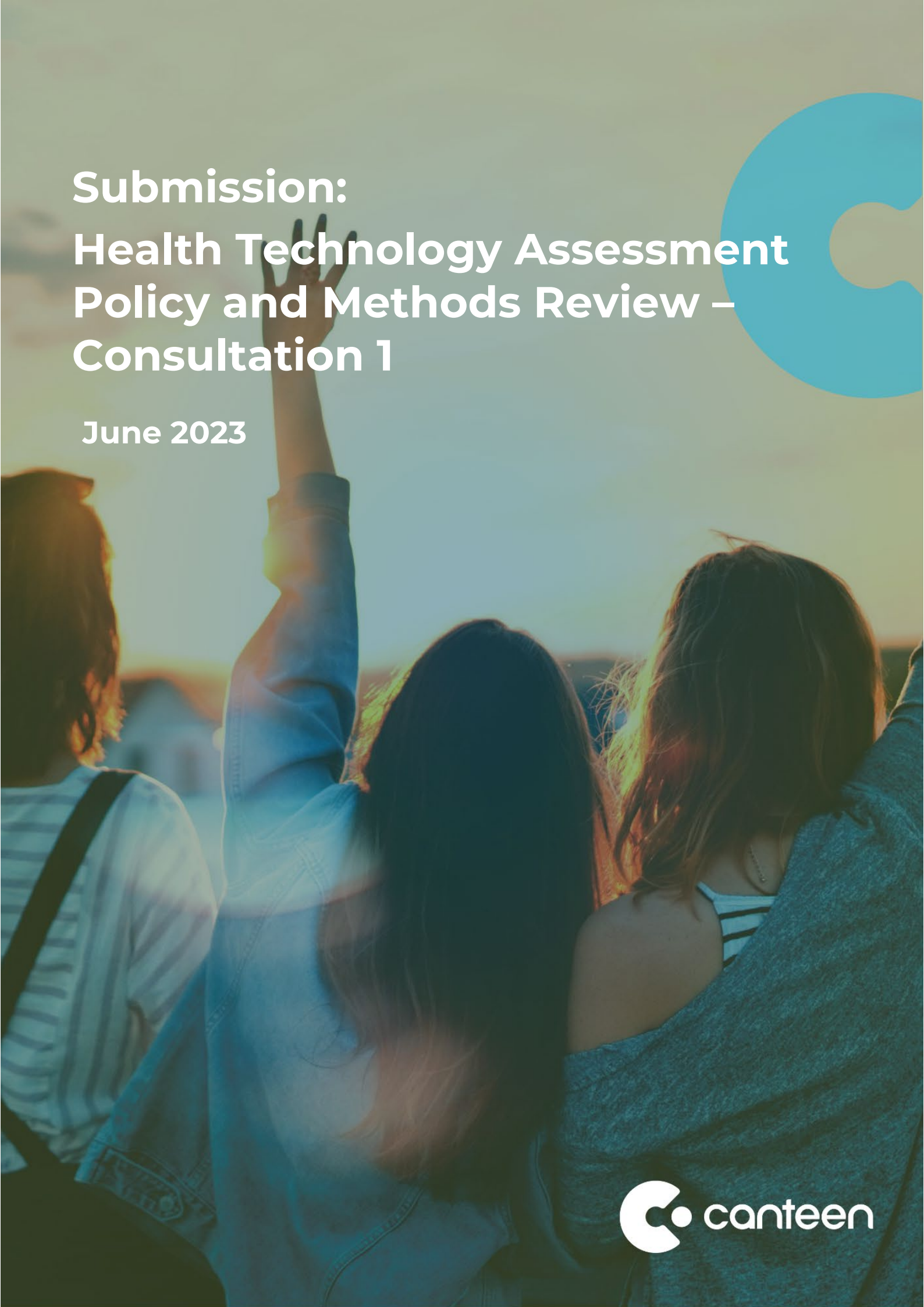
Submission:

Health Technology Assessment Policy and Methods Review – Consultation 1

June 2023



canteen

About Canteen

Canteen is a national, non-government organisation that supports young people aged 12-25 whose lives are impacted by cancer, whether their own diagnosis or that of a family member.

Canteen works by having young people at the centre of everything we do. Our counselling services, individualised support, and youth-friendly resources help young people develop skills and resilience to cope with cancer. Young people can join our 24/7 online community or attend multi-day evidence-based programs or recreation days to connect with peers with similar cancer experiences. Canteen also supports parents of young people through their cancer diagnosis with free expert advice, counselling and facilitating connections to other parents in similar situations.

There are Canteen service hubs across Australia, in capital cities and major regional centres as well as the Canteen Connect online service. Together with Camp Quality and Redkite we also deliver Cancer Hub - a digital first point of call for families with children aged 0-25 years when cancer impacts the family.

Canteen also administers the multidisciplinary Youth Cancer Services, supporting young patients in hospitals across Australia.

Canteen provides services to, and advocates for, a diverse range of people. Above all we represent young people and their families who are impacted by cancer. Guided by our internationally regarded research into the impact of cancer and best-practice care, Canteen understands how cancer is different in a young person's world.

More information about Canteen and the work we do can be found at www.canteen.org.au.

About this submission

This submission is regarding the policy and methods for assessment of cancer medicines by the Pharmaceutical Benefits Advisory Committee (PBAC).

At Canteen we appreciate the opportunity to contribute to this important review and support the goals of the review.

As a patient-focused organisation, we have limited insight to the inner workings and decision-making processes of the PBAC and so we are not always able to identify the specific policy, method or mechanism that acts as a barrier or perverse incentive. What we do see clearly is the impacts of an inequitable system on young cancer patients and families.

We see the difficult choices that people are forced to make when innovative drugs to treat rare cancers do not pass the cost effectiveness test or are not put forward for assessment at all because pharmaceutical companies know they are unlikely to be successful. Choices such as whether to spend their savings on medicines that will provide good quality of life and precious extra months with their children, or whether to avoid leaving their family in debt by forgoing the medicine, suffering the pain and dying sooner.

When medicines are not subsidised by the PBS it creates inequities because some people can access the medicines they need, when they need them, and many cannot. When medicines are not subsidised, people may be offered, or not offered, medicines based on whether they are in the public or private system, in a paediatric, AYA or adult cancer service, or based on their doctor's judgement of their ability to pay.

We are advocating for change because we see the impacts of outdated assessment methods on young people and families, especially inequitable access to medicines for people with rare cancers. The current top-down approach to determining value and impact to inform funding decisions is insufficient and we need assessment methodologies that incorporate real value and impact to enable timely, equitable access and person-centred design and decision making.

Are there any elements and features of HTA policy and methods in Australia that are working effectively?

Health technology assessment (HTA) policy and methods in Australia are essential for ensuring effective and evidence-based decision-making about access to health technologies, such as medicines. Overall health technology assessment in Australia works effectively to provide timely and affordable access to safe, clinically effective medicines and treatments that people need. This is particularly true for high volume and low-cost medicines, such as for management of chronic conditions.

Positive and effective aspects of HTA in Australia are structured processes, independent and expert advisory committees, and emphasis on the use of robust scientific evidence to inform decision-making. However, we find that HTA is not working effectively for everyone. There are barriers to timely and equitable access to low volume and high-cost medicines to treat rare cancers and other rare diseases.

What are the elements and features of HTA policy and methods that are acting as a current barrier to earliest possible access?

The current HTA system is well structured for providing timely access to high volume and low-cost medicines. However, for rare cancers with small patient populations there are barriers to earliest possible access.

We believe that there is a lack of incentive for pharmaceutical companies to apply for new medicines to be listed on the PBS when there are very small patient populations. It can be difficult for applicants to meet clinical evidence requirements and demonstrate cost effectiveness with very small numbers of patients, and the cost of application can outweigh the benefits for companies.

This causes barriers to earliest possible access to cancer drugs that save or extend lives and improve quality of life for people with rare cancers. Due to the costs and complexities of applying for approval, companies may choose not to apply for PBS listing so there are delays for the patient who must raise the money to pay for non-PBS medication or travel overseas for access.

For therapies with the potential to treat multiple indications, pharmaceutical companies may apply for approval for the most common indications first, meaning people with rare cancers must wait longer for subsidised access. There are also instances where companies do not apply for approval for rare indications at all, because there is insufficient incentive to do so.

A further element acting as a barrier to earliest possible access is the process of price negotiation between government and industry, which can delay access to subsidised medicines.

We believe that as cancer treatments become more innovative and personalised there is a risk that the barriers to timely access for small patient populations will be exacerbated. There is a need for changes to the current process to provide incentives for applicants, or introduction of alternative early access pathways for small patient populations.

What are the elements and features of HTA policy and methods that are acting as a current or future barrier to equitable access?

The same elements that act as a barrier to early access also impede equitable access to cancer treatments. People with rare cancers and other small patient populations are far less likely to be able to access the medicines they need a subsidised price than people with common conditions.

When dealing with very small patient populations, the narrow range of factors considered in cost-effectiveness analyses and clinical effectiveness analyses disincentivise pharmaceutical companies from bringing treatments to Australia.

Are you able to provide details of any elements and features of HTA policy and methods that may be detracting from person-centeredness?

The current HTA policy and methods are not person-centred because they do not focus on the things that matter most to people and do not routinely measure the impacts of not funding cancer treatments for patients and the costs for children, partners, employers, governments, and communities. In a person-centred HTA system, reimbursement decisions should always consider the impact and benefits of medicines from patient perspectives.

The Counting the Cost report demonstrates how social return on investment (SROI) analyses can be used to put a monetary value on the benefits that flow to families, friends, communities and governments.

Social return on investment (SROI) analyses do not form part of the cost-effectiveness analysis under the current PBAC guidelines. Instead, there is provision for SROI analysis to be submitted as 'other' information, under part 5 of the guidelines, however this provision may be underutilised. Even the wording of this section detracts from person-centredness, stating that for some medicines and/or indications, non-health-related outcomes may be relevant to present; where from a patient's perspective, non-health outcomes are always relevant.

At Canteen we do not have direct insight to the HTA application and assessment processes, but we can speculate on the aspects that are not working effectively based on the impacts that we see for young people and families dealing with cancer. Elements that may be detracting from person-centredness, based on what we see, are a lack of incentives or understanding among applicants on how to incorporate person-centredness, including SROI into applications.

Potential solutions might include creating incentives or requirements for inclusion of patient-centred information in applications. Alternatively, a separate funding stream and or managed early access for small patient populations could provide a person-centred and equitable access to the medications that people need.

Are you able to provide details of elements of features of HTA policy and methods that are causing or could cause unintended consequence or perverse incentives?

The current HTA system appears to incentivise pharmaceutical companies to apply for PBS listing for medicines for large patient populations, but not for medicines for small patient populations. This may be because the costs and evidentiary requirements are the same for all applications. For small markets and rare diseases there may be benefit for pharmaceutical companies in delaying an application until evidence of success in other markets can be accumulated. Companies may also choose not to apply for PBS listing at all if they know approval is unlikely or if the expected price will not be worth the cost and time of application.

An early or managed access program for small patient populations could remove this perverse incentive. Programs such as the Cancer Drugs Fund in the United Kingdom support early and equitable access to treatment for people from small patient populations. International collaboration on standardised or shared assessment process could also support more person-centred and equitable access to the medications that people need in Australia.