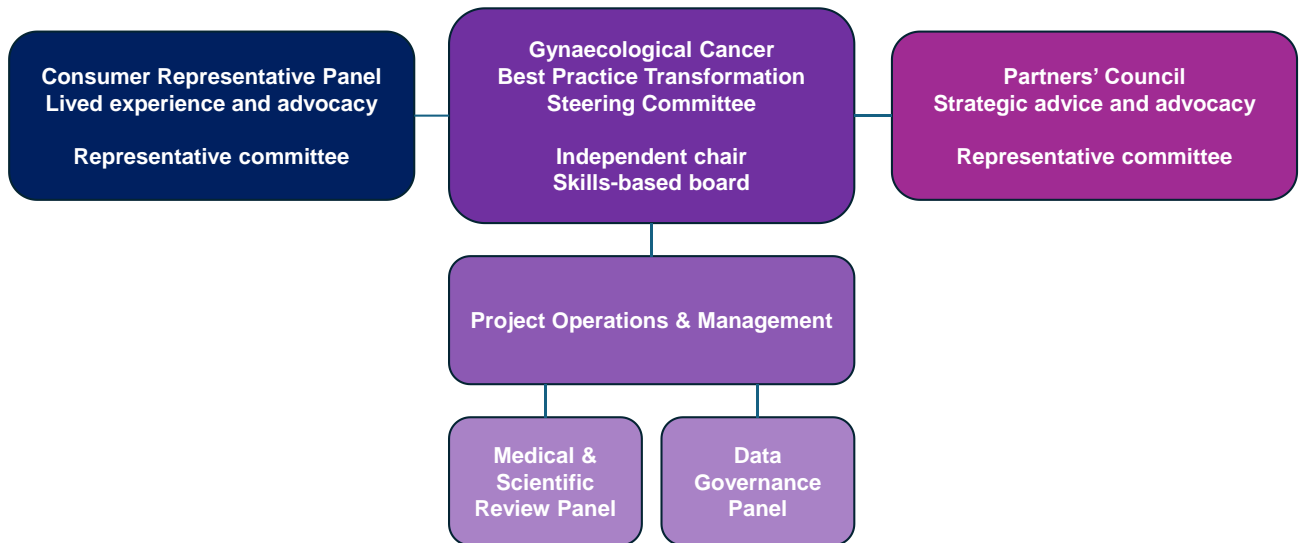
Therefore, the planned governance model establishes skills-based oversight of implementation and operations delivery, with clear lines of accountability for delivery (and risk management) to a skills-based steering committee, supported by specialist panels to focus expertise on medical & scientific and data governance issues. To manage the possibility of conflicting objectives, the skills-based steering committee will be chaired by a person independent of any Initiative partners.

Building on precedent, ANZGOG would act as the lead contractor for contracting clarity and cost efficiency—government may then contract with this single organisation for funding for delivery managed by the Steering Committee.

The advocacy and delivery partners of this Initiative have a purposeful role through the Partners' Council, to facilitate strategic advice and advocacy coordinated with the Steering Committee consistent with the memoranda of understanding with the Committee.

In addition, the Consumer Representative Panel provides the Steering Committee with perspectives of lived experience and patient/family advocacy to ensure governance is guided to the best practice treatment and survival outcomes for women with gynaecological cancers in Australia.

## Governance Model for GCTI



### The benefits

The Gynaecological Cancer Transformation Initiative will accelerate the realisation of the objectives of the National Framework for Genomics in Cancer Control in gynaecological cancers and serve as an exemplar of the coordinated approaches to reform contemplated by the Australian Cancer Plan.

**The Initiative will deliver more than five dollars of benefit for every dollar invested, with a benefit cost ratio (BCR) for the program expected to range from 4.1 to 5.8.**

Strongly aligned to government policy objectives, the Initiative delivers benefits across health and economic domains:

#### *World class health systems & rapid adoption of technology*

- Accelerating the adoption of comprehensive molecular profiling in routine clinical practice and improving access to precision medicine for more than 12,500 women over four years
- Improving prevention and early detection through knowledge curation using AI analytics and health science implementation research to rapidly transform care pathways
- Delivering an expected efficiency improvement of one per cent over the longer term in gynaecological cancer care, valued conservatively \$21.5 million in NPV<sub>7%</sub> terms
- Access to evidence-based psychosocial supportive care will be equitably available to all women with a gynaecological cancer
- Reduced disparities in health outcomes through education and outreach focused on improving clinical practice in regional and low-income regions and for First Nations women through Indigenous health partnerships
- Improved quality of life for women through the expansion of specialist patient support services focused on women from First Nations, low socioeconomic backgrounds, culturally and linguistically diverse and other priority populations

#### *Better health outcomes*

- Preventing the loss of life and years lived with a disability, valued at more than \$303.9 million to \$446.4 million in NPV<sub>7%</sub> terms



- Reducing the emotional burden of disease through access to specialist patient support, valued at \$2.3 million to \$7 million in NPV<sub>7%</sub> terms

### ***Economic growth***

- Attracting an additional 10-20 clinical trials to Australia in gynaecological cancer, with expected additional economic benefits based on ANZGOG and MTPConnect data:
  - Leveraging an additional \$16.8 million to \$33.6 million private sector investment into Australia
  - Between 480 and 960 more women would be able to access clinical trials in Australia because of the Transformation Initiative
  - Creating an additional 84 to 168 jobs in clinical trials research
- Catalysing a goal of matched \$100 million in additional philanthropic funding for gynaecological cancers, with \$1 million in funding already pledged if the Initiative is supported by government
- Creating an additional 10-15 jobs in cutting-edge data analytics utilising advanced analytics, including AI and other bioinformatic capabilities, in gynaecological cancer.

## **The impact for women and their families**

This report presents graph after graph, table after table, a substantial body of evidence showing at a macro, population-level, the systematic and inequitable effects of the dismissal and de-prioritisation of women, of inadequate and unequal access to precision medicine, of underinvestment in research, and of gaps in patient support.

But women are not numbers, they are not graphs. They are the very foundation and fabric of our communities.

This Initiative will have a real impact for women and for their families. It is vital that looking through the data presented in this report that we do not lose sight of this impact.

Realising too late that, if only you had been able to access molecular profiling; or, if someone had taken you and your symptoms more seriously; or, if more money had been put into research – *valuing women* – maybe then things would be different.

These are very real challenges and very real realities for women diagnosed with gynaecological cancers, who, at their most vulnerable, believe the system and community has not done enough and, for them, it is too late.

The Gynaecological Cancer Transformation Initiative wants to take the best from the programs supported by government and by linking these together deliver a future for women who save more lives.

### **Why Australian women want change**

"It is heartbreaking to turn away women who have the same issues and are having the same treatment because their cancer doesn't meet the definition of 'ovarian cancer'."

"If we have the tests we should be using them. Use the science we have available to us to save women's lives. Molecular profiling is a game changer to get the right treatments at the right time."

"We need this Transformation Program because at the moment there is more chaos than there needs to be. Women fighting cancer need some certainty where certainty can be provided."

## Appendices:

### **Ali's Story: Fighting for Hope amidst a diagnosis of very rare gynaecological 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.*”

## **ANZGOG Chair Prof Clare Scott AM – Foreword to the GCTI**

*This is a very sobering document.*

*I have never read anything that recapitulates the last decade of my life like this does. I am crying on the inside, and I can only imagine how families of women feel reading this. It doesn't bear thinking about, except that we must.*

*In my international engagement, I have never seen all the facets described so starkly and with nuanced connection.*

*We really need to go global on this – but establish in Australia first to demonstrate it can be done.*

*This reveals starkly that we have failed women for the last decade, for not being articulate or brave enough. That has to change.*

*Thank you, to our patient advocates and donors who have helped us advocate for change.*

**Prof Clare Scott AM**

MBBS PhD FRACP FAHMS GAICD

**Chair, Australia New Zealand Gynaecological Oncology Group**



Advancing research  
*saving lives*

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