

OVARIAN CANCER NATIONAL ACTION PLAN 2020-2025

ABRIDGED VERSION



 UNITED FOR CHANGE

Ovarian Cancer National Action Plan 2020–2025: Abridged version

Published by Ovarian Cancer Australia in collaboration with Australia New Zealand Gynaecological Oncology Group and Australian Society of Gynaecological Oncologists.

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Ovarian Cancer Australia

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The full version of this report is available at ovariancancer.net.au

We acknowledge the Traditional Custodians of the lands and seas on which we work and live, and pay our respects to Elders, past, present and future.

Foreword

We are delighted to introduce the Ovarian Cancer National Action Plan 2020–2025.

The National Action Plan is the result of careful consultation and review by organisations and individuals at the forefront of ovarian cancer treatment and research in Australia, along with women and families affected by ovarian cancer and consumer groups who work on behalf of women with ovarian cancer. We are proud of everyone's successful collaboration on this most important blueprint for ovarian cancer research and treatment over the next five years.

The 2020–2025 National Action Plan has been informed by goals set for the 2015–2020 plan, which proposed how Australia could best contribute to the global ovarian cancer research effort. The 2015–2020 plan was a significant milestone for the ovarian cancer community; since its launch, the sector has taken great strides towards better understanding ovarian cancer, resulting in improved treatments and more effective approaches to treatment.

The National Action Plan speaks to and on behalf of a sector that has united to endorse a collaborative and multidisciplinary approach to enable new research discoveries and translate successful approaches into clinical practice. At the heart of the current plan is our commitment to increase cancer survival rates, decrease the incidence of the disease, and assist those living with the disease and their families.

The COVID-19 pandemic occurred during the preparation of this plan, delaying our schedule, and, more importantly, disrupting the lives of many people already struggling with the realities of ovarian cancer. The full impact at this stage is uncertain, but we are aware that, for some women and their families, it added to their anxiety about future care and treatment. On a more encouraging note, COVID-19 increased opportunities for teleconferencing between women with ovarian cancer and their medical teams. This has positively reframed future care pathways for women and their families with ovarian cancer.

We dedicate this National Action Plan to the women living with ovarian cancer today, and to all who have been and will be touched by the disease. We thank you for your involvement in developing this plan, and for your resolve to support the community of women facing a diagnosis of ovarian cancer. Alongside you, we are working towards a future where the impact of ovarian cancer is greatly diminished.

At the heart of this plan is our commitment to increase cancer survival rates, decrease the incidence of the disease, and assist those living with the disease and their families.



Marina Go
Chair, Ovarian Cancer Australia (OCA)



Philip Beale
Chair, Australia New Zealand Gynaecological Oncology Group (ANZGOG)



Peter Sykes
Chair, Australian Society of Gynaecological Oncologists (ASGO)

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We need more than hope

by Caitlin Delaney

“ Together we are stronger. Together we stand a chance of rewriting the story of ovarian cancer. ”

I am Caitlin, diagnosed with ovarian cancer in 2017, at the age of 39, with two young daughters. I am extremely passionate about creating a better future for all those affected by ovarian cancer. This National Action Plan brings a lot of hope to me, my family and our community.

Together we are stronger. Together we stand a chance of rewriting the story of ovarian cancer.

The key to unlocking this horrific disease lies in true collaboration involving all the professional experts, those living with the disease, survivors and family members.

We need transparency and a clear unifying direction. We need to ensure that we focus on the right research, and that any advances are fast-tracked. We don't have time to waste. I don't have time to waste.



A handwritten signature in black ink that reads "Caitlin Delaney".

This is an abridged version of Caitlin's powerful introduction to the Ovarian Cancer National Action Plan 2020-2025; the full text is available at ovariancancer.net.au

Many needs,
many fears;
one goal,
one voice

Introduction

The 2020–2025 National Action Plan was developed over many months in partnership with key organisations and individuals and, most importantly, women with ovarian cancer.

The National Action Plan sets out the proposed priorities over the next five years in research, investment/infrastructure, diagnosis, treatment, support and medical care for women with ovarian cancer. It also examines the future role of support services such as counselling, social work and psycho-oncology.

At the heart of the current plan is our commitment to a shared approach for:

- improving survival rates and outcomes for women living with ovarian cancer in Australia
- decreasing the incidence of the disease
- assisting those living with the disease and their families.

The rigorous consultation and review process applied in developing the National Action Plan 2020–2025 resulted in three broad areas:

1. enabling system-wide progress
2. promoting sector infrastructure development and investment
3. identifying core priorities and their associated actions.

“Women with ovarian cancer and their families want to feel confident they can access high-quality care in specialised cancer centres, so that no woman with ovarian cancer walks alone.”

We need greater leveraging of existing shared fellowship models, and to seek opportunities to build partnerships across the research continuum.

1. Enable system-wide progress

The National Action Plan seeks to build a model of national and international collaboration with a wide range of organisations and stakeholders, including government, clinicians, researchers, consumers and industry, consolidating Australia's already strong reputation in ovarian cancer research, treatment and support. It also advocates for other measures to enable system-wide progress.

Collaboration will fast track progress by:

- greater sharing of information (e.g. building an Australian ovarian cancer research database)
- building shared resources for ovarian cancer research
- creating a coordinated approach to advocacy
- building advocacy and philanthropy capacity across the sector by providing clarity on organisations' objectives and responsibilities.

There is a strong appetite for sector-wide collaboration and engagement. It is important we value and play to the strengths of each organisation, aiming to encourage each one to contribute to and deliver on specific aspects within the priorities identified in the National Action Plan.

Establishing an Ovarian Cancer Alliance

It is proposed that the sector agree to establishing an Ovarian Cancer Alliance to help:

- drive advocacy
- formulate goals
- implement the National Action Plan.

The Alliance would concentrate on priority areas including:

- gaining stronger support for ovarian cancer research
- strengthening national collaboration between key organisations to drive a common approach to ovarian cancer research, treatment, advocacy and support
- encouraging the sector to speak with one voice about what is important
- streamlining access for women into clinical trials, both nationally and internationally.

The three key collaborators on the National Action Plan (Ovarian Cancer Australia, the Australia New Zealand Gynaecological Oncology Group and the Australian Society of Gynaecologic Oncologists) are well positioned to establish the Ovarian Cancer Alliance, with ongoing support to the alliance provided by a dedicated senior team member.

Other measures to allow system-wide progress

Australian researchers need funding for local research and clinical trials with a view to expand capacity to lead and open international recruitment. We need greater leveraging of existing shared fellowship models, and to seek opportunities to build partnerships across the research continuum. Those in the treatment workforce also need more support around data management, along with extra resources to enable participation in multicentre trials. Ongoing workforce development is critical to ensure clinical effectiveness. Efforts must be made to ensure funding is adequate not only to carry out necessary research, but also to implement research outcomes into the clinical setting / treatment workforce, to allow all women with ovarian cancer to access the best possible treatment.

Investment in infrastructure and capacity will enable greater collaborations, nationally and internationally, to deliver greater research impact.

2. Promote sector infrastructure development and investment

It is critical that Australia continues to collect, build and maintain world-leading national resources of tissue, cell lines and animal models and continues to support and develop the national Clinical Quality Registry.

Both are linked to better clinical outcomes for women. Investment in infrastructure and capacity will enable greater collaborations, nationally and internationally, to deliver greater research impact.

The National Action Plan strongly supports that Australia:

- continue to establish best practice clinical service models and access
- continue to collect, build and maintain world-leading national tissue and cell bank resources for ovarian cancer research and development of better treatments
- expand on its newly developed national Clinical Quality Registry.

These actions will lead to better clinical outcomes for women with ovarian cancer.

The National Action Plan supports investment in infrastructure and capacity. This will allow stronger relationships, both nationally and internationally, to help deliver better research outcomes. This will translate into faster development of new drugs and overall better treatments for women with ovarian cancer. It will also increase our understanding of:

- the various subtypes of ovarian cancer
- why ovarian cancer happens and recurs
- how to prevent ovarian cancer.

Prioritising investment into infrastructure will underscore Australia's position as a world leader in ovarian cancer research. More importantly, it will take less time for positive results from research to reach women with ovarian cancer. This is a high priority for women with ovarian cancer, no matter what the stage of their disease.

“These actions will lead to better clinical outcomes for women with ovarian cancer.”

Priority one is about providing optimal care and information right across the spectrum of services for women with ovarian cancer and their families.

3. Identify core priorities and their associated actions

The 2020–2025 National Action Plan outlines five core priorities for women with ovarian cancer:

- patient- and family-centred care and support
- diagnosis and treatment
- early detection
- biology/aetiology
- prevention.



It is ASGO's goal to improve outcomes by ensuring all Australian women with ovarian cancer have access to optimal treatment.

PROF PETER SYKES, CHAIR, AUSTRALIAN SOCIETY FOR GYNAECOLOGIC ONCOLOGY

We need to keep women with ovarian cancer, their families, friends and carers as the main focus, and we as the women with ovarian cancer need that. To downplay this would remove the patient from the core of the document.

STACEE, A WOMAN DIAGNOSED WITH OVARIAN CANCER



Priority 1: Patient- and family-centred care and support

Person-centred care is central to the whole National Action Plan, to ensure that women with ovarian cancer:

- always receive access to the best possible care
- are treated with dignity
- are involved in all decisions about their health and healthcare.

Consideration must always be given to what is being done for the women who are living with, or dying with, this disease today. There is a need for services to stay focused on the women with ovarian cancer.

Priority one is about providing optimal care and information right across the spectrum of services for women with ovarian cancer and their families. It is about how we 'package' this care to make it the best possible experience for all women.

Key actions

The optimal care pathway for women with ovarian cancer outlines the best cancer care that should be given at each step for women living with epithelial and non-epithelial ovarian cancers. Adherence to the pathway will result in quality cancer care and patient experiences. A full version of the optimal care pathway and a quick consumer reference guide are available at www.ovariancancer.net.au.

Other key actions include:

- ensuring all women with a suspected or confirmed diagnosis of ovarian cancer are referred to a gynaecological oncologist surgeon for treatment planning
- ensuring all women with ovarian cancer have easy access to gynaecological (and ovarian) cancer nurses to discuss options and pathways for care

- establishing and promoting gynaecological cancer centres of excellence (discussed under priority two) across Australia to deliver the best care possible
- establishing survivorship clinics and quality of life support pathways for women during and after treatment
- developing and supporting an active community of women with ovarian cancer who can provide insights into the experiences and needs of women living with the disease
- developing support systems to meet the social and emotional needs of carers, family and friends of women with ovarian cancer
- creating a central database for women with ovarian cancer and those close to them to include up-to-date information relating to research, treatment, access to clinical trials, symptoms and side effects, psychological care and support, screening, survivorship and support. Easy access to evidence-based information will allow women to make informed decisions about their care.



Research, research, research. Continue to find ways to improve treatment.
MARIE, A WOMAN DIAGNOSED WITH OVARIAN CANCER



Priority 2: Diagnosis and treatment

Priority two focuses on ensuring that the best possible research and resources are available every step of the way for diagnosis and treatment of all women with ovarian cancer. It is about optimising the use of current treatments, as well as developing new treatments.

It is crucial that women with ovarian cancer receive a diagnosis as quickly as possible. This will lead to earlier treatment and potentially, therefore, an improved prognosis.

After diagnosis, a woman should be:

- referred to the best specialist care possible
- informed about and have access to clinical trials
- informed about the different treatments and care for which they are eligible, and their clinical outcomes.

Women should have access to centres of excellence (specialist gynaecological cancer centres). Being cared for at a centre of excellence means that women have access to the multidisciplinary teams of experts in ovarian cancer treatment.

Ideally, women also may access genetic testing and tumour profiling. This will allow for the best targeted treatment for each woman diagnosed with ovarian cancer.

Key actions

Diagnosis

- Improve timely diagnosis by enhancing health professionals' awareness that the signs and symptoms of ovarian cancer are vague, but persistent, and early investigation is essential.
- Follow optimal care pathway.
- Promote genetic risk assessment and testing for all women with ovarian cancer.

Treatment

In the last five years, several aspects of ovarian cancer treatment have changed, including:

- an increase in the options for how chemotherapy is given (e.g. giving more regular doses of chemotherapy before surgery to help shrink the cancer or giving chemotherapy directly into the abdomen)
- advances in individualised treatment such as with poly ADP ribose polymerase (PARP) inhibitors for treating women with an identified gene fault
- more trials in newer targeted biological therapies (immunotherapies)
- advances in surgical treatments for small tumours.

The key actions are to:

- continue to explore ways to improve treatment pathways for every woman with ovarian cancer
- invest in further research to find new drugs and different ways of giving chemotherapy, as well as to gain a better understanding of drug resistance
- ensure all women have access to gynae-oncologists in the field of ovarian cancer surgery
- invest in further research into surgical treatment options
- improve our understanding of women's responses to existing treatments and why differences exist in clinical outcomes
- embed the optimal care pathway for women with ovarian cancer into all aspects of ovarian cancer medical care.

Clinical trials

- Strengthen clinical trials and improve consumers' access to and awareness about how clinical trials work.
- Support and invest in clinical trials through existing stakeholders and cancer centres.
- Position Australia as an international leader in carrying out research and conducting ovarian cancer trials.

“

Training for GPs. First point of contact who so often misdiagnose the disease in the early stages. A screening test is vital. **CHRISTINE, A WOMAN DIAGNOSED WITH OVARIAN CANCER**

Some women don't even know what type of cancer they have. There is a need to educate. Understanding the science behind the disease, the nuts and bolts of the whole thing, is very important.

JAN, A WOMAN DIAGNOSED WITH OVARIAN CANCER

”

Priority 3: Early detection

Established population screening tests (e.g. for breast, cervical and bowel cancer) are associated with significant improvements in early diagnosis as well as better survival rates overall. There is no reliable test for early ovarian cancer. Research is underway to try to develop better screening tests to detect ovarian cancer at earlier stages and improve outcomes for women with ovarian cancer.

Current research is looking into new ways to screen for ovarian cancer using blood and tissue samples from women with ovarian cancer.

Key actions

- Prioritise research into finding tumour markers to help screen and diagnose ovarian cancer subtypes, guide treatment and monitor cancer recurrence.
- Encourage and improve access to genetic testing for women who are at high risk of developing ovarian cancer.

Priority 4: Biology/aetiology

Improving our understanding of the science behind ovarian cancer, its behaviour, subtypes and its possible causes, is key for future research into ovarian cancer. Improved insights will help answer questions around reducing a woman's risk, early detection and improved treatments for ovarian cancer.

Key actions

There needs to be a focus on research into all areas of ovarian cancer, including:

- classifying tissue specimens to help discover and support new curative treatments, finding out how rare and other subtypes of ovarian cancer develop and express themselves
- understanding why some women become resistant to certain chemotherapy drugs
- the role of genetics in the causes, incidence and hereditary factors of ovarian cancer.



I think you are still missing the mark on the random diagnoses. I had no reason to believe I would experience this cancer. I have no family history and no genetic risk. I was not 'at risk'. Yet here I am facing my first recurrence after stage 3 diagnosis... **ANON, A WOMAN DIAGNOSED WITH OVARIAN CANCER**



Priority 5: Prevention

Research into both modifiable and genetic risk factors for ovarian cancer continues to be a priority. Particularly, there is a need to focus on:

- identifying high-risk subgroups for new genetic or other biomarker tests
- exploring the relationship between non-genetic risk factors, natural history and survival
- considering patterns and experience of disease in population subgroups (such as elderly women, women in remote and rural areas, Aboriginal and Torres Strait Islander women, and women from culturally and linguistically diverse backgrounds) and preventive measures.

The National Action Plan outlines ways to improve our understanding and awareness of risk factors for ovarian cancer, which could help wto stop ovarian cancer developing.

Key actions

- Target education and awareness campaigns to reach all people at risk, including minority groups. This involves more awareness about the importance of knowing your family history and identifying those at risk. Males can also inherit faulty genes that put them and their children at higher risk of developing ovarian cancer.
- Continue to research and educate the public about the risk factors we know we can control, including obesity, lack of exercise and smoking.
- Invest in research into genetic testing to help decrease the risk for women at high risk.
- Develop better ways for predicting risk of ovarian cancer in women carrying a high-risk gene fault and provide better information about preventive surgery, support and treatment pathways for these women.
- Ensure all women who are thinking about, or have, preventive surgery can access evidence-based information regarding menopause and, where required, can access a menopause clinic prior to their surgery.

Implementing the National Action Plan

Achieving the overall vision and objectives of the 2020–2025 National Action Plan will require strong and continued collaboration with women with ovarian cancer, to ensure that they are partners in decision-making and that their health needs are central to the ongoing approach to research, treatment and support.

Other key implementation partners are organisations and individuals from across the sector, operating nationally and internationally. Depending on the priority and action, partners may be required to work in direct collaboration or in parallel. Partners will work with and alongside governments, policymakers and industry partners across the health sector – and specifically women’s health, community organisations and advocacy sectors, families and carers – to oversee the actions outlined in this document.

APPENDIX: SUMMARY TABLE

Principal areas for action and priorities of the Ovarian Cancer National Action Plan 2020–2025

OUR TWO PRINCIPAL AREAS FOR ACTION

1. Enable system-wide progress	2. Promote sector infrastructure and investment
1.1 Establish an Ovarian Cancer Alliance	2.1 Invest in and support national tissue collection and biobanking
1.2 Strengthen national and international collaboration	2.2 Build experimental models and support translational research
1.3 Build advocacy and philanthropy capacity across the sector	2.3 Strengthen quality assurance through access to data and benchmarking
1.4 Include the voices of women with ovarian cancer when advocating for change	2.4 Promote investment in gynaecological cancer services
1.5 Support shared awareness of activity across the sector	
1.6 Fund Australian researchers to participate in, and where possible, to lead international studies	
1.7 Facilitate collaboration between laboratory research, clinical research and clinical trials by creating dual fellowship pairings	
1.8 Support the clinical and treatment workforce	

OUR CORE PRIORITIES AND ACTIONS THAT SUPPORT THESE PRIORITIES

3.1 Priority: Patient- and family-centred care and support
3.1.1 Improve equity of access to information
3.1.2 Improve equity of access to high-quality outcomes
3.1.3 Support gynaecological cancer units across Australia to deliver optimal care
3.1.4 Embed the optimal care pathway
3.1.5 Enhance quality of life and survivorship support
3.2 Priority: Diagnosis and treatment
3.2.1 Enhance patient diagnosis
3.2.2 Strengthen clinical trials
3.2.3 Improve targeted and optimal treatment pathways
3.3 Priority: Early detection
3.3.1 Continue to pursue mechanisms for early detection and screening
3.4 Priority: Biology/aetiology
3.4.1 Investigate identified action areas to deepen our understanding of the biology/aetiology of ovarian cancer
3.5 Priority: Prevention
3.5.1 Improve understanding and awareness of risk factors
3.5.2 Invest in risk prediction and information and support for risk reduction



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