

Leukaemia Foundation of Australia

*Election Platform 2025:  
Seeking a 'Fair Go' for  
blood cancer patients*

## EXECUTIVE SUMMARY

Australia has a world-class health system – however, blood cancer patients still face significant obstacles to ongoing survival and care.

Blood cancers are **the most expensive** cancers for patients and our health system to treat. They also **lack options available for other diseases**:

Figure 1: What makes blood cancers so uniquely formidable?

|              |    |                        |     |
|--------------|----|------------------------|-----|
| Screenable?  | NO | Difficult to diagnose? | YES |
| Preventable? | NO | Difficult to treat?    | YES |
| Hereditary?  | NO | High mortality?        | YES |
| Known cause? | NO | Expensive?             | YES |

As a result, blood cancer is Australia's **second-leading cause of cancer-related death** and the **third-most common cancer**.

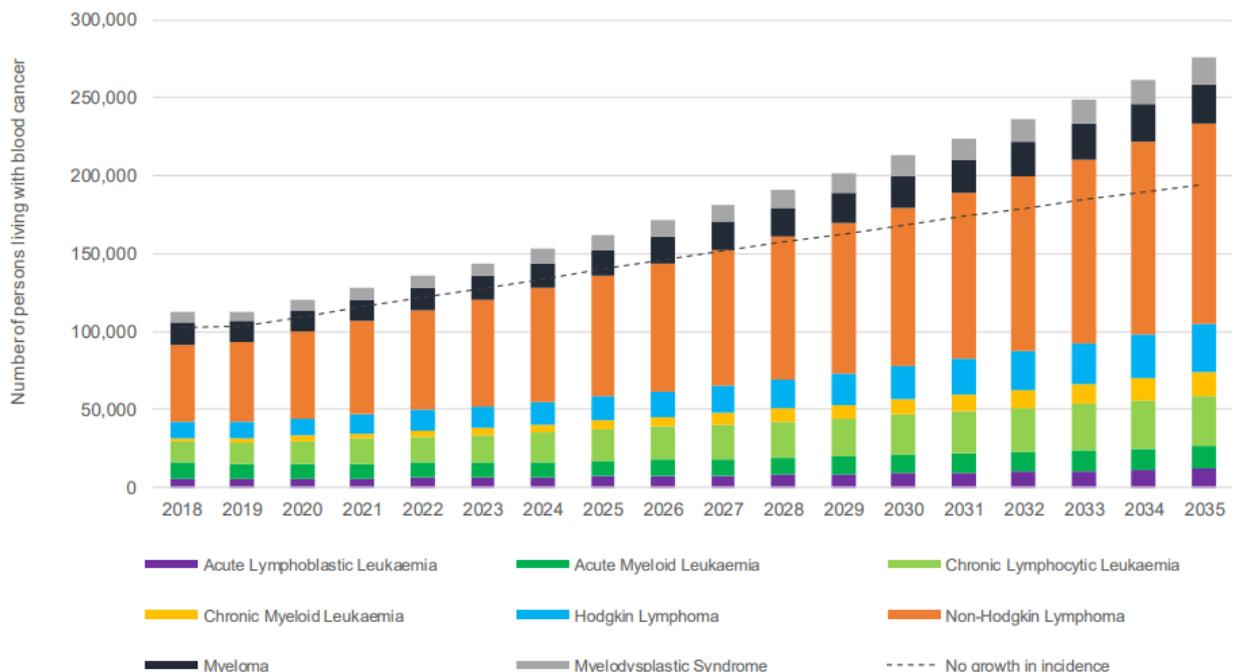
Many of its over 120 sub-types are individually rare, leading to additional challenges like limited treatment options, scarce clinical knowledge, reduced support networks, and delayed diagnoses.

Currently:<sup>1</sup>

- **over 150,000 Australians** live with blood cancer
- **6,324** are expected to die this year
- Acute lymphoblastic leukaemia is the **most common cancer in children**.

The situation is set to worsen, with the number of patients projected to **rise 47%** by 2035, to more than 275,000 (Figure 2).

Figure 2: The number of people living with a blood cancer (prevalence) – 2018 to 2035<sup>2</sup>



Urgent action is required to address these growing challenges.

## ***What patients want***

This election platform articulates what measures blood cancer patients want and need from those aspiring to be in Australia's next Parliament.

It is based on the lived experiences of over 4,600 patients surveyed, and the expertise we have generated through 50 years of supporting blood cancer patients.

It includes the support needs of patients at diagnosis, during treatment and post-treatment.

The patients we support are battling against many odds and the recommendations in this election platform provide clear, cost-effective ways of supporting the people who need it most – giving them a fair go against blood cancer.

## **SUMMARY OF RECOMMENDED COMMITMENTS**

- 1. Assist patients overcome systemic blood cancer care barriers:**
  - a. Support NGOs providing navigation and supportive care services
  - b. Ease the financial hardship through reforms to financial support programs that currently exclude many blood cancer patients, including NDIS and DSP.
  
- 2. Address inequitable blood cancer patient outcomes in rural and regional areas:**
  - a. Fund a pilot of the Leukaemia Foundation's new program to enable earlier diagnosis of rural and regional blood cancer patients (\$2.2 million over two financial years).
  
- 3. Make life-saving blood cancer treatments available to patients:**
  - a. Support implementation of Health Technology Assessment reforms to accelerate and modernise treatment funding pathways, update evidence requirements, and support the use of real-world evidence
  
- 4. Increase uptake of genomics in blood cancer treatment:**
  - a. Undertake a wider strategic assessment of blood cancer diagnostics service delivery across Australia
  - b. Support further MBS listings for blood cancer genomics tests.
  
- 5. Increase the pool of stem cell donors in Australia:**
  - a. Support donor recruitment drives
  - b. Commit to reforming stem cell donation governance and funding.

# 1. Assist patients overcome systemic blood cancer care barriers

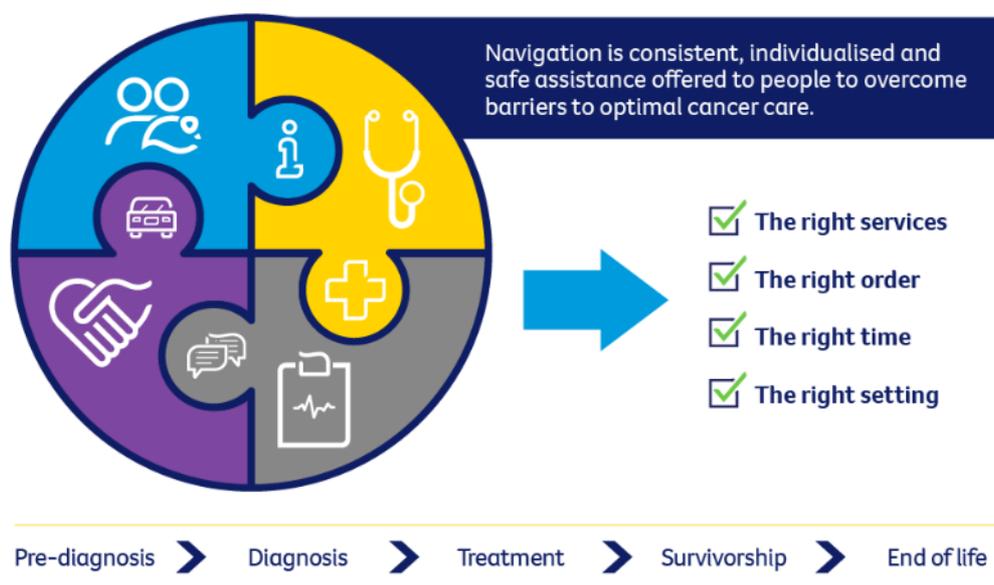
## *Issue: Patients face systemic and financial challenges in navigating blood cancer care*

### Navigating our complex health system

Blood cancer patients often struggle to navigate Australia's fragmented healthcare system and access support.<sup>3,4,5</sup>

Research shows this worsens the emotional strain, illness severity and costs, especially for patients with complex diseases – such as blood cancers – or educational and language barriers.<sup>6,7,8</sup>

Navigation support helps patients understand their treatment options, manage the healthcare system's complexities, and make informed decisions. This support reduces stress and ensures timely, coordinated care from diagnosis through to post-treatment:<sup>9</sup>



Source: Cancer Council<sup>10</sup>

Importantly, navigation support is one component of 'supportive care', which refers to the services, information and resources patients may need to meet their physical, psychological, social, information and spiritual needs from the time of diagnosis.<sup>11</sup>

Evidence has shown that supportive care can *improve* symptom control, quality of life and overall survival, and *reduce* emergency room and hospital admissions, chemotherapy deferrals, 30-day mortality after chemotherapy, and healthcare-related costs.<sup>12,13</sup>

Supportive care is also formally recognised as a standard or routine aspect of cancer care.<sup>14</sup>

However, **awareness and referrals for supportive care are often lacking**. Previous research shows only one in three patients have a supportive care discussion.<sup>15</sup> Leukaemia Foundation patient surveys have shown only one-third were told about our services at diagnosis. This is creating a clear care gap:

*"The Social Worker told me that there was no help with transport for Leukaemia. This was **very upsetting when I found out there was help.**"<sup>16</sup>*

*"I was **lost and confused** at first, I was not aware the Leukaemia Foundation could assist or help me"<sup>17</sup>*

"Even after my treatment I am still finding out things I did not know, e.g. things I was eligible for but not aware of."<sup>18</sup>

"When my legs became swollen, it would have been helpful to be directed to or given information on what would have helped with this side effect. We found out about lymphatic massages through friends."<sup>19</sup>

"There needs to be one simple go to point. When you're diagnosed, there is **so much coming at you**, it's overwhelming. **You need support** on who to go to for different things."<sup>20</sup>

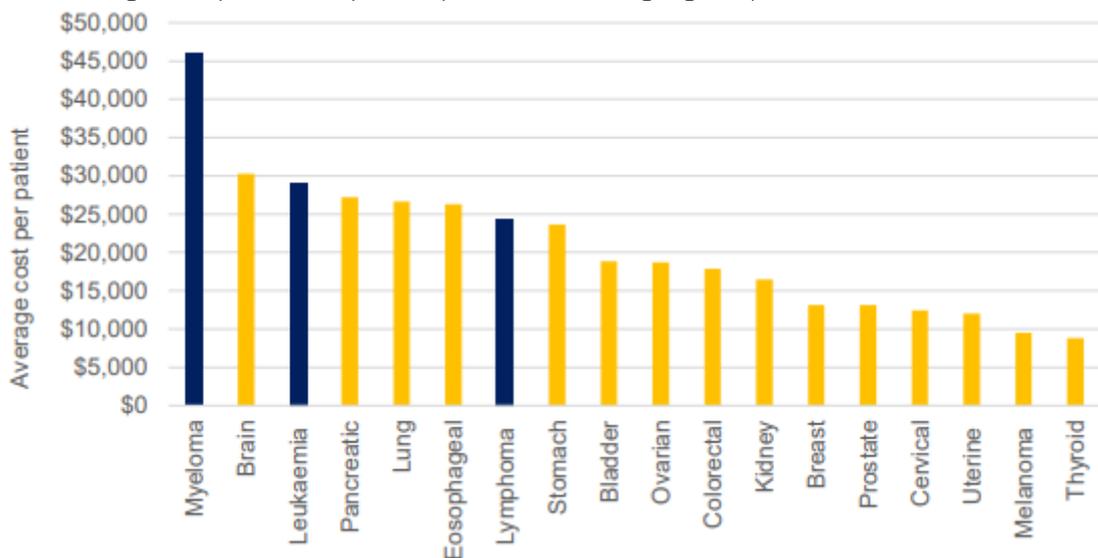
Increasing awareness and access to these services is essential to improve patient outcomes and enhance the quality of cancer care.

### Financial strain

A blood cancer diagnosis imposes a severe and immediate financial burden on patients and their families.

Blood cancers, including myeloma and leukaemia, are among the **most expensive cancers to treat**, with costs nearly three times higher than the average for other cancers:

Figure 4: Average cost per cancer patient (blood cancers highlighted)<sup>21</sup>



Treatment can be lengthy, with many patients experiencing **employment challenges**:<sup>22</sup>

- 32% of patients take over three months off work
- 23% have to leave their jobs, and
- 50% do not return to work.

This financial hardship is exacerbated by the **high out-of-pocket expenses associated with blood cancer treatment**, especially for patients who must travel long distances for care:

- Around 43% of blood cancer patients report out-of-pocket expenses, and
- Over one-third of these patients incur costs exceeding \$5,000.<sup>23</sup>

State-based Travel Subsidy Schemes are inadequate and often exclude travel for clinical trials – despite trials now being considered routine care.

Additionally, eligibility criteria for financial supports like the Disability Support Pension (DSP) and NDIS **often exclude blood cancer patients**, leaving them with insufficient options like JobSeeker, which is a short-term supplement payment not intended as a 'safety net' payment.

Cost of living increases are further exacerbating this hardship – in the past year alone, the Leukaemia Foundation has seen a **37% increase in requests for financial help**.

*"As a single woman in her own house with no income or superannuation, **expenses have made it impossible to live.**"<sup>24</sup>*

*"Having no income and still having bills to pay."<sup>25</sup>*

*"My illness is chronic and doesn't get much understanding...But it never stops. I struggle daily but I'm not sick enough for any financial assistance so I have to work. **There is not much understanding of blood cancers when compared to breast cancer.... It's really unfair.**"<sup>26</sup>*

*"My main costs were **having to be 500 km from home** but still having to pay my rent, electricity and water accounts as well as fuel and food for my daughter and me. It was **like keeping two houses** while we were away."<sup>27</sup>*

## **Solution**

The Leukaemia Foundation provides specialist navigation and support services. Demand is increasing year on year.

We are pleased to be providing telehealth specialist support services as part of the government's Australian Cancer Nursing and Navigation Program.

However, there is a clear need for further navigation support and better financial support mechanisms. This could include:

- *Fund community-based organisations to provide cancer navigation support for all Australians.*

Research shows that cancer patients have diverse, evolving needs for tailored information throughout their journey, and understanding treatment options improves when information is specific to their cancer type and personal context. Yet many patients struggle to access this essential guidance from their treatment teams.<sup>28</sup>

Funding the Foundation for our specialist navigation and support services would enable us to better support patients struggling with the cost of trying to survive blood cancer.

- *Revise the eligibility criteria for the Disability Support Pension (DSP) and the NDIS to include blood cancer patients, whose condition often excludes them.*

The Leukaemia Foundation delivers supportive care and financial assistance services – including through our trained Supportive Care Navigators – but requires financial support to meet the need.

### **RECOMMENDATION**

- 1) Assist patients overcome systemic blood cancer care barriers:
  - a) Support NGOs providing navigation and supportive care services
  - b) Ease the financial hardship through reforms to financial support programs that currently exclude many blood cancer patients including NDIS and DSP.

## CASE STUDIES: FINANCIAL IMPACTS OF BLOOD CANCER

### Kate

"A blood cancer diagnosis is excruciatingly abrupt. Conversely recovery is extraordinarily slow.

My savings are now exhausted...There is a missing middle-medium term support to rehabilitate my health, financial life, keep my home, ultimately preventing me being a more expensive burden on the system. Job seeker is not for purpose for people with long term recovery timeframes.

Some supports in the missing middle might be:

- Subsidies for out-of-pocket health costs. Increasing the income threshold for the Health Care Card would enable me to ease the cost of medication, utilities and dental care, inevitable after chemo, while working part time.
- A program – perhaps through access to superannuation, for paying mortgages or rent, would remove current and future housing insecurity.

My wish is that we could fill the missing middle with supports for us to thrive - to enable people with blood cancer to rehabilitate their lives, to stay well, be financially independent and ultimately reduce the cost we have to the system."

### Deb

"I'm from Melbourne's Western Suburbs and was diagnosed with Primary Myelofibrosis in 2019.

Before my diagnosis, I led a very independent life. I was earning a strong income, had the opportunity to travel the world, and owned my own home.

However, my condition drastically changed everything. In particular:

- My illness has left me unable to work, resulting in my reliance on the disability pension. This has been a significant challenge, leading to 2.5 years of homelessness. During this time, I found myself couch surfing and, on many nights, sleeping in my car.
- I want to highlight the severe housing and cost issues faced by blood cancer patients. The financial burden and lack of stable housing not only add to the stress of dealing with the illness but also severely impact our quality of life and recovery."

## 2. Address rural inequities faced by Australian blood cancer patients

### ***Issue: Australians in non-metro areas have poorer blood cancer outcomes***

Around 41% of blood cancer patients live in non-metropolitan areas and their outcomes are significantly worse than for those in metropolitan centres:

- Blood cancer patients living in regional areas are **17 times more likely to report locational and financial barriers** to care than people living in metropolitan areas.<sup>29</sup>
- **29 per cent of blood cancer deaths can be avoided through consistent adherence** to national standards of timely and accurate diagnosis, treatment, and care.<sup>30</sup>
- If the metro-regional blood cancer divide were to be removed, more than **7,000 deaths (over the 2022-2035 horizon) could potentially be avoided.**<sup>31</sup>

This inequity is universally acknowledged, including in government policy publications:

- the Australian Cancer Plan **identifies Australians in rural and remote areas as a priority population**
- the *Mid-Term Review of the National Health Reform Agreement Addendum 2020-2025* highlights "**equitable access to primary care in rural and remote areas**"<sup>32</sup>

Unlike many solid tumour cancers, blood cancers are neither preventable nor can they be easily identified through population screening.

Instead, reducing blood cancer mortality relies on prompt and accurate diagnosis, and access to best practice treatment and care.

Unfortunately, blood cancers are challenging to readily diagnose in primary care settings, given their vague symptoms and rarity of specific subtypes.<sup>33</sup>

### ***Solution: Fast-track the creation of a new rural and regional care program***

The Leukaemia Foundation is seeking funding to pilot a new program for regional, rural and remote patients that improves symptoms awareness and cancer recovery support.

It will lead to increased proactive health engagement, prompt diagnosis, referral to appropriate care, and to patients having a better quality of life post-diagnosis.

Program elements will include:

- Increase community awareness through education of primary healthcare workers, other than a GP.
- Development of a decision-making tool to support GP decision making and enable automated alerts for GPs when a patient presents with blood cancer symptoms.
- "Phone a Friend" specialist haematologist advice for primary healthcare practitioners who have identified the possibility of blood cancer.
- Creation of a Blood Cancer Wellness Program that provides patients with information and evidence informed practices for living well with blood cancer.

Program delivery will be shared with a variety of our primary care partners.

This is a practical solution to addressing inequitable outcomes at two levels:

1. The need to support specific population groups facing inequitable health outcomes, such as rural and regional Australians, and
2. The need to support cancer patients with cancer types – such as blood cancers – that cannot be addressed through other measures such as population screening or preventative measures (e.g. lifestyle change).

#### **RECOMMENDATION**

- 2) Address the inequitable outcomes of blood cancer patients in rural and regional areas:
  - a) Fund a pilot of the Leukaemia Foundation's new program to enable earlier diagnosis of rural and regional blood cancer patients (\$2.2 million over two financial years).

### 3. Better access to life-saving treatments

#### *Issue: Blood cancer patients are missing out on life-saving treatments*

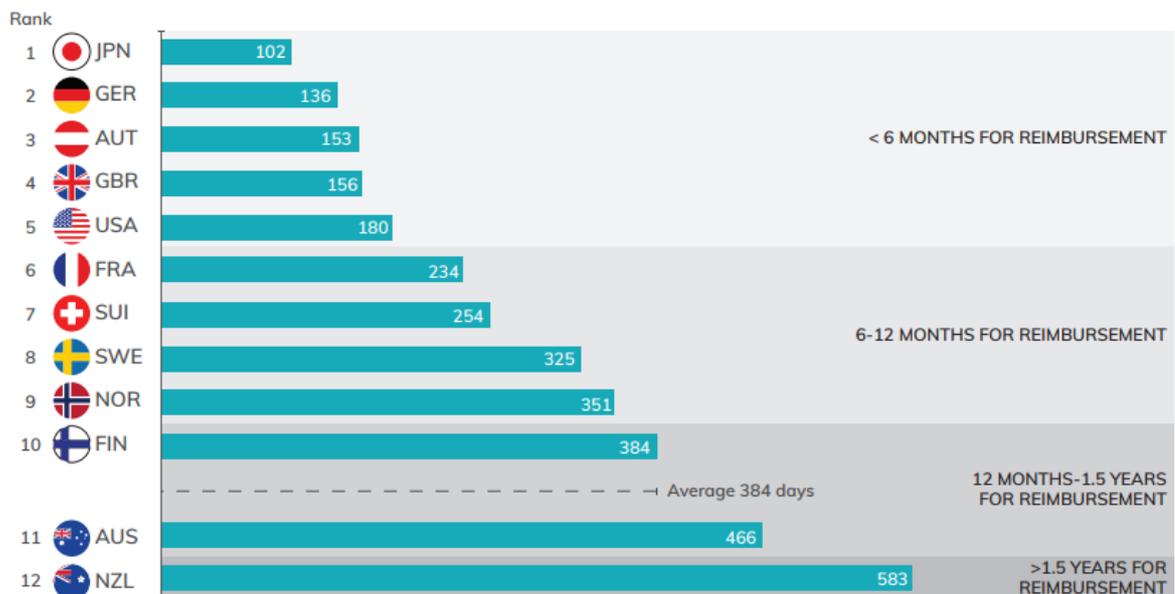
Life-saving treatments available overseas are taking too long to be accessible to Australians – even after regulatory approval.

This is primarily because our system for subsidising treatments (e.g. inclusion on the PBS):

- has **not kept pace** with new treatment discoveries
- requires an **amount of evidence that is hard to generate for rare cancers**, because smaller populations and sample sizes means less evidence can be generated.
- Includes lengthy, non-transparent pricing negotiations between the government and pharmaceutical companies

As a result, Australia lags the rest of the developed world when it comes to providing affordable access to drugs after regulatory approval:

Figure 5: Average time from registration to reimbursement in other OECD nations from 2016-2021<sup>34</sup>



For oncology medicines, the average time from registration to being subsidised is 442 days.<sup>35</sup>

This delay is critical for blood cancer patients because many blood cancers are aggressive and have high mortality.

For example, in the case of acute myeloid leukaemia (AML)<sup>36</sup>:

- **over half (56%) die within one year**
- **around 75% die within 5 years**

Therefore waiting 442 days to commence a treatment is simply not feasible.

This also leads to an inequitable 'postcode lottery' because very few people can afford full-priced blood cancer medication, which routinely costs hundreds of thousands of dollars:

| Drug | Blood cancer type | Price |
|------|-------------------|-------|
|------|-------------------|-------|

|                  |                               |                                  |
|------------------|-------------------------------|----------------------------------|
| Acalabrutinib    | Chronic lymphocytic leukaemia | \$96,700 per year <sup>37</sup>  |
| Zanubrutinib     | Waldenström macroglobulinemia | \$104,000 per year <sup>38</sup> |
| Tisagenlecleucel | Acute lymphoblastic leukemia  | \$510,000 once-off <sup>39</sup> |

Research demonstrates that this contributes to potentially preventable loss of life, poor quality of life, and inequitable outcomes across patient groups.<sup>40</sup>

This situation contradicts Australia's commitment to equitable healthcare – and a 'fair go.' It also contradicts Australia's National Medicines Policy, which promises "equitable, timely, and affordable access to medicines."

Lengthy subsidy processes also contribute to a broader reality – that many blood cancer treatments and diagnostics used in routine clinical practice overseas are not used routinely in Australia (see Appendix A for examples).<sup>41</sup>

Further, there is a need for clear and consistent assessment and funding for innovative therapies – such as CAR T – through PBAC, MSAC and all Federal/State funding arrangements:

- The establishment of CAR T-cell centres has been ad hoc, complicated by State/Federal funding models, and affected by cost-shifting and competition.<sup>42</sup>
- The NHRA Roadmap acknowledges: "The current approach to HTA...is fragmented," which hinders coordinated and timely responses to emerging technologies such as CAR T.<sup>43</sup>
- The 2024 NHRA Review found that a unified national HTA process for the assessment and delivery of high-cost, highly specialised therapies under the NHRA is needed (Recommendation 30). Provisioning for high-cost, highly specialised therapies is important as their inclusion enables equity of access to new and novel therapies.<sup>44</sup>

Improving access to blood cancer treatments is essential. This is both for patient outcomes and economic value, with every \$1 invested in cancer treatment generating \$3.06 in social and economic benefits.<sup>45</sup>

#### **Blood cancer patients speak about access to treatment**<sup>46</sup>

*"When it comes down to the wire for patients, the lengthy approval/denial/repeat process in Australia is devastating...Being told **"there's nothing else we can do"** is tough, especially when you know that there is, just that it's only there for the wealthy few who could afford to travel overseas and pay for it."*<sup>47</sup>

*"It is frustrating when I know **there is a better medication for my polycythemia vera but it is not available in Australia**. Besremi is readily available overseas. Why do we always have to wait for the best treatments?"*<sup>48</sup>

*"We begged, borrowed, worked, planned and devoted months of our lives to holding events so that we could have the money for treatment, which has been \$130,000 so far...It has meant that I didn't die...I constantly think about the fact that **people overseas, particularly in the US, have easy access to this drug, and I don't.**"*<sup>49</sup>

*"I feel second class in regional NSW regarding accessing best treatments and trials."*

### ***Solution: Enhance access to newer, life-saving blood cancer therapies***

Australia needs better and faster ways of subsidising potentially life-saving blood cancer treatments.

While a managed entry scheme exists for drugs with uncertain clinical benefits, it is underutilised.<sup>50</sup>

To enhance access, Government should consider:

- Adopting funding options that use earlier and varied clinical data, inclusive of supporting relevant Health Technology Assessment Review recommendations when released.<sup>51</sup>
- Allowing assessment committees a more flexible approach to evidence evaluation, especially for rare diseases and innovative treatments, as the UK has recently implemented.<sup>52</sup>
- Implementing a "Right to Trial" program to systematically trial new treatments lacking PBS listing, as supported by the House of Representatives' Inquiry into approval processes for new drugs and novel medical technologies<sup>53</sup>

This would improve access to new therapies, develop necessary evidence, and reduce reliance on industry-led research.

#### **RECOMMENDATION**

- 3) Make life-saving blood cancer treatments available to patients:
  - a) Support implementation of Health Technology Assessment reform to accelerate and modernise treatment funding pathways, update evidence requirements, and support the use of real-world evidence.

## **4. Normalising genomics as standard treatment**

### ***Issue: Challenges in integrating genomics into cancer care remain***

Genomic testing is a critical tool in blood cancer treatment that can help significantly improve outcomes.<sup>54</sup> It does this by enabling:

- a more accurate diagnosis, which leads to more targeted treatment choices
- less side effects, stemming from more targeted treatment choices.

This precision is particularly vital for blood cancers, which are difficult to treat, progress rapidly, and have high mortality rates – making them the second leading cause of cancer-related deaths in Australia.

Despite its importance, access to genomic diagnostics in Australia is limited<sup>55</sup> and inequitable.<sup>56</sup> Usage is inconsistent across the population,<sup>57</sup> with **only 21% of blood cancer patients reporting that genomic testing was used** to confirm their diagnosis.<sup>58</sup>

Embedding genomic testing in Australia faces several obstacles:

- **Cost:** While some genomic tests have been subsidised recently, other approved tests remain financially out of reach for some patients (summarised at Appendix B).

- **Data gaps:** There is insufficient information on the current uptake of genomic testing and the reasons it is not routinely used.

Expanding access to genomic testing is widely recognised as crucial. The World Health Organisation recently identified genomics (for early and precise diagnosis and to guide treatment) as *the* most promising innovation in global health.<sup>59</sup>

The *State of the Nation 2023* report also shows that **31% of patients who underwent genomic testing had their diagnosis and treatment plans altered**,<sup>60</sup> highlighting its critical role in patient care.

The Medical Services Advisory Committee – the relevant scientific body advising Government on genomic subsidies – has warned that *without* genomic testing in blood cancers specifically, patients may be misdiagnosed and receive incorrect treatment.<sup>61</sup>

#### **Blood cancer clinicians speak about genomics:**<sup>62</sup>

*"Genomic testing is critical. There's no comprehensive coordinated testing process, which needs to be addressed as it underpins everything we do. An accurate diagnosis is absolutely necessary for provision of best quality care."*

*"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."*

*"We know that genomic testing can inform treatment choices, but the process for accessing genomics testing is difficult and patients often do not want to pay out of pocket. By implication, patient access is variable which results in sub-quality treatment."*

*"Systemic genomic/genetic testing is the biggest point of concern. We need a systematic way of undertaking testing, rather than a piece-meal, inconsistent one."*

### **Solution**

The upcoming establishment of Genomics Australia and development of Cancer Australia's proposed genomics framework are promising, as is the funding of some blood cancer genomic tests since November 2023.<sup>63</sup>

However, it's uncertain if these steps alone will significantly and sufficiently boost genomic testing uptake for blood cancers.

Australia must:

- Conduct a strategic assessment and stocktake of blood cancer diagnostic services to identify current barriers to uptake, and ways of improving and expediting access to genomic testing for blood cancer patients nationwide.
- Expand MBS funding to include more genomic tests, ensuring equitable access for all patients.

#### **RECOMMENDATION**

- 4) Increase uptake of genomics in blood cancer treatment:

- a) Undertake a wider strategic assessment of blood cancer diagnostics service delivery across Australia
- b) Support further MBS listings for blood cancer genomics tests.

## 5. Supporting stem cell donation

### **Issue: Australia's pool of stem cell donors is so low that 75% of donations are from overseas**

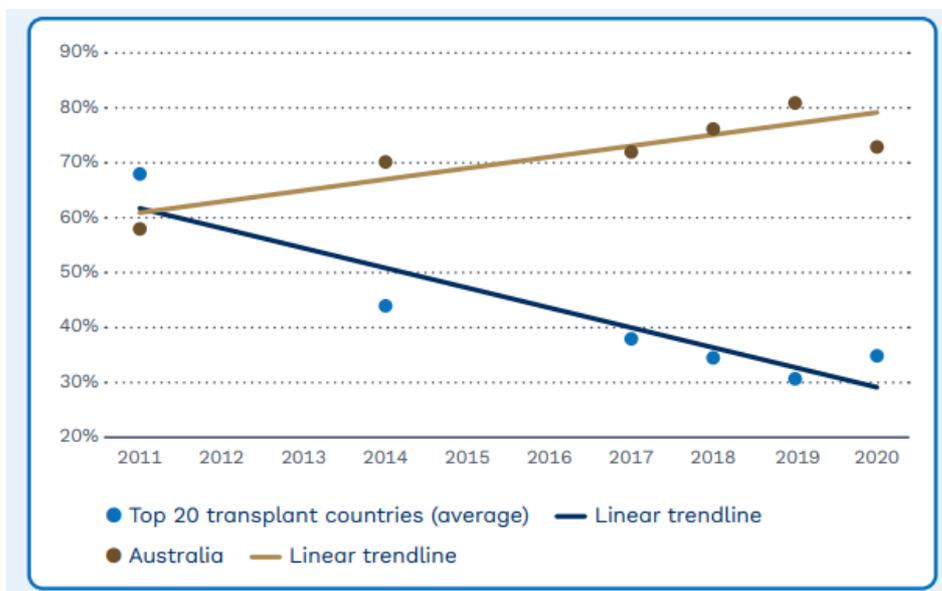
Stem cell (bone marrow) transplants are relatively unique to blood cancer.

It is a last-resort therapy used only when other treatments fail. If needed but not accessed, a patient's prognosis is generally poor.

However, **not enough suitable Australians are registered as a stem cell donor**. As a result, about **three in four of all stem cell donations are sourced from overseas donors**.

The donor pool size has also been declining over time. This contrasts sharply with overseas trends:

Figure 6: Trend in proportion of patients depending on overseas donors, Australia compared to others<sup>64</sup>



Less than 1% of Australians aged 18 to 35 (the ideal age for donors) are registered.<sup>65</sup>

The rising use of international donors for stem cell transplants in Australia led to the government spending about \$13.2 million on import fees in 2022–23.<sup>66</sup>

This mismatched supply to clinical need creates three problems:

- 1) A **reliance on overseas donors**, especially from Germany which alone accounts for 60% of donors to Australians
- 2) A **security of supply issue**, underlined by COVID-19. Delays associated with travel can impact the viability of the donor cells. Overseas donations also cost significantly more.
- 3) The inadequate donor pool **disproportionately and adversely affects minority groups and First Nations peoples**. First Nations people generally cannot find matches overseas.

The reasons for insufficient donors to meet clinical demand are complex, but include:<sup>67</sup>

- Low awareness about stem cell donation, the stem cell registry, and the need for more registered stem cell donors.
- Some people incorrectly think that by donating blood they have donated stem cells.

- Misconceptions about the process that can deter people from registering, such as still believing the process is painful or requires anaesthetic in hospital.

Stem cell donations are managed through a complex web of organisations and contracts, including the ABMDR, Lifeblood and the Department of Health. A government-commissioned PwC review found governance of Australia's stem cell sector is fragmented, with responsibilities spread across many different organisations.



### Larry

Three-year old **Larry** was diagnosed with aplastic anaemia. His identical twin brother, Henry, and his older sister, Matilda, were ruled out as donors.

His mum, Jess, said “We looked on the Australian registry but couldn’t find a match. **Larry is part Chinese-Malaysian, and there’s not enough ethnic diversity on our registry.**” Finally, nearly a year after his diagnosis, a German donor responded to the call.



### Lauren

**Lauren** required not one, but two, transplants. She says: "by the time we've come to this relapse and I'm about to get a second transplant and the doctors have told me again, **"In the registry, we don't really have many people that are a match to you."**

Lauren promoted her own story, including on radio, tv and putting her picture on bus stops all around the city.



### Nikiya

In May 2022, **Nikiya** was diagnosed with blood cancer when 17 weeks pregnant, and eventually found a donor from Germany.

She says: “We need more donors...If there’s one thing that I would love, it would be to know that people are out there talking about stem and blood cell donations and going out to join the registry.”

“This is really important, and I feel strongly about it. I want to do everything I can in my power to raise awareness. **There are not many people that know about it unless they’re in the industry or know of somebody going through blood cancer.**”

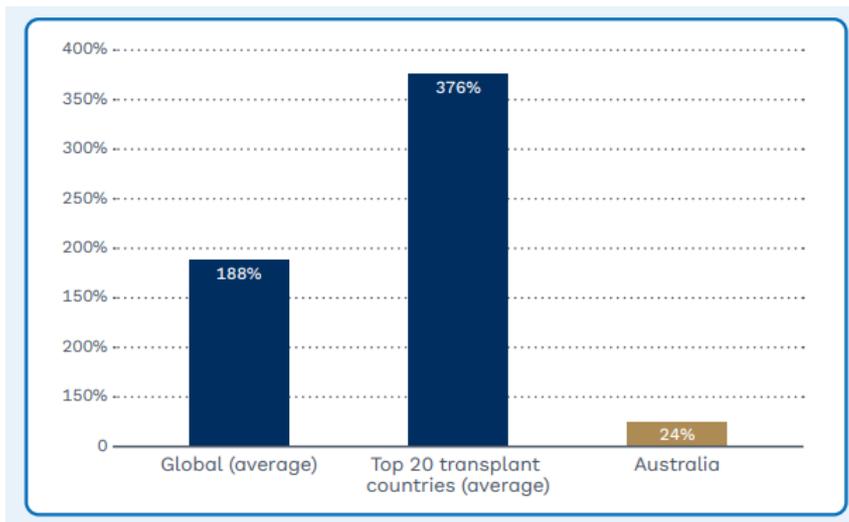
## ***Solution: Support stem cell donor recruitment***

Government can take action by supporting recruitment drives and reforming collection activities.

The German registry has said the keys to success are marketing, education and easy registration processes.<sup>68</sup>

Australia has a clear opportunity to increase donors by promoting awareness and supporting donor recruitment.

Figure 7: Growth in stem cell donors aged 18 to 35, from 2016–2020<sup>69</sup>



Recruitment campaigns should target younger Australians and those from ethnically diverse backgrounds through initiatives like education campaigns in schools or higher education institutions.

Australia can also continue modernising its recruitment practices through cheek swab recruitment, such as by supporting the Australian Bone Marrow Donor Registry's "Strength to Give" cheek swab-based enrolment program.

Increasing recruitment activities and targets, and running cheek swab campaigns, aligns with recommendations made in 2023 by Australia's HPC Sector Clinical Advisory Group.<sup>70</sup>

#### RECOMMENDATION

- 5) Increase the pool of stem cell donors in Australia by:
  - a) Supporting donor recruitment drives
  - b) Commit to reforming stem cell donation governance and funding.

## APPENDIX A: Access gaps in blood cancer diagnosis and treatment

| Sub-type                                     | Diagnosis or monitoring testing   | First line treatment options   | Relapsed and refractory treatment options  |
|--|---|--|--|
| <b>ALL</b>                                   | <p>Minimum Residual Disease testing and monitoring which allows for assessment of the depth of remission following therapy and optimise the use of allogeneic stem cell transplantation.</p> <p>Lack of funding options for advanced diagnostics (PCR, genomic array, NGS). As a result, several WHO defined ALL sub-entities are not routinely discoverable with current standard of care diagnostics, precluding selection of optimal therapy</p> | <p>blinatumomab<br/>                     imatinib for Ph-like ALL<br/>                     nilotinib for Ph-like ALL<br/>                     dasatinib for Ph-like ALL<br/>                     ponatinib for Ph-like ALL</p> <p>PBS restrictions on TKI use beyond 2 years of maintenance</p>  | <p>CAR T-cell therapy for adults (over 25)<br/>                     Lack of options for relapsed T-ALL</p>   |
| <b>AML</b>                                   | <p>Lack of funding options for advanced diagnostics (MRD PCR and flow, microarray, NGS), which may impact on transplant decisions.</p>  | <p>Many drugs are not funded for inpatient use despite being available on the PBS, which is restricted to outpatient medication use, with major examples including midostaurin, gemtuzumab, ozogomycin, venetoclax-azacitidine.</p> <p>gliteritinib (<i>FLT3</i> inhibitor)<br/>                     IDH-1 and 2 inhibitors (enasidenib, ivosidenib)</p> | <p>Certain MRD monitoring is not undertaken post diagnosis due to the lack of targeted treatment options for some of those markers if they were to relapse/progress.<br/>                     Cell therapy</p> |
| <b>Lower Risk MDS</b>                        | <p>Molecular testing unfunded/unavailable</p>   | <p>Therapies that improve cytopaenias and /or transfusion dependence are largely unavailable or unfunded (e.g. EPO and luspatercept)</p>   | <p>Therapies for relapsed / refractory MDS are nonfunded or unavailable</p>  |
| <b>Intermediate and / or higher risk MDS</b> | <p>Molecular testing unfunded/unavailable and this may change risk and /or allotransplant decisions</p>   | <p>Therapies for patients with 10-20% blasts are limited with CR rates&lt;50% and /or significant toxicities for combination therapy (e.g., venetoclax)</p>  | <p>Nonfunded or unavailable for MDS phenotype unless patient progresses to AML</p>   |
| <b>CML</b>                                   | -   | -  | -  |

|                         |   |  |   |
|-------------------------|---|--|---|
| <b>CLL</b>              | <p>Access to gene array and mutation screening by NGS (e.g. TP53)</p> <p>Frontline young patients no access to novel agents</p> <p>Inequitable access of genetic testing necessary to inform prognosis</p>  | <p>acalabrutinib ± obinutuzumab, venetoclax + obinutuzumab for younger patients</p> <p>zanubrutinib</p> <p>ibrutinib</p>   | <p>CAR-T cell therapy</p> <p>Triple refractory population- gaps in drug options</p> <p>Richter's Transformation - gaps in drug options</p> <p>Access to venetoclax retreatment</p> <p>Double refractory treatment options</p> <p>pirtobrutinib</p>  |
| <b>Lymphoma</b>         | <p>Lack of funding options for advanced diagnostics (NGS and MRD) for lymphomas in general, including MYD88 status in WM, EZH2 status in Follicular lymphoma, P53 in CLL and MCL, Gene Expression Profiles in Diffuse Large B-Cell, (and T-cell) and Whole Exome Sequencing analysis of MYC, bcl 2 and bcl 6.</p> <p>FISH testing used to diagnose HGBL-double hit.</p> | <p>critizotinib (ALK+Lymphoma, histiocytosis) for first line or relapse</p> <p>BRAF inhibitors for hairy cell leukaemia and histiocytosis.</p> <p>Thiotepa for transplant therapy in primary central nervous system lymphoma</p> <p>bortezomib for abc-DLBCL, and in mantle cell lymphoma</p> <p>polatuzumab for frontline DLBCL</p> | <p>azacitidine (T-Cell)</p>   |
| <b>Hodgkin lymphoma</b> |   | <p>brentuximab vedotin (CD30) in Advanced stage (AAVD)</p>   | <p>CAR T-cell therapy (Follicular)</p> <p>CAR T-cell therapy (Richter's)</p> <p>CAR T-cell therapy (Mantle cell)</p> <p>Bi-specific antibodies including mosunetuzumab in FL, glofitimab and epcoritamab in DLBCL.</p> <p>tafasitabam and lenalidomide and polatuzumab BR for Diffuse Large B-Cell</p> <p>PD1 inhibitors for extranodal natural killer/T-cell</p> <p>EBV-specific CTL lines for extranodal natural killer/T-cell and other ebv-PTLDs</p> <p>pirtobrutinib in Mantle Cell Lymphoma</p> <p>tazemetostat in EZH2-mutated Follicular Lymphoma</p> |
| <b>Myeloma</b>          | <p>CT/PET and whole body STIR MRI skeletal surveys</p> <p>Lack of availability for MRI AND PET means that it is not possible to differentiate between smouldering myeloma and myeloma based on SLIM-CRAB criteria.</p> <p>Lack of funding options for advanced diagnostics (NGS and MRD), including gene expression profile for baseline risk stratification.</p>       | <p>bortezomib, lenalidomide, and dexamethasone (VRd)</p> <p>Bendamustine</p> <p>Daratumumab-RevDex for non-transplant eligible patients</p> <p>Specific regimens for high-risk myeloma, such as KCRD-daratumumab</p> <p>daratumumab-VTD induction for some patient cohorts</p>   | <p>daratumumab-Pd</p> <p>KPd</p> <p>CAR-T cell therapy (both idecel and ciltacel)</p> <p>BCMA T cell engager - teclistamab</p>  |

Source: State of the Nation, using data from NCCN, ESMO and NICE clinical guidelines; Department of Health, 2022, Application 1684, Genetic testing for variants associated with haematological malignancies; and National Action Plan for Blood Cancer, Chapters 3 and 5.<sup>71</sup>

## APPENDIX B: Possible genomic testing subsidy gaps<sup>72</sup>

|                                       |   |
|---------------------------------------|---|
| Acute Lymphoblastic Leukaemia         | <ul style="list-style-type: none"> <li>• Minimum Residual Disease testing - this is now funded but suffers from public hospital admission issues.</li> </ul>  |
| Acute Myeloid Leukaemia               | <ul style="list-style-type: none"> <li>• There has been lack of funding options for advanced diagnostics (MRD PCR and flow, microarray, NGS), which may impact on transplant decisions - NGS is funded now for this since Nov 1 for medicare eligible patients, but uptake remains low.</li> </ul>  |
| Lower risk MDS                        | <ul style="list-style-type: none"> <li>• Molecular testing has been unfunded/unavailable - NGS is funded now for this since Nov 1 for medicare eligible patients, but uptake remains low.</li> </ul>  |
| Intermediate and / or higher risk MDS | <ul style="list-style-type: none"> <li>• Molecular testing unfunded/unavailable and this may change risk and /or allotransplant decisions<br/>NGS is funded now for this since Nov 1 for medicare eligible patients, but uptake remains low.</li> </ul>   |
| CLL                                   | <ul style="list-style-type: none"> <li>• Access to gene array and mutation screening by NGS (e.g. TP53)<br/>NGS is funded now for this since Nov 1 for medicare eligible patients, but uptake remains low.</li> <li>• Frontline young patients no access to novel agents</li> <li>• Inequitable access of genetic testing necessary to inform prognosis</li> </ul>  |
| Lymphoma                              | <ul style="list-style-type: none"> <li>• Lack of funding options for advanced diagnostics (NGS and MRD) for lymphomas in general, including MYD88 status in WM, EZH2 status in Follicular lymphoma, P53 in CLL and MCL, Gene Expression Profiles in Diffuse Large B-Cell, (and Tcell) and Whole Exome Sequencing analysis of MYC, bcl 2 and bcl 6. NGS is funded now for this since Nov 1 for medicare eligible patients, but uptake remains low.</li> <li>• FISH testing used to diagnose HGBL-double hit</li> </ul> |
| Hodgkin Lymphoma                      | <ul style="list-style-type: none"> <li>• None up until recently - NGS is funded now for this since Nov 1 for medicare eligible patients, but uptake remains low.</li> </ul>   |
| Myeloma                               | <ul style="list-style-type: none"> <li>• Lack of funding options for advanced diagnostics (NGS and MRD), including gene expression profile for baseline risk stratification<br/>NGS is funded now for this since Nov 1 for medicare eligible patients. Gene expression profiling and MRD are not. MRD funding would make a significant difference in myeloma.</li> </ul>  |

***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:

1. 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
2. Accommodation near major hospitals around Australia and help getting to and from the many appointments that come with a blood cancer diagnosis
3. 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.

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