

National Medicines Policy Review Secretariat  
[NMP@health.gov.au](mailto:NMP@health.gov.au)

25 October 2021

Dear National Medicines Policy Review Secretariat

**Re: consumer comments on the consultation survey for the National Medicines Policy review on behalf of people living with blood cancer in Australia**

Thank you for the opportunity to provide comments on the National Medicines Policy (NMP) review. As the only national organisation that represents all Australians living with blood cancer, we are anxious to ensure the specific needs of people living with blood cancer are well represented in this important national policy framework.

The Leukaemia Foundation's submission largely addresses issues around patient centricity for the NMP; ultimately, we want to see consumers brought into the formulation of strategic health policy, concepts and outcomes from the very beginning.

Many of the concepts raised in the [National Strategic Action Plan for Blood Cancer](#) (National Action Plan) are relevant to the NMP, including its four priority areas: enabling access to novel and specialised therapies, achieving best practice, accelerating research, and above all, **empowering patients and their families**. A copy of the National Action Plan is attached as part of this submission.

Our submission is accompanied by a corresponding submission from the Blood Cancer Taskforce, which also draws on the National Action Plan and address issues around access to therapies. We fully support and endorse that submission.

### **About us**

More than 18,000 Australians will be diagnosed with blood cancer in 2021; more than 5,800 Australians will lose their lives to blood cancer and there are more than 127,000 Australian blood cancer survivors estimated to be living in Australia's communities today. Blood cancers are the most common form of cancer for children and young adults, and a significant cause of death and reduced quality of life among older Australians. This represents a major policy priority for Australian communities and governments.

The Leukaemia Foundation is attacking every blood cancer, from every direction, in every way we can. We make sure every Australian with blood cancer gets access to the trusted information, best-practice treatment, and essential care they need. Thousands of Australian families are able to better navigate a blood cancer diagnosis because they have access to trusted information, best practice treatment and essential supportive care through the Leukaemia Foundation.

Through our accommodation and supportive care services, over the last five years more than 4,500 rural and regional families were kept together during treatment and more than 5,500 families received a lifeline through financial support. Our transport services over this period avoided household expenditure of \$6.4 million. In that same period, we invested \$13.87 million into blood cancer research in Australia. In turn, this investment leveraged an additional \$8.2 million from international NGO and private sector industry investments into Australian blood cancer research.

Support provided by the Leukaemia Foundation reaches the most disadvantaged groups impacted by blood cancer. More than one in three people we support live in Australia's most socio-

economically disadvantaged areas and in the absence of our services, 73 per cent would not otherwise have access psychosocial services.

When combined, the Leukaemia Foundation's support services and research investments generate an additional \$853 million for Australia's GDP, resulting from health gains and economic effects. This suggests a return on investment of \$3.35 for every \$1 donated to the Leukaemia Foundation from its support and research services.<sup>1</sup>

## Responding to the National Medicines Policy review

**Are these proposed principles appropriate? With regard to the proposed principles, is anything missing or needing to change?**

**Are these four Objectives still relevant? Should any be modified, or any additional objectives be considered? If so, how and why?**

The Leukaemia Foundation observes that part of the problem of the current objectives are that they are very broad, and so can be defined to include, or preclude, other interpretations. The proposed principles go a considerable way towards addressing this and providing necessary context of *values* (i.e. equity) rather than only specific actions (i.e. access to medicines), although the Leukaemia Foundation concurs with Rare Voices Australia's suggested additional principles: accountability for *timely* access to new medicines, and flexibility - future-proofing of the NMP to emerging therapies.

How these objectives fundamentally determine the operation of the NMP and its administrative arms remains more of an open question, that should be clearly defined in any future draft of the NMP. 'Equity' is appropriate as a key proposed principle, but the NMP review process is silent on how that would translate to other health policy instruments that facilitate access to therapies, such as the Pharmaceutical Benefits Scheme, the Medicare Benefits Schedule, and special access schemes.

The Leukaemia Foundation agrees with the proposed principles – equity; a consumer-centred approach; a partnership-based approach; accountability and transparency; stewardship – as additions to the NMP and are keen to see how these are realised in practice. To put this into practice, taking the example of the current NMP review, in future, we would like to see more transparency in the development and consultation processes, including consumer involvement from the outset; more flexible and longer lead times for consumer contribution, including pro-actively seeking feedback from consumers at all stages of development; and more support and guidance for consumers to participate in these critical policy processes. More support for this would likely enable more consumer representative organisations to provide comprehensive and high-quality responses.

The Leukaemia Foundation is nevertheless enthusiastic about the opportunity to contribute the consumer perspective to a refreshed NMP, which will ideally consider these issues with much more clarity than what was achieved two decades prior.

The relationships between the NMP Review and other health policy reviews and strategies currently underway – the Efficient Funding of Chemotherapy Scheme review, the National Preventative Health Strategy, the Australian Cancer Plan, and The House of Representatives Standing Committee on Health, Aged Care and Sport *Inquiry into approval processes for new drugs and novel medical technologies in Australia* have not been detailed. The NMP Discussion Paper makes ready reference to the latter Inquiry but does not detail how the findings of these dovetailed, interconnected and interdependent processes will be synchronised. The Leukaemia Foundation

---

<sup>1</sup> Insight Economics, 2021, *The Health, Social and Economic Impacts of the Leukaemia Foundation*, available at [https://www.leukaemia.org.au/wp-content/uploads/2021/09/Phase-1-Investment-Case\\_16-September-2021.pdf](https://www.leukaemia.org.au/wp-content/uploads/2021/09/Phase-1-Investment-Case_16-September-2021.pdf)

believes that an outline of how this Review fits into these strategic policy development processes would be a positive outcome of this current consultation.

Addressing these issues and outlining a clear governance structure overall that prioritises transparency should be a priority for an updated NMP.

## **How can the NMP's focus on consumer centricity and engagement be strengthened?**

### **What opportunities are there to strengthen governance arrangements for the NMP? What would these be, and why?**

## **How can communication about the NMP be enhanced or improved?**

The NMP provides the overarching philosophy behind access to medicines and the framework governing a significant portion of the health policy landscape, but nevertheless remains opaque to consumers. It is known better by the roles and responsibilities of the administrative arms that effect the policy – the Pharmaceutical Benefits Advisory Committee (PBAC), the Medical Services Advisory Committee (MSAC), and the Australian Technical Advisory Group on Immunisation (ATAGI); the Therapeutic Goods Administration (TGA); and various working and reference groups.

The Discussion Paper notes that an updated NMP will need to recognise that consumers are becoming more active and informed participants in their care and broader health policy. 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 NMP overall and for its administrative arms.

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.

PBAC has sought over the last several years to improve its mechanisms for seeking genuine consumer input into submissions made for drug reimbursement, but the actual influence consumer voices have on recommendations is unknown. MSAC processes for consumer engagement are even less advanced, although we are pleased to see more formal consumer input processes being implemented, and we are hopeful that further improvements will be realised.

ATAGI and the TGA, on the other hand, are totally opaque in how they seek and utilise consumer input, if at all. By way of recent example, consumers were unable to formally contribute any input at any stage of TGA and ATAGI consideration of registration and access to COVID-19 vaccines.

Australian health policy has, over time, sought to increase consumer awareness and involvement in their own health decisions. Information provision and health literacy campaigns, including digital health literacy, have worked to enrich and empower Australians with the knowledge and familiarity to take ownership of their healthcare. The NMP and its administrative arms also need to work to empower their consumers, who are the ultimate beneficiary of those decisions – up and including restructuring its governance, including the operation of the HTA system, to achieve this.

**Genuinely empowered consumers control more of the decision-making in their healthcare,** and the Leukaemia Foundation believes that is a fundamental pillar to a modern healthcare system. The strategic health policy processes and its administrative arms therefore must enshrine and ensure that genuine consumer input into decisions that affect them is sought, actioned and understood, at all stages of decision-making.

The Leukaemia Foundation agrees that improved communications, including clear descriptions about what the NMP is, how it operates, and the links between various policies and initiatives that are associated with the NMP, would reduce the perception of and actual fragmentation and lack of coordination relating to medicines policy. As stated in the Discussion Paper, the NMP is not prescriptive about the programs and processes used to deliver on its objectives, by design. This allows some flexibility in delivery but is not transparent, and assumes a high level of understanding from a consumer to be able to appreciate where each arm sits in the strategic framework.

## **How should the NMP's 'partnership-based' approach be defined?**

## **What is missing from the policy's reference to the NMP partners? Are there other partners that should be included in the policy? Who would they be and why?**

The current NMP states "all partners need to enact their part of progressing the National Medicines Policy in a manner which is both cognisant and respectful of the interrelationships and expertise of other partners," and goes on to outline the various partners that would have prime carriage for implementing the pillars of the NMP. Where consumers are noted to have carriage, it is largely for self-determinacy: for quality, safety and efficacy, in considering both the benefits and the risks of medicines; for quality use of medicines, by taking responsibility for good health outcomes; and for a responsible and viable medicines industry, through a recognition of the benefits of accessing quality medicines and information.

Consumers do not have carriage of any aspects of *access to medicines*, a fundamental pillar which affects them directly. It is difficult to see how consumers can have input into this pillar without being first recognised as a partner within it. This is a clear area for improvement.

The NMP further states "different partners, or groups of partners, bear responsibility for the various outcomes, and to various degrees". These responsibilities, accountabilities and reciprocities must first be considered and then outlined in more depth and detail in any future version of the NMP. Of particular importance to us as a consumer representative organisation is that consumers are not relegated to recipients, rather as participants, in the process. The Discussion Paper outlines 'stewardship' as: "all stakeholders have a shared responsibility to ensure that the policy's objectives are met in an equitable, efficient, and sustainable manner, as stewards of the health system." Consumers should be included as stakeholders with responsibilities, and its corollary.

While the Leukaemia Foundation was not involved in the Stakeholder Forum, we concur with its outcomes as briefly noted in the Discussion Paper: that future iterations of the NMP must include "higher levels of transparency, including the management of conflict of interests".

The Leukaemia Foundation appreciates the opportunity to participate in the consultation process for the NMP review. We look forward to participating in future rounds of stakeholder consultation as the review progresses.

Sincerely,



Chris Tanti  
**CEO, Leukaemia Foundation**  
**Co-chair of the Blood Cancer Taskforce**