Leukaemia Foundation

January 2024

Insurance Unit
Financial System Division
Treasury
Langton Cres
Parkes ACT 2600

Via email: geneticstestinglifeinsurance@treasury.gov.au

Dear Treasury

Re: Use of genetic testing results in life insurance underwriting

Thank you for the opportunity to provide a submission to the *Use of genetic testing results in life insurance underwriting* consultation.

We write in support of **Option 2 – "Legislating a ban: Under this option, the Government would legislate a total or partial prohibition on the use of adverse genetic testing results by life insurers."**

The Leukaemia Foundation is the only national organisation representing all Australians with blood cancer. We provide wraparound health services, fund leading-edge research and campaign for change alongside our community.

This submission draws on an evidence base that includes but is not limited to:

- our *State of the Nation: Blood Cancers in Australia Reports*, including a survey of over 4,600 Australians living with blood cancer, plus interviews with other stakeholders,
- Australia's first ever *National Strategic Action Plan for Blood Cancer* (2020),
- our Leukaemia Foundation Consumer Engagement Group, and
- our ongoing daily interactions with, and support for, the patients receiving our services.

We support Option 2 because:

1. Genomics helps accurately diagnose and guide blood cancer treatment – not identify genetic risk.
2. Genomic testing is a critical part of blood cancer treatment and should be incentivised, not disincentivised.
3. Genetic discrimination is unethical.
4. Removing barriers and increasing uptake will include overall health and economic benefits.

Genomic tests are vital diagnostic tools for treatment planning, not indicators of genetic risk. Using the results of these tools to discriminate against people is not only unethical, it also disincentivises best practice care and potentially punishes patients for a clinical decision that aims to afford them the best possible care for blood cancers – the second highest cause of cancer-related death in Australia.

Leukaemia Foundation
ABN 57 057 493 017
GPO BOX 9954
BRISBANE QLD 4001
1800 620 420

1. Genomics helps accurately diagnose and guide blood cancer treatment – not identify genetic risk

Blood cancers are spontaneous and not linked to a genetic predisposition.

The approach to diagnosing blood cancer involves looking for symptoms, elevated protein levels, and then conducting additional tests to determine the specific type of cancerous cells. This process focuses on understanding the cancer's characteristics rather than predicting or revealing a genetic predisposition.

Genomic tests for blood cancer patients therefore are not used to reveal an inherent genetic risk in the individual and do not indicate a genetic predisposition to the disease.

Instead, genomic tests conducted for blood cancer patients are crucial for identifying the specific nature of the blood cancer, which directly influences treatment decisions.

2. Genomic testing is a critical part of blood cancer treatment and should be incentivised, not disincentivised.

Unlike many solid tumour cancers and other diseases, blood cancers are neither preventable (e.g. mitigating risk through lifestyle factors) nor can they be easily identified through population screening.

Instead, reducing mortality relies on access to prompt and accurate diagnosis, access to best practice treatment and care, public health messaging to alert individuals to the signs and symptoms of blood cancer, and further scientific discovery that enhances treatment and care.

This underscores the importance of ensuring Australian blood cancer patients have access to effective diagnostics, treatment options and services.

Genomic testing is critical in the diagnosis and treatment of blood cancers because it allows greater accuracy in the diagnosis of the over 120 sub-types, which directly influences treatment decisions.

This importance of genomics testing for blood cancer treatment (and other cancers) is now well-recognised:

- Our recent *State of the Nation 2023* report contains new data showing **31 per cent of blood cancer patients** who had a genomic test had their diagnosis and treatment plan altered.[1]

- WHO recently (July 2023) identified genomics as the most important emerging technology and scientific innovation: **"application of genomics for early diagnosis and pre-diagnosis of diseases**…to enable a precise diagnosis and to guide management and treatment.[2]

- The Novel Therapies Parliamentary Inquiry found "…affordable access to genomic testing is needed **not only for patients but for the future of Australia's health system**."[3]

- The Medical Services Advisory Committee (MSAC) provided landmark support for next-generation sequencing gene panel testing for genetic variants associated with blood cancers. Importantly, MSAC noted that:

- **'genetic testing is now standard of care for patients with [blood cancers]'**
- 'without genetic testing, patients may be incorrectly diagnosed and potentially receive ineffective or incorrect treatment'[4] – *MSAC, March 2023*

> "The complexity of blood cancers needs to be clearly understood. We know they're complex…This really speaks to the need for precision medicine and genomic testing."
>
> *– 'State of the Nation' clinician respondent*

> "We know that genomic testing can inform treatment choices, but the process for accessing genomic testing is difficult – you do not have the same sponsor support as drugs, hospital management may decide that tests are too expensive, and patients often do not want to pay out of pocket. By implication, patient access is variable, which results in sub-quality treatment." [1]
>
> *– Blood Cancer sector stakeholder*

> "Regarding genomics, we will need to ensure it can be made accessible to everyone"[1]
>
> *– Blood Cancer sector stakeholder*

Clinical decisions should be based on optimising patient outcomes, not distorted by concerns over discrimination or financial penalties for patients that may result from those clinical decisions.

Genomics is recognised as a powerful tool in cancer treatment and we should be encouraging its use, not creating uncertainty and potential reasons for clinicians not to use it.

3. Genetic discrimination is unethical

It is unfair that patients be penalised for use of technology during treatment that may help save their lives.

Genomics is part of treating patients and the results should not be used to punish patients and disallow insurance.

If insurers were to make decisions based on the outcomes of these blood cancer genomics tests, it would be unfairly penalising patients for information that is a diagnostic tool for blood cancer, rather than an indicator of genetic risk for blood cancer or used to make a judgement of the likelihood of that patient developing another cancer.

This would create a scenario where patients might be discriminated against for seeking essential diagnostic information that is crucial for their treatment.

In our *State of the Nation* reports, the coverage of private health insurance of services for blood cancer was reported to already be low, and the cumulative impact of specialist visits, tests and scans, and other medical services creating substantial stress for people and their supporters.[5]

> "Private Health Insurance discriminates against blood cancers. They're not supposed to, but they do."
>
> *– Blood Cancer Sector stakeholder*[6]

> "Datasets are getting bigger and bigger and how to deal with multiple markers is challenging. There are huge ELSI risks for more systematic testing that need to be addressed. For healthcare it changes the prices, for life insurance you can't get it."
>
> *– Blood Cancer Sector stakeholder*[7]

We also believe it is also not ethical to allow discrimination based on the biological profile we are born with, and to apply barriers and potential punishments on those seeking to stay alive.

4. Removing barriers and increasing uptake will include overall health and economic benefits

Myeloma and leukaemia are the first and third most expensive cancers for our health system to treat,[8] and blood cancers together will cost the economy $71.9 billion each year by 2035.

Genomics can provide financial and broader economic benefits because it allows clinicians to tailor treatments and better match treatments to a patient's blood cancer profile. This can help find appropriate treatments sooner and avoid expensive treatments for late-stage disease.

For example, the cost of genetic testing is significantly lower compared to the expense of a stem cell transplant, which is often a last resort. Therefore, encouraging the use of genetic testing could lead to more efficient and cost-effective treatment strategies, benefiting both patients and the healthcare system.

As articulated in the first *State of the Nation* report prepared by Insight Economics, a test at the Christine and Bruce Wilson Centre for Lymphoma Genomics at Peter MacCallum provided clinically important information in 61 per cent of patients tested — changing their diagnosis, understanding of prognosis and treatment plan.

Considering the benefits of more widespread applications of this test, in 2019 it was expected that 12,570 people are likely to be diagnosed with a lymphoid malignancy. Given the potential error rates suggested by the pilot data for lymphoid malignancy, these data suggest that in the absence of a genetic or genomic testing in 2019 alone:

- 3,900 people may be mis-diagnosed and inappropriately treated
- 5,500 people may be over- or under-treated

- 1,500 people could benefit from the selection of the best therapy for their specific tumour and genetic profile.

The report found that only very small changes in the health outcome need to be realised to justify the cost of the Christine and Bruce Wilson Centre for Lymphoma Genomics test. For example:

- **Extensions of life through better** treatment **selection** — If only 10 per cent of patients identified to have a directly targetable lesion saw an improvement in survival of one additional year (150 people gaining one more year of life), applying a value of $50,000 to these years of life gained would see the investment in the test break even. If a higher cost per QALY were assumed, or if more people received the right treatment compared to a counterfactual where no test was available, the benefit cost ratio would exceed 1.0.

- **Improved health system efficiencies** — A better understanding of prognosis allows for treatment choice that spares patients from interventions for potentially little gain. The potential to avoid stem cell transplants in particular could deliver an improvement to the health care system and patients.

  A 2009 study of the cost of allogenic and autologous bone marrow transplants estimated the cost per transplant in NSW ranged from $62,812 per autologous adult stem cell transplant to $227,286 per allogenic transplant in a paediatric hospital, with a weighted average of approximately $106,500 in $2009 (or $127,000 in $2018).

  If only 1.1% of patients that might have been provided a stem cell transplant are spared this treatment, the test would break even holding all else constant. Because the cost of transplant is so high, the benefit cost ratio is very sensitive to the assumptions for the percentage of people who might avoid transplants.[9]

In this context, genomics can assist in achieving health system efficiencies.

We seek regulatory reform to life insurance to ensure there are no unnecessary deterrents to genetic and genomic testing that could improve survival outcomes for people living with blood cancer specifically, and other diseases more generally.[10]

Thank you for your consideration of the issues highlighted in this submission. We would be happy to discuss further and can be contacted at ctanti@leukaemia.org.au.

Sincerely,

Chris Tanti
Chief Executive Officer

About the Leukaemia Foundation

The Leukaemia Foundation is the only national organisation that represents all Australians living with blood cancer – including leukaemia, lymphoma, myeloma, myeloproliferative neoplasms (MPN), myelodysplastic syndromes (MDS) and amyloidosis.

We provide the following free services to patients:

- Personalised information and support from highly trained Blood Cancer Support Coordinators for patients and their loved ones alongside a range of health and wellbeing services
- Accommodation near major hospitals around Australia and help getting to and from the many appointments that come with a blood cancer diagnosis
- Trusted information to empower people to navigate the road ahead, including critical education, support groups, booklets, newsletters, and online information

The Leukaemia Foundation's research program drives rapid advancements in blood cancer treatments, encourages the careers of promising scientists, and helps give Australians access to global clinical trials.

About blood cancers

- Blood cancers are a **complex group of individually rare diseases**, each with a host of genetically distinct subtypes requiring bespoke treatment and care.
- There are over 120 discrete blood cancers, including more than 40 unique sub-types of leukaemia. Other rare sub-types include myeloproliferative neoplasms (MPN) and myelodysplasia (MDS).
- Over the past 10 years, the **incidence of blood cancer has increased by 47%**, and 135,000 Australians are now living with a blood cancer.
- **One in 3 will not survive** five years after their diagnosis.
- Blood cancers require, in many instances, highly specialised and complex care throughout the treatment period. Many blood cancers can have repeated acute episodes of treatments, remission and relapse.
- Some blood cancers can become refractory to current treatments, leaving patients with very limited options. Treatments are often aggressive, highly toxic and can result in debilitating lifelong side effects.
- By 2035, blood cancer will **cost the economy $71.9 billion each year**. Myeloma and leukaemia are the first and third most expensive cancers for our health system to treat.[xi]

Leukaemia Foundation
ABN 57 057 493 017
GPO BOX 9954
BRISBANE QLD 4001
1800 620 420

[1] *State of the Nation: Blood Cancers in Australia Report 2023*
[2] *2023 Emerging technologies and scientific innovations*, World Health Organisation, 2023: https://www.who.int/publications/i/item/9789240073876.
[3] New Frontiers report, p.229: https://parlinfo.aph.gov.au/parlInfo/download/committees/reportrep/024755/toc_pdf/TheNewFrontier-DeliveringbetterhealthforallAustralians.pdf;fileType=application%2Fpdf
[4] Medical Services Advisory *Committee (MSAC) Public Summary Document: Application No. 1684 – Genetic testing for variants associated with haematological malignancies* http://www.msac.gov.au/internet/msac/publishing.nsf/Content/0E3364FCF94B9002CA25874F00283CE5/$File/1684%20Final%20PSD-Nov%202022.pdf
[5] https://www.leukaemia.org.au/wp-content/uploads/2020/06/State-of-the-Nation-Blood-Cancer-in-Australia_Leukaemia-Foundation.pdf
[6] State of the Nation 2019, p.73: https://www.leukaemia.org.au/wp-content/uploads/2020/06/State-of-the-Nation-Blood-Cancer-in-Australia_Leukaemia-Foundation.pdf
[7] State of the Nation 2029, p.101: https://www.leukaemia.org.au/wp-content/uploads/2020/06/State-of-the-Nation-Blood-Cancer-in-Australia_Leukaemia-Foundation.pdf
[8] Merollini, K.M.D., Gordon L.G., Ho, Y.M., et al., 2022, Cancer Survivors' Long-Term Health Service Costs in Queensland,
Australia: Results of a Population-Level Data Linkage Study (Cos-Q), Int J Environ Res Public Health, 19(15), 9473, doi: 10.3390/ijerph19159473.
[9] State of the Nation 2019, Prepared by Insight Economics, p.89: https://www.leukaemia.org.au/wp-content/uploads/2020/06/State-of-the-Nation-Blood-Cancer-in-Australia_Leukaemia-Foundation.pdf
[10] STON 2019, p.109: https://www.leukaemia.org.au/wp-content/uploads/2020/06/State-of-the-Nation-Blood-Cancer-in-Australia_Leukaemia-Foundation.pdf
[xi] Merollini, K.M.D., Gordon L.G., Ho, Y.M., et al., 2022, Cancer Survivors' Long-Term Health Service Costs in Queensland,
Australia: Results of a Population-Level Data Linkage Study (Cos-Q), Int J Environ Res Public Health, 19(15), 9473, doi: 10.3390/ijerph19159473.