



SAVE LIVES SUPPORT WOMEN

Senate Enquiry:

Equitable access to diagnosis and treatment for individuals with rare and less common cancers

Ovarian Cancer Australia wishes to make this submission on behalf of those impacted by ovarian cancer in Australia.

Ovarian Cancer Australia is an independent national not-for-profit organisation, supporting people diagnosed with ovarian cancer their families and friends. Our focus is to provide care and support for those affected by ovarian cancer; and represent them by leading change. Our vision is to save lives and ensure no person impacted by ovarian cancer walks alone.

Ovarian Cancer Australia is proud to work on behalf of women with Ovarian Cancer and their families to ensure:

- Women living with ovarian cancer have a strong, united voice
- We advocate and work collaboratively to make ovarian cancer a national priority
- We deliver tailored, evidence-based, and accessible support and information free of charge to Australians impacted by ovarian cancer
- A vibrant and growing national ovarian cancer research effort in Australia informs practice and translates into improved quality of life and survival for women

Cancer Australia estimates that in 2022, 1815 people were diagnosed with ovarian cancer, and 1016 people died from the disease. Only 49% of those diagnosed are still alive at 5 years after diagnosis, making ovarian cancer the sixth most common cause of death from cancer in females, and the deadliest gynaecological cancer.¹

Rare cancers are those cancers diagnosed in less than 6 people per 100,000. Less common cancers are diagnosed in less than 12 people per 100,000.² Ovarian cancer is considered a less common cancer, and the different subtypes of ovarian cancer are considered rare. Therefore, Ovarian Cancer Australia appreciates the opportunity to submit to this inquiry on behalf of our community.

Ovarian Cancer Australia directly supports those affected by ovarian cancer, understanding firsthand the barriers to equitable, evidence-based care and optimal outcomes commonly experienced by rarer, poor prognosis diseases. We have included some examples below within each of the Terms of Reference which outline the barriers and experiences of our community. We have also incorporated some feedback from our community, sharing their lived experience of ovarian cancer.

¹ <http://www.canceraustralia.gov.au>. (2019, December 18). Ovarian cancer statistics in Australia | Cancer Australia. <https://www.canceraustralia.gov.au/cancer-types/ovarian-cancer/statistics#:~:text=In%202020%2C%20there%20were%20944>

² What is a Rare Cancer. (n.d.). ARC Portal. Retrieved August 30, 2023, from <https://www.arcportal.org.au/page/90/what-is-a-rare-cancer>



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- a. barriers to screening and diagnosis, including the impact of factors such as:
- i. geographic location,
 - ii. cost,
 - iii. cultural and language barriers,
 - iv. type of cancer, and
 - v. availability of treating practitioners

There is not yet an effective screening test for ovarian cancer, and timely detection is often challenging for a range of reasons. The majority of ovarian cancer cases are diagnosed at an advanced stage, with individuals experiencing vague symptoms.³ These symptoms overlap with other many other more common conditions, and because of the rarity of ovarian cancer, many working in primary healthcare see only a few cases during their career, making the timely recognition and diagnosis of ovarian cancer incredibly difficult.

Effective screening leading to early detection has made incredible difference to survival rates in more common female cancers such as breast and cervical cancers,⁴ and it must be a priority for ovarian cancer. Whilst the incidence is lower in ovarian cancer than these cancers, it is also a deadlier disease, so we must view screening as a deserving recipient of increased research and funding focus.

“An early detection test is a MUST. Early detection improves outcomes. We must give our women opportunities to avoid the consequences of this insidious disease.

More research into treatment options for disease at all stages. Survival rates are hideously low. Way below that achieved through improved research into other cancers. This is not acceptable to women or their families living through ovarian cancer.

Research into preventative strategies. Young, at-risk women (for example women who carry genetic mutations) are making life altering decisions that affect their fertility, child bearing options, life goals and future health in order to avoid this disease.” **Woman with a lived experience of ovarian cancer**

Challenges with diagnosis are also heightened as surgery for suspected ovarian cancer should be performed by a gynaecological oncologist working within an MDT. These specialists aren't always easy to access, especially for those living outside of metropolitan areas. For a lower incidence cancer, with poor outcomes who require such specialty care from the time of initial surgery and diagnosis, this exacerbates the frustrations and isolation felt by the ovarian cancer community.

³ Menon U, Gentry-Maharaj A, Burnell M, Singh N, Ryan A, Karpinskyj C, et al. Ovarian cancer population screening and mortality after long-term follow-up in the UK Collaborative Trial of Ovarian Cancer Screening (UKCTOCS): a randomised controlled trial. *The Lancet*. 2021;397(10290):2182–93. doi: 10.1016/S0140-6736(21)00731-5

⁴ Health. (2019, September 2). *About the BreastScreen Australia Program*. Australian Government Department of Health and Aged Care. <https://www.health.gov.au/our-work/breastscreen-australia-program/about-the-breastscreen-australia-program>



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In the UK, recommendations for investigations are based on NICE clinical guidelines and specify when referral should be made to a gynaecological cancer service. Reform is required to ensure all women receive investigations and treatment for suspected ovarian cancer within a gynaecological cancer centre.⁵

For those living in regional and rural areas who recognise that optimal care states they should receive surgery by a gynaecological oncologist, and treatment managed by a multi-disciplinary team with expertise in their disease, the logistics involved can be a barrier.

Financial toxicity is an issue for many cancer patients, but those with a rarer disease can be more at risk from travel costs to find disease expertise, to funding second opinions and then the cost of self-funding medicines not yet listed for their indication.

“As the survival rate for ovarian cancer is much lower than other gynaecological cancers and the funding has been much lower than for breast cancer, I think access to [new treatments and novel therapies] would put women suffering from ovarian cancer on a much more equal basis when it comes to effective treatments.” **Woman with a lived experience of ovarian cancer**

b. barriers to accessing appropriate treatment;

Whilst we have an optimal care pathway to guide the management of ovarian cancer patients, we know variation in care exists and not all patients are being treated as per the pathway. This is particularly true for the rarer subtypes of ovarian cancer, where there isn't always supporting data and therefore consensus on the best treatment regimens. Centres of excellence that oversee the management of ovarian cancer patients could assist in this challenge. Where possible care should be delivered close to home, but oversight of the care and planning from a centralised MDT would allow better access to specialists and specialised treatment planning, especially for those with less common subtypes of ovarian cancer. This has been called out previously in the National Women's Health Strategy but is yet to be implemented.⁶

After remaining the same for many decades, the landscape of ovarian cancer treatment has started to evolve. Historically all ovarian cancer patients were treated with the same approach of cytoreductive surgery and platinum-based chemotherapy however now we understand ovarian cancer to be an umbrella term for many subtypes of disease which respond differently to existing chemotherapy regimens. Whilst this greater knowledge of ovarian cancer is welcome, it also means that the group for whom each new development or treatment benefits, is smaller, “rarer.”

⁵ Recommendations organised by site of cancer | Suspected cancer: recognition and referral | Guidance | NICE. (n.d.). [www.nice.org.uk. https://www.nice.org.uk/guidance/ng12/chapter/Recommendations-organised-by-site-of-cancer#gynaecological-cancers](https://www.nice.org.uk/guidance/ng12/chapter/Recommendations-organised-by-site-of-cancer#gynaecological-cancers)

⁶ Health. (2021, May 6). National Women's Health Strategy 2020–2030. Australian Government Department of Health and Aged Care. <https://www.health.gov.au/resources/publications/national-womens-health-strategy-2020-2030?language=en>



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“Ovarian cancer is one of the hardest cancers to beat with appalling statistics and very little hope of survival. The drugs we rely on are many years old and anything that brings hope will only benefit us if it is affordable - we do not live long enough to have our voices heard, having this decision made quickly will benefit many women who may not survive long enough to wait for the bureaucrats to make a decision.” **Woman with a lived experience of ovarian cancer**

The evolution of personalised medicine in ovarian cancer allows a more individual and nuanced approach to a patient’s treatment plan to take advantage of the new learnings we have about the disease subtypes. The exciting progress of a personalised approach to cancer treatment also brings challenges, however.

“The sooner the better please, we have been given the same one size fits all treatment for decades but the disease is as individual as we are, the initial treatment should be followed up with something more tailored to the patient, recurrences threaten us constantly and current ongoing treatments only work for a little while, we live on rollercoaster ride of fear and pain that never ends” **Woman with a lived experience of ovarian cancer**

Recruitment for clinical trials becomes slower and more difficult as there is an even smaller pool of patients to select from. This means that attracting clinical trials to Australia for this group is hard, as it is more resource intensive for the company (due to needing to keep the trial open for longer during recruitment, through to challenges at listing time.)

Basket trials have assisted in this, however the burden of proof requires a high enough number of patients in each cohort, so doesn’t completely solve the problem. Examples exist in ovarian cancer of a trial arm being open for subgroups of our populations for medicines such as immunotherapies and targeted therapies which show promise; however, applications aren’t made by industry for listing due to the small sample size and stringent data requirements.

Low grade serous ovarian cancer is one of these examples. This type of ovarian cancer accounts for approximately 10% of epithelial ovarian cancers, and typically responds poorly to standard of care chemotherapy. We now know that low grade serous ovarian cancers have distinct features, and targeted therapies have been identified that demonstrate benefit. These new therapies such as MEK inhibitors sadly haven’t yet translated into listing in Australia, and therefore remain accessible only via clinical trial (which are few and far between.)

Registries, more robust data collection and tissue banking could also assist in these challenges. If the government is to truly understand the challenges experienced by rare and less common cancers, valuing and funding data collection to better understand the significant variation in care for rare and less common cancers is vital. Ovarian Cancer Australia is a collaborator on the National Gynaecology-Oncology Registry⁷ so we understand firsthand the value of clinical quality registries. However, Government funding is required to ensure that registries are sustainable so their full potential can be reached over a period of time.

⁷ National Gynaecology-Oncology Registry (NGOR). (n.d.). National Gynaecology-Oncology Registry (NGOR). Retrieved August 30, 2023, from <https://ngor.org.au/>



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Prioritising funding of translational research programs which capture the rarer and more complex disease types can also assist in the challenge of clinical trials access. If Australia can demonstrate efforts to more easily identify patients with rarer subtypes, therefore easing recruitment challenges, it will make it more appealing for industry to bring their trials here and see medicines through to listing.

Subsidised listing of tests and medicines on the MBS and PBS look to these clinical trial outcomes to ensure the medicine or test is safe and effective which of course is essential, however it would be great to know consideration is given to this unique challenge experienced by rarer conditions. We know that these problems mean many people with rare and less common cancers are self-funding medicines, often at a significant cost. Ovarian Cancer Australia's 2021 Consumer Survey from the end of 2021 demonstrated that 20% of people with ovarian cancer had self-funded treatment. We understand this tends to occur when they are aware of a medicine that has shown benefit but isn't yet subsidised and won't be in time for them to use. The current review into Health Technologies in Australia will hopefully address some of these complexities so Ovarian Cancer Australia is engaging with that review too.

We also know that rarer diseases often have worse clinical outcomes, which is a further disincentive to bring novel therapies to the country. Any measures we can consider to make it more feasible and enticing for industry to bring their products here would make a significant difference across the sector, especially for rarer and poor prognosis conditions.

c. the adequacy of support services after diagnosis

Thanks to Federal Government funding received in 2019, Ovarian Cancer Australia has been able to deliver on a program that has long been requested by our community, access to specialist ovarian cancer nurses. The telehealth model of the program allows us to reach women across the country, including in regional and remote areas, to identify and address significant areas of unmet need.

Support and expertise from specialist cancer nurses is particularly important for ovarian cancer as a rarer, poor prognosis cancer. We know our patient population experiences significant isolation after a diagnosis of ovarian cancer, in addition to the challenges outlined above in seeking access to optimal, evidence-based care.

Access to specialist support services such as delivered by Ovarian Cancer Australia can reduce the variation in care experienced by rarer diseases, as well as address the high distress such diagnoses can involve. Accessing reliable and accurate information about their disease is more difficult for someone with a rare or less common cancer, so education is also an important aspect of the specialist nursing role.

This Federal Government funded specialist nursing program is an effective way of navigating some of the difficulties expressed above, reducing variation in care and improving access to timely, evidence-based information and support. Programs such as Ovarian Cancer Australia's Teal Support Program that support all people diagnosed with ovarian cancer, regardless of disease type, must be valued and sustained over time.



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d. the adequacy of Commonwealth funding for research into rare, less common, and neuroendocrine cancer

“We have been neglected for so long. Fairness means it is our turn” **Woman with a lived experience of ovarian cancer**

Ovarian Cancer Australia was pleased to see Medical Research Future Funding awarded to ovarian cancer a few years ago, aligning with the National Women’s Health Strategy recognising the need to support research into low survival gynaecological cancers such as ovarian cancer.⁸ This was an encouraging step for the ovarian cancer research space in Australia, however significant changes in outcomes rely on both significant and sustained funding efforts. It has been challenging to keep a disease like ovarian cancer on the radar of Government, because rare and less common cancers don’t have the same profile as other cancers, with the known impact (or lack thereof) of celebrities and profile as discussed in the recent report of Cancer Research Funding in Australia.

It was also encouraging to see the Federal Government announce more funding in 2022 for rare cancers and rare diseases research, and it is essential this sort of prioritising of rare and less common cancers continues, to close the gap between the outcomes of communities like ours, and the outcomes of more common cancers.

Whilst these more recent investments in rarer cancers like ovarian cancer are welcomed, they are not nearly enough to turn the tide on disease outcomes. We must provide researchers with ongoing funding to see the breakthroughs we have in other cancer types, as opposed to one off funding injections. We need to encourage involvement in research of rare and less common cancers by ensuring it is a sustainable area to work in for the dedicated researchers who invest in these smaller diseases. It cannot continue to be so hard for them to persist in their work. Without their perseverance as experts in rarer cancers, we cannot see the breakthroughs we desperately need.

“It has been heartbreaking to learn that rarer cancers like ovarian do not get similar funding per patient for research or treatment in Australia that other cancers do. It is devastating to be diagnosed with ovarian cancer and know the majority of women like myself are less than 60 years of age, and are working mums with children still at home and yet have poor chance of even a 5 year survival. The government urgently needs to fast track access to treatments, new drugs, immunotherapy and novel technologies for ovarian cancer.

Men and women with breast, prostate, bowel or lung cancer can hold onto greater hope for recovery with the knowledge that treatments are advancing, and drug trials and immunotherapy have increased survival measures significantly.” **Woman with a lived experience of ovarian cancer**

⁸ Health. (2021, May 6). National Women’s Health Strategy 2020–2030. Australian Government Department of Health and Aged Care. <https://www.health.gov.au/resources/publications/national-womens-health-strategy-2020-2030?language=en>



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e. any other related matters.

Ovarian Cancer Australia thanks the Senate Standing Committee on Community Affairs for referring this Inquiry, thereby demonstrating a willingness to listen to the voices of this under-represented community and provide hope that leadership in the rare and less common cancers space might result in real, meaningful change.

Whilst economic considerations must be included across healthcare (including rare and less common cancers,) where significant inequities exist, we must move beyond the dollars it would cost to implement change and look at measures that are sustainable and have long term benefits across the broader Australian community. Ovarian Cancer Australia implores the Committee to think radically and bravely about how we can make access to diagnosis, treatment including clinical trials access and novel therapy funding, and support, better for all Australians.

Thank you for hearing the voice of the ovarian cancer community. Please don't hesitate to contact us for further information.

Advocacy Manager, Ovarian Cancer Australia