

OCA NAP 2020-2025
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Ovarian Cancer National Action Plan 2020–2025

Working together to change the ovarian cancer story

Working Draft – January 2020

Ovarian Cancer National Action Plan 2020–2025

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Foreword

The Ovarian Cancer National Action Plan 2020–2025 is the product of many months of consultation with experts and leaders in ovarian cancer diagnosis, research, care and treatment in Australia.

Among the many dozens of people consulted were women with ovarian cancer, who provided significant feedback on the draft report. Throughout the ongoing development and implementation of the Plan we will continue to consult with and listen to the perspectives of women affected by ovarian cancer.

The rigorous consultation and review process applied in developing the Plan resulted in three broad areas:

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

The Plan is structured in line with these three areas.

<Foreword to be completed when review process is complete>

<To be signed by the committee members overseeing the Plan development, or an individual identified as best placed to sign>

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Acknowledgements

The Ovarian Cancer National Action Plan 2020–2025 (the Plan) was developed 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 reducing the incidence of ovarian cancer for women in Australia.

We acknowledge the following key stakeholders who have been involved in the development of this Plan and recognise the commitment of these key organisations to work together to achieve the Plan.

<Logos for each of the key organisations involved in the development of the Plan will be included here>

A complete list of the individuals and organisations who contributed to this Plan is included at [Appendix C](#).

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Introduction

The Ovarian Cancer National Action Plan 2020–2025 (the Plan) 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 promoting 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,¹ published in 2015.

This 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.

The Plan 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 is seeking to operationalise the identified priorities by providing a framework for action and an implementation approach to achieve progress.

At the heart of this 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, 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 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 several different cancers, with a wide range of origins and subtypes.² 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.³ Further detail regarding the biology and classification of ovarian cancer can be found in the first (2015–2020) Plan.

This 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,⁴ as the symptoms associated with the disease are vague and easily mistaken for other, more common health issues. This often results in delayed action, leading to women being diagnosed at a late stage of the disease.⁵

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.

Ovarian cancer has a poor prognosis, with only 46 of every 100 women diagnosed still alive five years after their diagnosis.⁶

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.⁷ 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. However, it should be noted that, in comparison to other countries, 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.⁸

<For final Plan - Insert infographic with statistics>

From the perspective of women with ovarian cancer

<The final version of the Plan will include a page reflecting the feedback on the draft plan that we have heard through our consumer feedback sessions.>

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What the first (2015–2020) National Action Plan achieved

It is important to acknowledge the many achievements and significant progress made across the sector in response to the first National Action Plan. We must use these as leverage to drive further change. This section highlights key achievements and investments.

It raised the profile of ovarian cancer in Australia

The development of 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 first 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. The first Plan 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 underestimated.

Another major achievement for the sector has been to secure 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 gynaecological cancers, including ovarian cancers.

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

It strengthened awareness, visibility and advocacy

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

It generated ovarian cancer awareness and fundraising campaigns

The sector has achieved a huge amount of visibility and fundraising support through ongoing awareness campaigns, including:

- White Shirt campaign (Ovarian Cancer Research Foundation)

- Save the Box campaign (Australian and New Zealand Gynaecological Oncology Group (ANZGOG))
- Ovarian Cancer Awareness month, which incorporates Teal Ribbon Day (Cancer Australia) and Paint the Town Teal (Ovarian Cancer Australia (OCA) fundraising and awareness campaigns
- It's time for Ovary-Action campaign (OCA).

It improved partnerships

Uniting the sector through the development of the first Plan, and the clear articulation of priorities for research in ovarian cancer, has increased collaboration between researchers around Australia as well as with international research groups. 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 opportunities 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.

It facilitated 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](#).

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 diagnosis and researching possible screening methods
- improving quality of care and better treatments
- 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 it is developed with them, and in their best interests
- invest in improving quality of care and outcomes for women with ovarian cancer
- better understand the barriers for women accessing the right care
- focus on ensuring women get the right treatment at the right time in the right place
- progress the quality assurance work to continue to improve practice
- increase research and funding into the biology of the disease, as well as new treatments for ovarian cancer
- build local and international sector collaboration to drive progress.

The Plan is in three major sections. The first two sections 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 the period 2020–2025, and associated actions.

The summary table illustrates the layout of the Plan.

Summary table. Principal areas for action and priorities of the second Ovarian Cancer National Action Plan

Our two principal areas for action		Our core priorities
1. Enabling system-wide progress	2. Promoting sector infrastructure and investment	3. Actions that support our core priorities
1.1 Establish an Ovarian Cancer Alliance	2.1 Invest in and support national tissue collection and biobanking	3.1 Priority: Patient and family-centred care 3.1.1 Improve equity of access to information and high-quality outcomes 3.1.2 Establish and support gynaecological cancer centres of excellence across Australia to deliver optimal care 3.1.3 Embed the optimal care pathway for to facilitate systematic coordinated care and support for all women with ovarian cancer 3.1.4 Enhance quality of life and survivorship support
1.2 Strengthen national and international collaboration	2.2 Build experimental models and support translational research	3.2 Priority: Biology/aetiology 3.2.1 Investigate identified action areas to deepen our understanding of the biology/aetiology of ovarian cancer
1.3 Build advocacy and philanthropy capacity	2.3 Ensure quality assurance through access to data and benchmarking	3.3 Priority: Prevention 3.3.1 Improve understanding and awareness of risk factors 3.3.2 Invest in risk prediction and information and support for risk reduction
1.4 Include the consumer voice		3.4 Priority: Early detection 3.4.1 Continue to pursue mechanisms for early detection and screening
1.5 Support shared awareness of activity		3.5 Priority: Diagnosis and treatment 3.5.1 Enhance patient diagnosis 3.5.2 Strengthen clinical trials 3.5.3 Improve targeted and optimal treatment pathways
1.6 Support funding for Australian researcher		
1.7 Facilitate research collaboration		
1.8 Support the research and treatment workforce		

Further detail is provided in the following sections of the Plan.

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1. Enable system-wide progress

This 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 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 Plan.

It is proposed that the sector establish an Ovarian Cancer Alliance. This would allow the development of a comprehensive approach to improving outcomes for women with ovarian cancer, and would include driving advocacy for, and implementation of, the Plan.

The Alliance could take collective action to accelerate progress, reduce duplication, and ensure stronger alignment of research, clinical care and advocacy activity. It would support the sector to speak with one voice about what is important. It 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 Plan. Everyone would work together to collectively target increased funding to address ovarian cancer.

The Alliance would follow the principles of the Australian Charter for Ovarian Cancer Research Excellence proposed in the first National Action Plan for Ovarian Cancer Research (see [Appendix A](#)), based on the 'collective impact' framework⁹ to tackle deeply complex problems. The collective impact framework is an innovative and structured approach to making collaboration work across government, business, philanthropy, non-profit organisations and community to achieve significant and lasting change.

1.2 Strengthen national and international collaboration

National collaboration

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) (see [Appendix B](#)) demonstrates how collaborative effort within the sector has been able to provide a platform to facilitate a wide range of high-impact, translational research in ovarian cancer.

International collaboration

Australia already successfully collaborates via AOCS and TR-ANZGOG for tissue collection. There are also 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 (OCAC) and the Ovarian Tumor Tissue Analysis Consortium (OTTA) is crucial.

1.3 Build advocacy and philanthropy capacity across the sector by providing clarity on organisations' objectives and responsibilities

There is a need for organisations in the ovarian cancer area 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.

1.4 Include the consumer voice when advocating for change

Advocacy is strengthened when people affected are heard. It would benefit the sector to routinely consult with consumers to overcome barriers and drive change.

1.5 Support shared awareness of activity across the sector by building an Australian ovarian cancer research database

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.

1.6 Support funding for Australian researchers to participate in, and where possible, to lead international studies

Australian researchers need support to access funding to take part in and lead international studies. 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 Provide support to the research and treatment workforce

There is a great need to support ovarian cancer researchers and the clinical workforce in Australia, particularly by engaging and funding a new wave of young ovarian cancer researchers and providing opportunities to connect with existing research networks.

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

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 facilitate system-wide progress.

Table 1. Priorities and actions to enable system-wide progress

Priority	Actions/details
1.1 Establish an Ovarian Cancer Alliance to drive accountability and delivery against the Plan	<ul style="list-style-type: none"> • Priorities of the Alliance could address: <ul style="list-style-type: none"> – alliance governance ethics review processes – streamlining access to clinical trials – sharing, integration and governance of data – implementation and funding for Plan priorities – advocacy with government for priorities funding
1.2 Strengthen national and international collaboration between key organisations to drive a systemic approach to ovarian cancer research, treatment, advocacy and support	<ul style="list-style-type: none"> • Key sector organisations will include ANZGOG, Australian Society of Gynaecologic Oncologists, OCA, Ovarian Cancer Research Foundation and AOCS • Bring in relevant professional colleges, such as: <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 (CNSA) • Include other relevant partners: <ul style="list-style-type: none"> – Psycho-oncology Cooperative Research Group – familial cancer clinics – Kathleen Cuningham Foundation Consortium for research into Familial Breast cancer (KConFab) – industry partners
1.3 Build advocacy and philanthropy capacity across the sector by providing clarity	<ul style="list-style-type: none"> • Agree on and articulate objectives and priorities within each organisation and contribution to the shared vision for the sector

<p>on organisations’ objectives and responsibilities</p>	<ul style="list-style-type: none"> • Provide transparency around fundraising impacts
<p>1.4 Include the consumer voice when advocating for change</p>	<ul style="list-style-type: none"> • ‘Ensure consumers’ 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’
<p>1.5 Support shared awareness of activity across the sector by building an Australian ovarian cancer research database that captures information on researchers, previous and current research projects, studies, trials and treatment information</p>	<ul style="list-style-type: none"> • 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
<p>1.6 Support funding for Australian researchers to participate in, and where possible, to lead international studies</p>	<ul style="list-style-type: none"> • Support Australian women with ovarian cancer to participate in existing and future international studies • Facilitate broader OCAC and OTTA involvement
<p>1.7 Facilitate collaboration between laboratory research, clinical research and clinical trials by creating dual fellowship pairings of clinical and basic researchers</p>	<ul style="list-style-type: none"> • Leverage off 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)
<p>1.8 Provide support to the research, clinical and treatment workforce</p>	<ul style="list-style-type: none"> •

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 (CQR). Both are linked to better clinical outcomes for women. Investment in infrastructure and capacity will enable greater collaborations, both 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 it recurs
- how it can be prevented.

Maintaining these resources will allow us to continue in the position of 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 AOCS biobank and 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.

Women with ovarian cancer, researchers and clinicians would all benefit from a systematic approach to tissue collection across the country to maximise collection and biobanking. Resources are needed prior to surgery to facilitate patient consent, and for management of the tissue sample from excision, through pathology and sending on to a biobank.

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 animal 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.

There is a need to improve the culture of research – to provide protected time for clinical research and funding for non-commercial clinical trials.

2.3 Strengthen quality assurance through access to data and benchmarking

Quality data underpins 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, 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 (NGOR) which is a clinical quality registry capturing data about women with newly diagnosed gynaecological cancers. Expansion of this registry would help to determine a national set of clinical benchmarks and collect information on compliance with benchmark standards. 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.¹⁰

There is a newly established registry within Australia, the National Gynae-Oncology Registry (NGOR), 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.¹¹ With further investment and support, the NGOR could be expanded to become more beneficial for all gynaecological cancers.

Fully implemented, for every woman diagnosed with ovarian cancer in Australia, a clinical quality registry would track information on:

- diagnosis
- bio-specimen details
- prognosis
- treatment
- clinical outcomes.

This would allow development of benchmarks and provide real-time insights 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 NGOR would also allow for the collection of Patient Reported Outcomes and Experience Measures (PROMs and PREMs) and could facilitate accreditation for gynaecological cancer centres of excellence.

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.

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
2.1 Invest in and support national tissue collection and biobanking	<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 – Consider ‘light’ biobanking and pre-clinical models
	<ul style="list-style-type: none"> • Improve tissue collection mechanisms and protocols for treatment and analysis purposes and embed in systemic practice <ul style="list-style-type: none"> – 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 • Leverage off 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 education for patients to make an informed choice regarding donating biospecimens to build the biobank resource • Explore options for fresh tissue collection for research
2.2 Build experimental models and	<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

<p>support research translation</p>	<ul style="list-style-type: none"> • 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 – Dedicate ‘protected time’ for clinical research
	<ul style="list-style-type: none"> • Establish a new concept development fund to translate promising research findings into new products and psychosocial supportive care interventions <ul style="list-style-type: none"> – 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
<p>2.3 Strengthen quality assurance through access to data and benchmarking</p>	<ul style="list-style-type: none"> • Recognise and support the need for better data integration across the sector <ul style="list-style-type: none"> – Recognise and expand the work being undertaken by BioGrid Australia and NSW Health
	<ul style="list-style-type: none"> • Continue to support the expansion of the NGOR for gynaecological cancers <ul style="list-style-type: none"> – 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
	<ul style="list-style-type: none"> • Identify and address existing barriers for expansion of NGOR <ul style="list-style-type: none"> – 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

	<ul style="list-style-type: none">– 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
	<ul style="list-style-type: none">• Maximise patient-reported outcome data captured in clinical trials<ul style="list-style-type: none">– Use patient reported outcome measures (PROMs) captured in clinical trials from ovarian cancer and other cancers to translate into clinical practice and to inform patient care– Link PROMs to a national NGOR to measure impact

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3. Core priorities and associated actions

The Plan outlines five core priorities for women with ovarian cancer:

- Patient and family-centred care and support
- Biology/aetiology
- Prevention
- Early detection
- Diagnosis and treatment

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

3.1 Patient and family-centred care and support

Person-centred care is central to the whole Plan, to ensure that women with ovarian cancer always receive access to the best possible care, are treated with dignity, and 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 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 proactively support women and their families during and after treatment, such as routine screening for psychological distress and by focusing on wellness and survivorship.

3.1.1 Improve equity of access to information and high-quality outcomes

Women need greater access to an evidence database about ovarian cancer, including consistent messaging around screening and risk factors, information regarding access to clinical trials, advances in treatment and where to access optimal care.

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.

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 Establish and support gynaecological cancer centres of excellence across Australia to deliver optimal care

Women whose complex ovarian cancer surgery is undertaken in designated specialist centres are more likely to have better outcomes than women presenting to non-specialist centres.¹² 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, and subsequent access to a range of multidisciplinary services at dedicated gynaecological cancer centres of excellence. This will result in improved referral pathways and better outcomes for women requiring complex ovarian cancer surgery and treatment.

3.1.3 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.¹³ 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.¹⁴ 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 clinical practice guidelines to enhance the optimal care pathway.**

3.1.4 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 OPAL study (see [Appendix B](#)). This and other research studies have led to the incorporation of patient-centred endpoints in clinical trials. OCA are 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. 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 common symptoms affecting women 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.

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 and high-quality outcomes</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 • Repository to include information on: <ul style="list-style-type: none"> – Understanding screening – Symptom and side effect management – Supports for women making choices about fertility – Palliative care • 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 Establish and support gynaecological cancer centres of excellence across Australia to deliver optimal care</p>	<ul style="list-style-type: none"> • Centres of excellence could include distributive networks that assist the major treatment centres by linking with these centres and providing a pathway for treatment, advocacy and support for women and their families • Criteria for recognition as a centre of excellence could include a requirement to: <ul style="list-style-type: none"> – Embed the optimal care pathway for women with ovarian cancer – Be multidisciplinary, including gynaecological oncologist, gynaecological cancer nurses, and psychosocial support – Demonstrate ongoing collaboration between clinicians and researchers – Contribute to a national NGOR – Provide education to referring healthcare professionals to emphasise the value of referring a patient to a centre of excellence
<p>3.1.3 Embed the optimal care pathway to</p>	<ul style="list-style-type: none"> • Invest in, and support access to, gynaecological cancer nurses for patients to discuss options and pathways for care <ul style="list-style-type: none"> – Nurses need to be supported and provided with training to upskill as a gynaecological cancer nurse

<p>facilitate systematic coordinated care and support for all women with ovarian cancer</p>	<ul style="list-style-type: none"> • Support access to the best possible treatment for all Australian women with ovarian cancer, including access to optimal surgery <ul style="list-style-type: none"> – Continue to advocate for optimal care across the patient pathway, including identifying and addressing barriers to receiving optimal care and support for best possible end-of-life care and support • All women diagnosed with ovarian cancer should be referred to a gynaecological oncologist for treatment planning¹⁴ • Establish national case management program <ul style="list-style-type: none"> – OCA telehealth service supporting women with complex needs and psychosocial concerns following diagnosis, treatment and after clinical trials
<p>3.1.4 Enhance quality of life and survivorship support</p>	<ul style="list-style-type: none"> • 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 <ul style="list-style-type: none"> – Provide ongoing follow-up care for women with low survival rates and high incidence of recurrence – Connect survivorship clinics with the OCA case management program – Include psych-oncology support post-surgery – Provide access to specialised information on fertility, menopause and psychosexual counselling – 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 – Assess the current research landscape and identify research priorities in the area of psychosocial health with respect to 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
	<ul style="list-style-type: none"> • Support consumer-based research to involve the consumer in translation of research into policy and practice <ul style="list-style-type: none"> – Continue to support the OPAL study (see Appendix B) – Undertake further quality of life and exercise studies

	<ul style="list-style-type: none"> • Develop and support an active consumer community to provide insights into the experiences and needs of women living with ovarian cancer <ul style="list-style-type: none"> – Provide support mechanisms for families and carers of women with ovarian cancer – Develop an online platform to manage common symptoms in cancer survivors
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3.2 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.¹⁵

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

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.

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 3.2.

Table 3.2. Priorities and actions related to the biology/aetiology of ovarian cancer

Priority	Actions/details
3.2.1 Investigate identified action areas to deepen our understanding of the biology/aetiology of ovarian cancer	<ul style="list-style-type: none"> • 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 the natural history and latency of all rare and other subtypes of ovarian cancer to identify precursors for earlier detection and treatment <ul style="list-style-type: none"> – Consider where international collaboration may be important for participation in larger research cohorts

	<ul style="list-style-type: none"> • Invest in research and the development of experimental or pre-clinical models that are representative of the disease in women <ul style="list-style-type: none"> – Continue to support OCELIS (see Appendix B) to ensure researchers and laboratories have access to and use cell lines that are representative of the disease in women
	<ul style="list-style-type: none"> • Understand 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 poly ADP ribose polymerase (PARP) inhibitors – Explore treatments used in cancer streams with successful responses, such as melanoma treatment
	<ul style="list-style-type: none"> • Understand genetics as an important biological component 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

3.3 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.

3.3.1 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.¹⁶ 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, or the impact of physical inactivity for risk and for long-term survival.

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

Cancer genetics research has undergone significant advancements 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.¹⁷

There has been significant progress in understanding the risks of developing cancer for women with the BRCA1 or BRCA2 mutation, and what options there are to reduce this risk. Further research is needed into other high and moderate-risk ovarian cancer genes, so evidence-based advice can be given to mutation carriers about their cancer risk over their lifetime and risk management options.

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.

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.¹⁸ 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. 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 3.3 lists prevention priorities and actions.

Table 3.3. Priorities and actions for the prevention of ovarian cancer

Priority	Actions/details
3.3.1 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
	<ul style="list-style-type: none"> • 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 healthcare 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

	<ul style="list-style-type: none"> – Monitor the ongoing protective benefit of the newer lower dose oral contraceptive pills to measure hormonal influences on the risk of ovarian cancer
<p>3.3.2 Invest in risk prediction and information and support for risk reduction</p>	<ul style="list-style-type: none"> • Improve rapid access to, and uptake of, genetic testing for women who are at high risk <ul style="list-style-type: none"> – 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 – Develop and encourage genetic/familial counselling and testing 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 family history
	<ul style="list-style-type: none"> • Reduce the incidence of ovarian cancer by promoting genetic testing for women who are at high risk of carrying a gene fault <ul style="list-style-type: none"> – 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.
	<ul style="list-style-type: none"> • Undertake further research to develop better models for predicting risk of ovarian cancer in women with a high-risk gene fault and why ovarian cancer develops at different rates <ul style="list-style-type: none"> – 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)
	<ul style="list-style-type: none"> • Improve risk-reducing surgery information, support and treatment pathways for women with a high-risk gene fault <ul style="list-style-type: none"> – Develop treatment pathways to help women make more informed decisions about prophylactic 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
	<ul style="list-style-type: none"> • Conduct further research, including developing risk prediction models, into the effectiveness of bilateral salpingectomies only in reducing the risk of ovarian cancer <ul style="list-style-type: none"> – Supported by participation in international collaborations – Undertake studies on women’s responses to risk prediction models

3.4 Early detection

It is well documented that cancer survival rates increase with early detection.¹⁹ 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.²⁰

3.4.1 Continue to pursue mechanisms for early detection and screening

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 pre-malignant phase and lack of biological barriers between the ovaries and other organs – complicates the quest for the development of 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.

It is recognised that funding and research investment needs to be spread across the pipeline and focus 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 3.4.

Table 3.4. Priorities and actions for early detection of ovarian cancer

Priority	Actions/details
3.4.1 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 off 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
	<ul style="list-style-type: none"> • Ensure that where there is an evidence base for screening it is made available to the appropriate section of women • Continue to support initiatives that lead to an agreed screening protocol/guideline
	<ul style="list-style-type: none"> • Continue to pursue multimodal screening (MMS) options for the development of general population screening

- Support continued research into MMS 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

3.5 Diagnosis and treatment

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 genetic and somatic testing, tissue collection and molecular profiling to optimise targeted treatment for each individual 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.

3.5.1 Enhance patient diagnosis

According to the World Ovarian Cancer Coalition Every Woman Study, Australian women with ovarian cancer experience a longer than average time from first symptoms to diagnosis.²¹ Reducing time to diagnosis may not lead to an earlier stage diagnosis, but earlier diagnosis may lead to earlier treatment and an improvement in five-year survival rates. It is essential to refer to the optimal care pathway and the timelines stipulated in this document. Women who are symptomatic need earlier access to diagnostic tests, including pelvic examination, ultrasound and tumour markers. This in turn would prevent emergency hospital admissions, which are associated with a poor prognosis. 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 relative's risk of developing cancer.²²

3.5.2 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 pre-clinical 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 (see [Appendix B](#)) and small SMART trials approach.

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.²³ There is still more work to be done at molecular subtyping level, but there are now opportunities to produce positive

research results through smaller study sizes with more trials based on genomic and or molecular profiling and targeted treatment based on typing.

3.5.3 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 (HIPEC) chemotherapy. There have also been significant advances in individualised treatments, for example using 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 3.5](#).

Table 3.5. Priorities and actions for diagnosis and treatment of ovarian cancer

Priority	Actions/details
<p>3.5.1 Enhance patient diagnosis</p>	<ul style="list-style-type: none"> • Improve education and awareness for healthcare 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
	<ul style="list-style-type: none"> • Promote and support genetic risk assessment and genetic testing for all women diagnosed with high-grade non-mucinous epithelial ovarian cancer regardless of age or family history <ul style="list-style-type: none"> – High-risk gene fault status has a major influence on survival in ovarian cancer patients – genetic testing looking at all high-risk gene faults needs to be part of a treatment regime – Identify and address current barriers for women accessing genetic testing
<p>3.5.2 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 – Build on existing national resources such as the leadership provided by ANZGOG – Improve consumers’ understanding about how clinical trials work – Hold forums or webinars where clinicians provide education around clinical trials
	<ul style="list-style-type: none"> • 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
	<ul style="list-style-type: none"> • 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 improve access to tissue and biospecimens to support clinical trial activity

	<ul style="list-style-type: none"> • Support funding for the translation of clinical trials <ul style="list-style-type: none"> – Recognise that understanding why something didn't work can provide valuable insights into future research and treatment
	<ul style="list-style-type: none"> • Position Australia as an international leader in ovarian cancer trials <ul style="list-style-type: none"> – Leverage off existing international collaborations, model off successful small trials in other cancer types
3.5.3 Improve targeted and optimal treatment pathways	<ul style="list-style-type: none"> • Continue to explore ways to optimise diagnosis and treatment pathways for every patient <ul style="list-style-type: none"> – 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 OCA national case management program implemented in December 2019 – Facilitate prospective tissue and blood collection from every woman undergoing surgery to bank tissue in a way that could be analysed to optimise individual treatment – 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
	<ul style="list-style-type: none"> • Conduct further research into advancing systemic responses and treatments <ul style="list-style-type: none"> – Continue to explore the efficacy of different chemotherapy treatments such as HIPEC, neoadjuvant and pressurised 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
	<ul style="list-style-type: none"> • Support access to optimal surgery for women with ovarian cancer <ul style="list-style-type: none"> – Advocate for Medicare Benefits Schedule item numbers for ovarian cancer surgeries specifically for gynaecological oncologists – Embed the optimal care pathway throughout the system
	<ul style="list-style-type: none"> • Invest in further surgical research to define optimal surgical treatment <ul style="list-style-type: none"> – Continue to support surgical trials to look at residual disease and survival

Implementing the Plan

Implementation partners

Achieving the overall vision and objectives of the 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 Plan.

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 this Plan
- establish the Ovarian Cancer Alliance.

Facilitate and drive implementation of the Plan

Further work is required to operationalise each of the priorities in the Plan; 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.

Establish the Ovarian Cancer Alliance

Collaborative effort is required to agree:

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

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

Common agenda

- Develop a shared vision for change and a mutual plan of action involving a joint approach. The 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, 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.
- Each organisation to be able to deliver their specific contribution to achieve the agreed common agenda.

Shared measurement system

- Developing a shared measurement system is essential 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.²⁴

Involvement of women with ovarian cancer

- Key to the Plan is to provide a stronger ongoing mechanism to allow true engagement with women who have ovarian cancer. 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 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 alliances vision in coordinating activities and supporting the enablers as described in the Plan.

Appendix B: Ovarian Cancer Trials

OASIS

OASIS, the Ovarian Cancer Alliance for Signal Seeking studies, are 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 OCA.

Contact: David.Bowtell@petermac.org

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.

Contact:

The 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.

Contact:

Australian Ovarian Cancer Study (AOCS) and AOCS II

AOCS is a biospecimen bank containing more than 2000 tissue samples donated by Australian women with ovarian cancer. The 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.

AOCS II 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:

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.

Contact: David.Bowtell@petermac.org

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:

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 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. For further information see https://ascopubs.org/doi/abs/10.1200/JCO.2018.36.7_suppl.88.

Contact:

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

DRAFT

Abbreviations

ALLOCATE	Australian Ovarian Cancer Assortment Trial
ANZGOG	Australian and New Zealand Gynaecological Oncology Group
AOCS	Australian Ovarian Cancer Study
CQR	Clinical Quality Registry
INOVATe	Individualised Ovarian Cancer Treatment through Integration of Genomic Pathology into Multidisciplinary Care
NGOR	National Gynae-Oncology Registry
OASIS	Ovarian Cancer Alliance for Signal Seeking studies
OCA	Ovarian Cancer Australia
OCAC	Ovarian Cancer Association Consortium
OCELIS	Ovarian Cancer Cell Line Study
OPAL	Ovarian Cancer Prognosis and Lifestyle study
OTTA	Ovarian Tumor Tissue Analysis Consortium

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