Leukaemia Foundation

Health Technology Assessment Review Secretariat
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Dear Health Technology Assessment Review Secretariat

Re: Leukaemia Foundation response to the *Review of discount rate in the Pharmaceutical Benefits Advisory Committee guidelines* (Phase 2)

Thank you for the opportunity to provide comments on the *Review of discount rate in the Pharmaceutical Benefits Advisory Committee guidelines* (the "Review"). As the only national organisation that represents all Australians living with blood cancer, we want to ensure the specific needs of people living with blood cancer are represented. Our goal is zero lives lost due to blood cancer by 2035, and we are keen to see that reforms to Australia's Health Technology Assessment (HTA) instruments can help address barriers to access and best practice care for people with blood cancer.

HTA is a critically important policy area for the Leukaemia Foundation as the people with lived experience we represent are directly affected by the decisions reached through the Therapeutic Goods Administration (TGA), the Pharmaceutical Benefits Advisory Committee (PBAC) and the Medical Services Advisory Committee (MSAC). We understand that the HTA decision-making process involves many complex components, including considerations of the long-term economic effects of listing a therapy for public subsidy. We appreciate that government procurement rules require estimation of value for money, and discounting rates are just one component of those calculations.

As outlined in the *Review of the Discount Rate in the PBAC Guidelines report,* produced by the UTS Centre for Health Economics Research and Evaluation (CHERE) in support of this consultation, the 5% discount rate presently used in the PBAC guidelines was first set in 1995 as a midpoint in a fairly wide confidence interval (3-8%). Unlike many comparable jurisdictions for HTA, this rate has not changed since, and is at a higher level: for example, Canada's discount rate dropped from 5% to 1.5% in approximately 2015; Japan has used a 2% discount rate since 2015; New Zealand's variable discount rate of 8% for cost and 3% for benefit was amended to a flat 3% in 2010; the UK went from variable discount rate of 6% for cost and 3% for benefit to a flat 3% rate from 2005; and the rate used United States has varied between 3% and 3.5% over the last decade. This in and of itself is not an argument for change, but there has been no theoretical rationale provided by the Department on the initial setting of the figure and its stasis since.

The Leukaemia Foundation:

- Concurs with CHERE that there is no good evidence that simply reducing the base discounting rate (or introducing a variable rate between cost and benefit, as in some jurisdictions) would have significantly altered PBAC's decisions to not recommend certain submissions.
- Nevertheless agrees that international comparison with high-income countries with similarly advanced HTA systems supports a reduction in the base discounting rate, particularly with the increasing trend towards precision therapies. For blood cancers, the following statement in the CHERE report is particularly relevant: "*all else equal, discounting future costs and*

health benefits will have a higher impact on the estimated cost-effectiveness of therapies with relatively high up-front costs and long-term realisation of health benefits."

New and novel therapies, including combinations of therapies, are changing the treatment paradigm for many blood cancers. While these come at a significant cost, they have been shown to significantly improve survival outcomes either with curative potential or changing prognoses from short-term high mortality to a chronic (but survivable) illness. The Leukaemia Foundation believes that the economic evaluations used to assess these therapies for subsidy need to be flexible enough to take these factors into account.

- Further agrees with CHERE that a reduction of the discounting rate, or introduction of a variable rate, would need to be accompanied by a broader consideration of the potential economic impacts, including displacement effects on the health budget. The Leukaemia Foundation believes this consideration should be transparent and include the perspective of patients.

The Leukaemia Foundation would like provide our perspectives on the transparency of decision-making processes for new treatments, services, devices and diagnostics.

Transparency on decisions to recommend a therapy for subsidy

The Leukaemia Foundation has been vocal on the need for greater transparency in decision-making in HTA. While we appreciate there are unavoidable commercial-in-confidence aspects to these decisions, consumers are largely left in the dark on what weight is given to economic factors, versus those of efficacy, and consumer benefit over the short and long term.

For example, in our response to the National Medicines Policy (NMP) Review Discussion Paper, we noted:

> *The lack of transparency and genuinely accessible avenues for engagement hampers consumer contributions to decisions that directly affect them. Consumers are not currently involved in all aspects and at all relevant stages of strategy or outcomes, both for the National Medicines Policy overall and for its administrative arms [TGA, PBAC, MSAC]. The lack of involvement is partly historical; the HTA system has been designed as a procurement tool, with suppliers and government as key parties. It has over time been amended to include consumers in some stages of decision-making, but this can be symbolic and perfunctory, depending on the arm. It is unknown how broader economic and societal values are considered alongside technical/medical ones, and whether or not those values have any impact on purchasing decisions.*

The Leukaemia Foundation appreciates that the discount rate does not have primacy in decisions of economic value which would impact a recommendation, and we do not believe simply lowering the discount rate will greatly affect the outcome or quality of those decisions; rather, it is part of a suite of economic factors that come into play when examining issues including cost/benefit over the long term. However, there is a lack of transparency on how these economic factors, such as the discount rate, affect the ultimate outcome of assessments of the PBAC and MSAC.

Consumers, as taxpayers, deserve to understand the full basis on which products receive positive or negative recommendations for public subsidy. We understand this issue is the subject of a separate review, and we will be providing further contribution to that review.

Transparency on negotiations between government and sponsor

The negotiation process between the sponsor and the Government following a positive recommendation is opaque, owing to the constraints of commercial confidentiality. It is unknown what weight, if any, is given to the specific needs and perspectives of consumers when compared to commercial aspects of the application. To the extent that decisions are made on behalf of Australian consumers, they are largely in the dark as to *how* those decisions are made.

This is important in the context of the objectives of the NMP – under which HTA ultimately sits. The proposed NMP states as a pillar "timely, equitable and reliable access to medicines that are needed, at a cost that individuals and the community can afford," and adds transparency and accountability as a key principle. We believe that this transparency can and should carry over to HTA agencies in their price negotiations, and that NMP principles be reflected in those decisions.

Post PBAC negotiations between the Government and sponsors typically take several months, but they can take longer, and for this period consumers are left in the dark on the status of the medicine in question. If there are substantial disagreements between the Government and the sponsor which are contributing to an unexpected delay, the Government should state the cause of the delay (supply, price considerations including cost/benefit, etc) without disclosure of commercial terms. This would assist health consumers to understand the rationale for the delay and provide some clarity on what to expect at the end of the process.

The Leukaemia Foundation appreciates the opportunity to comment on the review of the discount rate.

Sincerely,

Chris Tanti
CEO, Leukaemia Foundation