

HTA CONSULTATION 2 OVARIAN CANCER AUSTRALIA

Ovarian Cancer Australia welcomes the next stage of Australia's review into Health Technology Assessment and the opportunity to provide feedback on behalf of those impacted by ovarian cancer.

Ovarian Cancer Australia is an independent, national not-for-profit organisation, supporting those diagnosed with ovarian cancer. Our focus is to provide care and support for those affected and represent them by leading change.

Ovarian Cancer Australia is proud to work on behalf of those diagnosed with ovarian cancer, and their loved ones 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

As the national organisation supporting those with lived experience of ovarian cancer, we welcome the opportunity to contribute to robust reform of the HTA, to ultimately improve access to medicines and health technologies for all Australians and ensure Australia remains a desired destination for clinical trials and innovation.

Ovarian Cancer Australia has reviewed the options paper and notes the promising proposed improvements. Outlined below, we have addressed the key areas which pertain to the ovarian cancer community, as well as noting areas where we see further potential for clarification and consideration.

Ovarian Cancer Australia would also like to highlight its involvement in the joint consumer organisation submission.

1.1. Transparency, communication and stakeholder involvement in HTA

Plain language summaries:

As articulated within the options paper, summaries of outcomes are currently published in a way that does not take into consideration the variable degrees of health literacy within the community. This can leave the community unclear of both the outcome and reasoning, as well as next steps including any plans for resubmission or recommendation.

Ovarian Cancer Australia's experience engaging with HTA processes these past few years in advocacy for new tests and medicines has seen us better understand the needs of the community when providing information on recent submissions and their outcomes. Ovarian Cancer Australia now develops frequently asked questions when sharing details of recent outcomes or upcoming submissions, to support increased engagement and understanding for our community. Whilst we have the inhouse capacity and expertise to facilitate this level of support, we are mindful this isn't always the case for other patient populations.

In addition, the option to publish plain language summaries alongside upcoming PBAC agendas to see increased representation from those with lived experience would be a welcome addition, better equipping the Australian community to engage in HTA.

Further to these options, Ovarian Cancer Australia would welcome a shift from the outcome announcements occurring on a Friday evening. As experienced by the community of people impacted by ovarian cancer, the outcomes of 'game-changing' technologies and medicines are something that the community await eagerly, as they can have immense impact on their treatment pathways and survival.

Having outcomes presented at this time can make responding in a timely matter to enquiries and concerns raised, a challenge. Support is often required for both positive and negative outcomes, particularly with a patient population such as ours with more limited treatment options and poorer outcomes.

Improvements to the HTA website including development of a dashboard:

Improvements to the HTA website and proposed dashboard would be a welcome improvement to information dissemination and understanding of the community, as well as improve transparency around processes and options for input from a stakeholder perspective.

As articulated above, it is important to tailor information to varying degrees of health literacy and understanding within the community. Better articulation of the process as well as clear outline of opportunities for stakeholder and consumer input within the dashboard may support a more equitable approach.

In order to provide and develop a website and dashboard hub that meets the needs of consumer and stakeholder organisations, it is vital that this development is undertaken with thorough input and engagement from those with lived experience.

1.2. Consumer, clinician and other stakeholder engagement and consideration in HTA

Develop an engagement framework:

The addition and development of an engagement framework to guide and facilitate earlier and more effective and equitable consumer and stakeholder input is a crucial option within this review.

Ovarian Cancer is a rare gynaecological cancer, with approximately 1,815 women diagnosed in Australia each year. Ensuring that we capture the experience and voice of these women is crucial to ensuring we address unmet needs and provide accurate support to guide submissions. Having a clearer framework for this input would enable organisations such as Ovarian Cancer Australia and our community to better anticipate and gather these accounts appropriately.

In addition, an engagement framework would better demonstrate to the community the areas in which their voices have been used, and at which points along the continuum they can share their experiences. Documenting and sharing personal stories can take a toll on patients, and we must ensure we honour their commitment and engagement to the process with a clear framework as to how and when their contributions will be sought.



Strengthen consumer evidence:

In addition to an engagement framework, strengthening the pathway and process for obtaining real-world evidence and real-world data would enable more equitable and meaningful evidence to be provided to guide submissions, particularly in the area of lived experience.

As a lower incidence cancer with many rare subtypes, it can be challenging to meet the burden of proof from randomised control trials alone. Optimising other sources of data such as from registries and translational research programs may assist where there is uncertainty. Further to that, the voice of lived experience can articulate what data and information is of most value.

Ovarian Cancer Australia was recently involved in two lengthy concurrent submissions assessed by PBAC and MSAC. There were some challenges to overcome before the committees felt comfortable to recommend subsidies of the test and medicine. Ovarian Cancer Australia offered to have lived experience representation at the meeting to support the decision-making process, an offer that was declined. We see this as a potential area where lived experience may have played a critical role and aided in the timing and comfort for these submissions. Ovarian Cancer Australia welcomes the proposed options to reform within this area.

1.3. First Nations people involvement and consideration in HTA

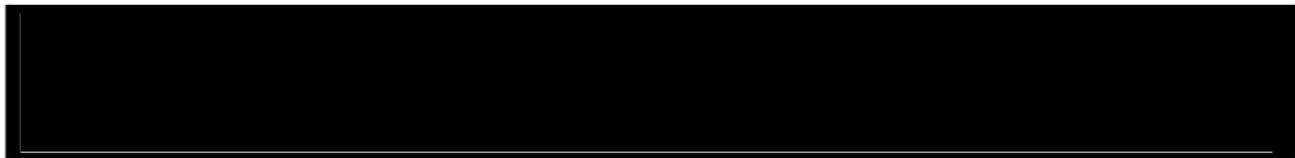
First Nations people's partnership in decision making:

As discussed within the options paper, the issues raised with the current HTA process described current First Nations involvement as Ad Hoc. Ovarian Cancer Australia welcomes the opportunity within the options paper for a more equitable and formal approach to engagement with First Nations peoples.

This may provide the opportunity whereby an organisation may not have already engaged with consumers with First Nations backgrounds to provide input and have greater engage in these areas, ensuring more equitable outcomes for all.

If we are to truly represent the interest of all Australians, and create a fair and equitable landscape, then reform within this area is critical for change.

With the rapid nature of evolving therapies, we need to ensure that any possible challenges of access (including the risk of widening existing variation in care) are discussed proactively and early in the process, as opposed to requiring a reactive approach following listing.



2.1. Streamlining and aligning HTA pathways and advisory committees

Expanding role of PBAC

Unified HTA pathway for all health technologies with Commonwealth funding:

After supporting recent concurrent submissions for PARP inhibitors through the PBAC and MSAC, we observed opportunities for greater efficiencies in the ways different parts of HTA communicate and engage with each other. The committee schedules didn't remain in sync, despite being co-dependent. Ovarian Cancer Australia welcomes expanding the role of the PBAC in instances such as these in attempts to reduce time between submission, assessment, and listing.

5.1. Proactively addressing areas of unmet clinical need and gaps in the PBS

Development of a priority list:

Ovarian Cancer Australia welcomes the option to develop a priority list for high unmet clinical need, to be regularly reviewed in consultation with relevant stakeholders and consumers. As articulated in the paper, stakeholders like Ovarian Cancer Australia recognise the current process within Australia as reactive. This option and proposed reform would enable facilitation for a more proactive system, that is directly influenced by the needs of the community.

Identifying therapies to meet priority list (horizon scanning):

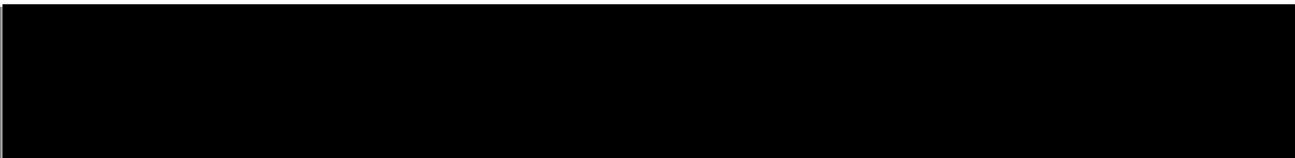
Ovarian Cancer Australia also supports the option of more formal and in-depth horizon scanning, to proactively address the needs of the community outlined within the priority list.

Ovarian Cancer has seen growing changes in the availability of more targeted treatments to improve survival and outcomes for those diagnosed in recent years. However, whilst these improvements are novel and game-changing for those within Australia, they have been standard of care for international patients for some years, including in the US and UK.

In the example of the recent expanded listing of PARP inhibitors for women with HRD and BRCA wildtype, it is estimated that approximately 300 additional women per year will now have access to this therapy. Within the time it took to achieve expanded listing, approximately 600 women would have had to either self-fund, gain compassionate access or miss out on these therapies. There is an [REDACTED] experience to provide reassurance with novel technologies and therapies so as not to delay patient access.

"It would be amazing – I see so many people overseas having access to different drugs to what are on offer in Australia and to be given a lifeline to extend the quality of my life, would be the best".

Furthermore, an important role of Horizon scanning and earlier projected submissions is the ability to forecast and ascertain whether the current health system policies and procedures are set up to deliver the innovative technologies to ensure equitable and effective access within the community.



Ovarian Cancer Australia developed consensus guidelines in collaboration with clinicians, on tissue collection in relation to HRD testing. It became evident throughout this project that not all health centres were equipped with the changes and information required to best facilitate this development. The guidelines, widely endorsed within the sector, create a best-practice summary of how and when tissue should be collected for HRD testing. Without best practice guidelines to work towards, patients may not have optimal care and access to medications such as PARP inhibitors.

Early assessment and prioritisation of potentially promising therapies:

Ovarian Cancer Australia welcomes the early assessment and prioritisation of potentially promising therapies. Further to the example given above, whereby medicines are already being used internationally and are standard of care, it would be wonderful to see these promising therapies prioritised. Often for ovarian cancer and other poor prognosis diseases, medicines being put forward are filling a gap that exists where there are commonly no alternate options available outside of clinical trial setting. Where patient options are limited and survival may be impacted, we must prioritise efficient access.

“Access to a new medicine would mean I would not have had to go through the anxiety of knowing I could possibly benefit from it but cannot afford it anyway. It would lessen my anxiety that I was able to do something at least for it not to recur. It would give me a big chance at least to see my son graduate.”

We thank you for the opportunity to participate and collaborate in this review. It is promising to see change occurring within this area, and we eagerly anticipate reform that will enable more timely access to medicines and health technologies.

We welcome any further discussion or to answer any questions that you may have.

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