

OVARIAN CANCER NATIONAL ACTION PLAN 2020-2025



 UNITED FOR CHANGE

Ovarian Cancer National Action Plan 2020–2025

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

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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 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
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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, and I am extremely passionate about creating a better future for all those affected by ovarian cancer. This National Action Plan brings much-needed hope to me, my family and our community. It brings together the knowledge and experience of leading scientists, professors and specialist health professionals who have been working tirelessly on this disease for decades.

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. I was 39 when first diagnosed with stage 4 clear cell ovarian cancer in 2017. My daughters were only two and four at the time. A scientist myself, I was furious to discover that ovarian cancer was associated with grim statistics, a devastating lack of awareness, and, most critically, a significant lack of funding. I was envious of the more popular, better resourced, and consequently more successful cancer groups. I vowed to make noise about this disease and have since become a passionate advocate despite periods of gruelling treatment and recovery. I was lucky to remain cancer free for two and a half years. I was hopeful that despite the odds, maybe I would not get sick again. Then, in February 2020, exactly three years since my initial diagnosis, I found out that my cancer is back, though now in my liver and lymph nodes. I am terrified and heartbroken. I desperately want to see my beautiful little girls grow up, and to grow old with my husband. Most people can take these hopes for granted. Ovarian cancer has robbed me of so much: my work, my health, my future. The pain and grief I feel at the start of this recurrence, even now as I write, is unbearable.

Although every woman's journey is different: our hopes and needs are the same. We must see a significant increase in ovarian cancer funding. Only then can we hope to have a better understanding of the disease and improve treatment options, to help us live as long as possible. Our dream for those of us already living with the disease is that we can face it as a chronic illness, rather than an illness that, for most, is terminal.

It is crucial that all our daughters, wives, sisters and mothers have access to clinical trials, genetic testing, leading cancer hospitals, and the latest research and treatments. Ovarian cancer is a lonely and isolating disease. We too need specialised ovarian cancer nurses to support us through diagnosis and treatment. Implementation of patient, and family-centred care should be mandatory. Patients and families need psycho-oncology support, and our loving carers need help too. We also need survivorship support to counter the feeling of abandonment after treatment.

Until this disease can be detected early, through screening and timely diagnosis, we need to educate our emerging medical students and current GPs on the signs and symptoms of ovarian cancer, and the diversity in how this disease presents.



What would 2025 look like for ovarian cancer if there is more than just hope? I believe that collaboration and campaigning can lead to a massive increase in funding and awareness, and subsequently huge progress in research. I want to see the five-year survival rate on the way to being doubled. I hope, more than anything in the world, that I am around to see that.

Caitlin Delaney

Many needs,
many fears;
one goal,
one voice

Many needs, many fears; one goal, one voice

At any one time, it is estimated that over 4000 families are impacted by ovarian cancer throughout Australia (Ovarian Cancer Australia 2020).

The women themselves are of various ages, come from geographically diverse locations and tell us that not one ovarian cancer experience is the same as another. However, the one thing they all have in common is the way they feel. They feel underrepresented; they feel scared and isolated. They all long for answers to the same nagging questions:

- Why don't more people know about ovarian cancer?
- When will ovarian cancer's survival rate improve and give me better odds?
- When will there be new and better treatments for ovarian cancer?
- What will I do if my cancer comes back?
- Why are clinical trials my only hope for living a little longer?
- Why does the psychological impact feel more difficult than the physical one?
- Will this be my last Christmas with my family?

United, these women and their families feel an urgency to break down the enormous barriers preventing them from having answers to their questions. The biggest barrier is the funding required to allow further research into earlier diagnosis, genetics, risks and causes. They want a future where women and girls don't have to fear this disease and its prognosis. Mostly, in the absence of a solution for early detection, they just want to live longer. Therefore, they long for new and targeted treatments, a better understanding of the disease and its subtypes, and psychosocial support. 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.

In December 2019, we shared the draft of this 2020–2025 National Action Plan with several groups of women who have ovarian cancer, and their carers, who all provided significant feedback. They were also invited to participate in consultation sessions, either individually or as a group.

The feedback reassured us that the priorities outlined in the plan reflect the needs and hopes for the future of women with ovarian cancer. There was one voice. This voice not only agreed on the priorities but were resolute that collaboration is essential to delivering the National Action Plan in a timeframe that will save lives.

The five core priorities for women with ovarian cancer were:

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

There was no doubt that the resounding theme was **'we need to do more'**. Everyone was so pleased to see women with ovarian cancer uniting with the health professionals who care for them to develop one solution. This promise of advocacy, collaboration and action gave them all a strong sense of hope for the future treatment and care of women with ovarian cancer.



Collaboration, transparency and clear direction is crucial, especially with regards to research.

WANDA

People living and fighting this disease should be given a much larger voice. **MICHELLE**

I think collaboration between government, researchers and clinicians should definitely be a priority so that they can develop a united strategy, with much greater funding improvements for research, treatment and patient care. All of these can then lead to an improved survival rate for women. Breast cancer is a great model as it has developed such united strategies resulting in wonderful survival rates. **DIANE**

Harnessing everyone to form a group is better for the future. There is so much more brain power when you collaborate. It is great to drive the [National Action] Plan with a united front. **JAN**

Central database. More information, more easily available is critical for everyone touched by this cancer. **ANON**

Collaboration is needed in providing a united front to increase awareness and support for ovarian cancer. At the moment there is little understanding of what treatments are available, where to direct monies raised and what support is available for women and their families. **JEN**



Through all three consultation processes, feedback was used to fine-tune the National Action Plan's five priority areas, with an emphasis on the impact on women. Access to knowledge appeared to underpin all five priority areas and this was linked to women needing to be in control. All priority areas were considered important, with some holding more importance, sometimes for personal reasons.

Responses to the following question provide an example of what several women believe is most important. Under each priority area in the National Action Plan, you will hear more from the women who came forward with their thoughts.

Of the priority areas identified, which are the areas you would most like to see progress in?



GP training and awareness. Early detection. Education. **CHRISTINE**

Patient- and family-centred support could also improve significantly. We've seen the benefits our sisters with breast cancer have with support from specialised breast cancer nurses. Imagine the outcomes for women with ovarian cancer if they also received the same level of support from specialised ovarian cancer nurses. **CAITLIN**

An early detection screening test, combined with a GP awareness program. **WANDA**

Understanding the disease and its causes and early detection. **MEREDITH**

Support for patients to receive treatment at leading hospitals. **WANDA**

Early detection followed by patient- and family-centred care. **LISA**

Early detection and prevention. This must be a priority as this is what saves lives. Instead of GPs first thinking the minor symptoms are digestive problems, they must be made aware that they should be checking for ovarian cancer. **KAREN**

Ovarian cancer patients need better access to drugs and have them included on the Pharmaceutical Benefits Scheme. **MICHELLE**

Treatment for resistance and for rare cancers. **NATHALIE**



Acknowledgements

The National Action Plan was developed over many months in partnership with key organisations, women with ovarian cancer and opinion leaders who play an instrumental role in research, treatment and support aimed at improving survival rates and quality of life and reducing the incidence of ovarian cancer in Australia.

We gratefully acknowledge the input from a large number of health professionals – including medical and gynaecological oncologists, clinical geneticists, nurses, psychologists, policy and strategy advisers, and researchers. We recognise the commitment of these people to work together to achieve the Plan. In addition to participating in one-on-one interviews, many gave up their time and paid their own expenses to attend our summit over a weekend in August 2019. Others contributed their feedback through an online survey and/or teleconference.

We sincerely thank everyone who has provided input and influenced the outcome of the National Action Plan. A complete list of the individuals and organisations who contributed is included at Appendix C.

Throughout the implementation of the National Action Plan we will continue to consult with and listen to the perspectives of women affected by ovarian cancer.



Executive summary

The 2020–2025 National Action Plan is the result of careful consultation and review.

It was developed over many months with eminent organisations and individuals at the forefront of ovarian cancer treatment and research, and, importantly, with women and their families living with ovarian cancer. At its heart is our commitment to a shared approach for improving survival rates and outcomes for Australian women living with ovarian cancer.

The National Action Plan sets out the proposed priorities over the next five years for research, investment/infrastructure, diagnosis, treatment, support and medical care for women with ovarian cancer.

It seeks to build a more structured model of national and international partnerships with a wide range of organisations and stakeholders, including government, clinicians, researchers, consumers and industry, consolidating existing collaborations and Australia's already strong reputation in ovarian cancer research, treatment and support.

The National Action Plan proposes two principal areas for action and five core priorities.

The two principal areas for action are to:

- **enable system-wide progress**
- **promote sector infrastructure and investment.**

The five priorities relate to:

- **providing optimal care and information across all services for women with ovarian cancer and their families.** We want to enable the best possible experience for women. Key to this is developing and supporting an active community of women with ovarian cancer and their carers, family and friends, who can continuously provide insights into the experiences and needs of women living with the disease.
- **ensuring that the best possible research and resources are available for diagnosis and treatment.** It is crucial that women with ovarian cancer receive a diagnosis as quickly as possible. This will lead to earlier treatment and potentially, therefore, improved prognosis. Women should also have access to centres of excellence (specialist gynaecological cancer centres).
- **improving approaches to the early detection of the disease.** We hope to improve the chance of women living longer by improving early detection / screening approaches.
- **improving our understanding of the science of ovarian cancer** – its behaviour, subtypes and possible causes.
- **improving our understanding and awareness of risk factors for ovarian cancer,** which could help prevent ovarian cancer.

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.

Due to the length of the plan, we have created an abridged version, which is available at www.ovariancancer.net.au.

Introduction

The Ovarian Cancer National Action Plan 2020–2025 identifies our priorities for ovarian cancer research, treatment and support. It outlines a collective approach for action, to improve survival rates and reduce the impact and incidence of ovarian cancer in Australia. We identify two broad areas for action – enabling system-wide progress and stimulating sector infrastructure development and investment. We also identify our core priorities and important actions associated with those priorities.

This is the second National Action Plan for women with ovarian cancer. It builds on the first National Action Plan for Ovarian Cancer Research (Ovarian Cancer Australia 2015).

This 2020–2025 plan provides an update of research activities and priorities. It then extends to include priorities and actions around awareness education, clinical care and support. It is about putting the patient first.

It highlights the range of investments and achievements made across the sector over the last five years, identifies current gaps and reaffirms the priorities for ovarian cancer, building on the expertise and skills available in Australia. It aims to:

- inform investment and advocacy
- drive targeted and coordinated action over the next five years across the sector
- address priority-driven, high-impact research, treatment and support to address ovarian cancer on multiple fronts.

This plan seeks to operationalise the identified priorities by providing a framework for action and an implementation approach to achieve progress. It provides a critically important road map to optimise ovarian cancer research and treatment in Australia.

At the heart of this 2020–2025 plan are the women living with ovarian cancer today, those who will be diagnosed tomorrow, and all those who have been and will be impacted by the disease. These women and their loved ones (partners, families and friends) demand and deserve the:

- most reliable ways of detecting and treating the disease
- best approaches to providing care and support
- most efficient ways to use available resources.

We want this plan to create a tangible change that will show an improvement in diagnosis methods/timeframes, treatments, services/resources, patient care/support and research into ovarian cancer. We are working towards a world in which ovarian cancer outcomes are better than they are today.

Our goal is for this plan to be owned and authored by the whole sector, recognising we need all members of the sector to drive change, improve survival rates and reduce the incidence of ovarian cancer.

What is ovarian cancer?

Ovarian cancer is a highly complex disease comprising a wide range of origins and subtypes (Ovarian Cancer Australia 2019). Ovarian cancer results from abnormal cell development in or on the ovaries (key components of a woman's reproductive system). It is now widely accepted that the categorisation of ovarian cancer includes cancers originating in the fallopian tubes and primary peritoneal cancer (cancer in the tissue lining the abdominal wall/organs in the abdomen) (ACS 2019). Further detail regarding the biology and classification of ovarian cancer can be found in the first (2015–2020) plan (Ovarian Cancer Australia 2015).

The 2020–2025 plan adopts the broader categorisation of ovarian cancer, and therefore the priorities and actions identified in the plan are intended to include all ovarian cancer subtypes and related cancers.

Ovarian cancer is the most common cause of gynaecological cancer death (AIHW 2018), as the symptoms associated with the disease are vague and easily mistaken for other, more common health issues. Death rates can be attributed to:

- delayed or inappropriate action to investigate symptoms, leading to women being diagnosed at a late stage of the disease (i.e. when it has spread) (WOCC 2018)
- a wide range of metabolic or structural properties within ovarian cancer cells leading to drug resistance.

Understanding ovarian cancer as a diverse collection of diseases with different cellular appearances and molecular characteristics, which simply share an anatomical location, is fundamental for furthering development of new diagnostic techniques and targeted treatments.

Ovarian cancer in Australia: incidence, burden of disease and outcomes

In the next five years in Australia, nearly 8000 women will be diagnosed with ovarian cancer and over 4000 will die from the disease (Cancer Australia 2020).

Ovarian cancer has a poor prognosis, with only 46 of every 100 women diagnosed still alive five years after their diagnosis (Cancer Australia 2019).

Ovarian cancer causes the greatest burden of disease from gynaecological cancers. It accounts for 5% of all the female burden of disease attributed to cancer in Australia. In 2012, ovarian cancer resulted in 12,100 years of life lost (YLL) due to premature mortality (AIHW 2017). When ovarian cancer is measured by disability-adjusted life year (DALY), it falls into a poor prognosis/high burden cluster demonstrating a high degree of unmet need.

In comparison to other, well-funded tumour streams in Australia, there is still an enormous amount of work to be done to improve survival statistics. However, it should be noted that Australia's outcomes for women with ovarian cancer have improved. We now have an overall five-year survival rate of 46%, which is one of the best in the world (Arnold et al. 2019).

Achievements since the first (2015–2020) National Action Plan

It is important to acknowledge the many achievements and significant progress made across the sector since the first National Action Plan.

While specific successes may be directly attributed to the first plan, others can clearly be credited to collaboration of researchers and initiatives within the sector. An example is the Australia New Zealand Gynaecological Oncology Group (ANZGOG), established in 2000, which has been at the forefront of clinical trials in Australia for many years. With more than 1000 members representing clinical, allied health and pure research specialities, ANZGOG clinical trials are conducted at over 50 hospital sites and include both local and global collaborations to ensure the best research is available for women (ANZGOG 2019).

We must use all these achievements as leverage to drive further change. This section highlights key achievements and investments throughout the sector since the 2015–2020 plan.

Raised profile of ovarian cancer in Australia

The first National Action Plan was a standalone major achievement for the sector. It helped raise the profile of ovarian cancer in Australia, which in turn led to further investment and achievements across the sector.

The development of the 2015–2020 plan not only articulated the priorities for ovarian cancer research, it also provided significant credibility for the sector and created a platform for raising other issues more broadly. It enabled the sector to shine a light on this under-funded and under-recognised disease. It brought it to the attention of key stakeholders and decision-makers at a federal government level. The achievement of uniting the sector to create the first plan and articulate the priorities for improving survival rates and reducing the incidence of the disease cannot be overstated.

Ovarian Cancer Australia based its submission for additional ovarian cancer funding on the National Action Plan and secured significant Australian Government funding for ovarian cancer research. On 9 April 2019, the Federal Minister for Health, The Hon. Greg Hunt MP, announced \$20 million to go towards research to help Australian women with ovarian cancer. The funding, from 2019–2020 to 2022–2023, will support ovarian cancer research under the new Medical Research Future Fund. There is also the addition of government funding announced in September 2019 with \$15 million being allocated for clinical trials involving reproductive cancers, including ovarian cancers.

Continuing to raise the profile of this disease is critical for ongoing investment into addressing ovarian cancer.

Strengthened awareness, visibility and advocacy

Increased advocacy, community awareness and social media campaigns have meant a significant increase in the visibility of ovarian cancer, philanthropic involvement and overall support for ovarian cancer, for example:

- a commitment of \$16.2 million from the Australian Government Department of Health's Medical Research Future Fund, following a 2019 parliamentary breakfast, to fast-track eight ovarian cancer research projects
- the Jill Emberson story and media publicity (refer to www.nowtolove.com.au/lifestyle/daily-life/teal-ribbon-day-jill-emberson-62692).

This type of awareness, visibility and advocacy continues to increase.

Messaging and education, with an emphasis on 'knowing your risk', has increased and drawn greater attention to familial risk factors for ovarian cancer. This has improved the opportunities for women at risk to access genetic testing and specialist services as early as possible.

Strengthened ovarian cancer awareness and fundraising campaigns

Significant ovarian cancer awareness campaigns have been strengthened or generated since the 2015–2020 National Action Plan. The sector has achieved a huge amount of visibility and fundraising support through ongoing awareness campaigns, including:

- It's Time for Ovary-Action (Ovarian Cancer Australia)
- Ovarian Cancer Awareness Month, which incorporates Teal Ribbon Day and Paint the Town Teal (Ovarian Cancer Australia supported by Cancer Australia)
- Team Teal (ANZGOC)
- Save the Box (ANZGOC)
- Survivors Teaching Students (ANZGOC)
- White Shirt (Ovarian Cancer Research Foundation).

Improved partnerships

Collaboration between researchers around Australia and internationally has increased following the uniting of the sector through the 2015–2020 plan and the clear articulation of priorities for research in ovarian cancer. More Australian researchers are now working with overseas researchers to access larger sample sizes for their research.

There are more opportunities for local researchers, not only for existing researchers, but increased opportunities are encouraging the brightest new researchers into the field. Through increased partnerships and fellowships, there has also been a greater interest from basic scientists in ovarian cancer.

A highlighted need for investment in research

Targeted investment in ovarian cancer research has facilitated the development of significant studies and trials. Many of these are outlined in Appendix B.

“ More Australian researchers are now working with overseas researchers to access larger sample sizes for their research.”

What we want to achieve with the Ovarian Cancer National Action Plan 2020–2025

Our **vision** is to improve outcomes for women diagnosed with ovarian cancer by:

- accelerating progress with earlier diagnosis and researching possible screening methods
- improving quality of care and developing more effective and targeted treatments through clinical research
- using resources effectively and overcoming barriers such as lack of awareness, education, infrastructure and collaboration between sectors.

Our **objectives** are to:

- ensure women are at the heart of this plan and that it is developed with them, and in their best interests
- improve the quality of life for women with ovarian cancer, with a focus on a holistic approach to their care
- increase research and effort into identifying and communicating the optimal standards of care and to better understand the barriers for women and providers in accessing the right care
- invest in improving quality of care and outcomes for women with ovarian cancer
- focus on ensuring women get the right treatment at the right time in the right place (e.g. women will have access to a specialised cancer centre or specialists affiliated to one of these centres) and their surgery is performed by an experienced surgeon
- progress the quality assurance work to continue to improve practice
- increase research and funding into the biology of the disease, as well as develop more effective and targeted treatments through clinical research for ovarian cancer
- strengthen local and international sector collaboration to drive progress.

The following summary table outlines the principal areas for action and priorities of the Ovarian Cancer National Action Plan 2020–2025. The first two cover our two principal areas for action: enabling system-wide progress, and promoting sector infrastructure development and investment. The third section outlines our core priorities for 2020–2025 and associated actions.

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

Further detail is provided in the following sections.

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.

1.1 Establish an Ovarian Cancer Alliance

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.

It is proposed that the sector establish an Ovarian Cancer Alliance based on a collective impact framework outlined in the Stanford University model of social innovation (SSIR 2011). (The Australian Charter for Ovarian Cancer Research Excellence also follows this framework, as proposed in the first National Action Plan for Ovarian Cancer Research – see Appendix A.)

The collective impact framework was developed to tackle deeply complex problems, with its five critical success factors being:

1. a common agenda
2. a shared measurement system
3. mutually reinforcing activities
4. continuous communication
5. establishing a backbone organisation.

Given such a framework, this National Action Plan represents the common agenda and other elements. The backbone organisation would need to:

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

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.



I think that the [Ovarian Cancer] Alliance is a fabulous idea. Collaboration, transparency and clear direction is crucial, especially with regards to research. Why can't Ovarian Cancer Australia, ANZGOG and Australian Society of Gynaecologic Oncologists collaborate with consumers and other stakeholders to ensure that funds raised are going to research that will actually make a difference? **CAITLIN**



The Ovarian Cancer Alliance could take collective action to accelerate progress, reduce duplication, and ensure stronger alignment of research, clinical care and advocacy activity. It could contribute to securing more long-term funding so that innovative ideas can be pursued, and to collectively address barriers that can frustrate research and inhibit translation to better outcomes. Examples of such barriers include:

- complex governance requirements and restrictions on access to medical records
- high costs for accessing material from pathology labs
- an increasing clinical workload.

All significantly affect the ability of centres to contribute to collaborative research and clinical trials.

The Ovarian Cancer Alliance would support the sector to speak with one voice about what is important. A great deal of research currently occurs in 'silos'. There needs to be more awareness of what everyone else is doing; with greater awareness we can work together to build stronger research.

The Ovarian Cancer Alliance would lead a concerted approach by funders, research organisations, researchers and clinicians, together with significant and meaningful consumer involvement, to oversee the implementation of the National Action Plan. Everyone would work together to collectively target increased funding to address ovarian cancer.



It is very encouraging you have been able to align these groups who it sometimes felt were always individually just re-inventing the wheel. It is an outstanding achievement to bring everyone together and it feels more hopeful, and it is great to drive the [National Action] Plan with a united front. **JAN**



“There needs to be more awareness of what everyone else is doing; with greater awareness we can work together to build stronger research.”

1.2 Strengthen national and international collaboration

National collaboration

The value of national/local collaborations should continue to be emphasised, given the potential to improve care pathways. Current knowledge should be applied in a systematic way specific to Australia and jurisdictions within Australia.

A number of individual researchers already have strong international ties/collaborations, which could be further leveraged. Greater sharing of information and building shared resources for ovarian cancer research, alongside a coordinated approach to advocacy, philanthropy and investment, will help to accelerate progress. With key organisations working together, there will be a greater collective impact on ovarian cancer.

The approach modelled through the Australian Ovarian Cancer Study (AOCS) and Individualised Ovarian Cancer Treatment through Integration of Genomic Pathology into Multidisciplinary Care (INOVATe) (see Appendix B) demonstrates how collaborative effort within the sector has facilitated a wide range of high-impact, translational research in ovarian cancer.

Where possible, the Ovarian Cancer Alliance would take advantage of existing mechanisms for national collaborative funding of research in priority areas, such as Cancer Australia's Priority-driven Collaborative Cancer Scheme.

International collaboration

The need to focus on international collaborations is well established, given the importance of the global community for breakthroughs in biological science, risk factor analysis and therapies. ANZGOG has successfully collaborated internationally for clinical trials since it was established in 2000. There are several other state and national programs fostering international collaboration.

However, further international collaboration needs to be encouraged and supported to enable greater access to, and involvement in, much larger studies. Given that ovarian cancer is a relatively uncommon disease, with so many histological variations, it is difficult to collect substantial numbers of samples of specific tumour subtypes or to conduct large studies solely within Australia. Continued involvement in international consortia such as the Ovarian Cancer Association Consortium and the Ovarian Tumour Tissue Analysis Consortium is crucial.

1.3 Build advocacy and philanthropy capacity across the sector

There is a need for ovarian cancer organisations to agree on and articulate their objectives to enable a shared vision for the sector. There is also a need for greater transparency around fundraising impacts. Greater collaboration between the major groups, such as Ovarian Cancer Australia and ANZGOG, to align research priorities and streamline grants/philanthropic support to investigators (senior/mid/early career) will be extremely beneficial.

1.4 Include the voices of women with ovarian cancer when advocating for change

Advocacy is strengthened when people affected are heard and included/educated in research from concept development through to review processes. For example, ANZGOG provides education to women affected by ovarian cancer and their carers who volunteer on their Consumer Research Panel to review research projects, representing all women diagnosed.

It would benefit the sector to routinely consult with women with, and who have had, ovarian cancer to overcome barriers and drive change.

1.5 Support shared awareness of activity across the sector

The establishment of an Australian ovarian cancer research database will help identify Australian ovarian cancer research contributions over the last five years. The database should account for Australian involvement in international trials and flag opportunities for future collaboration, and identify relevant research institutions, researchers and roles. Such a database will need dedicated ongoing resources to ensure it is maintained and can continue to grow.

Other mechanisms to share awareness/research need to be explored as well, to allow information to be delivered more efficiently in our increasingly time-poor world. This could include more use of social media, for example, to share new ovarian cancer-related publications and trial results.

1.6 Fund Australian researchers to participate in, and where possible, to lead international studies

Research funding is very competitive, and it is essential to ensure quality projects are being put forward that address the needs of women with ovarian cancer. Australian researchers need funding for local research and clinical trials with a view to expand capacity to lead and open international recruitment. This could include supporting Australian women with ovarian cancer to participate in existing and future international studies.

1.7 Facilitate collaboration between laboratory research, clinical research and clinical trials by creating dual fellowship pairings

We need greater leveraging of existing shared fellowship models, and to seek opportunities to build partnerships across the research continuum. In some cases, we can apply successful approaches used in other cancer research (e.g. melanoma research).

1.8 Support the clinical and treatment workforce

There is a great need to support the ovarian cancer clinical workforce in Australia, in particular by:

- developing training positions
- implementing demand management strategies
- enabling allied health data collection
- supporting clinical and translational research.

Further opportunities for fellowships funding and recurrent funding over a sustained timeframe will help to secure current and future research workforce for ovarian cancer. 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.

Demand management involves searching for better or different methods of meeting the same needs. This will help us understand, predict and shape the demand for services, and work to ensure the clinical and treatment workforce has capacity to meet this demand. Allied health data collection will help determine demand and identify priority areas of development so that the health/clinical needs of individual women with ovarian cancer and populations are best served with the available resources. The purpose of allied health data collection must be clear so the results can be translated into useful information and evidence.

Those in the treatment workforce also need more support around data management along with extra resources to enable participation in multicentre trials.

Table 1 summarises the priorities and actions needed to enable system-wide progress.

TABLE 1: PRIORITIES AND ACTIONS TO ENABLE SYSTEM-WIDE PROGRESS

PRIORITY	ACTIONS / DETAILS
<p>1.1 Establish an Ovarian Cancer Alliance</p>	<ul style="list-style-type: none"> ■ Priorities the Ovarian Cancer Alliance could address include: <ul style="list-style-type: none"> > providing a framework for considered collaborative research between all sectors, with a focus on the future > ensuring all Australian women have access to optimal care > representing a professional body to which government and clinical services can turn when they need a sector-wide view of future needs > addressing challenges in the governance and ethics review processes > streamlining access to clinical trials > consulting on the acquisition, sharing, integration and governance of data > coordinating implementation and funding for National Action Plan and other research priorities > advocating with government for priority funding > providing a united front to invest in tissue collection and capturing clinical information
<p>1.2 Strengthen national and international collaboration</p>	<ul style="list-style-type: none"> ■ Key sector organisations will include ANZGOC, the Australian Society of Gynaecologic Oncologists, the Ovarian Cancer Research Foundation, Ovarian Cancer Australia and other sector institutions and organisations ■ Bring in relevant professional bodies, for example: <ul style="list-style-type: none"> > Royal Australian and New Zealand College of Obstetricians and Gynaecologists > Royal Australian College of General Practitioners > Australian College of Rural and Remote Medicine > Royal College of Pathologists of Australasia > Cancer Nurses Society of Australia ■ Include other relevant stakeholders: <ul style="list-style-type: none"> > Psycho-oncology Cooperative Research Group > familial cancer clinics – e.g. Kathleen Cuninghame Foundation Consortium for Research into Familial Breast Cancer
<p>1.3 Build advocacy and philanthropy capacity across the sector</p>	<ul style="list-style-type: none"> ■ Agree on and articulate objectives and priorities within each organisation and their contribution to the shared vision for the sector ■ Provide transparency around fundraising impacts
<p>1.4 Include the voices of women with ovarian cancer when advocating for change</p>	<ul style="list-style-type: none"> ■ Ensure women, their families and friends are consulted and their voices are heard and represented when advocating for change, and learn from and unite with other cancer / rare disease voices to overcome barriers and drive change ■ Include trained consumers in research, from concept development to review and funding

PRIORITY**ACTIONS / DETAILS**

1.5 Support shared awareness of activity across the sector

- Identify Australian ovarian cancer research contributions over the last five years, including what is happening and what is yet to be published
- Include Australian involvement in international trials and flag opportunities for future collaboration
- Include a list of relevant research institutions, researchers and roles

1.6 Fund Australian researchers to participate in, and where possible, to lead international studies

- Fund Australian researchers for local research and clinical trials with a view to expand capacity to lead and open international recruitment
- Support Australian women with ovarian cancer to participate in existing and future international studies
- Ensure quality projects are being put forward that also address the needs of women with ovarian cancer
- Facilitate broader Ovarian Cancer Association Consortium and Ovarian Tumour Tissue Analysis Consortium involvement

1.7 Facilitate collaboration between laboratory research, clinical research and clinical trials by creating dual fellowship pairings

- Leverage existing shared fellowship models
- Build partnerships across the research continuum to establish these links
- Replicate other cancer research where this approach has been successful (e.g. melanoma research)

1.8 Support the clinical and treatment workforce

- Ensure clinical services have adequate resources to:
 - > support clinical research that will enable the provision of optimal treatment and care
 - > access quality data
 - > implement demand management strategies
 - > enable allied health data collection to determine demand and identify priority areas of clinical development
 - > take part in clinical trials (this is especially important for surgical studies where there is currently no industry source for funding)
 - > access funding, training and administrative support (data, grants) and address geographical barriers for trial logistics
 - > establish and/or promote mentoring or internship opportunities for early career researchers

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.

Importantly, this will accelerate the development of new therapies for better treatments, as well as increasing our understanding of:

- various ovarian cancer subtypes
- why ovarian cancer occurs
- why ovarian cancer recurs
- how ovarian cancer can be prevented.

Maintaining these resources will allow us to continue as a leader in ovarian cancer, and translation efforts will be expedited.

2.1 Invest in and support national tissue collection and biobanking

Australia is developing world-leading tissue and cell bank resources for ovarian cancer research and development of better treatments, particularly through the Australian Ovarian Cancer Study biobank and the Ovarian Cancer Cell Line Study (OCELIS) (see Appendix B) resources. However, there is a need for further investment to support national coordination of collection and access to biospecimens, with a biobank informing genomic profiling, leading to better outcomes for women. A priority area of the Ovarian Cancer Alliance would be linking datasets.

Women with ovarian cancer, researchers and clinicians would all benefit from a systematic approach to tissue collection across the country to facilitate further research and maximise collection and biobanking. Investment into tissue and cell bank resources must include the collection of associated clinical, pathology and treatment data, as the resources are of limited value without clinical data annotation.



The core infrastructure activities that support good research and clinical care that I'd like to see happen include both data (clinical and research) and tissue (through tissue banks such as Tr-ANZGOG). These represent important prerequisites to asking the right questions and having well-annotated tissue resources, which, when shared across a broad range of researchers, can have a significant positive impact. **ASSOC PROF TAREK MENIAWY, DIRECTOR, ANZCOG**



Resources are needed:

- prior to surgery to facilitate patient consent
- for management of the tissue sample from excision, through pathology and sending on to a biobank
- for processing, storage and distribution of samples to researchers
- for data management support.

2.2 Build experimental models and support translational research

To enable a personalised medicine approach rather than a 'one size fits all' approach, it is critical Australia builds resources for developing clinically relevant animal models of disease. It is difficult for researchers to source funding to support in vitro models, yet it is an important resource for testing potential drug candidates. Investment is required for research focused on developing patient-derived xenograft models that can test and validate new precision medicines, leading to identification of new drug targets.

Currently there are a lack of funding opportunities for:

- development and validation of potential new treatments (e.g. new drug candidates)
- diagnostics for guiding targeted treatments or to better identify high-risk women
- biobanking resources such as staff, biospecimen processing / storage / distribution infrastructure (equipment, data management).

There is a need to improve the culture of research to provide protected time for clinical research and funding for non-commercial clinical trials. While the pharmaceutical industry is key to the development of new technologies and medicines and getting them into market, we need greater acknowledgement of the importance of independent clinical trials (not just in rural/regional areas) and supporting not-for-profit research.

2.3 Strengthen quality assurance through access to data and benchmarking

Quality data underpin all aspects of ovarian cancer research, clinical care and support. Everyone across the sector would benefit from better access to coordinated and linked data. Researchers, clinicians, study coordinators, supportive care nurses and other allied health professionals need to be able to access data as well as input data (through synoptic reporting in real time) into a national database for everyone to use.

National Gynae-Oncology Registry

Not enough is known about the pattern of care within Australia for women with ovarian cancer. There are several important unanswered questions, including:

- Should all women receive follow-up care?
- What proportion of women are seen by a gynaecological oncologist?
- How many cancers are accurately staged or debulked and are these rates acceptable?

There is considerable support across the sector for the expansion of the National Gynae-Oncology Registry, which measures and monitors patterns of care for women diagnosed with ovarian cancer receiving treatment through a range of participating public and private hospitals across three states (NGOR 2019). Internationally, such registries have been noted as being critical to improving the quality of healthcare for patients by systematically collecting and analysing key biological and clinical information (Bouchardy, Rapiti & Benhamou 2014).

With further investment and support, the National Gynae-Oncology Registry could be expanded to become more beneficial for all gynaecological cancers and should be supported to become a population-wide registry.

A clinical quality registry is a valuable resource. It could be strengthened through innovations to encourage clinicians to contribute data and through promoting linkages with population-level datasets. Fully implemented, for every woman diagnosed with ovarian cancer in Australia, a clinical quality registry would track information on:

- diagnosis
- biospecimen details
- prognosis
- treatment
- clinical outcomes.

All of this would allow development of benchmarks and provide real-time insights and longitudinal data for clinicians and researchers to improve outcomes and quality of life for patients. It would:

- provide insight into the best-performing treatment and treating centres
- monitor appropriate treatment and provide early warning signs on deteriorating outcomes
- identify variations in treatment and impact on outcomes
- identify deficiencies in access to treatment
- flag poor-performing treatment centres.

An expanded National Gynae-Oncology Registry would also allow for the collection of patient-reported outcomes and experience measures (PROMs and PREMs) and could facilitate accreditation for gynaecological cancer units (gynaecological cancer centres of excellence) (Department of Health 2019).



I'm very keen to see something like INOVATe expanded nationally. I also feel that increasing infrastructure and clinical research capacity at rural/regional centres is a priority. With the drive to have patients treated at centres of excellence, we need to recognise that in Australia this involves great distances. Systemic therapy can and will be given in regional centres and the more this is possible in the context of clinical trials the greater access patients will have.

DR ALISON DAVIS, ANZGOG DIRECTOR



The aspiration is to ensure all women with ovarian cancer are part of a national clinical registry that informs clinical care and that the registry acts as a repository of data for clinical trials and translational research.

2.4 Promote investment in gynaecological cancer services

Promoting investment in gynaecological cancer services will ensure all Australian women have access to up-to-date clinical services, and the infrastructure and personnel to support clinical research.

Table 2 details priorities and actions to promote sector infrastructure development and investment.

TABLE 2: PRIORITIES AND ACTIONS TO PROMOTE SECTOR INFRASTRUCTURE DEVELOPMENT AND INVESTMENT

PRIORITY	ACTIONS / DETAILS
<p>2.1 Invest in and support national tissue collection and biobanking</p>	<ul style="list-style-type: none"> ■ Provide funding and infrastructure for the development of Australian-wide biobanking facilities and reduce silos <ul style="list-style-type: none"> > Prioritise investment in AOCS II and facilitate national recruitment > Consolidate biobanking and preclinical models > Improve tissue collection mechanisms and protocols for treatment and analysis purposes and embed in systemic practice > Develop a protocol for tissue sample donation from women undergoing de-bulking surgery where some tissue could be used for biobanking > Work with pathologists to embed preservation of all biospecimens > Support more protected pathology time/support and prevent sending large numbers of samples out of the country for pathology input, as is happening now > Leverage the NSW Health Statewide Biobank Consent Toolkit to support national expansion for unspecified consent for use of biospecimens > Consider the role of consumer organisations in lobbying for preservation of biospecimens and biobanking, including lobbying for all tissue blocks to be preserved > Provide survival outcome data for tissue blocks and build these data into the registry > Provide education for patients to make an informed choice regarding donating biospecimens to build the biobank resource > Explore options for fresh tissue collection for research
<p>2.2 Build experimental models and support translational research</p>	<ul style="list-style-type: none"> ■ Invest in experimental models that will translate into new treatments <ul style="list-style-type: none"> > Support funding for patient derived xenografts and predictive cell models to facilitate new drug development > Invest in new cell line models, including organoid models, representing the different molecular and histological ovarian cancer subtypes, to provide important shared resources > Invest in mechanisms to allow wider access to shared infrastructure required for mouse models and high-throughput drug screening in cell lines and organoids ■ Invest in infrastructure and capacity at clinical sites to support more clinical trials <ul style="list-style-type: none"> > Utilise existing clinical trials networks such as ANZGOG to develop innovative trial concepts > Identify and address barriers to undertaking clinical trials, particularly outside of major clinical centres > Provide support for funding of non-commercial clinical trials > Effectively utilise telehealth in rural and remote areas > Foster appropriate allocation > Dedicate 'protected time' for clinical research

- **Establish a new concept development fund to translate promising research findings into new products and psychosocial supportive care interventions**

- > High-impact projects could include reaching proof-of-concept with new or re-purposed drug candidates in validated preclinical experimental models of disease, or accessing drug libraries for testing in cell-based assays
- > Prioritise research into high-impact psychosocial supportive care interventions across the trajectory of care and survivorship

2.3 Strengthen quality assurance through access to data and benchmarking

- **Recognise and support the need for better data integration across the sector**

- > Recognise and expand the work being undertaken by BioGrid Australia and NSW Health (e.g. mapping and integrating data from different data sources and linking patient records across datasets)
- > Develop a recruitment database (i.e. a place where women can register interest in being contacted about research)

- **Continue to support the expansion of the National Gynae-Oncology Registry (NGOR) for gynaecological cancers**

- > Ensure the NGOR is population-wide and based around the existing cancer registries in each jurisdiction
- > Link the NGOR with a national tissue biobank

- **Develop a minimum core outcome dataset for women with ovarian cancer**

- **Identify and address existing barriers for expansion of NGOR**

- > Recognise that NGOR activity should be underpinned by an innovative vision supporting the use of data collected for both clinical care and research purposes
- > Provide core funding for resources and training for cancer services to collect data
- > Improve interoperability between clinical information systems to reduce duplication and align data entry
- > Work with data regulators and ethics committees to facilitate disclosure, collection, linkage and reporting of patient-level data
- > Align with the principles and strategic objectives of the Australian Government's National Clinical Quality Registry Strategy 2019-2029
- > Provide pathways and processes to maximise patient and clinician participation in a national NGOR

- **Maximise patient-reported outcome data captured in clinical trials**

- > Use patient-reported outcome measures captured in clinical trials from ovarian cancer and other cancers to translate into clinical practice and to inform patient care
- > Link patient-reported outcome measures to a national NGOR to measure impact

2.4 Promote investment in gynaecological cancer services

- **Promote investment in gynecological cancer services to enable all women to have access to up-to-date clinical services, and the infrastructure and personnel to support clinical research**

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

3. Core priorities and 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.

In this section we discuss each priority and outline proposed actions relating to each priority.



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 OF GYNAECOLOGIC ONCOLOGISTS**



3.1 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 patient: to understand the extent of access to, and use of, specialist gynaecological cancer treatment services and to explore ways to support women and their families during and after treatment, such as routine screening for psychological distress and by focusing on wellness and survivorship.

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. The focus is on delivering the services/information in a way that is easy for women to find and digest, while maintaining the ability to tailor to individuals' specific needs to provide holistic care.

From the voices of the women we consulted

Support for patients and families was enthusiastically embraced and was viewed by most women as a 'foundation pillar'.

Some women are struggling to get basic support for themselves and their families, during and after treatment. Access to support services was identified as difficult in regional areas (i.e. equity of access), and there was a high stated need for advocacy to improve this situation.

Women want to feel they are central to their care and to the medical processes they experience. Getting the right support for themselves, as well as for those caring for them, is key. A central database, specialised ovarian cancer nurses and survivorship clinics were all considered priorities that should be progressed.

A few women felt they were already well supported and although patient and family support were a priority, clinical areas and funding were seen as more deserving of attention. Their preference was to focus on keeping them alive through more research into new and better treatments.



I feel priority one underpins everything through diagnosis, prevention and treatment. It goes together with all the other priorities. **ROBYN**

We need to keep women with ovarian cancer, family 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**

Patient-centred care encompasses all of the psychological aspect, as well as the physical side of the disease. **JANE**

A dedicated ovarian cancer nurse – didn't even know they existed. Would have made a huge difference to me to have someone. **ANON**

Priority one is the key area for me. There is literally nothing where I live, except Ovarian Cancer Australia and Cancer Council. So, [Ovarian Cancer Australia's] case management program is really important for me, as I feel quite alone without that extra support. **STACEE**

Overall, this is a commendable list, most of which has not been available to me. Although some can be relatively easily implemented in the major cities, I wonder how this can be possible in regional areas. For example, Darwin and Canberra don't have gynaecological surgeons. **JEN**

I think survivorship clinics are very important, as one feels abandoned after finalising treatment, and like you are a "dead woman walking", just waiting for the cancer to come back. **CAITLIN**

Central database. More information, more easily available is critical for everyone touched by this cancer. **ANON**



3.1.1 Improve equity of access to information

Women need greater access to evidence-based information about ovarian cancer, including consistent messages about screening and risk factors, information regarding access to clinical trials, advances in treatment and where to access optimal care.

There is also a need for culturally and linguistically appropriate resources for Aboriginal and Torres Strait Islander women, women from culturally and linguistically diverse backgrounds and women with disability.

3.1.2 Improve equity of access to high-quality outcomes

Optimal surgery and appropriate chemotherapy is the current standard of care for women with ovarian cancer. We should ensure that all women, regardless of ethnicity, age, domicile and socio-economic status, can access optimal treatment and care for their ovarian cancer. Further, there is a need to identify ways to improve outcomes for women living with ovarian cancer (quality of life, treatment, side effects, psychosocial and psychosexual concerns), exploring links between quality of life and time to recurrence and survival outcomes. And importantly, there is a need to provide early referral to palliative care services and, when needed, end-of-life support for women, their families, and carers.

3.1.3 Support gynaecological cancer units across Australia to deliver optimal care

Treatment for women with ovarian cancer usually involves complex surgery and multimodal/multidisciplinary care. For high-quality care/outcomes, women with ovarian cancer should be referred to a 'gynaecological cancer unit' (centre of excellence). These centres should:

- provide patient/family-centred care supported by educational resources and opportunities
- improve treatment and clinical outcomes (physical and emotional) for women with ovarian cancer through early detection and timely, appropriate treatment
- manage patient and family care to ensure the best plan of care and treatment options are offered to women
- create a transparent system of exceptional management and outcomes for women with ovarian cancer.

Women whose complex ovarian cancer surgery is undertaken in designated gynaecological cancer units are more likely to have better outcomes than women presenting to non-specialist centres (Woo et al. 2012). Information on, and referral to, gynaecological cancer specialist centres varies across Australia, with some women still not treated by a gynaecological oncology specialist. It is crucial that urgent action is taken that will enable **all women with suspected ovarian cancer to be referred to specialist gynaecological oncologists** (as well as medical and radiation oncologists where necessary).

All women with ovarian cancer should also have access to a specialist gynaecological nurse and subsequent access to a range of other multidisciplinary services at a dedicated gynaecological cancer unit. This will result in improved referral pathways and better outcomes for women requiring complex ovarian cancer surgery and treatment.



I would like to see that all women with ovarian cancer are able to access a gynae nurse, being educated about symptom management, have access to clinical trials (biobank, quality of life trials, new therapeutics).

DR YEH CHEN LEE, MEDICAL ONCOLOGIST



3.1.4 Embed the optimal care pathway

Optimal cancer care pathways outline the best care for specific tumour types to promote quality cancer care and patient experiences (CCA 2020). The Optimal Care Pathway for Women with Ovarian Cancer maps the best care journey for women with ovarian cancer, providing an understanding of the whole pathway and the individual components for promoting quality care, from prevention through to end-of-life care (Cancer Australia 2015). The optimal care pathway needs to be embedded throughout the health system as a foundation for improving equity of access, treatment, outcomes and support for all women with ovarian cancer in Australia. There also needs to be consideration for developing further, more defined and acceptable clinical practice guidelines to enhance the optimal care pathway (see Appendix A).

There is also an opportunity to link a clinical quality registry with the optimal care pathway, which, while supported in-principle by all governments in Australia, is not supported by an implementation plan or formal evaluation. Registry data could therefore provide critical insights into the take-up and promotion of the optimal care pathway.

3.1.5 Enhance quality of life and survivorship support

There has been a significant shift over the last five years to focus on quality of life rather than just survival for women with ovarian cancer. Australian researchers have made a major contribution to the field of quality of life research and patient-reported outcomes through research such as the Ovarian Cancer Prognosis and Lifestyle (OPAL) study (see Appendix B). This and other research studies have led to the incorporation of patient-centred endpoints in clinical trials. Ovarian Cancer Australia is also trialling a case management project to improve the psychosocial wellbeing of women with ovarian cancer.

There are still gaps around supportive care and survivorship needs for women with ovarian cancer, such as evidence-based guidelines for managing menopause after ovarian cancer. For example, there won't be available data informing us whether salpingectomy alone is effective in high-risk women for more than 10 years. There are no current trials powered to address this. In the meantime, we need better information and resources for managing early menopause in high-risk women, including research and clinical management tools.

Ovarian cancer places a unique psychological burden on women and their families, with women typically reporting feelings of isolation and a fear of recurrence that may adversely affect quality of life. Current research work in the area of psychosocial health is of high quality but is often fragmented and siloed.

An online platform could provide information about:

- the long-term side effects and emotional impacts for cancer survivors
- tools for self-management
- links to online treatment programs
- pathways to specialised care.

This could be a cost-effective way to increase the proportion of cancer survivors with effective treatment options and reduce pressure on tertiary services.

Table 3.1 outlines priorities and actions to improve patient and family-centred care and support.

“Ovarian Cancer Australia is also trialling a case management project to improve the psychosocial wellbeing of women with ovarian cancer.”

TABLE 3.1: PRIORITIES AND ACTIONS TO IMPROVE PATIENT- AND FAMILY-CENTRED CARE AND SUPPORT

PRIORITY	ACTIONS / DETAILS
<p>3.1.1 Improve equity of access to information</p>	<ul style="list-style-type: none"> ■ Create a repository of research, treatment and support information for women with ovarian cancer, their families and carers to inform decision-making ■ Provide and support a regularly updated evidence base ■ Include in the repository information on: <ul style="list-style-type: none"> > understanding screening > symptom and side effect management > supports for women making choices about fertility > palliative care ■ Establish a higher level of advocacy for women to access support services in regional areas ■ Provide a range of culturally and linguistically appropriate resources for Aboriginal and Torres Strait Islander women, women from culturally and linguistically diverse backgrounds and women with disability
<p>3.1.2 Improve equity of access to high-quality outcomes</p>	<ul style="list-style-type: none"> ■ Identify ways to improve outcomes for women living with ovarian cancer (e.g. quality of life, treatment/side effects, psychosocial and psychosexual concerns) ■ Explore links between quality of life and time to recurrence and survival outcomes ■ Provide early referral to palliative care services and, when needed, end-of-life support for women, their families and carers
<p>3.1.3 Support gynaecological cancer units across Australia to deliver optimal care</p>	<ul style="list-style-type: none"> ■ Enhance the experience of women with ovarian cancer by promoting gynaecological cancer units, with outreach ■ Include (in gynaecological cancer units) distributive networks that assist the major treatment units by linking with these units and providing a pathway for treatment, advocacy and support for women and their families ■ Ensure familial cancer centres are part of the multidisciplinary treatment, thereby improving care and research opportunities ■ Set a clinical standard of care that will empower women to question why they may not be being offered this high level of care ■ Require, as a condition of recognition as a gynaecological cancer unit, that the unit: <ul style="list-style-type: none"> > embed the optimal care pathway for women with ovarian cancer > be multidisciplinary, including a gynaecological oncologist, gynaecological cancer nurses and psychosocial support who can educate about symptom management and clinical trials (biobank, quality of life trials, new therapeutics) > demonstrate ongoing collaboration between clinicians and researchers > contribute to a National Gynae-Oncology Registry

3.1.4 Embed the optimal care pathway

- **Invest in, and support access to, gynaecological cancer nurses for patients to discuss options and pathways for care**
 - > Ensure all women with ovarian cancer can access a specialised gynaecological nurse who can educate about symptom management, clinical trials, etc. (akin to breast cancer nurses)
 - > Support and train nurses to upskill as gynaecological cancer nurses
 - > Have a 'road map' for women and their families from diagnosis and ongoing
- **Support access to the best possible treatment for all Australian women with ovarian cancer at all stages of their care, including access to optimal surgery**
 - > Continue to advocate for optimal care across the patient pathway, including identifying and addressing barriers to receiving optimal care and support for best possible support and end-of-life care
 - > Optimise palliative psychosocial and clinical care as there are many aspects in this area, including end-of-life care, that are challenging for women with ovarian cancer
- **Work to ensure that all women diagnosed with ovarian cancer are referred to a gynaecological oncologist for treatment planning**
- **Incorporate patient-reported outcome measures into clinical care**
 - > for example, the Measure of Ovarian cancer Symptom and Treatment concern (MOST), established through the Symptom Benefit Study (an Australian-led international study of >1000 women), may be incorporated into routine practice to prompt women about symptoms and empower them to voice their concerns to their doctor
- **Support the national case management program (implemented by Ovarian Cancer Australia in December 2019), which supports women with complex needs and psychosocial concerns following diagnosis, treatment and after clinical trials**

3.1.5 Enhance quality of life and survivorship support

- **Establish and provide multidisciplinary supportive follow-up services for women and their families when and where they need it and establish quality of life treatment pathways**
 - > Provide ongoing follow-up care for women with low survival rates and high incidence of recurrence
 - > Ensure all women can receive optimal care and gain access to survivorship clinics
 - > Connect survivorship clinics with Ovarian Cancer Australia's case management program (implemented in December 2019)
 - > Include psycho-oncology support post-surgery
 - > Provide access to specialised information on fertility, menopause and psychosexual counselling
 - > Provide better information and resources for managing early menopause in high-risk women, including research and clinical management tools
 - > Support more research into how to best coordinate, resource and provide more multidisciplinary support services for women
 - > Develop evidence-based guidelines for managing menopause after ovarian cancer

- > Provide palliative care and end-of-life care support for women with ovarian cancer, their families and carers
- > Identify research priorities into psychosocial health and the impact of ovarian cancer
- > Identify psychosocial health research priorities for ovarian cancer
- > Develop psychosocial supports to meet the needs of younger women (aged 50 and under) with ovarian cancer
- > Develop psychosocial supports to meet the needs of family and friends of women with ovarian cancer
- > Consider the psychosocial impact on long-term survivors
- **Support consumer-based research to involve the consumer in translation of research into policy and practice**
 - > Continue to support the OPAL study (see Appendix B)
 - > Undertake further quality of life and exercise studies
 - > Build relationships/pathways between consumers and researchers/clinicians/policymakers
- **Develop and support an active consumer community to provide insights into the experiences and needs of women living with ovarian cancer**
 - > Provide support mechanisms for families and carers of women with ovarian cancer
 - > Develop an online platform to manage common symptoms in cancer survivors

3.2 Diagnosis and treatment

This section 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, from a clinical perspective. This is in contrast to the previous section, which discusses how services are experienced by women with ovarian cancer, and how they can access the best package of care from these services.

This section considers some of the issues from a different viewpoint, and is about clinical research defining optimal treatment (i.e. optimising the use of current treatments, as well as developing new treatments).

Women with ovarian cancer should be diagnosed as quickly as possible and receive timely access to the best available specialist treatment. Ideally, investigations should include tissue collection and molecular profiling to optimise targeted treatment for each woman diagnosed with ovarian cancer.

Women should be made aware of and have access to clinical trials, should be aware of clinical variations in treatment and care, and should be referred to the best specialist care possible. There should also be a focus on continued monitoring and improved management of side effects and adverse reactions to treatments.

From the voices of the women we consulted

Research into ovarian cancer treatments was considered of great importance and the areas identified in the National Action Plan were broadly endorsed. There was a call for better support for regional and remote areas where there are currently limited services, adding travel and limited options to the stress of diagnosis and treatment. Women want access to research, testing, clinical trials, and new treatments and treatment information.



Treatment is most important to me. If you can't save my life, I don't care about the other priorities. **JACINTA**

Not all oncologists are across all trials – we need to have a reference organisation who can interpret the trials and eligibility to assist with matching – we need to be able to go directly to the source. **ANON**

I have had three lines of treatment in four years, so I am quickly running out of options, which is a frightening path to be headed down. **SARAH**

The gap is getting into the system; the issue is the GP roadblock. It took eight to 10 months for my diagnosis – I was told to lose weight and get more sleep. **CLARE**

Anything that improves diagnosis is important. Treatment is so debilitating – more specific ovarian cancer targeted treatment is needed. **CHRISTINE**

It isn't that easy to find out about trials. You need to check with your specialist doctors about trials, including your surgeon. It would be great to be able to speak to one person who can tell you which trials you are eligible for. **JESS**

I Research, research, research. Continue to find ways to improve treatment. **MARIE**



3.2.1 Enhance patient diagnosis

According to the Every Woman Study, Australian women with ovarian cancer experience a longer than average time from first symptoms to diagnosis (WOCC 2018). Reducing time to diagnosis may not lead to an earlier stage diagnosis, but earlier diagnosis may lead to earlier treatment and less complex surgery.

It is essential to refer to the optimal care pathway and the timelines it stipulates.

Women who are symptomatic need earlier access to diagnostic tests, including pelvic examination, ultrasound and tumour markers. For women with relevant subtypes of ovarian cancer, a genetic risk assessment and consideration of BRCA1 and BRCA2 genetic testing is considered standard care, and as result, has an impact on patient treatment options and their relatives' risk of developing cancer (Cancer Australia 2017).

3.2.2 Strengthen clinical trials

Novel and existing molecular and tumour-specific targeted therapies need to be progressed as rapidly as possible through clinical development and made available to patients. There is a need for preclinical studies to identify and validate new subtype-specific therapeutic targets, and identify and develop to proof-of-concept new, or re-purposed, drugs, to provide quicker answers with fewer patients and to conduct early-stage clinical researching adopting the OASIS Initiative and small SMART trials approach (see Appendix B).

Individualisation of medicine and molecular profiling is leading to dramatic changes in the clinical trial landscape. Where the focus used to be on large Phase 3 clinical trials, where all ovarian cancer patients were included, it is now known that a 'one size fits all' approach does not work with ovarian cancer as there are so many histological and molecular subtypes (ANZGOG n.d.). Collaboration between laboratory researchers and clinicians fosters the identification of nimble, cost-effective early phase clinical trials of targeted new and repurposed drug therapies and molecular subtypes of ovarian cancer. These signal-seeking studies offer a faster turnaround of results and opportunities for biomarker and other translational outcomes.

3.2.3 Improve targeted and optimal treatment pathways

In the last five years, the treatment landscape for ovarian cancer has changed significantly. There has been an increase in the options for delivery of standard treatment, for example, through neoadjuvant, dose-dense or hyperthermic intraperitoneal chemotherapy. There have also been significant advances in individualised treatments, for example using poly ADP ribose polymerase (PARP) inhibitors for treating patients with an identified gene fault, and molecular profiling leading to more people trialling newer targeted immunotherapies.

Advances have also been made into surgical treatments for ovarian cancer, for example in improving rates of optimal cytoreduction, which improves survival. Further research is needed into surgical treatment options, considering residual disease and survival. There is a need to improve our understanding of responses to existing treatments and why differences in clinical outcomes and mortality exist.

Priorities and actions for diagnosis and treatment are provided in Table 3.2.

TABLE 3.2: PRIORITIES AND ACTIONS FOR DIAGNOSIS AND TREATMENT OF OVARIAN CANCER

PRIORITY	ACTIONS / DETAILS
<p>3.2.1 Enhance patient diagnosis</p>	<ul style="list-style-type: none"> ■ Improve education and awareness for health professionals around the difficulties of recognising signs and symptoms of ovarian cancer <ul style="list-style-type: none"> > Continue to raise awareness that the signs and symptoms of ovarian cancer are vague, but persistent symptoms must be investigated > Promote the importance of using the optimal care pathway to aid in relevant investigations > Continue the Survivors Teaching Students program (ANZGOG) ■ Promote and support genetic risk assessment and genetic testing for all women diagnosed with high-grade ovarian cancer regardless of age or family history <ul style="list-style-type: none"> > Support the national Familial Cancer Support network in integrating genetic testing for all women diagnosed with a high-grade ovarian cancer at point of care (high-risk gene fault status has a major influence on survival in ovarian cancer patients) > Identify and address current barriers for women accessing genetic testing
<p>3.2.2 Strengthen clinical trials</p>	<ul style="list-style-type: none"> ■ Improve education and awareness of access to, and participation in, clinical trials – provide information and support for patients and their families/carers <ul style="list-style-type: none"> > Improve coordination of access to clinical trials by providing a central information access point > Improve consumers’ understanding about how clinical trials work > Hold forums or webinars for women, family and friends by clinicians to provide education about clinical trials ■ Consider and address challenges preventing patients accessing clinical trials <ul style="list-style-type: none"> > Recognise the need to partner with the pharmaceutical industry for clinical trials > Empower ANZGOG to prioritise non-commercial studies in regional and rural areas around Australia > Support OASIS (see Appendix B) to conduct more innovative SMART trials > Deliver clinical trials for rarer ovarian cancer subtypes ■ Support clinical trial units to explore ways to streamline their processes and take a patient-centred approach to treatments <ul style="list-style-type: none"> > Support and invest in the expansion of studies such as INOVATe, ALLOCATE (see Appendix B) and Stafford Fox Rare Cancer Program > Explore ways to support improved access to tissue and biospecimens to support clinical trial activity, including translational research components

- **Support funding for the translation of clinical trials**

- > Recognise that understanding why something didn't work can provide valuable insights into future research and treatment

- **Position Australia as an international leader in ovarian cancer trials**

- > Leverage existing international collaborations, model off successful small trials in other cancer types

3.2.3 Improve targeted and optimal treatment pathways

- **Continue to explore ways to optimise diagnosis and treatment pathways for every patient**

- > Undertake molecular profiling of tumours at diagnosis and at relapse to guide treatment choices
 - > Continue to research the potential role of immunotherapy for both recurrent and first-line treatment
 - > Monitor outcomes and benefits of the Ovarian Cancer Australia national case management program (implemented in December 2019)
 - > Facilitate prospective tissue and blood collection (with consent) from every woman undergoing surgery to bank tissue in a way that could be analysed to optimise individual treatment and potentially for use in broader research
 - > Ensure every woman has access to appropriate surgery and platinum-based chemotherapy
 - > Continue to develop and facilitate optimal psychosocial support and palliative care pathways of care

- **Conduct further research into advancing systemic responses and treatments**

- > Continue to explore the efficacy of different chemotherapy treatments such as hyperthermic intraperitoneal, neoadjuvant and pressured intraperitoneal aerosol chemotherapy
 - > Focus on understanding the mechanisms of drug resistance to PARP inhibitors and expanding PARP activity beyond patients with a high-risk gene fault

- **Support access to optimal surgery for women with ovarian cancer**

- > Advocate for Medicare Benefits Schedule item numbers for ovarian cancer surgeries specifically for gynaecological oncologists
 - > Embed the optimal care pathway throughout the system

- **Invest in further surgical research to define optimal surgical treatment**

- > Continue to support surgical studies into the surgical approach, patient selection, residual disease and survival

3.3 Early detection

It is well documented that in some cancers survival rates increase with early detection (HWHW 2018). Cancers that have a population screening test, such as breast, cervical and bowel cancer, have seen dramatic improvements in both early detection and overall survival rates (AIHW 2019).

From the voices of the women we consulted

Early detection of ovarian cancer was seen by women as the overwhelming priority – with those with personal experience pushing for an education campaign (as for breast cancer) to raise awareness of the key signs and symptoms of ovarian cancer. Raising awareness was considered a powerful tool in early detection and community awareness was identified as a key to battling misinformation and missed diagnosis: ‘Some women still think that a pap smear will provide early detection’.

Some women commented that other cancers receive more focus: ‘A lump on the breast gets so much more attention’. Empowering (or driving) women to ‘push’ their GPs to look for ovarian cancer signs and symptoms was an important message from most women. All the priorities are important but ‘We shouldn’t lose sight that identifying ovarian cancer early reduces treatment burden’.

There was some emphasis on research into early detection, such as a system for tracking health outcomes and identifying early stage symptoms. Educating GPs to recognise the symptoms of ovarian cancer was a key priority for women, with many women upset and believing they should have been diagnosed sooner.

Women urged making information easily accessible and less ‘happenstance’, with clearer signposting: there is insufficient collation of common factors leading up to diagnosis.



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

I was diagnosed at stage 4; I had no idea of signs and symptoms of ovarian cancer. There should be a television advertising campaign making women aware of the signs and symptoms. **ELIZABETH**

I know so many friends whose GPs missed diagnosing them and they were sent off to other specialists instead of doing tests for possible ovarian cancer. But it is such a long, drawn-out process getting specialists’ appointments. If GPs are missing it, then they are not being educated enough. **CLARE**

I would like to see less reluctance of GPs to refer women for ultrasound testing if the woman still has concern, due to symptoms which, although vague, could be a sign of ovarian cancer. **SUE**

Tumour markers, tumour markers. I believe priority into finding reliable tumour markers is so important and for regular screening to be available to all women, as it is for breast cancer. My tumour markers were the only indication that there may be cancerous tissue in my ovarian cyst, however I was lucky the cyst grew so large for me to be able to discover it was there. CA-125 is not reliable for everyone so we are in desperate need to find new reliable markers. **MEREDITH**



“Educating GPs to recognise the symptoms of ovarian cancer was a key priority for women.”

“Population screening is also very hard because, even with an almost perfect test, there will be many more false positives than true positives, and this comes at a cost to women.”

3.3.1 Continue to pursue mechanisms for early detection and screening

The evidence base related to screening for early detection for ovarian cancer is now extensive and indicates that it is possible to detect ovarian cancer in asymptomatic women with high sensitivity, specificity and positive predictive value and to achieve a stage shift through screening. To date there is no evidence that these interventions achieve a reduction in ovarian cancer mortality. However, there is currently one largescale randomised trial of ovarian cancer screening underway. It will report on mortality in 2021. If a mortality reduction is demonstrated, and the health economics are satisfactory, there will be important implications for clinical care.

If the randomised trial doesn't reveal a mortality reduction, it will be at least a decade before the mortality impact of any novel ovarian cancer screening tests can be assessed given the scale and duration of the necessary trials. In the meantime, more research is needed on pathways to earlier diagnosis, population-based screening, developing biomarkers for identifying disease subtypes for diagnosis, and guiding treatment and monitoring disease recurrence.

The biology of ovarian cancer – its heterogeneity and diversity, its short premalignant phase and lack of biological barriers between the ovaries and other organs – complicates the quest for a screening test for early detection. There is a pressing need to reduce public confusion around available screening methods for finding ovarian cancer early: it must be made clear there are currently no safe or effective screening options for ovarian cancer.

Population screening is also very hard because, even with an almost perfect test, there will be many more false positives than true positives, and this comes at a cost to women. We need to be able to reliably identify high-risk women who should then have access to targeted screening. Barriers such as impact to insurance, fear (sometimes based on misinformation about the test/implications) and access need to be addressed.

It is recognised that funding and research investment needs to be spread across the sector and focused on areas of high impact and high yield. Efforts need to continue into possible early detection, with international collaboration critical for driving progress.

Identified action areas and further details are provided in Table 3.3.

TABLE 3.3: PRIORITIES AND ACTIONS FOR EARLY DETECTION OF OVARIAN CANCER

PRIORITY	ACTIONS / DETAILS
3.3.1 Continue to pursue mechanisms for early detection and screening	<ul style="list-style-type: none">■ Prioritise early detection research investment in studies focused on biomarkers of ovarian cancer<ul style="list-style-type: none">> Leverage existing studies with a similar focus that are demonstrating progress, such as:<ul style="list-style-type: none">- studies identifying circulating tumour DNA for high risk endometrial cancer- the CancerSEEK study in the United States, where preliminary results for identifying biomarkers are quite promising for ovarian cancer- research into identifying tumour-educated blood platelets as biomarkers for ovarian cancer> Focus on international collaboration■ Reduce public confusion around methods for finding ovarian cancer early■ Ensure that where there is an evidence base for an early detection test, it is made appropriately available■ Continue to support initiatives that lead to an agreed screening protocol/guideline■ Continue to pursue multimodal screening options for the development of general population screening<ul style="list-style-type: none">> Support continued research into multimodal screening options and long-term survival benefit> Consider screening trials, for the purposes of risk assessment, for the general population in Australia> This would require clear identification of the current limitations of population screening, including the uncertainty around effect on mortality

“ Efforts need to continue into possible early detection, with international collaboration critical for driving progress.”

3.4 Biology/aetiology

Improving our understanding of the biology and aetiology of ovarian cancer is seen to be the foundation for future research questions around risk reduction, detection and treatment of ovarian cancer for women (CCA n.d.).

From the voices of the women we consulted

Classifying tissue specimens, investigating therapy resistance and hereditary factors were all endorsed as areas in need of investigation. Women expressed distress/anger relating to the length of time it can take before being given pathology results. The complexities surrounding the many types of ovarian cancer were acknowledged, and women agree understanding the disease better will help speed up diagnosis. But the consensus was: this needs to happen faster.



More research into drug resistance because we need successful treatments and rare ovarian cancers because I have one and it's personal for me. **ANON**

My case took months to diagnose correctly due to waiting, and three different pathology reports on the exact same things because I live remotely. **STACEE**

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**

Understanding why some people react well to chemo, and why some never have a recurrence, would be beneficial. It would also be great to find out more about the rarer types. **CAITLIN**

Why women become resistant to treatment. Less focus in research on women who are not BRACA [which only make up 15% of all ovarian cancer patients]. **MYRINE**



“Women expressed distress/anger relating to the length of time it can take before being given pathology results.”

3.4.1 Investigate identified action areas to deepen our understanding of the biology/aetiology of ovarian cancer

The treatment options for women with ovarian cancer, particularly the rare subtypes, are very limited. Continuing research on the biology of ovarian cancer is required to inform diagnosis, early detection, treatment pathways and research translation, with a focus on the classification of disease subtypes to identify new therapeutic targets and why tumours respond to and resist treatment. Treatment resistance is one of the main reasons limiting survival following a diagnosis of ovarian cancer and is therefore a high priority for research. Understanding the natural history of subtypes is critical for making advances in ovarian cancer research to:

- identify precursors for earlier detection and treatment
- develop, assess and enable access to models and cell lines consistent with ovarian cancer subtypes, to facilitate research into targeted treatments.

Identified action areas and further details are provided in Table 3.4.

TABLE 3.4: PRIORITIES AND ACTIONS RELATED TO THE BIOLOGY/AETIOLOGY OF OVARIAN CANCER

PRIORITY	ACTIONS / DETAILS
<p>3.4.1 Investigate identified action areas to deepen our understanding of the biology/aetiology of ovarian cancer</p>	<ul style="list-style-type: none"> ■ Understand the role of genetics and interactions between hereditary and lifestyle factors in the causes of different histological subtypes of ovarian cancer <ul style="list-style-type: none"> > Further explore the role of genetics in causation, epidemiology, hereditary components and risk > Identify and map the genetic faults that cause cancer and exploit these for targeted treatment and screening tests > Explore the role of other (non-BRCA) inherited gene mutations such as BRIP1, PALB2 in high-grade serous ovarian cancer ■ Understand the natural history and latency of all rare and other subtypes of ovarian cancer to identify precursors for earlier detection and help discover new treatment strategies <ul style="list-style-type: none"> > Understand the drivers within each subtype to develop new treatments (the underlying alterations differ significantly between histological subtypes of ovarian cancer) > Consider where international collaboration may be important for participation in larger research cohorts ■ Invest in research and the development of experimental or preclinical models that are representative of the disease in women <ul style="list-style-type: none"> > Continue to support OCELIS and ACOS (see Appendix B) to ensure researchers and laboratories have access to and use cell lines that are representative of the disease in women ■ Focus on molecular profiling and histology to identify and validate new therapeutic targets for treatment <ul style="list-style-type: none"> > Explore mechanisms underpinning exceptional response to treatment > Include considerations for integrating big data ■ Understand and explore the basis of intrinsic and acquired drug resistance <ul style="list-style-type: none"> > Continue to explore the tumour-immune microenvironment to identify targets for therapy > Compare recurrent with initial disease to understand factors that influence resistance to treatment > Prioritise research into understanding responses and resistance to PARP inhibitors > Explore treatments used in cancer streams with successful responses, such as melanoma treatment

3.5 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.

From the voices of the women we consulted

Prevention is seen as important, but women believe it should have a wider scope. While improving understanding and awareness of risk factors and investing in risk reduction and information are viewed as positive and widely supported, the women we consulted feel the emphasis is too much on high-risk women. This strategy neglects detection and education among the general population of women who may also be at risk of developing 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. Much of what is listed here is for women at risk. ALL women are at risk if there is insufficient collation of common factors leading up to diagnosis. **ANON**

About 80% of women don't have the BRCA gene fault, but every meeting you go to they are talking about the BRCA fault and treatment. What is being done for us without the BRCA gene fault? **CLARE**

I would like to see the researchers look more into the backgrounds of women with ovarian cancer (e.g. diet, lifestyle, trauma, chemical exposure). **ANON**

We need to get it out there that genetic testing is free. Some of us are being sent to private clinics and it is costing us \$2500. **ROBYN**

Early detection and diagnosis and treatment need to be a higher priority than prevention. This is simply because there are so many women right now either facing the disease or unaware that what they are experiencing physically may need investigation. **MYRINE**



3.5.1 Improve understanding and awareness of risk factors

There has been a general increase in awareness regarding ovarian cancer over the last five years. But there remains an incomplete understanding of the risk factors for ovarian cancer, and the correlation between each risk factor and the propensity to develop ovarian cancer. This has been observed nationally and internationally (Ovarian Cancer Australia 2015). For example, many people are not aware of the link between gene faults (that are well known to increase risk of breast and prostate cancer) and an increased risk of ovarian cancer and endometrial cancer, or the impact of physical inactivity for risk and for long-term survival for women with some types of gynaecological cancers.

3.5.2 Invest in risk prediction and information and support for risk reduction

Cancer genetics research has undergone significant advances in the last five years with the contribution of cancer geneticists to ovarian cancer research teams. Genome-wide research has identified new genetic risks for women, which has helped with progress towards developing risk prediction models for ovarian cancer (WOCC 2018).

Evidence for increased risk of ovarian cancer due to inherited alterations in BRCA1 and 2 is well established. However, mutations are now being identified in other related genes, such as BRIP1. It is not always clear what advice needs to be given to women carrying alterations in these genes. More research is needed into the level of risk for specific variants in genes such as BRIP1, PALB2, to provide evidence-based advice for prevention. Research must also focus on detecting mutations in women **with** ovarian cancer, to ensure family members are offered appropriate testing. This will hopefully assist to prevent future cases of ovarian cancer.

With Lynch syndrome as a known genetic risk factor for ovarian cancer, there needs to be information and support for appropriate gynaecological cancer risk management for women identified through mainstreaming of Lynch syndrome testing for colorectal cancer.

Given histology indicates that a lot of ovarian cancer originates in the fallopian tubes rather than the ovaries, there is some research to suggest that removing just the fallopian tubes is effective in reducing the risk of ovarian cancer in high-risk women (Wang et al. 2014). This has significant repercussions for younger women wanting to preserve fertility and those wanting to avoid early-onset menopause. Current trials are researching this, and more women are looking at removing just their fallopian tubes, although the safety of this approach is currently uncertain. It is important to ensure that all women receive optimal care around all aspects of risk-reducing surgery and we develop evidence-based pathways for managing women after risk-reducing surgery. Further research is required to explore the adoption of risk-reducing surgical methods in high-risk women and on the long-term effects of risk-reducing surgery.

Table 3.5 lists prevention priorities and actions.

TABLE 3.5: PRIORITIES AND ACTIONS FOR THE PREVENTION OF OVARIAN CANCER

PRIORITY	ACTIONS / DETAILS
3.5.1 Improve understanding and awareness of risk factors	<ul style="list-style-type: none"> ■ Facilitate targeted education and awareness campaigns around modifiable risk factors <ul style="list-style-type: none"> > Tailor education and awareness campaigns for specific population groups > Deliver resources across a range of digital platforms, including tele-support, online forums and webinars > Increase collaboration with the Cancer Council, combining modifiable risk factor messaging ■ Continue to build evidence on potential modifiable risk factors such as obesity, physical inactivity and smoking, and their potential adverse impact on survival <ul style="list-style-type: none"> > Provide education for primary health providers regarding preventable modifiable risk factors > Monitor current trials exploring the benefits of aspirin as a preventive measure, the impact of breastfeeding in reducing risk, and the impact of socioeconomic status on risk > Monitor the ongoing protective benefit of the newer lower dose oral contraceptive pills to measure hormonal influences on the risk of ovarian cancer

3.5.2 Invest in risk prediction and information and support for risk reduction and promote established familial cancer centres

- **Improve rapid access to, and uptake of, genetic testing for women who are at high risk**
 - > Encourage genetic/familial counselling and testing at known familial cancer centres throughout the country, for women with a family history of high-risk gene faults or where a relative has been diagnosed with ovarian or breast cancer regardless of immediate family history
 - > Support studies such as AOCS and TRACEBACK (see Appendix B) and promote investment for, and recruitment into, these studies
 - > Emphasise the importance of timeliness for genetic testing, with a framework for follow-up care
- **Reduce the incidence of ovarian cancer by promoting genetic testing for women who are at high risk of carrying a gene fault**
 - > Develop a national framework for clinical genetic testing, with integrated algorithms of risk prediction
 - > Monitor the pilot study JeneScreen (see Appendix B), which is currently providing founder mutation screening for people of Ashkenazi Jewish descent – a known high-risk population group.
- **Undertake further research to develop better models for predicting risk of ovarian cancer in women with a high-risk and moderate gene fault and why ovarian cancer develops at different rates**
 - > Support the principle that every woman with ovarian cancer should have the opportunity to have her tumour stored / genome sequenced
 - > Explore how people with high-risk gene faults develop cancer at different rates to develop risk prediction models
 - > Recognise the importance of assessing genetic risk in women before they die and also to undertake genetic testing of tissue from women who have died
 - > Support mechanisms for intergenerational testing through studies such as TRACEBACK (see Appendix B)
- **Improve risk-reducing surgery information, support and treatment pathways for women with a high-risk gene fault**
 - > Develop treatment pathways to help women make more informed decisions about preventive surgery options
 - > Ensure all women who have risk-reducing surgery have recommended pathological examination (SEE-FIM protocol) to exclude occult cancer
 - > Continue to examine the long-term effects of bilateral salpingo-oophorectomies on women, such as the potential impact on bone and cardiovascular health
 - > Inform women considering preventive surgery about long-term menopausal symptoms and support them regarding fertility, considering the surgery is irreversible
- **Conduct further research, including developing risk prediction models, into the effectiveness of bilateral salpingectomies only in reducing the risk of ovarian cancer**
 - > Support participation in international collaborations
 - > Undertake studies on women's responses to risk prediction models

Implementing the National Action Plan

Implementation partners

Achieving the overall vision and objectives of the 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. Dependent 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.

Next steps

It is proposed that a small Working Group is established across the lead sector organisations to coordinate a collective effort to:

- facilitate and drive implementation of the National Action Plan
- establish the Ovarian Cancer Alliance.

Facilitate and drive implementation of the National Action Plan

Further work is required to operationalise each of the priorities; specifically, action is needed to:

- coordinate the effort to develop an interventional timeline to prioritise the actions
- identify the key implementation partners responsible for driving implementation of each action
- determine how to progress implementation to achieve the overall objectives of the plan
- determine how to measure progress.

Establish the Ovarian Cancer Alliance

Collaborative effort is required to agree on:

- how the alliance will work in practice
- immediate priorities for funding
- how collaborative applications for funding would be informed, led and managed.

“Achieving the overall vision and objectives of the National Action Plan will require strong and continued collaboration with women with ovarian cancer.”

Appendices

Appendix A: Foundation of the Australian Charter for Ovarian Cancer Care Excellence

Common agenda

- Develop a shared vision for change and a mutual plan of action involving a joint approach. The National Action Plan should be adaptive and responsive to environmental change and should deliver a clear value proposition.
- Establish and implement national priorities for research, clinical and quality assurance initiatives with the greatest potential to deliver impact in improving the lives of women with ovarian cancer.
- Participate in regular review and evolution of goals and priorities through established mechanisms.

Collaboration

- Explore and develop collaborative approaches between women with ovarian cancer, funders, research organisations, government policymakers, researchers/clinicians and the community to appropriately resource, review and deliver high-impact research and development programs.
- Enable sharing of resources, information and outcomes as a fundamental basis for an effective research and clinical and quality assurance effort – a strong basic and applied research base, access to patient populations, and an integrated and standardised dataset of longitudinal molecular, clinical and outcomes data.
- Ensure each organisation is able to deliver their specific contribution to achieve the agreed common agenda.

Shared measurement system

- Develop a shared system on the ways success will be measured and reported. Collecting data and measuring results consistently on a short list of indicators, across all participating organisations, not only ensures all efforts remain aligned, it also enables the participants to hold each other accountable and learn from each other's successes and failures (SSIR 2011).

Involvement of women with ovarian cancer

- Provide a stronger ongoing mechanism to allow true engagement with women who have ovarian cancer and increase meaningful engagement across the spectrum, including in advocacy activities, research planning, review processes, participation (e.g. establishing appropriate quality of life measures), conduct, evaluation and governance (e.g. establish a group of women with ovarian cancer to help review all aspects of care and support in this area, who can also report back to the overall National Action Plan Working Group).

Consistency

- Align efforts to develop a consistent approach towards the collection of specimens and data and the analysis of results.
- Develop an evaluation framework to span the research and development continuum to improve our ability to measure research impact and progress. Research would be assessed to determine what knowledge was produced and how it was disseminated, whether that knowledge contributes to the development of products, policies or clinical guidelines, as well as what health sector, social and/or economic benefits it provides.

Continuous and transparent communication

- Communicate consistently and openly with funders, research organisations, researchers, clinicians, consumers and the community to engage, build trust, assure shared objectives and to recognise and work to overcome barriers to development.
- Adopt transparent and accountable standards for the public reporting of ovarian cancer infrastructure, research, clinical and development funding and achievements.

Backbone support

- Ensure there is adequate resourcing to enable the required support for independent administration, funding, evaluation, reporting and to enable transparent and accountable practice. The backbone function is critical in achieving the alliance's vision in coordinating activities and supporting the enablers as described in the National Action Plan. The backbone body will aim to move the initiative forward by:
 - > guiding vision and strategy
 - > supporting aligned activity
 - > establishing shared measurement practices
 - > building public will
 - > advancing policy
 - > mobilising funding (SSIR 2011).

Appendix B: Key multistate collaborative ovarian cancer initiatives/studies

Australian Ovarian Cancer Assortment Trial (ALLOCATE)

ALLOCATE was developed as a pilot study based in Melbourne to test the feasibility of molecular profiling for eligible patients with recurrent ovarian cancer, with the aim of allocating patients to targeted therapies based on the genomic profile of their tumours. ALLOCATE successfully demonstrated the feasibility of providing targeted treatments based on molecular profiling. Profiling patients earlier in their disease course, and improved access to targeted therapies and clinical trials, will enhance the utility of the ALLOCATE panel.

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More information: <https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=368219>

Australian Ovarian Cancer Study (AOCS) and AOCSII

AOCS is a biospecimen bank containing more than 2000 tissue samples donated by Australian women with ovarian cancer. AOCS provides access to these tissue samples and related data to ovarian cancer researchers from across Australia and internationally. AOCS is a unique resource for ovarian cancer research, made possible through collaboration between clinicians, nurses, pathologists and scientists throughout Australia, and through the willingness of thousands of women who participate in the program.

AOCS is one of the largest and most sophisticated ovarian cancer cohort studies in the world. It has enabled more than 90 national and international research collaborations consistently producing excellence in research. AOCS has been pivotal in:

- categorisations of the different subtypes of ovarian cancer (i.e. understanding that ovarian cancer is not one single disease)
- understanding of genes involved in resistance to chemotherapy, which has potential to change future treatment strategies.

Work continues to identify genetic and biochemical changes in ovarian cancers that dictate how a woman will respond to chemotherapy and predict overall survival.

AOCSII commenced recruitment in 2017, with a focus on renewing participant enrolment in biospecimen collection, to increase the number of biospecimens available for research and to create a cohort of women exposed to newer treatment agents and regimes.

Contact: David.Bowtell@petermac.org

Individualised Ovarian Cancer Treatment through Integration of Genomic Pathology into Multidisciplinary Care (INOVAte)

INOVAte is a research study aimed at developing a personalised approach to the management of women with ovarian cancer by developing strategies to better define ovarian cancer patient subsets. The study uses both tumour genomic profiling and established histological subtyping to optimise the selection of patients for novel molecularly targeted clinical trials and ultimately to individualise treatment. INOVAte is open at nine study sites across Sydney and with further investment has the potential to extend to other states.

Contact: anna.defazio@sydney.edu.au

More information: [https://www.westmeadinstitute.org.au/research/featured-projects/inovate-\(1\)/overview](https://www.westmeadinstitute.org.au/research/featured-projects/inovate-(1)/overview)

JeneScreen

JeneScreen is a targeted genetic screening research program aimed at reducing the incidence of ovarian and breast cancer among the Ashkenazi Jewish community. Research has found people of Jewish descent have an increased risk of carrying BRCA gene faults compared to the general population, and therefore have an increased risk of developing cancer. JeneScreen offers free genetic testing to eligible Jewish women irrespective of a family history of cancer.

Contact: Belinda.creighton@ovariancancer.net.au

Ovarian Cancer Alliance for Signal Seeking studies (OASIS)

OASIS refers to a series of nimble, cost-effective clinical trials based on matching new drug treatments with molecular subtypes of ovarian cancer. These 'SMART' trials are specially designed to more rapidly identify improved response signals.

OASIS has made good progress in early phase 'proof of principle' trials and is key to the delivery of precision medicine and improved treatment outcomes. OASIS represents an opportunity for Australian women with ovarian cancer to access a range of new, experimental therapies.

OASIS is an alliance of ANZGOG, AOCS and Ovarian Cancer Australia.

Contact: Alison.Evans@anzgog.org.au

Ovarian Cancer Cell Line Study (OCELIS)

OCELIS is an international consortium led by AOCS to develop new cell line models reflective of the range of ovarian cancer disease subtypes. Cancer cell lines are cancer cells that keep dividing and growing over time, under certain conditions, in a laboratory. They are used in research to study the biology of cancer and to test cancer treatments. The cell line suite will be available to researchers, to enable research in novel, targeted treatments and companion diagnostics.

This world-first cell line resource provides experimental models reflective of the range of ovarian cancer subtypes found in women. The consortium has attracted contributions from industry and research leaders internationally.

Contacts: David.Bowtell@petermac.org, anna.defazio@sydney.edu.au

Ovarian Cancer Prognosis and Lifestyle (OPAL) study

OPAL is a 10-year longitudinal study exploring the impacts of potentially modifiable behaviours, such as diet and lifestyle, on quality of life and survival outcomes for women with ovarian cancer. It addresses the question of whether lifestyle choices during or after treatment could positively impact quality of life and, ultimately, survival.

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More information: https://ascopubs.org/doi/abs/10.1200/JCO.2018.36.7_suppl.88

Ovarian Tumour Tissue Analysis (OTTA) consortium

OTTA is a forum of investigators of tumour studies of ovarian cancer, formed in April 2010. Many groups are conducting studies with the aim of identifying tumour factors that may be related to the prognosis of ovarian cancer. The aim of the group is to combine data from many studies, to provide a reliable assessment of the risks associated with specific tumour features.

More information: www.ottaconsortium.org/

TRACEBACK

TRACEBACK is a ground-breaking study (funded by the Australian Government) aiming to reduce the number of new ovarian and breast cancers diagnosed in Australia. It will identify families that may have a hereditary risk of developing cancer because of inherited gene faults in BRCA1, BRCA2 and other cancer predisposition genes.

TRACEBACK aims to facilitate free genetic testing for:

- women with ovarian cancer who have not had genetic testing
- family members of someone who had previously been diagnosed with ovarian cancer and was not offered genetic testing before dying.

This study will draw on the AOCs cohort but will also recruit new women. It is anticipated that a further 500–1000 research participants will be identified through TRACEBACK over the next two to three years.

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More information: www.ovariancancer.net.au/traceback-research-project/

Appendix C: Individuals and organisations who contributed to the development of this plan

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Women with ovarian cancer who responded to our survey and/or attended a 'think tank' session

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Abbreviations

ALLOCATE	Australian Ovarian Cancer Assortment Trial
ANZGOG	Australia New Zealand Gynaecological Oncology Group
AOCS	Australian Ovarian Cancer Study
INOVATe	Individualised Ovarian Cancer Treatment through Integration of Genomic Pathology into Multidisciplinary Care
MOST	Measure of Ovarian cancer Symptom and Treatment concern
NGOR	National Gynae-Oncology Registry
OASIS	Ovarian Cancer Alliance for Signal Seeking studies
OPAL	Ovarian Cancer Prognosis and Lifestyle study
OTTA	Ovarian Tumour Tissue Analysis Consortium
PARP	poly ADP ribose polymerase

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