

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

3 October 2022

Dear National Medicines Policy Review Secretariat

## **Re: Leukaemia Foundation response to the updated Draft National Medicines Policy**

Thank you for the opportunity to provide comments on the updated Draft National Medicines Policy (the NMP). 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 well represented. Our goal is zero lives lost due to blood cancer by 2035, and we want to ensure the Policy enables us to realise this goal.

Appreciating the intended scope of the NMP and where it sits in the ecosystem of national health policies, the Leukaemia Foundation agrees with its overarching vision – to achieve the best health, social and economic outcomes for all Australians through a highly supportive medicines policy environment – and its broader aims:

- **Equitable, timely and affordable access** to high-quality and safe medicines and medicines-related services for all Australians;
- Medicines are used optimally with a focus on **person-centred care**;
- Support for a positive and sustainable environment to drive **innovation and research**, including translational research, and the development of medicines and medicines-related services.

Patient (or person)-centricity ideally should be at the core of any health policy, including making information accessible to those people. The Leukaemia Foundation appreciates that this new draft provides visual summaries of the NMP, going some way towards supporting consumers to understand the document. We believe that additional consideration needs to be given to consumers in explaining the policy context – and why the NMP is important within that context. This would include how the policy itself *and* its legislative instruments sit within other national and state/territory health frameworks, and how it will dovetail with other national health policies currently under development (namely the Australian Cancer Plan and the Health Technology Assessment Review).

The Leukaemia Foundation appreciates that some of this task is necessarily part of the governance and evaluation arrangements that are yet to be developed, and are considered by the NMP Secretariat to be beyond the scope of this current process. We understand that the Secretariat has provided advice to the Minister on governance and, presumably, evaluation frameworks for the NMP, and we await the opportunity to review and contribute to stakeholder reviews of these proposals at a later date.

With regards to the partnerships outlined in the NMP, the Leukaemia Foundation notes that the roles and responsibilities of consumer organisations, individuals, carers and their families includes a responsibility to '**promote and facilitate** consumer involvement'. In our submission to the February 2022 Consultation Draft of the NMP, we stated:

*"The Leukaemia Foundation, and other non-government organisations, provide these philanthropically-funded services because there are gaps in Australia's healthcare system. We are relatively large and well-supported in our fundraising, but this is not true of all patient representative organisations. Particularly for rarer conditions, many other advocacy groups operate in the spare*

*time, and on scant funds, of few volunteers whose voices struggle to be heard. Even so, we step in where there are gaps in support and services – which should be provided by government.”*

We appreciate that defined roles and responsibilities of consumers enables their centrality in the NMP partnership to be formally recognised. At the same time, as noted above, many consumer representative organisations – not to mention individual consumers – can be constrained in many ways in their capacity to do so. The Leukaemia Foundation would suggest that an additional role or responsibility for *governments* may be to ensure consumers and consumer organisations are supported to achieve this. This support might take the form of a coordinated approach to consumer engagement, such as demonstrated in this NMP Review process or the consumer engagement framework presently being developed through the Health Technology Assessment Review – nevertheless it should be specifically delineated in the NMP that consumers are not expected to organise their own advocacy in every instance. This would align more appropriately with the ‘person-centred’ principle in action:

Consumers will be **supported** and **enabled** to be informed and active participants in all decision-making, acknowledging their aspirations, diversity and lived experience. This includes developing and building health literacy, so that individuals, carers and families, and the broader community are informed and active participants in decision-making. Consumers will be **supported** to be involved at all levels of the NMP, including in the co-design and development, implementation and evaluation of its related policies, strategies, programs and initiatives.

The Leukaemia Foundation appreciates the opportunity to participate in the consultation process for the Policy. We look forward to seeing our perspectives realised in the final document.

Sincerely,



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