

STATE OF THE NATION IN OVARIAN CANCER: EXECUTIVE SUMMARY



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NATION 2020

OVARIAN
CANCER
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FOUNDATION



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If a woman is diagnosed with ovarian cancer, the chance that she will still be alive five years later is just 46%. That's if it's caught early: historically 70% of women diagnosed were already at an advanced stage of the disease, and just 29% of them survive beyond five years.

That's mothers, given less than half a chance to raise their children. Wives, grappling with the fact their partner will grow old alone. Sisters and daughters, facing the unimaginable.



Ovarian cancer is one of the most lethal and least understood cancers and over the next 10 years, an estimated 14,000 Australian women will die of it. We want to change that.

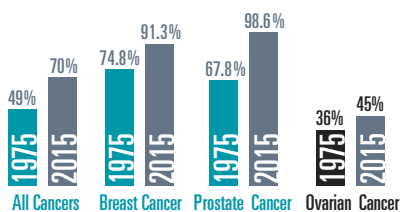
The Ovarian Cancer Research Foundation's State of the Nation report shows us what we need to do to reach our goal of a 50% survival rate by 2025, and our intention of nearly doubling the current survival rate for the next generation of women. We surveyed researchers, those living with ovarian cancer, and clinicians, and they overwhelmingly agreed on three things:

- 1 *We need an early detection test.*
- 2 *We need increased funding for a national approach to treatment and research.*
- 3 *And we need to act now.*

CURRENTLY, WOMEN ARE DIAGNOSED TOO LATE

A woman's chances of surviving ovarian cancer are low because most are diagnosed at a late stage, where the cancer has already spread. Breast, uterine and cervical cancers are usually found while the cancer is still localised but the signs and symptoms of ovarian cancer can be vague. They are often misdiagnosed as common female complaints, such as cramping and bloating, and by the time the cancer is detected it has spread.

There is currently no early detection test, and the State of the Nation report found that this was the most significant barrier to improving survival outcomes.



The five-year survival rate for ovarian cancer today is lower than the five-year survival rate for all cancers in 1975, when the modern cancer research era began.

An early detection test for the next generation of women has the potential to double the survival rate, and save the lives of more than 8,000 Australian women over a decade.

Vague symptoms and a lack of an early detection test means most women are diagnosed after the cancer has already spread

TREATMENT OPTIONS ARE LIMITED, AND LOW FUNDING HAS SLOWED RESEARCH BREAKTHROUGHS

Breakthroughs in ovarian cancer research have been slow because we don't fully understand the underlying biology of the disease.

This affects how it is treated: compared with other cancers, there is a lack of treatment options for ovarian cancer. Women are initially treated with surgery and chemotherapy, but, in more than 80% of cases, the cancer returns and becomes resistant to treatment. We need to know more about how the disease behaves so we can find more personalised and effective treatments.

In order to do that, we need research funding – and compared to

other major cancers, funding for ovarian cancer has been low. Sadly, there are only a small number of survivors to advocate for change.

The State of the Nation report shows around an extra \$20 million in funding each year is needed to improve the lives of women diagnosed with ovarian cancer today and find an early detection test for the next generation of women.

World-wide, governments are starting to recognise the need for more funding to address cancers with low survival rates. In the United States, legislation passed in 2012 mandated investment to improve survival for so-called 'recalcitrant' cancers. And in 2017, Australia's Senate Select Committee called for urgent investment to increase survival outcomes for low survival cancers to 50% by 2027. Recently, the Australian Government awarded a further \$16.2 million in Medical Research Future Fund grants to eight ovarian cancer research projects. This is a welcomed and positive sign, but we know more is needed if we want to see impactful change.

We need more treatment options, and we need funding to find them

WHY WE COMMISSIONED THIS REPORT

The Ovarian Cancer Research Foundation (OCRF) is the largest non-governmental funder of ovarian cancer research in Australia. We undertook this audit to understand where research funding currently goes, and where the funding gaps are, so that we can develop a roadmap for improving the stagnated survival rates for women with ovarian cancer. Each year, more than 1,800 Australian women are diagnosed with ovarian cancer. More than 1,100 of those women will die as a result. Over the next decade, more than 2.2 million women will die from ovarian cancer globally. We want to change that.

The report looks at historical funding data and research, and ovarian cancer researchers, clinicians and consumers were surveyed. Patient support organisations, Medicines Australia's Oncology Industry Taskforce, governments and allied charitable foundations were all consulted.

We need to know where funding gaps are so that we can stop ovarian cancer from taking the lives of so many women



WHAT WE NOW KNOW ABOUT RESEARCH FUNDING

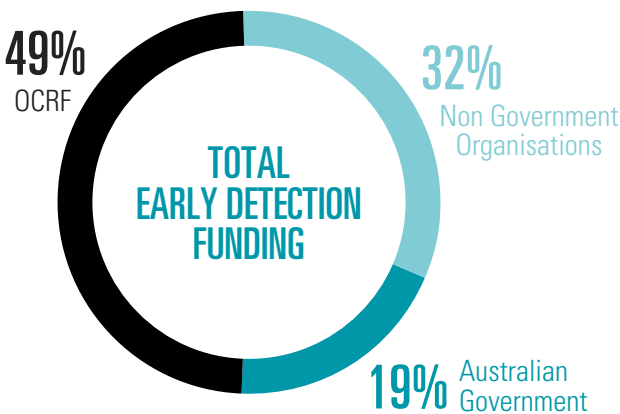
The State of the Nation report shows that the majority of funding globally for ovarian cancer research to date has come from the United States. Annually, US government departments and agencies invest more than \$180 million in ovarian cancer research. The National Cancer Institute and National Institutes of Health have been the largest funders.

The global biopharmaceutical industry spends around \$770 million in clinical research annually. The majority of studies originate in the US.

Australia has also played a crucial role in funding and research. The Federal government accounts for 60% of all Australian funding over the 2010-2020 period; since 2005, it has funded over \$100 million in ovarian cancer research, at an average of \$8 million per year. In 2020, the Australian Government announced an increase on historic funding levels of \$4 million a year through the Medical Research Future Fund.

After the Australian Federal government, the Ovarian Cancer Research Foundation has been the largest funder of ovarian cancer research in Australia and New Zealand.

Between 2010 and 2020, the OCRF has funded 10% of all ovarian cancer research. Since 2010, we have contributed more than \$17 million, and more than \$25 million since we were founded 20 years ago. The OCRF has funded research at an average of \$1.6 million per year between 2010-2020. Funding in the past three years has increased to \$1.8 million per year.



Following the OCRF, the next major funder of ovarian cancer research has been state-based cancer councils and state governments. All state governments combined fund an average of \$1.1 million in research each year.

The US has led the way in research funding, but Australia plays an increasingly crucial role – as does the Ovarian Cancer Research Foundation

WHERE IS FUNDING CURRENTLY SPENT?

Most of the funding for ovarian cancer research in Australia has gone towards improving what we know about the disease and developing new treatments.

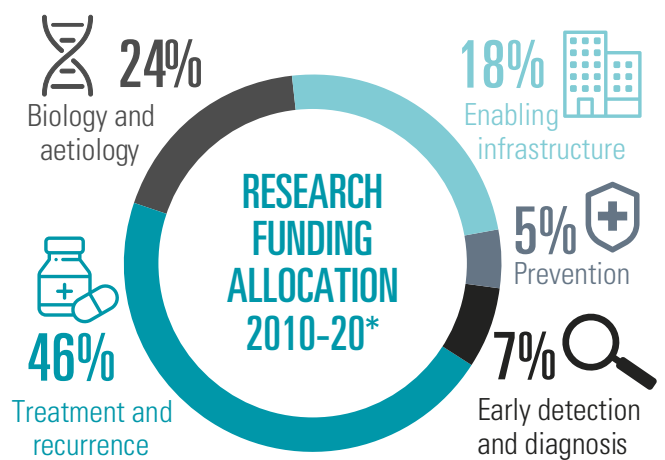
+ 46% of all funding has gone into research for treatment. Excluding industry-led trials, research into treatment has accounted for nearly half of all funding.

+ 24% of funding has gone to understanding the disease biology and exploring potential causes.

+ 7% of funding has been allocated for research into early detection methods. 49% of that figure has been funded by the OCRF.

+ 5% has been put towards research aimed at prevention.

+ 18% has been directed to infrastructure, including improving biobanking capabilities and research fellowships.



The majority of funding has been spent on understanding the disease and how we can treat it

WHAT WE NEED TO DO FROM HERE

Unanimously, researchers, those living with ovarian cancer, and clinicians all agree the key to improving survival rates lies in an early detection method.

Following that, researchers and clinicians say finding more treatment options and ways to prevent the disease from coming back is a priority. For those living with ovarian cancer and their families, stopping the disease from spreading and recurring is the priority.

PRIORITIES FOR RESEARCH TO IMPROVE SURVIVAL:





If we are going to find solutions, there is an urgent need for more comprehensive research. We need:

+ A national approach to clinical best practice. While the national 5- year survival rate is 46%, currently each state and territory in Australia has a different approach to treating ovarian cancer and some states have reported 5-year survival rates above 50%. We need to quickly establish a best practice approach nationally, reduce variation in care, expand awareness of ovarian cancer risk and uptake of preventative surgery by high-risk women.

+ A greater understanding of what causes the disease and its fundamental biology. Importantly, this includes funding research to better understand disease progression.

+ More research into treatment options. We need to invest in the development of precision medicine capabilities in ovarian cancer and better understanding of how to best prevent disease recurrence.

+ More funding allocated to early detection research. We need a way to identify early indicators of ovarian cancer more clearly, particularly among those at high risk.

+ More funding allocated to prevention research. We need to better understand the role of lifestyle and environmental factors in ovarian cancer development so that we can start to prevent the disease before it occurs.



We need a national approach to research so we can more quickly find an early detection method, and ways to stop the disease in its tracks

OUR VISION IS TO IMPROVE SURVIVAL FOR WOMEN WITH OVARIAN CANCER

Based on what the State of the Nation report found, we have set out a vision for a future where women live without ovarian cancer. We propose improvements in survival outcomes over the short, medium and longer terms:

- 50%** We want to improve survival rates to 50% for women today by rapidly implementing recent advances in knowledge in clinical practice nationally.
- 50%** We want to improve 5-year survival rates beyond 50% for the next generation of women. We do this through development, testing, and increased access to new and innovative personalised treatments.
- 90%** We want to improve 5-year survival rates towards 90% through the development of new methods for early detection and diagnosis.

These are ambitious but achievable goals. To reach them, we need funding for a strategic, high impact program of research, supported by collaboration between governments, researchers, and the wider community.

We want to build on and extend the important and welcome first steps made by the Federal government to improve survival rates through its recent Medical Research Future Fund commitments.

Most importantly, we need funding for a new, nationally collaborative approach to solving the challenges of ovarian cancer.

We want a future that is free of ovarian cancer, and we need a national and collaborative research program to get there

THIS IS WHERE FUNDING NEEDS TO GO

+ Implementing current best practice equitably around Australia

Currently, there are variations in the implementation of clinical best practice around Australia. We need to increase awareness and understanding in the community, improve education and training for GPs, and expand access to the most up-to-date management and care for ovarian cancer.

- Funding needed: Up to \$2.5 million a year

+ Finding personalised treatments for women with ovarian cancer

This is a critical priority for researchers and clinicians. Treatment has moved from an historical 'one size fits all' model of care to a more individualised approach but this work has only just begun. We can accelerate it by establishing a national precision medicine program for clinical trials research.

- Funding needed: \$11 million per year, over three years.

+ The establishment of an Australian Centre of Excellence for Early Detection in Ovarian Cancer

Finding an early detection method is paramount. We need to establish an Australian Centre of Excellence in Early Detection, so that we can have a national focus on the goal. A targeted scoping study for the establishment of the Centre is the first step.

- Funding needed: \$6 million a year and \$500,000 for a scoping study

Funding needs to go towards finding an early detection method and personalised treatment options. Ensuring equitable access to clinical best practice, access to individualised treatment approaches and establishing a National Centre of Excellence for Early Detection will help us reach our goals faster.



WHAT WE CAN ACHIEVE

When we achieve the goals set out by this report, we will see the lives of women in Australia and around the world extended and saved.

- **Achieving a 50% 5-year survival rate by 2025 will save 680 women between now and 2035**

Between now and 2035, nearly 14,000 Australian women are expected to die from ovarian cancer. Finding better and more personalised treatments and establishing a national approach to clinical best practice could save more than 680 of those women.

- **By doubling the current survival rate for the next generation of women, we will save 8,000 women over a decade**



Developing an early detection test for the next generation of women has the potential to double the current survival rate and save the lives of more than 8,000 Australian women over a decade. Globally, an early detection test could save the lives of more than 1.3 million women.

The establishment of an Australian Centre of Excellence in Early Detection will accelerate our ability to find that crucial early detection method.

History shows that where communities, governments and industry come together big improvements in survival can be realised, and countless lives can be saved. Ovarian cancer has been left behind in the last 45 years of modern cancer research, but it can be the success story of the next generation.

"I want to know what hope I can give my daughter... I share lots of things with her, and unfortunately, I've shared these cancer genes with her. I want to know what will be available for our daughters. We need to keep all of the mothers around as long as we can, but that's what keeps me going, what gives me hope... that we can make things different for our daughters."

- Ovarian cancer survivor

To learn more or to take action in support of women facing ovarian cancer visit www.ocrf.com.au

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