Independent Health and Aged Care Pricing Authority
Darlinghurst, NSW 1300

Via email: submissions.ihacpa@ihacpa.gov.au

June 2025

Dear IHACPA

Re: *Pricing Framework for Public Hospital Services 2026-27*

Thank you for the opportunity to provide a submission to the *Pricing Framework for Public Hospital Services 2026-27*.

The Leukaemia Foundation is the only national organisation that represents the over 150,000 Australians living with blood cancer – including leukaemia, lymphoma, myeloma, myeloproliferative neoplasms (MPN), myelodysplastic syndromes (MDS) and amyloidosis.

The Leukaemia Foundation and the patients we represent have a direct stake in these funding agreements, which ultimately shape access to vital, life-saving treatments.

Funding arrangements between the Commonwealth and the States and Territories determine what services are available, where they can be accessed, and at what cost. We welcome this review and acknowledge the complexity of pricing negotiations, but the framework must deliver tangible improvements for patients by addressing the fragmentation that continues to limit equitable care.

This consultation is especially relevant to blood cancer, as nearly all of the cancers listed in Section 5.4 relate to blood cancers – highlighting the central role of high-cost, highly specialised therapies such as CAR-T in our sector.

Yet access to these therapies remains uneven. Patients in regional and remote areas face significant financial and logistical barriers – not just the cost of treatment itself, but also travel, accommodation, and time away from work or family. Programs like PATS and subsidised accommodation directly influence whether people can afford to access care.

As a provider of accommodation services near major hospitals, we see firsthand how critical these supports are. Future pricing and funding models must take into account not only the cost and complexity of treatment, but also the broader geographic, financial, and social realities shaping access in the real world.

Responses to consultation questions

9. After accounting for current pricing model adjustments and block funding arrangements, what are some drivers of unmet cost variation in public hospital service delivery for people residing in rural and remote areas of Australia? (page 22)

Several key factors continue to drive unmet cost variation in public hospital service delivery for people in rural and remote areas, particularly those affected by blood cancer:

- **Travel and accommodation costs**: Due to the complexity of blood cancer treatment, many patients must travel from regional and remote areas to metropolitan hospitals for care such as stem cell transplants or CAR-T therapy.

  The direct and indirect costs of this – including transport, accommodation, and time away from work – can be prohibitive and vary widely depending on location.

  Patient Assistance Transport Schemes (PATS), while intended to alleviate this burden, are inconsistent, inadequately funded, and often exclude patients ineligible due to rigid criteria (e.g. distance thresholds or exclusion of clinical trial-related travel).

  The 2024 report of the Senate Community Affairs References Committee's *Inquiry into equitable access to diagnosis and treatment for individuals with rare and less common cancers* stated the Committee was 'alarmed' by inadequacies in these travel schemes.[1]

  Patients are also required to stay within certain time periods from the treatment centre (e.g. within 30 mins during the first 80-100 days after stem cell transplantation).[2]

  "Because we live less than the required 100km (90 km) from the hospital post [stem cell] transplant but are required to live close to the hospital for follow-up tests and treatment, we do not qualify to receive patient transport and accommodation rebates. This meant we've paid more than $10,000 which is a big expense for an aged pensioner."[3]

  "We were forced to sell our home in NSW and move to Victoria where we have direct access to a haematologist from Peter Mac and other specialist services. The WM has affected my eyes so I see an ophthalmologist and the PN has affected my bladder so I can also see a urologist locally."[4]

  "Treatment needs to be more accessible in regional hospitals. Travel to cities puts a huge strain on families."[5]

  "Cancer patients in regional areas do not have the same choice in specialists as city patients."

  "Some regional areas are completely without GPs."[6]

- **Availability of supports**: Access to treatment is shaped not just by the services themselves, but by whether patients can afford to reach and remain near them. The absence or inadequacy of wrap-around supports – like accommodation and travel subsidies – contributes to cost variation and acts as a barrier to equitable access. The Leukaemia Foundation provides accommodation near major hospitals, but demand exceeds capacity, and public supports are not always sufficient or timely.

We know that provision of the Leukaemia Foundation's accommodation services has positive effects for government as well as patients. Separate research by Insight Economics has found:[7]

- The total benefit to government arising from the Leukaemia Foundation's accommodation service is estimated to be $148.3 million over the 2015 – 2040 period.
- The Leukaemia Foundation's accommodation services enable at-risk families to overcome significant barriers to blood cancer treatment.
- Without access to Leukaemia Foundation accommodation:
  - 5% of families would have declined treatment
  - 10% would have sought less optimal care closer to home, likely leading to poorer outcomes
  - Roughly 80% would have exhausted their savings and incurred higher out of pocket costs if they had to self-fund their accommodation.

- **Geographic inequities in access to novel therapies**: Many of the newest, most specialised blood cancer therapies are only available at major metropolitan hospitals or through clinical trials, which are inaccessible to many rural patients. Those on lower incomes may be unable to self-fund access to non-PBS therapies or participate in trials due to associated travel and accommodation costs.

  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.[8]

  Blood cancer outcomes are significantly worse for the 41% of patients living in non-metropolitan areas compared to those in cities. Regional patients are 17 times more likely to face locational and financial barriers to care. [9]

  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"[10]
  - The Victorian Cancer Plan notes "Patients living in regional and rural areas had lower survival compared with patients from major cities for haematological, lung and upper gastrointestinal cancers."[11]
  - one in 10 people in outer regional NSW wait more than three years for a haematology appointment.[12]

- **Delayed diagnosis and higher acuity on presentation**: Distance from specialist haematology services and a lack of accessible diagnostic expertise can delay diagnosis in rural areas. As blood cancers are often aggressive and complex, delays can lead to emergency hospital admissions or more advanced disease requiring intensive and

costly care. These avoidable escalations add to the cost burden on public hospitals and reduce the efficiency of care.

> *"The patient took over 3 years before a diagnosis was made despite presenting with enlarged lymph nodes (ultrasound but no biopsy). So those medical costs, all the CT and biopsies and testing, and medical visits pre-diagnosis was borne out of pocket. Should have been treated at stage 1 not stage 4."* – Medical practitioner, State of the Nation survey[13]

- **Fragmented governance in key services**: The complexity of stem cell (bone marrow) transplant and donor systems – which involve multiple Commonwealth and state agencies – can lead to inefficiencies in service delivery, access gaps, and cost duplication. These issues disproportionately affect rural patients who already face logistical and systemic hurdles in accessing this last-resort, high-cost therapy.

  Not every state/territory can offer patients stem cell transplants i.e. paediatric transplants and allogenic stem cell transplants are not available nationally.

  In February 2023, the Federal Health Minister underscored some of the challenges, noting in Parliament that:
  - "Bone marrow donations provide the stem cells that are required for stem cell transplants, life-saving treatments today for people who are fighting leukaemia and a range of other blood cancers…

    Part of the problem is that no single government between the Commonwealth and the states and territories has sole responsibility or sole authority to make sure that Australia keeps pace with the rest of the world and with these advances in technology."

Despite pricing model adjustments and block funding, these factors drive real and persistent variations in hospital service delivery costs for rural and remote patients. Addressing them requires coordinated investment in travel and accommodation support, decentralised access to diagnostics and care, and better integration of supportive services across jurisdictions.

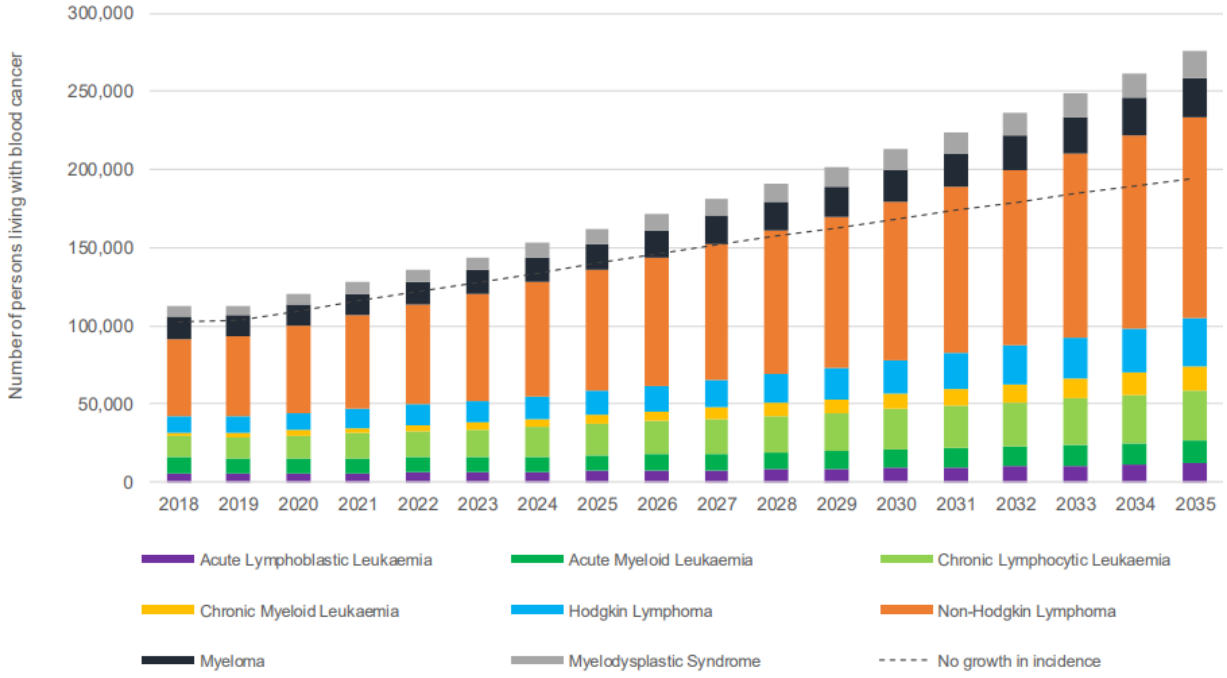
15. As the current arrangements for high cost, highly specialised therapies have been in place since 2020, what, if any, refinements are required to ensure they remain fit-for-purpose? (p.28)

Australia needs funding arrangements that allow faster access to emerging treatments for blood cancer patients.

Almost all of the treatments identified in the "High cost, highly specialised therapies" section (section 5.4 – p.27) of the consultation document relate solely to blood cancers, with all but one of the cancers listed in this section being a blood cancer. This reflects the high mortality, highly complex, and difficult-to-treat nature of this cancer type.

The number of patients is projected to **rise 47%** by 2035, to more than 275,000 (Figure 1).

Figure 1: The number of people living with a blood cancer (prevalence) – 2018 to 2035[14]



This highlights the need for clear and consistent assessment and funding for innovative therapies – such as CAR T – through PBAC, MSAC and all Federal/State funding arrangements, especially given:

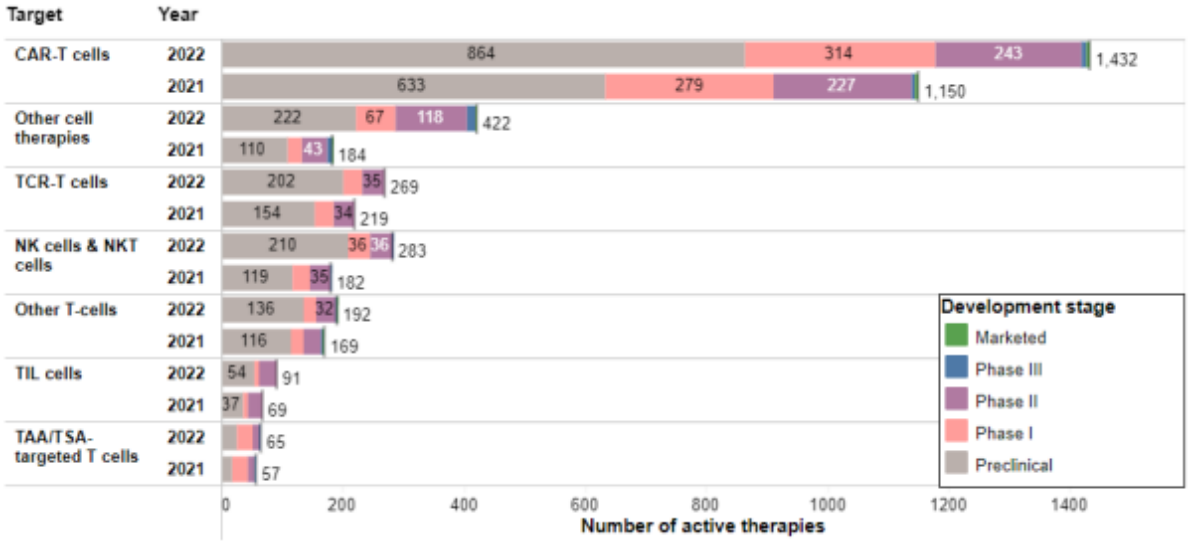
- The establishment of CAR T-cell centres has been ad hoc, complicated by State/Federal funding models, and affected by cost-shifting and competition.[15]
- The NHRA Roadmap acknowledges: "The current approach to HTA…is fragmented," which hinders coordinated and timely responses to emerging technologies such as CAR T.[16]
- 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.[17]

CAR T-cell therapies are reliant on a complicated funding mix from both the Federal and state and territory governments. Nine centres provide CAR T-cell therapy in Australia, but are concentrated in NSW (3 centres), Victoria (3 centres), Queensland (2 centres), and WA (1 centre), with an unclear process for establishing sites.[18]

There is a significant pipeline of cell and gene therapies being developed globally, ultimately attempting to enter mainstream clinical practice. This is good for patients, but our fragmented system is not ready.

Figure 1: A wave of CAR T-cell therapies on the horizon[19]



Ultimately, the specific funding mechanism adopted by Commonwealth and state and territory governments is a matter for them. However, ensuring better and more timely access to high-cost, highly specialised therapies is essential if the system is to remain fit-for-purpose – particularly for Australians living with blood cancer.

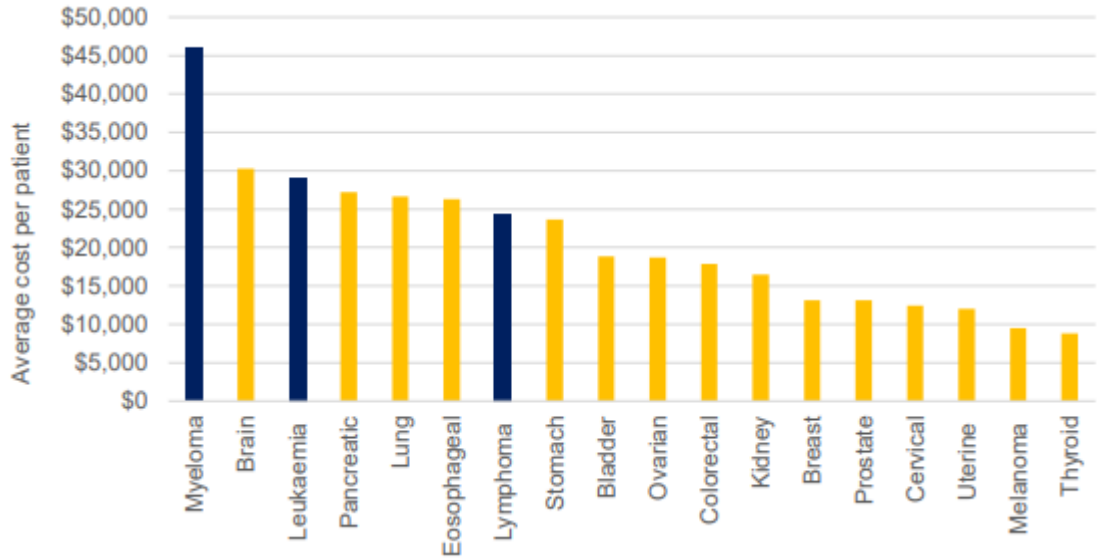
These patients are not only part of the broader community that funds our public health system but are also facing a disease that is rising in incidence and claiming more lives each year. System refinements, including through financial mechanisms, should therefore be guided by the urgent need to match medical innovation with equitable access, ensuring that all patients benefit from the best available care.

16. What pricing considerations are pertinent for these and other high cost, highly specialised services? (p.28)

Pricing for high-cost, highly specialised therapies must reflect not only the immediate financial outlay but also the broader health system and societal context in which these treatments are delivered.

For blood cancers in particular – which are among the most expensive cancers to treat, with costs nearly three times the average for other cancers – pricing frameworks must be sensitive to the unique and complex pressures faced by patients, clinicians, and funders alike.

Figure 2: Average cost per cancer patient (blood cancers highlighted)[20]



Treatment can also be lengthy, with many patients experiencing employment challenges. [21]

Key pricing considerations include:

- **Timeliness and equity of access**

  Delays in access to therapies such as CAR T-cell treatments – often caused by lengthy pricing negotiations and misaligned funding mechanisms – can be catastrophic for patients with aggressive blood cancers.

  These delays not only reduce survival chances (e.g., in acute myeloid leukaemia, where more than 50% die within a year[22]) but also impose greater downstream costs on the health system through emergency admissions and more intensive care.

  Fragmented funding and assessment processes further delay innovative therapies like CAR T-cell treatments. [23,24,25]

  Pricing frameworks must therefore incorporate mechanisms for faster access and managed entry, especially for time-sensitive indications.

- **Inclusion of genomic and diagnostic costs**

  High-cost therapies are increasingly guided by genomic testing and precision diagnostics. 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. [26]

  However, access to these tests remains inequitable, with only 21% of blood cancer patients reporting genomic testing at diagnosis. [27]

  Pricing models should account for the essential role of diagnostics in ensuring patients receive the right treatment at the right time, and that expensive therapies are appropriately targeted to those most likely to benefit.

- **Patient-centric cost burden**

  Current pricing models often fail to factor in the significant out-of-pocket costs patients incur alongside treatment, particularly for those living in rural or remote areas. Travel, accommodation, loss of income, and ongoing supportive care all contribute to financial hardship.

  Blood cancer patients also face some of the highest treatment costs of any cancer, often three times the average. Many of these patients experience significant financial hardship, with 32% taking over three months off work[28] and 43% of patients incurring out-of-pocket expenses.[29]

  Pricing frameworks should be developed in tandem with policies that mitigate these indirect costs, such as expanding support schemes like PATS or embedding accommodation supports into care pathways.

- **Health system readiness and workforce capacity**

  Even when pricing is resolved, therapies like CAR T require substantial investment in workforce training and infrastructure. Consultation with clinicians has shown that today's health system is underprepared to deliver these therapies at scale. [30] Pricing arrangements should therefore consider the true cost of implementation – including resourcing, staffing, and system upgrades – as part of ensuring value for money.

- **Variation across jurisdictions**

  Currently, disparities exist between states in terms of age cut-offs and availability of therapies like CAR T. A nationally consistent approach to pricing and service access is critical to avoid postcode-based inequities and to uphold the principles of Australia's National Medicines Policy, which promises "timely and affordable access to medicines."

'Disparity between states on availability of CAR T [has been an issue], also cut-off ages for treatments varies between states.'

Blood cancer patient – State of the Nation 2023

Ultimately, pricing must balance affordability with urgency, equity with sustainability, and innovation with implementation. Without reforms that reflect the full patient journey – including diagnostics, access supports, and workforce delivery – Australia risks falling behind in providing timely, life-saving treatments to those who need them most.

Conclusion

We urge governments to ensure the Pricing Framework actively supports more timely, equitable access to high-cost, highly specialised therapies – particularly for people living with blood cancer.

This includes addressing systemic funding fragmentation, recognising the real-world costs faced by patients, and ensuring pricing models reflect the full care pathway, including diagnostics, travel, accommodation, and workforce capacity. Above all, reforms must be grounded in what matters most: ensuring every Australian can access life-saving treatment, regardless of where they live or their financial means.

Please contact Andrew Mosley, Head of Government Relations and Policy, for further details at amosley@leukaemia.org.au.

Yours sincerely,

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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 Supportive Care Case Managers 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.

[1] p.141: https://parlinfo.aph.gov.au/parlInfo/download/committees/reportsen/RB000168/toc_pdf/Equitableaccesstodiagnosisandtreatmentforindividualswithrareandlesscommoncancers,includingneuroendocrinecancer.pdf

[2] Association of Distance from Transplant center and Place of Residence on Outcomes after Allogeneic Hematopoietic Cell Transplantation, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4905774/

[3] Blood cancer patient cited in *State of the Nation 2023*, p.8.

[4] Blood cancer patient cited in *State of the Nation 2023*, p.8.

[5] Blood cancer patient cited in State of the Nation 2023, p.38.

[6] Blood cancer sector stakeholder cited in State of the Nation 2023, p.38 – https://www.leukaemia.org.au/wp-content/uploads/2023/02/Leukaemia-Foundation_Final-Report_State-of-the-Nation-Blood-Cancers-in-Australia-Report-2023.pdf.

[7] Insight Economics Pty Ltd, The Health, Social and Economic Impacts of the Leukaemia Foundation, February 2021: https://www.leukaemia.org.au/wp-content/uploads/2021/11/AnnualReport_DigitalA4_November21.pdf

[8] Counting the Cost Report, p.8: https://rcararecancers.blob.core.windows.net/assets/contentpage_htmlcontent/RCA4279%20Counting%20the%20Cost%20Report-final.pdf

[9] NAP 2020, p.3: https://www.leukaemia.org.au/wp-content/uploads/2020/09/National-Strategic-Action-Plan-for-Blood-Cancer_June-2020.pdf
[10] NHRA Mid-Term Review, p.103: https://www.health.gov.au/sites/default/files/2023-12/nhra-mid-term-review-final-report-october-2023.pdf
[11] Victorian Cancer Plan, p.19.
[12] https://grattan.edu.au/wp-content/uploads/2025/06/Grattan-Institute-Special-Treatment.pdf (p.8)
[13] Medical practitioner cited in *State of the Nation 2023*, p.8.
[14] Source: Insight Economics projections to 2035 based on AIHW incidence data 2009-2014 by blood cancer sub-type, based on ABS Series B population projections (mid case population projections) - https://www.leukaemia.org.au/wp-content/uploads/2020/06/State-of-the-Nation-Blood-Cancer-in-Australia_Leukaemia-Foundation.pdf, p.17.
[15] *State of the Nation*, p.78 – https://www.leukaemia.org.au/wp-content/uploads/2023/02/Leukaemia-Foundation_Final-Report_State-of-the-Nation-Blood-Cancers-in-Australia-Report-2023.pdf
[16] *National Health Reform Agreement (NHRA) – Long-term Health Reforms: Roadmap*, https://www.health.gov.au/sites/default/files/documents/2021/10/national-health-reform-agreement-nhra-long-term-health-reforms-roadmap.pdf, p.7.
[17] https://www.health.gov.au/sites/default/files/2023-12/nhra-mid-term-review-final-report-october-2023.pdf
[18] *State of the Nation: Blood Cancers in Australia Report 2023*, p.78.
[19] https://www.leukaemia.org.au/wp-content/uploads/2023/02/Leukaemia-Foundation_Final-Report_State-of-the-Nation-Blood-Cancers-in-Australia-Report-2023.pdf, p.83.
[20] Source: 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.
[21] State of the Nation 2023: p.6: https://www.leukaemia.org.au/wp-content/uploads/2023/02/Leukaemia-Foundation_Final-Report_State-of-the-Nation-Blood-Cancers-in-Australia-Report-2023.pdf
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[23] https://www.health.gov.au/sites/default/files/2023-12/nhra-mid-term-review-final-report-october-2023.pdf
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[25] *National Health Reform Agreement (NHRA) – Long-term Health Reforms: Roadmap*, https://www.health.gov.au/sites/default/files/documents/2021/10/national-health-reform-agreement-nhra-long-term-health-reforms-roadmap.pdf, p.7.
[26] 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
[27] *State of the Nation: Blood Cancers in Australia Report 2023,* p.49.
[28] State of the Nation 2023: p.6: https://www.leukaemia.org.au/wp-content/uploads/2023/02/Leukaemia-Foundation_Final-Report_State-of-the-Nation-Blood-Cancers-in-Australia-Report-2023.pdf
[29] *State of the Nation 2023*, p.6.
[30] *State of the Nation: Blood Cancers in Australia Report 2023,* p.53.