Leukaemia Foundation

National Medicines Policy Review Secretariat
NMP@health.gov.au

2 March 2022

Dear National Medicines Policy Review Secretariat

Re: Leukaemia Foundation response to the Draft National Medicines Policy

Thank you for the opportunity to provide comments on the Draft National Medicines Policy (the Policy). 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.

As a foundational strategic document for medicines and medical therapies, we believe the Policy has considered the need for flexibility in the definitions of 'medicines' to encompass advances in therapies. However we feel that the Policy should also consider the changes in treatment *paradigms*. For many blood cancers, advances in therapies have changed the prognosis for patients from acute diseases with high mortality, to chronic diseases, which have altogether different therapy and management strategies. It remains to be seen the Policy deals with these changes now and in the future, and how it will ultimately filter down to its agencies and schemes to speed up access.

We echo the concerns of other organisations that the development of this Policy has been undertaken on an unnecessarily short timeframe. The original Policy was developed over the course of several years, and while we understand that the COVID-19 likely delayed the commencement of this review, we feel that the truncated timeframe may not allow appropriately broad and considered consultation with all relevant stakeholders. Ultimately we believe that this may have a detrimental impact on the quality of the final document.

The Leukaemia Foundation makes the following specific comments:

Aim / Scope

- As stated above, we agree with the scope of the policy with regards to its definition of 'medicines', which broadens to encompass novel therapies. While this may need revisiting in future revisions of the Policy, we believe this is sufficient to cover the near future of *medicines* – but also needs to consider the changing context of treatment *paradigms*.

Principles

- In our response to the Discussion Paper, the Leukaemia Foundation's overarching concern was to see that consumers were made central to the foundations of this important strategic health policy. We are pleased to see that 'person-centred' as a foundational principle of the Policy, especially with regards to the empowerment of individuals, carers, their families and their communities.

  The National Strategic Action Plan for Blood Cancer provides some words that may be used to expand on this concept: "Central to this is empowering patients and their families to make choices for their wellbeing, so that: patients and their families know what questions to ask at every stage of their cancer journey; patient autonomy and choice is valued and supported; all patients and especially high-risk patients receive the help they need to equitably access services; patients and their families are supported to avoid financial hardship.”

- While we are pleased to see that equity issues in access to medicines are recognised in the Policy, it’s not clear that the responsibility of government in *reducing* these inequities has been equally recognised. For instance, the Policy states “progression of science and medicine can lead to inequity in access to needed medicines for some people living with rare diseases including under-recognised conditions. These inequities can be caused by the technical complexities of generating the data and evidence required to assess treatments used for such rare conditions. The Policy supports the ongoing commitment by all Partners to work collaboratively together in addressing such inequities.” This acknowledges that inequities impact access to medicines but does not directly state that it is ultimately the responsibility of governments in this Partnership, not consumers, to reduce this inequity.

Enablers

- We concur with all of the enablers stated, including and especially the focus on data and technology and the opportunities these provide to bridge gaps. The Cancer Council has identified a need for and recommended the development a digital information strategy for all cancers to fill this information gap. This also aligns with a recommendation of the National Strategic Action Plan for Blood Cancer and is supported by the Leukaemia Foundation.

Governance

- We are pleased to see that consumers – individuals, carers, families and communities – have been brought to the centre of the Policy’s partnership structure, with responsibilities as a partner under the relevant proposed pillars. We do observe that this structure does not appear to require consumer representation at all levels of governance, which is a telling oversight. Consumer involvement must be actively sought – and in a manner sensitive to differences in health and technological literacy – at all possible stages and should be a minimum requirement.

- We understand the NMP is not designed to be prescriptive about the programs and processes used to deliver on its objectives. We also appreciate that it is not the intent of the Policy to describe all governance structures that exist between all partners for carriage of their responsibilities. At the same time and repeating our statements in response to the Discussion Paper, it would be useful for this document to clearly define how the Policy fits in with the overall broader health system to help all partners appreciate the significance and breadth of the Policy.

  Specifically, this document needs to describe in plain English what the Policy is, how it operates, and the links between various policies and initiatives that are associated with the Policy. It needs to define *how* it interacts with the administrative instruments that effect the policy – the Pharmaceutical Benefits Advisory Committee, the Medical Services Advisory Committee, the Australian Technical Advisory Group on Immunisation; the Therapeutic Goods Administration; and various working and reference groups.

  The Policy also needs to clearly and concisely detail the relationship between it 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, the recommendations of the House of Representatives Standing Committee on Health, Aged Care and Sport’s *Inquiry into approval processes for new drugs and novel medical technologies in Australia*, and the upcoming Health Technology Assessment review.

Central Pillars

- Pillar 1, “timely, equitable and reliable access to needed medicines at a cost **that individuals and the community can afford**” (our emphasis) – we are concerned that this emphasis on individual and community cost places undue emphasis on individuals and not enough on the responsibility of governments to fund healthcare. The Leukaemia Foundation appreciates that avoiding any cost burdens for consumers is not possible in every instance, but as taxpayers, consumers should not have equal weight placed on them in funding responsibility.

- In Pillar 1, consumer organisations and peak bodies are stated to have a broad responsibility and function to “support consumer engagement and participation in the health sector at individual, service, and system levels” and “support the distribution of information, coordination, and advocacy for individuals and groups, particularly those who may experience inequity of access.” Consumer organisations such as the Leukaemia Foundation do provide a wealth of support and trusted information to people living with blood cancer and we consider this one of our primary functions. However, this is a function we fulfill in the *absence* of such information, coordination and support from official sources such as state and territory health departments. It is not appropriate to formally shoulder consumer organisations with this burden that rightfully belongs with governments, especially without corresponding resourcing or funding to do so.

- Pillar 3, quality use of medicines, appropriately states that the broad responsibility and function of all governments is “to coordinate **and fund** programs and processes that promote the quality use of medicines and medicines safety, including addressing misuse, overuse and harmful use of medicines, and raising awareness among the public and health professionals” (emphasis ours). It is curious that this responsibility of resourcing is not similarly reflected in the other three pillars for state or federal governments; instead the Policy uses language such as ‘deliver’, ‘promote’ and ‘facilitate’. Governments have accountability for adequately resourcing the delivery of health services and the functioning of the health system, and this should be reflected in their responsibilities for all the Pillars.

Implementation

- As a document facing its first review since its initial drafting more than 20 years ago, failing to include an appropriately regularly forward review timeframe within the Policy is an omission. Given the pace of change in the medicines space, reviewing the Policy ad-hoc is insufficient. It may not be the remit of the Policy to directly commit the Commonwealth to a specific review timeframe, but a suggestion to government could be noted and justified within the Policy, such as in the following sentence: “The role of the Commonwealth will be to facilitate, coordinate and monitor the identification, engagement, and commitment of partners to achieving the Aim of the NMP, within an agreed transparent reporting structure [and with regular review]”.

Evaluation

- We appreciate that accountability measures for each of the partners is assumed rather than detailed and it is beyond the scope of this document to stipulate accountability measures for every aspect. That being said, it may ease community concerns about of *lack* of accountability if the Policy specifically stated that partners with carriage of responsibilities under each Pillar were expected to develop and fulfil their own accountability measures. This is alluded to in the ‘Evaluation’ section but not explicitly stated.

For example, under timeliness in Pillar 1, "…appropriate and efficient registration, health technology assessment and subsidisation processes support timely access. This includes the flexibility to rapidly respond to changing, emerging, and disruptive technologies, including innovative and highly specialised therapies and services. **These processes and their outcomes need to be communicated to all stakeholders, including the public, to build and maintain the community's understanding and confidence in their application and rigour**" (emphasis ours) – we suggest it would be appropriate here to add words to the effect of 'and accountability measures for timeliness be developed and implemented'.

Accountability measures for the interdependence of partners should also be explored – including, for example, the critical importance of consumers being recognised as a partner in health technology assessment processes (as alluded to in our response to the Discussion Paper).

General comments

- Health literacy is a central enabler of the document, and in many ways is a necessary prerequisite to a health system that truly empowers patients with information to make decisions for their own healthcare. However, this Policy document as drafted is likely beyond the reach of many consumers, both in its language use and lack of context. It assumes a very high level of understanding from a consumer to be able to appreciate where each arm sits in the strategic framework, what they do, and why.

  The Leukaemia Foundation suggests that the Policy would benefit from measures to improve its readability to help consumers understand its content and to place the Policy in context. Consumer-friendly documentation, which aligns to the Australian Government Style Manual recommendations of a Year 7 reading level, may also be drafted alongside and complementary to this document.

Finally, as we stated in the Discussion Paper:

The Leukaemia Foundation aims to ensure 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.[1]

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.

The Leukaemia Foundation's ultimate goal as an organisation, beyond achieving zero lives lost to blood cancer by 2035, is obsolescence. We want to empower patients with information, and arm them to be their own advocates, and we also want governments to fulfil their duties to provide necessary services and support for people to access the health system unhindered. It is important to us that governments' essential roles in the delivery of healthcare not be understated or undermined – and we believe the Policy must further emphasise this primacy.

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

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[1] 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