

NATIONAL ACTION PLAN

OVARIAN CANCER 2020-2025

CONSUMER GUIDE

CARING FOR WOMEN WITH THE DEADLIEST FEMALE CANCER IN AUSTRALIA

BACKGROUND INFORMATION

Ovarian Cancer Australia (OCA) is working alongside Australia New Zealand Gynaecological Oncology Group (ANZGOG), and the Australian Society of Gynaecologic Oncologists (ASGO) to lead the development of the National Action Plan for Ovarian Cancer 2020-2025. This is a refresh, and expansion of the first Ovarian Cancer National Action Plan developed in 2015¹. It will not replace but rather be a companion to the first plan.

The 2020-2025 Plan sets out the proposed priorities over the next five years in terms of research, investment, treatment, support and medical care for women with ovarian cancer (consumers). It also examines the future role of support services such as counselling, social work and psycho-oncology. It suggests a shared approach for action to improve survival rates and outcomes for women with ovarian cancer. And also, to reduce the impact and incidence of ovarian cancer in Australia.

The initial focus for the updated Plan has been to consult one-on-one with over 30 different experts in the field of ovarian cancer including:

- > medical and gynaecological oncologists
- > clinical geneticists
- > nurses and allied health (counselling, social work and psycho-oncology)
- > policy and strategy advisors
- > researchers.

They were asked to share their professional view relating to the most urgent needs for women with ovarian cancer over the next 5 years. This was followed by a one-day National Summit with 50 leading experts in the field. A draft summary of the findings has been written. It outlines the areas of key priorities and actions that were identified. These priorities are outlined in two sections:

1. Sector collaboration and infrastructure & investment
2. Core priorities

YOUR ROLE AS WOMEN AFFECTED BY OVARIAN CANCER

Our focus now is to ensure that all women with ovarian cancer are at the heart of this 5-year plan. That you are given the opportunity to shape its direction. We are sending you this document, and attached survey questions, to gather your input.

We want to be sure your views and voice is heard throughout the document. The following pages summarise the core priorities and why these are important for women with ovarian cancer. It also outlines the key actions and desired outcomes.

Now, we welcome and value your feedback as a woman affected by ovarian cancer. We need to know if the priorities and actions reflect your feelings on how best to improve outcomes for women with ovarian cancer. We ask you to draw on the experiences during your diagnosis, treatment, and follow-up care. This will help us to find any trends in thoughts and opinions and allow us to go deeper into any problems.

We also need to know if you think any priorities are missing. Please share with us how your personal experience with ovarian cancer has guided your focus. It is essential that you, and other women, are confident that the collaboration and plan proposals will help to improve outcomes for women diagnosed with ovarian cancer.

There is a link at the end of this document to an online survey. All members of the community are welcome to participate in the survey, which will be open for a two week period ending 1st December. We would also like to seek your expressions of interest in taking part in a "think tank" to be held in early December. Details of how to register are at the end of the survey or you can contact us at ovariancancer@ovariancancer.net.au if you would like to participate.

SUMMARY: WHAT WE WANT TO ACHIEVE

Our vision is to improve outcomes for women diagnosed with ovarian cancer through speeding up progress, using resources effectively and overcoming barriers.

- > Our aim is to: ensure women are at the heart of this Plan – it is developed with them and in their best interests
- > invest in improving quality of care and outcomes for women with ovarian cancer
- > understand more about the barriers for women accessing the right care
- > focus on ensuring women get the right treatment at the right time in the right place
- > undertake further research into quality assurance to improve practice
- > build local and international sector collaboration to drive progress

To enable this progress throughout all areas of ovarian cancer care we believe we will need to focus on sector collaboration and sector infrastructure and investment which are discussed in more detail below.

SECTOR COLLABORATION

The plan seeks to bring together a wide range of national organisations and stakeholders, to work in partnership, to gain better outcomes for women with ovarian cancer. This will include input from:

- > Government
- > Researchers
- > Clinicians
- > Consumers
- > Industry

This will lead to strengthening Australia's already strong reputation in ovarian cancer research, treatment and support. Collaboration will fast track progress by:

- > greater sharing of information
- > building shared resources for ovarian cancer research
- > creating a coordinated approach to advocacy, philanthropy and investment

With key organisations working together, there will be a greater combined impact on ovarian cancer.

Establishing an Ovarian Cancer Alliance

It is proposed that the sector agree to establishing an Ovarian Cancer Alliance. This will help make it easier to develop a widespread approach on how

to improve outcomes for women with ovarian cancer. The Alliance could concentrate on priority areas including:

- > forming an OCA 'women with ovarian cancer advisory group' who will be involved whenever advocating for change
- > reducing duplication and share planning and outcomes for women with ovarian cancer
- > gaining stronger support for ovarian cancer research
- > strengthening national collaboration between key organisations to drive a common approach to ovarian cancer research, treatment, advocacy and support
- > encouraging the sector to speak with one voice about what is important
- > streamlining access for women into clinical trials both nationally and internationally
- > encouraging international collaboration to enable access to, and involvement in much larger research studies.

SECTOR INFRASTRUCTURE AND INVESTMENT

The Plan strongly supports that Australia:

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

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

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

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

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

CORE PRIORITIES

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

1. Patient and family centred care and support
2. Understanding the disease and its causes
3. Prevention
4. Early detection
5. Diagnosis and treatment

Below is a summary of the proposed actions relating to each of these priority areas.

Priority 1

Patient and family centred care and support

Patient and family centred care is a way of doing things in healthcare to ensure the patient and their family feels confident that those caring for them, are doing what is best for them. It focuses on an individual's personal needs, wishes and goals. All medical care must meet their emotional, social and practical requirements. The patient and their family become central to the care and medical process. It allows for the highest quality of life and can mean putting a patient's needs, as they express them, above those healthcare professionals may see as the main concern.

Women with ovarian cancer should be able to access the best possible care. They need to feel they are being treated with dignity and that they are being involved in all decisions about their health and medical care. Feeling comfortable to ask questions about their diagnosis, treatment, emotional wellbeing and follow up care is extremely important. Women with ovarian cancer and those close to them **must** be at the heart of everything proposed in the Plan.

Key actions

The optimal care pathway for women with ovarian cancer² outlines the best cancer care that should be given at each step for women living with epithelial and non-epithelial ovarian cancers. This relates to prevention, diagnosis, during, and after treatment of ovarian cancer. The pathway is intended to guide health professionals through the optimal way to deliver "*consistent, safe, high-quality and evidence-based care for women with cancer*"².

Following the pathway encourages quality cancer care and patient experiences. It is essential all medical staff use this pathway of care as a way of improving all aspects of care for women with ovarian cancer. Full versions of the optimal care pathway, as well as quick reference guides³ for women with ovarian cancer, can be downloaded from the OCA website at www.ovariancancer.net.au.

Other key actions include:

- > Ensuring all women diagnosed with ovarian cancer are referred to a gynaecological oncologist surgeon for treatment planning.
- > All patients having easy access to gynaecological (and ovarian) cancer nurses to discuss options and pathways for care.
- > Establishing and promoting gynaecological cancer centres of excellence (discussed under priority 5) across Australia to deliver the best care possible.
- > Establishing survivorship clinics and quality of life support pathways for women during and after treatment.
- > Developing and supporting an active community of women with ovarian cancer who can continuously provide insights into the experiences and needs of women living with the disease.

Developing support systems to meet the social and emotional needs of carers, family and friends of women with ovarian cancer.

Create a central database for women with ovarian cancer and those close to them to include up to date information relating to:

- > Research
- > Treatment
- > Access to clinical trials
- > Symptoms and side effects
- > Psychological care and support
- > Screening issues
- > Survivorship
- > Support information

Easy access to this evidence-based information will allow women to make informed decisions about their care. Women will feel more in control of their situation knowing they can obtain reliable information relating to the best practices of care. By collecting clinical practice data on a large scale, we can also examine patterns of care in treatment centres. As we learn to better understand what works and what doesn't, clinical practice will improve.

Priority 2

Understanding the disease and its causes

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

Key actions

Focus on research into all areas of ovarian cancer including:

- > classifying tissue specimens to help discover and support new curative treatments
- > finding out more about how rare, and other subtypes of ovarian cancer develop and express themselves; which will help find early signs of the disease giving access to the best possible treatments
- > why some women become resistant to certain chemotherapy drugs
- > the role of genetics in the causes, incidence and hereditary factors of ovarian cancer.

Priority 3

Prevention

If we could find more accurate ways to detect ovarian cancer early, it could significantly help improve outcomes, and possibly cure rates. The Plan outlines ways to improve our understanding and awareness of risk factors for ovarian cancer, which could help with stopping ovarian cancer developing.

We need further research to better understand and identify:

- > genetic risk factors for ovarian cancer, including the relationship between the BRCA gene faults and ovarian cancer risk
- > high risk subgroups for new genetic or tumour marker tests
- > the links between non-genetic risk factors, disease history and survival and ways to prevent the disease in population sub-groups (e.g. the young and elderly, as well as minority groups including Aboriginal and Torres Strait Islander women and women with different cultural backgrounds)
- > the benefits, and long-term effects of risk reducing surgery (removal of both fallopian tubes and ovaries - bilateral salpingoopherectomies) in women at high-risk of developing ovarian cancer.

Key actions

- > Target education and awareness campaigns to reach all women (and men) at risk, including minority groups. This involves more awareness about the importance of knowing your family history and identifying those at risk. Males can also inherit faulty genes that puts themselves, and their children at higher risk of developing ovarian cancer.
- > Continue to research and educate the public about those risk factors we know we can control, including obesity, lack of exercise, smoking.
- > Invest in research into genetic testing to help decrease the risk for women at high risk.

- > Develop better ways for predicting risk of ovarian cancer in women carrying a high-risk gene fault.
- > Provide better information about preventative (prophylactic) surgery, support and treatment pathways for these women.
- > Ensure all women who are thinking about, or have preventative surgery, can access evidence-based information regarding menopause and where required access a menopause clinic prior to their surgery.

Priority 4

Finding ovarian cancer early - screening

If ovarian cancer can be found early, we hope to improve the chance of the woman living longer. Cancers with established screening tests, (breast and bowel cancer), have seen significant improvements in finding cancers early, as well as gaining overall better survival rates. Unlike breast and cervical cancer where we already have reliable population screening tests, there is no reliable test for early ovarian cancer. Research is underway to try and develop better screening tests in order to detect ovarian cancer at earlier stages and improve patient outcomes.

There is research currently going on looking into new ways to screen for ovarian cancer using blood and tissue samples from women with ovarian cancer. Samples have come from the women who took part in the large screening studies done overseas, as well as from those women who took part in the Australian Ovarian Cancer Study (AOCS). The AOCS is a collaborative research program between clinicians, scientists, patients and advocacy groups, aimed at improving the prevention, diagnosis and treatment of ovarian cancer.

Key actions

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

Priority 5

Diagnosis, treatment and clinical trials

According to the World Ovarian Cancer Coalition Every Woman Study, Australian women with ovarian cancer face a longer than average time from first symptoms to diagnosis. Decreasing the time to diagnosis may not mean the stage of the cancer will be found earlier. But getting a timely diagnosis of ovarian cancer may lead to earlier treatment and an improvement in five-year survival rates for women.

It is crucial women with ovarian cancer be given a diagnosis as quickly as possible. This will lead to earlier treatment and possibly an improvement in survival rates. Women should also have access to centres of excellence (specialist cancer centres).

The advantages of being cared for at a centre of excellence, is that women are given access to the best health professionals in the field of ovarian cancer. They are also more likely to have access to the most up to date treatment and clinical trials. Overall, these factors will improve outcomes for a woman with ovarian cancer.

After diagnosis, a woman should:

- > be referred to the best specialist care possible
- > be educated and have access to clinical trials
- > understand the different treatments and care and know how these relate to their clinical outcomes.

Ideally, women would also be given the opportunity to have genetic testing and tumour profiling. These tests will check for certain genes or gene faults, proteins, or other biomarkers in a sample of tissue. This depth of testing will allow for the best targeted treatment for each woman diagnosed with ovarian cancer.

Key actions

Diagnosis

- > Improve timely diagnosis by enhancing health professional's awareness to recognise the signs and symptoms of ovarian cancer are vague, but persistent. Early investigation is essential (follow optimal care pathway.)
- > Promote genetic risk assessment and testing for all women with ovarian cancer.

Clinical Trials

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

Treatment

In the last five years there has been a change to several aspects of ovarian cancer treatment including:

- > an increase in the options for how chemotherapy is given (e.g. giving more regular doses of chemotherapy before surgery to help shrink the cancer or giving chemotherapy directly into the abdomen).
- > advances in individualised treatment such as with PARP inhibitors for treating women with an identified gene fault.
- > more trials in newer targeted biological therapies (immunotherapies).
- > advances in surgical treatments for small tumours.
- > The key actions going forward are: Continue to explore ways to improve treatment pathways for every woman with ovarian cancer.
- > Further research to find new drugs, different ways of giving chemotherapy, as well as gain a better understanding of drug resistance.
- > Ensure all women have access to gynae-oncologists in the field of ovarian cancer surgery.
- > Further research into surgical treatment options, looking at survival.
- > A need to improve our understanding of women's responses to existing treatments and why differences exist in clinical outcomes.
- > Embed the optimal care pathway for women with ovarian cancer into all aspects of ovarian cancer medical care.

CONCLUSION

We will need strong and ongoing collaboration between all groups involved in developing and implementing the 2020-2025 Ovarian Cancer Plan. We need to ensure everyone remains part of the decision-making process. Central to this are women with ovarian cancer. Without your firsthand insight, suggestions and feedback, it will be impossible to progress our key actions relating to research, treatment and support for women with ovarian cancer. We are incredibly grateful to you for agreeing to be part of the initial, and vital part of this process. If you have any questions or would like further information, please contact Ovarian Cancer Australia on 1300 660 334.

APPENDIX

¹ Ovarian Cancer Australia. National Action Plan for Ovarian Cancer Research: The Comprehensive Report. 2014. <https://ovariancancer.net.au/research/national-action-plan-for-ovarian-cancer-research/>

² Cancer Council Australia. Optimal care pathway for women with ovarian cancer. https://www.cancer.org.au/content/ocp/health/optimal-care-pathway-for-women-with-ovarian-cancer-june-2016.pdf#_ga=2.4356467.1353139719.1568776491-2057422101.1543055415

³ Cancer Council Australia. Optimal cancer care pathways: quick reference guides for women with ovarian cancer www.cancer.org.au/content/ocp/quick/ovarian-cancer-quick-reference-guide-june-2016.pdf#_ga=2.2110896.1694003700.1573424945-1244715659.1566864163

HELPFUL TERMS

Bilateral salpingo-oophorectomy

Surgical removal of both fallopian tubes and both ovaries.

Biomarker

A molecule found in blood, other body fluids, or tissues that is a sign of a normal or abnormal development, or of a condition or disease. It may be used to see how well the body responds to a treatment for a disease or condition.

Biological therapies

Treatments that help to slow down or stop the growth of cancer cells. They work by boosting the immune system to kill the cancer cells, changing how cancer cells signal to each other to grow, or stopping the growth of the cancer's blood supply. Examples include immunotherapy, vaccines, monoclonal antibodies and gene therapy.

BRCA1 and BRCA2

A gene change (mutation) that may be inherited from your mother or father. These mutations are associated with a higher risk of breast, ovarian and other cancers.

CA125

A protein in the blood that can be raised due to a number of factors including cancer. For this reason, the CA125 protein can be referred to as a 'tumour marker'.

Chemotherapy

The use of medicines to slow the growth of or destroy cancer cells.

Epithelial ovarian cancer

This is the most common type of ovarian cancer, accounting for nine out of 10 cases.

Familial

A condition/disease that happens more often in family members than is expected by chance alone.

Family (or familial) cancer

When a gene fault causes higher rates of particular cancer/s within a family. These cancers often affect family members at a young age.

Family or familial cancer centre/service

A centre where genetic counsellors can talk to you about genetic testing if you have a family history of cancer and wish to consider testing for yourself, adult children or other family members.

Faulty gene (gene mutation)

A change in the structure of a gene. The gene fault (mutation) may be passed from parent to child during conception and can also be passed from generation to generation.

Genes

Small pieces of DNA: the material that acts as a 'master blueprint' for all the cells in your body. Your genes determine such things as what colour hair and eyes you have and how tall you are. If you inherit specific faulty genes, it may mean you have an increased risk of certain types of cancer.

Gynaecological oncologist

A gynaecologist who has done a further three years of specialist training in treating women with cancer of the reproductive organs, including ovarian cancer.

Gynaecological oncology nurse

A nurse who specialises in cancer care and may administer chemotherapy, assist with radiotherapy, and provide care, counselling, information and support.

HELPFUL TERMS CONTINUED

Medical oncologist

A doctor who specialises in medicines used to manage and treat cancer, including chemotherapy and pain medicine.

Oncologist

A doctor who specialises in the study and treatment of cancer.

PARP inhibitors

A substance that blocks an enzyme in cells called PARP (poly (ADP-ribose) polymerase inhibitor). In cancer treatment, blocking PARP may help keep cancer cells from repairing their damaged DNA, causing them to die. PARP inhibitors are a type of targeted therapy.

Philanthropy

The desire to promote the welfare of others, expressed especially by the generous donation of money to good causes.

Psycho-oncology

A field caring for the physical, psychological, social, and behavioural parts of having cancer for both patients and caregivers.

Qualitative research

A research method which observes and gathers information not using numbers or statistics. This type of research refers to meanings, concepts, descriptions of things and not to their measurements or numbers. It seeks to interpret meaning from this data to help us understand certain populations, places or diseases.

Stage

The stage of your cancer describes how advanced it is and how far it has spread.

Staging

The process of working out the stage of a cancer. This is done during the initial surgery for ovarian cancer.

Transvaginal ultrasound

An ultrasound examination where a small instrument is inserted into the vagina to give a clear picture of the inside of the uterus and the ovaries.

Tumour marker

A chemical given off by cancer cells which circulates in the blood.

Tumour Profiling

A laboratory test looking at a sample of tumour tissue to check for certain genes or gene faults (changes), proteins, or other biomarkers. It can be used to help plan treatment and predict whether cancer will come back or spread to other parts of the body.

**CONNECT
WITH US**



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