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Committee Secretary  
Select Committee into Funding for Research into Cancers with Low Survival Rates  
Department of the Senate  
PO Box 6100  
Canberra ACT 2600

## **Ovarian Cancer Australia submission to the Senate Select Committee into Funding for Research into Cancers with Low Survival Rates**

Dear Secretary,

We warmly welcome the opportunity to provide our perspective to the Senate regarding the urgent need for revised funding for research into cancers with low survival rates.

### **Introduction**

Ovarian Cancer Australia was founded in 2001 and is the independent national organisation that takes action for people affected by ovarian cancer. We provide support for women and their families, raise community awareness of ovarian cancer, advocate for improved services for women and promote and fund research. Our vision is to *save lives and ensure that no woman with ovarian cancer walks alone*.

Ovarian Cancer Australia is committed to delivering best practice, accessible support programs informed by consumers; we want Australians to know the signs, symptoms and impact of ovarian cancer; and we are determined to drive real change by striving to reduce the incidence of ovarian cancer by 25 per cent and improving the five-year survival rate by 25 per cent by the year 2025.

This year in Australia, 1580 women are expected to be diagnosed with ovarian cancer and a further 1200 will die from the disease. Ovarian cancer has a poor prognosis, with only 44 of every 100 women diagnosed still alive five years after their diagnosis, making ovarian cancer the most deadly of the gynaecological cancers.<sup>1</sup>

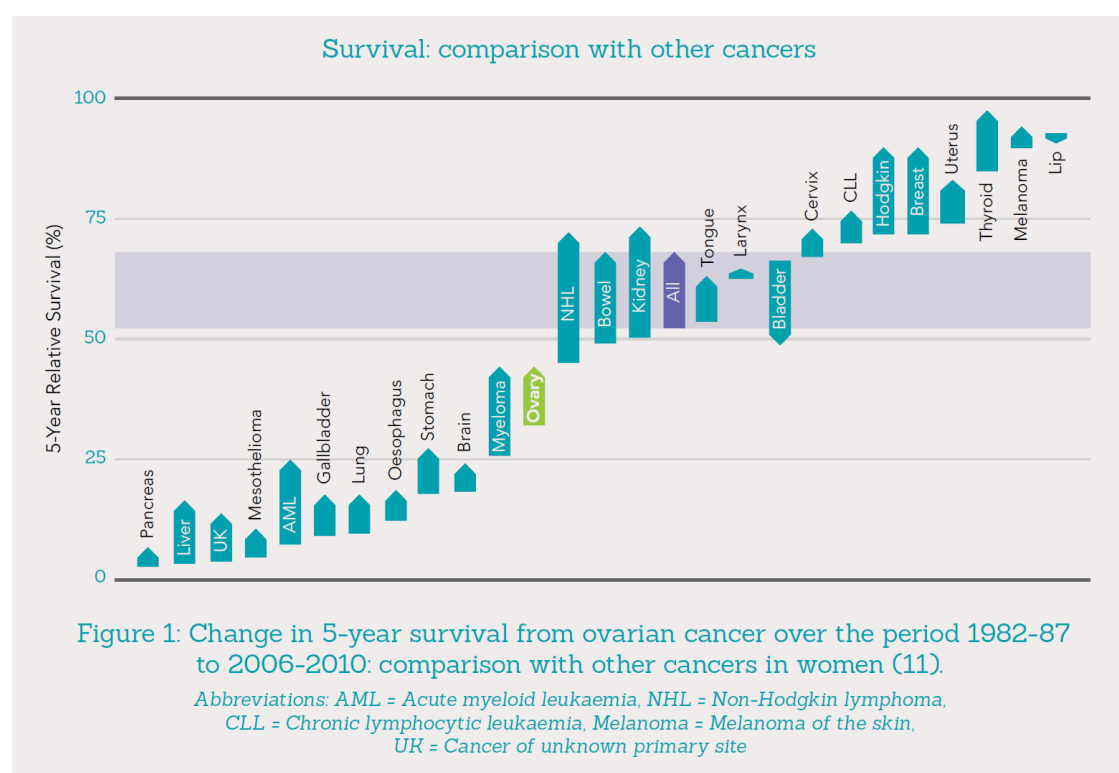
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<sup>1</sup>Australian Institute of Health and Welfare 2017. Cancer in Australia 2017. Cancer series no.100. Cat. no. CAN 100. Canberra: AIHW

Outcomes from ovarian cancer are poorer than for other cancers in women. In Australia, ovarian cancer is the sixth most common cause of cancer death. The burden of disease for women diagnosed is high, and the long-term impacts on women, their partners and families are significant.

Ovarian cancer is the leading cause of burden of disease from gynaecological cancers, and 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.<sup>2</sup> 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.

Figure 1 shows how the five-year survival rate for ovarian cancer has shifted only marginally compared to other cancers in women since 1982, and falls well below the average across all cancers. The prognosis for women diagnosed with ovarian cancer remains relatively poor. This is mainly due to the fact that the most aggressive forms of ovarian cancer, which comprise the majority of cases, are diagnosed at an advanced stage, when the cancer has spread to other parts of the body and is difficult to treat successfully<sup>3</sup>. Yet, because so little is known about the latency period and the rate and nature of progression of the aggressive forms, it is not yet clear how earlier diagnosis will be achieved and whether it will improve outcomes in these cases. What is profoundly clear is that women need better treatments. The five-year survival rates for ovarian cancer fall far behind those of other cancers affecting women in Australia, including breast cancer (89%), uterine cancer (82%), cervical cancer (72%) and bowel cancer (67%).<sup>4</sup> Improvements in prevention, early detection and/or treatment account for increased survival in these cancer types.



<sup>2</sup><http://ovariancancerday.org/>

<sup>3</sup>Australian Institute of Health and Welfare & National Breast and Ovarian Cancer Centre 2010. Ovarian cancer in Australia: an overview, 2010. Cancer series no. 52. Cat. no. CAN 48. Canberra: AIHW

<sup>4</sup>Australian Institute of Health and Welfare 2012. Cancer survival and prevalence in Australia: period estimates from 1982 to 2010. Cancer Series no. 69. Cat. no. CAN 65. Canberra: AIHW

The Terms of Reference for the Committee refer to ‘cancers with relatively lower rates of incidence’, but do not define this group of cancers. The Australian Institute of Health and Welfare (AIHW) considers cancers with fewer than 12 age-standardised cases per 100,000 population as low incidence cancers (defined, more specifically, as ‘less common’ or ‘rare’). Ovarian cancer meets this definition, having an age-standardised incidence of 10.6 per 100,000.

Further, the high burden of disease, poor prognosis and current paucity of available targeted treatments pose a significant challenge to the Australian and international research communities.

In 2014 Ovarian Cancer Australia released its National Action Plan for Ovarian Cancer Research, which was developed in consultation with the gynaecological cancer community including researchers, gynae and medical oncologists, medical and health professionals and consumers. The plan identified that significant investment in ovarian cancer research was required to improve the five-year survival rate, as has been the case in other tumour streams such as breast and prostate cancer.

Progress in genomics and proteomics has radically changed our understanding of the behaviour of cancer cells. We now know that ovarian cancer is not just one disease but a range of diseases with different cellular appearances, different molecular characteristics, and different trajectories. However, this new knowledge has not yet translated into new treatments or improved outcomes for women living with ovarian cancer. Ovarian cancer remains a poor prognosis cancer with limited treatment options available.

## **Response to the terms of reference**

Within the terms of reference of this enquiry into the impact of health research funding models on the availability of funding for research into cancers with low survival rates, we wish to address:

1. the current National Health and Medical Research Council funding model, which favours funding for types of cancer that attract more non-government funding, and the need to ensure the funding model enables the provision of funding research into low survival rate cancers;
2. the obstacles to running clinical trials for cancers with relatively lower rates of incidence, with regard to:
  - a. funding models that could better support much-needed clinical trials, and
  - b. funding support for campaigns designed to raise awareness of the need for further research, including clinical trials;
3. the low survival rate for many cancers, lack of significant improvement in survival rates, and strategies that could be implemented to improve survival rates and;
4. the need for investment in education and awareness raising to better understand how patients with cancer use the health system.

## 1. NHMRC funding models that disadvantage many low survival cancers

In the past 25 years, continued investment in research in Australia has resulted in significant improvements for some cancers, with survival rates increasing to 90% for breast and 94% for prostate cancer<sup>5</sup>. In order to achieve improvements in patients with ovarian and other low survival cancers, the same commitment to research is required.

**Table 1. Deaths from cancer, proportion and amount of funding (2009-2011) for the top 5 cancers in Australia, based on mortality<sup>5</sup>**

Cancer type	% cancer deaths	% of funding	Amount of funding (\$M)
Lung	18.5	5	16.3
Colorectal	8.7	14	47.2
Prostate	7.5	13	41.6
Breast	6.5	26	85.9
Pancreas	5.6	2	5.3

There appears to be a relationship between improvements in 5-year relative survival rates and levels of direct research funding.

Australia is fortunate to have multiple organisations that fund cancer research, including Commonwealth (National Health and Medical Research Council, Cancer Australia) and state and territory governments, community-funded cancer charities (including Ovarian Cancer Australia), and private sector organisations. However, different priorities, regulations and funding approaches mean this investment is fragmented, creating a cancer research funding environment that is competitive, inefficient, prone to duplication of effort and where cancers for which there is poor survival are, at best, under-funded and, at worst, neglected.

To address this lack of focus we recommend Australia develops a national strategy for coordinating the planning and funding of cancer research across the government, medical, health, research and philanthropic communities.

To ensure accountability, we suggest the government's commitment to such a strategy be enshrined in legislation, similar to the Recalcitrant Cancer Act in the United States (<https://www.congress.gov/bill/112th-congress/house-bill/733>)

Customised for Australia, the Act would require the National Health and Medical Research Council or Cancer Australia (in the US the responsibility lies with the National Cancer Institute) to develop scientific frameworks for cancers with poor survival rates, in consultation with consumer groups and other stakeholders. These frameworks would provide the strategic direction and guidance needed to make true progress against low survival rate cancers.

While setting the strategy, the frameworks would also set targets that demonstrate improved cancer survival. Annual reporting to Parliament on progress towards these targets would be mandatory, as is required for Closing the Gap, which aims to achieve health equality for Aboriginal and Torres Strait Islander Australians by 2030.

The current NHMRC funding model for research favours applications associated with the highest track record and research feasibility. These have often been associated with cancer types, such as

<sup>5</sup> Australian Institute of Health and Welfare & National Breast and Ovarian Cancer Centre 2010. Ovarian cancer in Australia: an overview, 2010. Cancer series no. 52. Cat. no. CAN 48. Canberra: AIHW

breast and prostate cancer, where significant research progress has already been made. Where tumour types are inherently difficult to treat, and research progress has been slow, it can be difficult to convince grant reviewers that a project's feasibility is high. Yet these cancers are those on which there should be increased focus, not less. The track record of the researchers is also weighted in the review process, which is a disadvantage to researchers investigating low survival cancers, where there is generally less pilot data or proof of concepts than for those researching more common cancers with better outcomes.

To address this discrepancy, we **recommend that the NHMRC sequester project grant funding for research into cancers with low survival, particularly less common and rare cancers, where funding is not currently directed.**

The feasibility of the projects and the track record of the investigators would continue to be judged on their merits, but would be compared to the other 'rare or low survival cancers', rather than against the track record and accomplishments of better researched cancer types.

The funding would be distinct from the existing Priority-driven Collaborative Cancer Research Scheme, the aims of which, while worthy, would not ensure a significant percentage of the NHMRC project grant funding would be directed towards low survival cancers.

**Further, the sequestered NHMRC funding we propose would cover both translational and basic science grants,** as these are both important to developing new and innovative approaches to diagnosis and treatment.

## **2a. New funding models to support appropriate clinical trials**

For women with ovarian cancer there are four issues that regularly rise in relation to clinical trials:

- i) As ovarian cancer is a low incidence cancer, clinical trial access is limited as the trials are not available in all major treatment centres;
- ii) access for patients in rural Australia is difficult as the trials often require frequent attendance at a capital city centre;
- iii) the time taken to establish a trial is disproportionately long compared to the survival time of many patients with ovarian cancer; and
- iv) pharmaceutical companies tend not to initiate ovarian cancer trials as the disease has a low incidence.

Given these issues are a reflection of structural issues in the health system, we do not believe new or amended funding models will have a significant impact. Rather, we suggest a new approach to clinical trial development would be required: This would include:

- i) **More basket trial designs**, where the focus is on a defined tumour mutation (or mutations) instead of a tumour type. Patients enrolled in the trial are put into individual study arms, or 'baskets' according to their tumour type (ovarian, bowel, brain etc).
- ii) **Supporting the Australasian Teletrial Model** developed by the Clinical Oncology Society of Australia Regional and Rural Group. The model encourages the recruitment of patients to a suitable clinical trial regardless of where they live within a state.
- iii) **Adding rare cancer cohorts to existing clinical trials.** We suggest that 10-20 per cent of a patient cohort for current clinical trials be patients with rare or low incidence cancer, once the clinical trial has reached phase 2/3. This ensures access for rare cancer patients to all therapeutics, once they have been proven to be safe. Data from the rare cancer patients should be collected and shared across trials, rather than being analysed within the specific trial.

Further, a major challenge for all clinical trials in cancer, not only those of low incidence or low survival, is the participation of patients from rural and regional areas of Australia. Patients from rural and regional areas opt out of trials because of the long distances travelled, the cost of travel and finding accommodation and the rigours of travelling while feeling unwell from their illness or the treatment they are undergoing. We recommend **expanding medical travel and accommodation reimbursement schemes to include registered clinical trial participation**. This would likely overcome the reluctance displayed by some rural and regional patients who would otherwise be ideally suited to participate in clinical trials.

## **2b. Funding support for campaigns designed to raise awareness of the need for further research, including clinical trials**

Ovarian Cancer Australia fully supports the implementation of publicly funded campaigns that raise awareness of the need for further research, including clinical trials, in rare and low survival cancers. At present, individual patient advocacy groups may campaign for more awareness or clinical trials, however these are necessarily focused on the specific cancer type for which they advocate. Adopting a national approach to advocacy for research and clinical trials allows for economies of scale to be achieved while also encouraging a coordinated national approach rather a piecemeal cancer-specific focus.

## **3. Strategies to improve survival rates among rare and low incidence cancers**

Patients across Australia do not have access to information about treating hospitals to help them make decisions about where to go to for treatment and care in order to receive optimal care.

Such information could be obtained via cancer-specific clinical quality registries. The potential for such registries to deliver positive health outcomes for Australia cancer patients has been acknowledged by the Australian Medical Research Advisory Board which has identified them as an Australian medical research and innovation priority for 2016-18.

We **recommend that a national clinical quality registry be developed for each low survival rate cancer**. Ovarian Cancer Australia has recently begun supporting the development of a pilot clinical quality registry of ovarian cancer treatment centres in eastern Australia. We believe that for ovarian cancer patients this will provide the information our consumers need in order to make an informed decision about where to go for treatment and care; and will subsequently improve their survival.

## **4. Increased investment in education and awareness-raising**

Studies attempting to explain cancer survival differences have focused on four main areas: stage at diagnosis and delay; treatment with curative intent; patient factors and; tumour and physiological/biological factors<sup>5</sup>. Evidence suggests that combinations of some or all of these factors explain survival differences, and each of these factors relate to and influence each other<sup>5, 6</sup>.

Every week we speak to women with ovarian cancer who were diagnosed at a late stage, and for whom the prognosis is poor, often this is due to one of the following factors:

- the woman didn't recognise her signs and symptoms as being cancer-related

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<sup>6</sup> Foot C, Harrison T. June 2011. How to improve cancer survival – Explaining England's relatively poor rates. The Kings Fund and Cancer Research UK.

- the woman underestimated the significance of her symptoms and delayed visiting her GP
- the woman's doctor didn't recognise the symptoms as cancer related, didn't investigate further and/or didn't refer the patient for specialist assessment

These scenarios are not unique to ovarian cancer, they are seen in a number of rare cancers in which the symptoms are non-specific or attributable to a number of other, less malevolent, causes.

To address we **recommend the government invest in education and awareness programs** that:

- Raise awareness of low survival cancers amongst GPs and other healthcare professionals to facilitate earlier diagnosis.
- Raise public awareness of cancer symptoms and encourage people to see their GP if they experience certain symptoms.
- Fund more research aimed at improving our understanding of the patient, doctor and system factors that result in diagnostic delay of low survival cancers, and cancer more broadly.

Ovarian Cancer Australia would welcome the opportunity to elaborate on the points raised above at a future committee meeting or hearing.

Yours sincerely,

Jane Hill

Chief Executive Officer