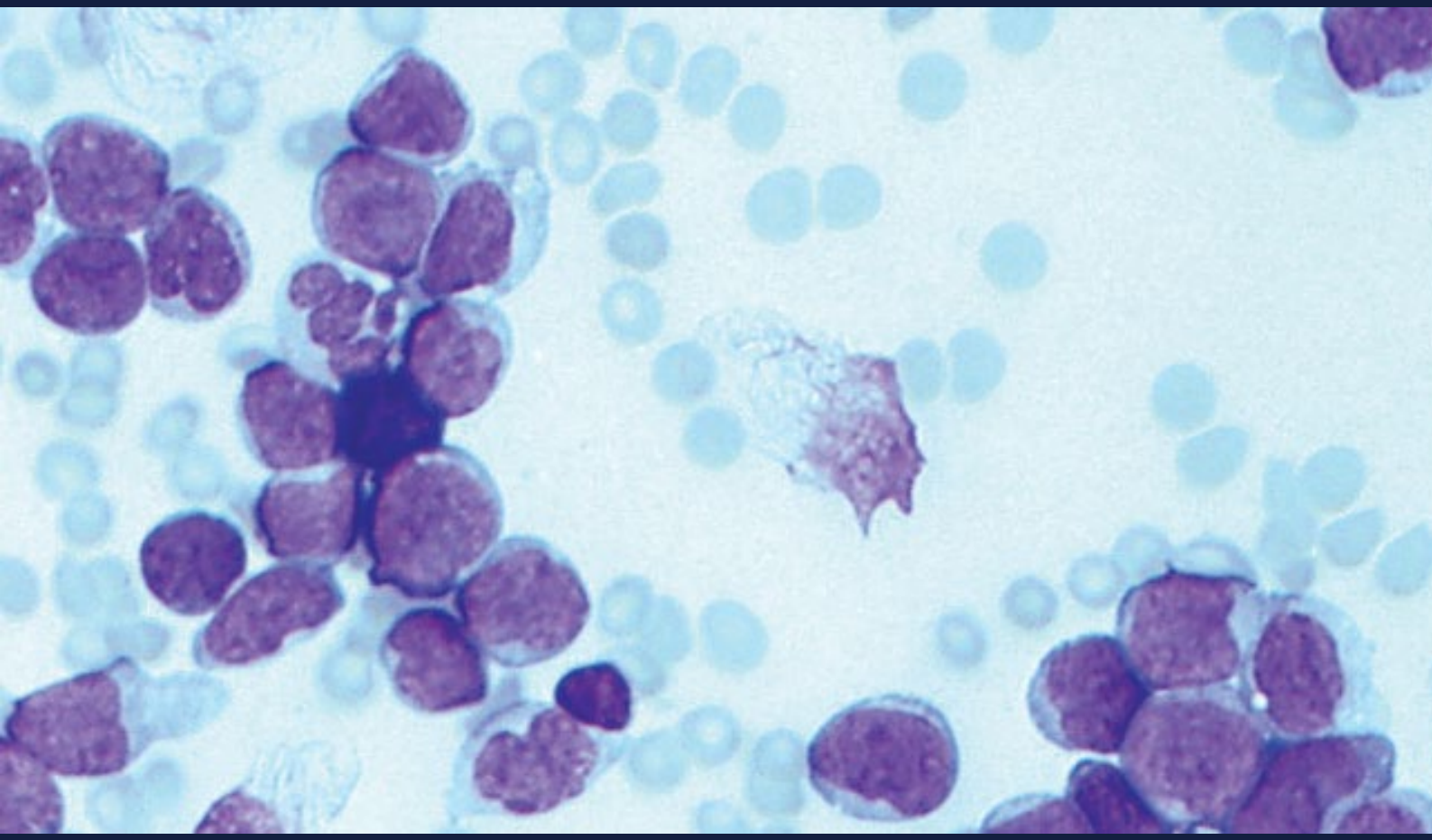
Investment Case for Phase 1 of the National Strategic Action Plan for Blood Cancer

Final Report

16 September 2021



Insight Economics

Public Policy Corporate Strategy

Insight Economics Pty Ltd

ACN: 141 097 565
ABN: 29 627 712 906

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Phase 1 Investment: Plan on a Page

Phase 1 funding for critical path activities urgently needed

Phase 1 recommendations of the National Strategic Action Plan for Blood Cancer, endorsed by the Federal Government and the wider blood cancer community, are the critical path activities needed for the realisation of the vision of the National Strategic Action Plan.

These activities will enable the realisation of the National Strategic Action Plan vision, and provide the foundation for nationally consistent, equitable access to clinical best practice, equitable access to novel therapies across Australia, and a rigorous framework for high impact research in blood cancer. Significant health and economic benefits are expected from the improvements in quality and safety that would be realised through activities identified by Taskforce as part of Phase 1 implementation.

Without funding for the implementation of Phase 1 of the National Strategic Action Plan, unwarranted variation and inequity will persist, resulting in preventable deaths. The National Strategic Action Plan will likely fail as the substantial in-kind time and expertise from the blood cancer community will lapse as the initiative loses momentum.

Health and economic outcomes

Implementation of Phase 1 enables the realisation of significant health and economic benefits:

- More than 25,000 years of life gained through the increased adherence to clinical best practice, valued at $704 million in $NPV_{1.5\%}$ terms ($50,000 per QALY gained)
- Increased workforce participation with more than 511 Australians returning to work on average per annum, or more than 11,000 additional FTE over the 2025-2040 period
- An increase in GDP of $735 million in $NPV_{1.5\%}$ terms over the 2025-2040 horizon arising from increased population and labour force participation, and an increase government revenues by $21 million per annum on average over the 2025-2040 horizon, associated with expanded economic output
- Additional private sector research funding of 17.6 cents to 30 cents for every $1 invested
- Health gains of more than 9,500 years of life through medical research, with a return on investment from health gains alone of $2.61 (BCR 3.6)
- Productivity spillovers of at least $1.30 for every $1 invested
- Highly skilled medical research jobs creation
- Total return on investment of $3.46 for every $1 invested (BCR 4.8) in blood cancer research
- Reduced inconsistencies and incomplete information to blood cancer patients and their carers through written treatment and survivorship care plan templates
- More equitable access to novel therapies, with enhanced regulatory transparency and evidence development for rare blood cancer sub-types.

Funding and implementation

Estimated funding of $3.7 million is required for Phase 1 over the forward estimates. This has been scaled to allow for funding for Patient Reported Outcomes, Blood Cancer Information Strategy and exercise oncology to be addressed through the Australian Cancer Plan and MRFF applications. Detailed governance arrangements and risk mitigation strategies have been developed as part of detailed project planning and costing in partnership with the Blood Cancer Taskforce.

Phase 1 Investments: Policy need, critical path dependencies and expected health and economic outcomes

To be implemented through National Strategic Action Plan for Blood Cancer

To be implemented through Australian Cancer Plan, announced following release of National Strategic Action Plan for Blood Cancer

Policy problem	Critical path dependencies		Outcomes
	Phase 1 – Years 1-2	Phase 2 – Years 3-5	Zero lives lost to Blood Cancer by 2035
Empower patients and their families • **One of five** people living with blood cancer report feeling '**completely uncertain' or having 'lots of questions**' about their diagnosis • **More than 10 per cent** report having '**a lot of questions' or 'feeling completely uncertain'** about their treatment plan • **Less than 50 per cent** of patients receive **written treatment and care plan** • **Supportive care never discussed** for more than 35 per cent of patients	Patient Navigation Services (Action 1.1) Blood Cancer Information strategy (Action 1.2) Patient Reported Outcomes for Blood Cancer (Action 1.5) **Epidemiological study of ATSI populations (Action 1.6.1)**	KPIs for written treatment and survivorship care plans (Action 1.3) Complex referral support tools (Action 1.4) Services to support high risk groups (Actions 1.6-1.9)	✓ **Patients and their families empowered to make informed choices** ✓ **Patient centred care enabled through a national system for Patient Reported Outcomes in blood cancer** ✓ **High risk-patients supported**
Achieve best practice • **High rates of unwarranted variation in treatment and care – 13% of deaths avoidable through adherence to clinical best practice** • **Advances in genomics leading to high rates of revision in diagnosis** • **Rapid advances in technology leaving** • **Supportive care never discussed** for more than 35 per cent of patients	**Develop Optimal Care Pathways AND Clinical Guidelines (Action 2.1)** **Develop Diagnostic Guidelines (Action 2.2)** **Develop treatment plan templates (Action 1.3.1)** Exercise Oncology in Blood Cancer (Action 2.5)	Make Precision Medicine Standard of Care (Action 2.3) Screen for supportive care needs (Action 2.5) Invest in workforce development (Action 2.6) Prevent financial hardship (Action 2.7)	✓ **More than 25,000 years of life gained, valued at $704 million in $NPV_{1.5\%}$ terms ($50,000 per QALY gained)** ✓ **Increased workforce participation with more than 511 Australians returning to work on average per annum, or more than 11,000 additional FTE over the 2025-2040 period** ✓ **An increase in GDP of $735 million in $NPV_{1.5\%}$ terms over the 2025-2040 horizon arising from increased population and labour force participation** ✓ **An increase in government revenues by $21 million per annum on average over the 2025-2040 horizon, associated with expanded economic output**
Accelerate research • **Even with improvements in clinical best practice and access to novel therapies, mortality from blood cancer will remain high, more than 3,900 deaths per annum** • **Achieving zero deaths from blood cancer requires new discovery** • **High impact research requires collaboration, strategic planning and high quality data**	**Research Roadmap (Action 3.1)** → Blood Cancer Research Mission Harness Benefits of Real World Data (Action 3.2)		✓ **Health gains valued at $2.70 for every $1 invested (BCR 3.7)** ✓ **Leveraged private sector research funding of 17.6 cents to 30 cents for every $1** invested by governments ✓ **Productivity spillovers of $1.30 for every $1 invested** ✓ **Highly skilled medical research jobs creation** ✓ **Total ROI of at least $3.80 for every $1 invested (BCR 4.8) in blood cancer research – with higher rate enabled through roadmap**
Enable access to novel and specialised therapies • **70% of clinicians reported access barriers to novel therapies compromised treatment plan for patients** • **Small market sizes prevent registration and reimbursement of therapies for rare blood cancer subtypes** • **Clinical trials not even discussed with more than 80 per cent of patients**	**Action 4.3: Improve Access to Novel Therapies**	KPIs for clinical trials (Action 1.1) Increase access for clinical trials (Action 4.2)	✓ **Improved equity of access nationally** ✓ **Regulatory transparency and predictability** ✓ **Opportunities to capture off-label use and develop evidence captured** ✓ **Improved survival for patients with rare sub-types** ✓ **Improved clinical trial participation and equity of access to trials**

Chapter 1

Phase 1 of the National Strategic Action Plan for Blood Cancer: Policy need, role for Government and strategic alignment

More than 18,000 Australians will be diagnosed with blood cancer in 2021. More than 5,800 Australians will lose their lives to blood cancer and there are more than 127,000 Australian blood cancer survivors estimated to be living in Australia's communities today. Blood cancer is a major policy priority for Australian communities and governments.

In the development of the National Strategic Action Plan for Blood Cancer it was shown that:

- *More than one in 10 patients and their families are not sufficiently empowered to understand their diagnosis, treatment and care*
- *Australia lacks clear guidance in clinical practice, which contributes to preventable deaths of nearly 1,000 Australians each year*
- *Seventy (70) per cent of treating clinicians indicated access barriers compromised the treatment of some patients*
- *Achieving the vision of zero lives lost to blood cancer will require investment in high impact blood cancer research.*

This chapter presents the policy need for investment in Phase 1 initiatives of the National Strategic Action Plan, its alignment with Australia's wider health and research policy frameworks, and the rationale for Australian Government investment in Phase 1 initiatives.

1.1 Policy need and strategic alignment: the National Strategic Action Plan for Blood Cancer

Blood cancer is one of the most significant health policy priorities facing Australian communities today. In 2021, Australian Institute of Health and Welfare data estimated that more than 18,000 persons would be diagnosed with a blood cancer, making blood cancers the second most commonly diagnosed cancers in the community, following breast cancer included in the national cancer data incidence data.[1] Blood cancers are also the second most common causes of death after lung cancer.[2]

Unlike breast, prostate, skin, and colorectal cancers, however, blood cancers cannot be prevented or detected early to realise a better outcome for patients and their families.

[1] AIHW, 2021, Cancer Data in Australia, accessed at: https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/contents/cancer-summary-data-visualisation
[2] Ibid.

Blood cancers also strike Australians of all ages; the successful treatment of blood cancers allow Australians to successfully return to their families and the workforce, supporting growth in social capital and economic output for the wider community. More than 127,000 blood cancer survivors are estimated to be living in Australia today.[3]

In addition to the sheer number of Australian families impacted by blood cancer, blood cancers are also a significant policy priority for Australian communities and the governments that represent them, because there are significant equity, safety and quality challenges in the diagnosis, treatment and care of patients diagnoses with these cancers in Australia today. It has been shown:

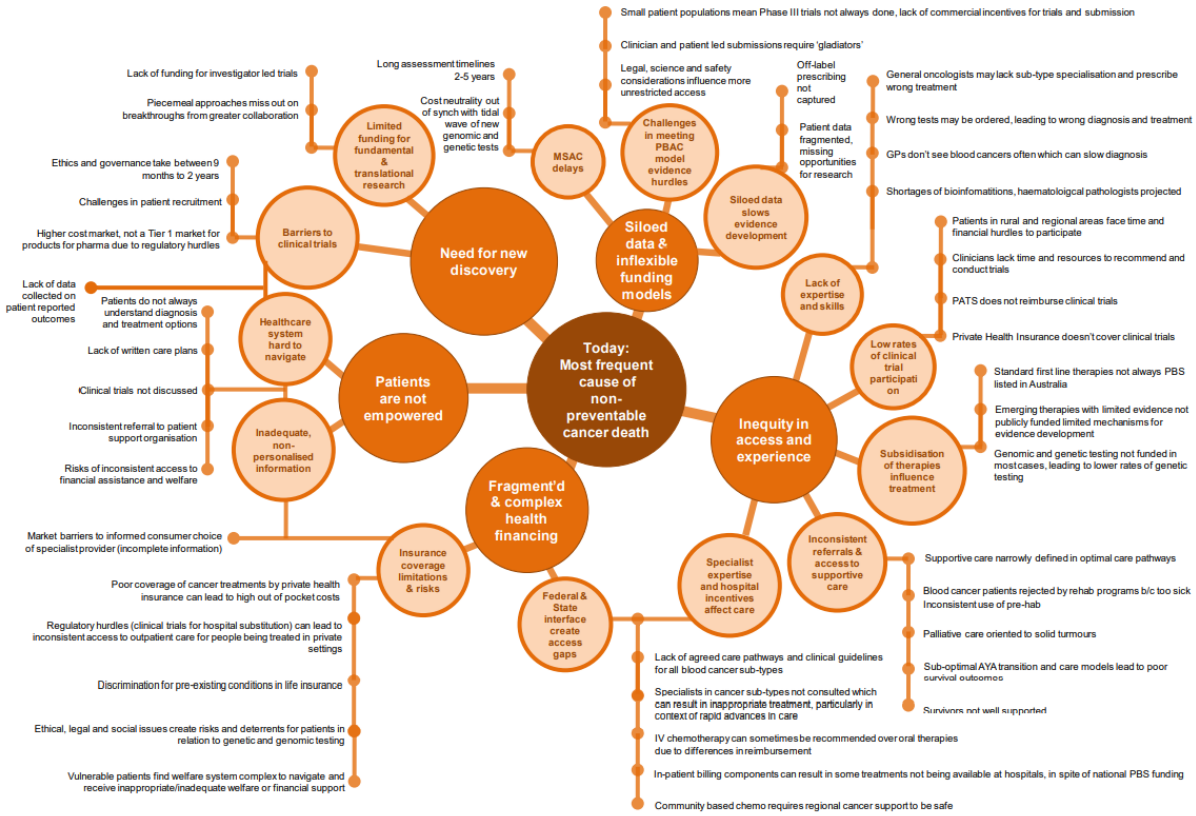
- Less than 50 per cent (40 per cent) of patients receive written treatment plans[4]
- More than one in five people reported not understanding their diagnosis[5]
- More than one in ten reported not understanding their treatment plan[6]
- Only one in three had supportive care discussed as part of their treatment planning, and for 35 per cent of patients supportive care was never discussed[7]
- Accurate diagnosis in blood cancer is challenging, with high rates of revision; studies have estimated routine rates of revision ranging from 17.8 per cent to 55 per cent[8]
- Access barriers were reported to have compromised patient treatment and care by 70 per cent of clinicians nationally[9]
- Less than 20 per cent of patients participate in clinical trials, in spite of rapid technological change in the sector, and for 87 per cent of patients the main reason they did not participate was because their clinician did not discuss clinical trial options with them[10]
- Regional patients see substantially poorer survival outcomes compared to their metropolitan counterparts, with the probability of survival at five years five per cent poorer[11]
- There is substantial variation in clinical practice; while adherence to clinical best practice is associated with a 40 per cent reduction in the risk of death, unwarranted variation in clinical practice is commonplace, particularly for vulnerable cohorts:
  - Geriatric patients (people aged >80 years) are 62 per cent less likely to receive treatment that complies with guidelines
  - Women are 32 per cent less likely to receive treatment that complies with guidelines

[3] Leukaemia Foundation, 2019, State of the Nation in Blood Cancer, available at: https://www.leukaemia.org.au/wp-content/uploads/2020/06/State-of-the-Nation-Blood-Cancer-in-Australia_Leukaemia-Foundation.pdf
[4] *Ibid*
[5] *Ibid*
[6] *Ibid*
[7] *Ibid*
[8] National Institute for Health and Clinical Excellence, Addendum to Haematological Cancers: improving outcomes (update), Service Guidance Addendum, Methods, evidence and recommendations, May 2016; Abimanyi-Ochom, J., Mudiyanselage, S.B., Catchpool, M., Firipis, M., et al, 2019, Strategies to reduce diagnostic errors: a systematic review, *BMC Medical Informatics and Decision Making,* 19:174; Bowen, J.M., Prry, A.M., Laurini, J.A., Smith, L.M., et al, 2014, Lymphoma diagnosis at an academic centre: rate of revision and impact on patient care, *British Journal of Haematology*, 166:202-208, doi: 10.1111/bjh.12880; Report of the Independent Cancer Taskforce, 2015, *Achieving World Class Cancer Outcomes. A Strategy for England 2015-202*0. http://www. cancerresearchuk. org/ sites/ default/ files/ achieving_ worldclass_ cancer_ outcomes_-_ a_ strategy_ for_england_ 2015- 2020. pdf
[9] ALLG and HSANZ 2019 Survey of Haematologists
[10] Leukaemia Foundation, 2019, State of the Nation in Blood Cancer, available at: https://www.leukaemia.org.au/wp-content/uploads/2020/06/State-of-the-Nation-Blood-Cancer-in-Australia_Leukaemia-Foundation.pdf, Patient and Carer Survey of more than 3,200 blood cancer survivors
[11] Analysis of State Cancer Registry data as of 2018

  - Regional and remote patients are 37 per cent less likely to receive treatment that complies with guidelines.

- Eliminating variation in survival outcomes would see a 13 per cent improvement in survival based on the technologies that are already approved and available in Australia today.[12]

Figure 1.1: Overview of quality, safety and access challenges for blood cancer patients



Source: Leukaemia Foundation, 2019, State of the Nation in Blood Cancer, available at: https://www.leukaemia.org.au/wp-content/uploads/2020/06/State-of-the-Nation-Blood-Cancer-in-Australia_Leukaemia-Foundation.pdf

In light of these data pointing to quality and safety issues for blood cancer patients, in 2019 and 2020, Australia's blood cancer community came together, supported by the Australian Government, to articulate a shared vision and plan for zero lives lost to blood cancer by 2035.

The vision of the National Strategic Action Plan for Blood Cancer (National Action Plan) set out by this community is:

> ***Zero lives lost to blood cancer by 2035, underpinned by zero preventable deaths, regardless of geography or background, through equitable access to best practice treatment and care for all Australians.***

This vision and the attendant National Action Plan was developed through the leadership of a Blood Cancer Taskforce, comprised of more than 30 leading experts across the blood cancer community, and informed by wide ranging consultation and document review by Australian governments, clinicians, patients, industry and researchers. More than 175 stakeholders (see Appendix A) were consulted over the course of the National Action Plan's development, in addition to a national survey of more than 3,200 Blood Cancer Patient and

[12] Analysis of State Cancer Registry data as of 2018

Carers and the receipt of 21 written submissions from Australian governments, charity, industry, research, provider and patient organisations.

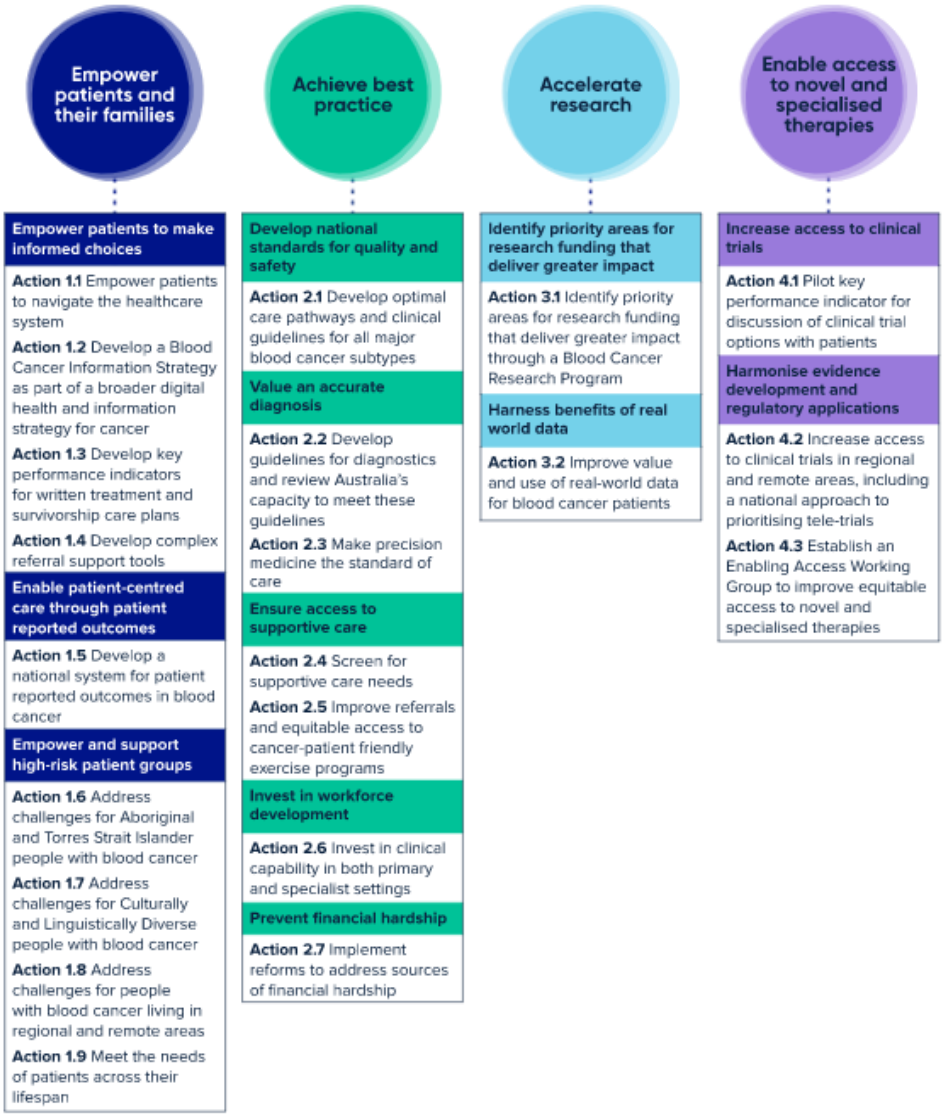
Figure 1.1: Consultations for the National Strategic Action Plan

Source: National Strategic Action Plan for Blood Cancer, available at: https://www.leukaemia.org.au/national-action-plan/

The National Action Plan was developed with reference to the Federal and State Government cancer and wider health and innovation policy context. The National Action Plan showed a strong alignment with Federal and State Government policies for reducing unwarranted variation in care and supporting the development of patient-centred care (See Appendix C).

The National Action Plan set out four major areas for reform, and within this a detailed set of actions for addressing the challenges and opportunities for people living with blood cancer and their families (Figure 1.2).

Figure 1.2: The National Strategic Action Plan for Blood Cancer – Plan on a Page



Source: National Strategic Action Plan for Blood Cancer, available at: https://www.leukaemia.org.au/national-action-plan/

The National Action Plan for Blood Cancer's vision and attendant strategy to improve outcomes for patients and their families accepted and endorsed by the Federal Department of Health, Cancer Australia and the wider blood cancer community, and launched by the Minister for Health on 27 September 2020.

1.2 Critical path activities for implementation: Phase 1 actions

In keeping with best practice for cancer plan development, the National Strategic Action Plan identified key phases for implementation.

Phase 1 recommendations of the National Action Plan are the critical path activities needed for the realisation of the vision of the National Action Plan (Figure 1.1). These activities are the minimum set of required steps needed for the implementation of the National Action Plan, with the implementation of other actions contingent on their completion.

Ultimately, these actions will enable nationally consistent, equitable access to clinical best practice, equitable access to novel therapies across Australia, and a rigorous framework for high impact research in blood cancer.

Figure 1.3: Critical path dependencies and project phasing

To be implemented through National Strategic Action Plan for Blood Cancer

To be implemented through Australian Cancer Plan, announced following release of National Strategic Action Plan for Blood Cancer

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Since the launch of the National Action Plan in September 2020, the Australian Government has announced the development of an Australian Cancer Plan, which will see the development and implementation of policy reforms and initiatives that cut across all cancers; in particular the Blood Cancer Taskforce has been advised the following initiatives identified in the National Action Plan will be addressed through the Australian Cancer Plan:

- Development of Patient Navigation Services for all cancers
- Development of a Digital Information Strategy for all cancers
- Development of Patient Reported Outcomes for all cancers
- Development of improved exercise oncology services for all cancers
- Development of cancer data sets to support improvements in clinical care and research.

This is also shown in Figure 1.3, which leaves the following action sin scope for Phase 1 implementation through the National Action Plan, while the Australian Cancer Plan is being developed:

- *Actions 2.1 and 2.2: Develop Optimal Care Plans, clinical and diagnostic guidelines* — This project will address gaps in Optimal Care Plans (OCPs) and treatment guidelines for different blood cancer subtypes. OCPs and treatment guidelines are interdependent and to be effective should be fully integrated into clinical practice. As the development of OCPs have received funding, remaining implementation requirements for Action 2.1 and 2.2 include the development of Australian-specific clinical and diagnostic guidelines for major sub-types leveraging existing international and Australian treatment guidelines; Phase 1 will develop guidelines for CML, CLL, DLBCL, Follicular, Myeloma, and Paediatric ALL.
- *Action 1.3.1: Minimum standards and templates for written treatment and survivorship care plans* — This project will develop minimum standards or 'template' for written treatment and survivorship care plans, for both acute and chronic blood cancers to ensure a nationally consistent, minimum standard approach to written communications to patients for treatment and survivorship planning, to ensure equity of access to information, treatment plans and supportive care services. The goal will be for treatment and survivorship plans to be dynamic, and remain relevant to the patient at different stages of their diagnosis and treatment and include guidance on supportive care considerations such as managing immunosuppression, community sourced infection, vaccination, diet, exercise, palliative care and any other psycho-social supportive care needs.
- *Action 3.1: Research Roadmap* — This project will develop a Research Roadmap for blood cancers, focused on the creation of a strategic, virtual network of Australian research partners organised around disease goals or technology strengths and with business models for streamlining and augmenting collaboration across research nodes of excellence nationally and internationally.
- *Action 4.3: Improve access to novel and specialised therapies* — This project will bring together a multidisciplinary Enabling Access Working Group, including consumers, to work across the blood cancer community and address challenges for patient access to novel and specialised therapies. The Working Group would have three specific tasks:
  - Develop a short-list of clinically important medicines and diagnostics that do not have public subsidy and where there are market barriers to evidence development. Work with the Federal Government and the blood cancer community to coordinate an approach to evidence development for each therapy,

which could include funding investigator-led clinical trials, or coordination of research and regulatory applications, including provisional registration, which may require participation in a registry to enable access to a novel therapy.

- Commission a review of access to novel and specialised therapies by state and territory to identify disparities in access to standard of care therapies and develop a plan to improve equity of access nationally.
- Engage with Government to develop a strategy to optimise the supply of suitable stem cell donors for Australian and international patients and to ensure equity of access to cellular and emerging therapies, including CAR T-cells for all Australians.

The Enabling Access Working Group would consider and complement work that is already underway to improve access to new therapies and diagnostics, including projects to be delivered through the MRFF, for example, the Health System Preparedness for Cancer and Paediatric Healthcare Initiative.

- *Action 1.6.1: Epidemiological study of blood cancer in Aboriginal and Torres Strait Islander people* — This project would fund an epidemiological and health services implementation research study to better understand limitations, improve data collection and statistics on blood cancers and to enable culturally sensitive care that improves primary health attendance and hospitalisation rates. The study would identify limitations to data collection and analysis for Aboriginal and Torres Strait Islander people with blood cancer and recommend options for addressing data limitations to enable better data collection and investment.

1.3 Need for government support for Phase 1 implementation

Australia's federated health system creates significant administrative complexity, which is compounded by the immense genetic heterogeneity inherent to blood cancers. Combined, these factors can give rise to:

- Confusion for patients seeking to understand their treatment plan and successfully navigate the healthcare system
- Unwarranted variation in clinical care
- Muted commercial incentives for evidence development
- Inequity among socioeconomic groups and geographies.

The National Action Plan was conceived to bring together disparate jurisdictions around common goals. Without funding for the implementation of the National Action Plan, this variation and inequity will persist.

While the blood cancer community stands ready to co-invest with government, both in terms of money and time contributions by senior leadership of the blood cancer community, the not-for-profit sector lacks the funds and scale to undertake these investments unilaterally. Australian government support is needed to continue the important work and implementation of the National Action Plan.

Funding for these initiatives will drive significant quality and safety improvements across Australia's healthcare system, leading to substantially reduced mortality, improved quality of life and workforce participation and continued investment in Australia's high quality research community.

Chapter 2

Health and economic outcomes from Phase 1 implementation

The implementation of Phase 1 initiatives will enable the realisation of significant health and economic outcomes. This chapter presents the evidence for the benefits to be realised from investment in Phase 1 initiatives.

The chapter shows that improved diagnostics and increased adherence to clinical best practice reduces preventable death and increases social and economic participation of blood cancer survivors in Australian communities. It shows strategic investment in Australian blood cancer research generates additional improvements in survival and catalyses further private sector investment and knowledge spillovers that further improve health and economic outcomes for Australian communities. It presents a series of case studies to demonstrate the need for improving access to novel and specialised therapies, as well as data to show the need to address information and data gaps for consumers and vulnerable groups.

2.1 Overview of expected health and economic outcomes

Phase 1 of the National Action Plan is core enabling infrastructure for the realisation of the National Action Plan's vision, and will deliver:

- More than 25,000 years of life gained through the increased adherence to clinical best practice, valued at $704 million in $NPV_{1.5\%}$ terms[13] ($50,000 per QALY gained)
- Increased workforce participation with more than 511 Australians returning to work on average per annum, or more than 11,000 additional FTE over the 2025-2040 period
- An increase in GDP of $735 million in $NPV_{1.5\%}$ terms over the 2025-2040 horizon arising from increased population and labour force participation, and an increase government revenues by $21 million per annum on average over the 2025-2040 horizon, associated with expanded economic output
- Additional private sector research funding of 17.6 cents to 30 cents for every $1 invested by governments
- Health gains of more than 9,500 years of life through medical research, with a return on investment from health gains alone of $2.61 (BCR 3.6)
- Productivity spillovers of at least $1.30 for every $1 invested
- Highly skilled medical research jobs creation

[13] All impacts are reported in today's dollars and future impacts are discounted at a social discount rate to reflect the time value of money, that is, it is generally better to have a dollar today than a dollar tomorrow. The risk-free rate is generally assumed to be the current rate for 20-year Commonwealth bonds, which currently sits at roughly 1.5 per cent. ASX, 2020, Government Bonds, Treasury Yield Curve, accessed at: https://www2.asx.com.au/markets/trade-our-cash-market/equity-market-prices/bonds, November 2020.

- Total return on investment of $3.46 for every $1 invested (BCR 4.8) in blood cancer research
- More equitable access to novel therapies, with enhanced regulatory transparency and evidence development for rare blood cancer sub-types
- Reduced inconsistencies and incomplete information to blood cancer patients and their carers through written treatment and survivorship care plan templates
- Improved information base to better support service development for Aboriginal and Torres Strait Islander communities.

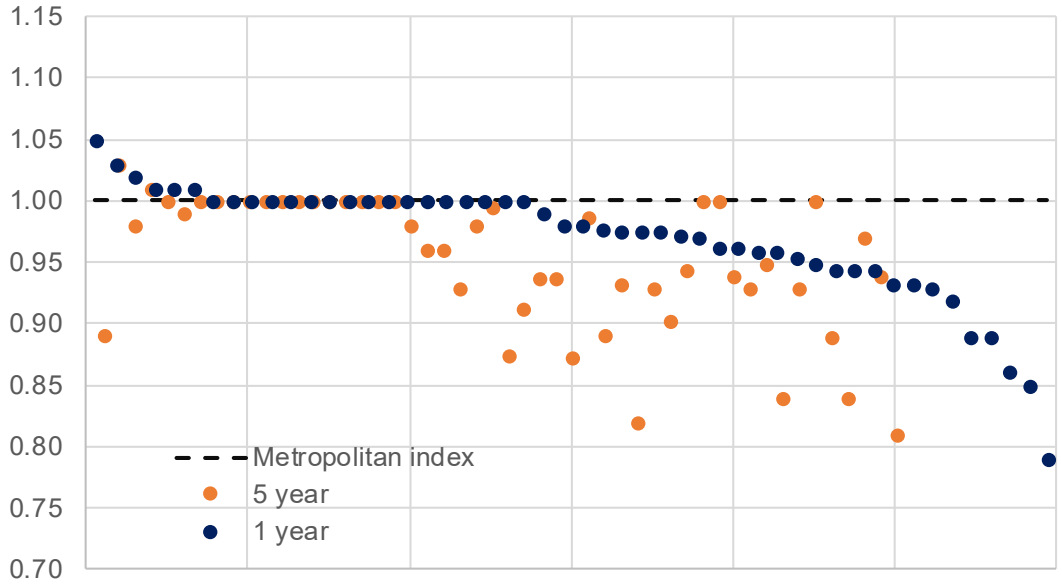
This chapter presents the evidence of impact by Phase 1 action.

2.2 Impacts of achieving clinical best practice (Actions 2.1, 2.2 and 1.3.1)

Australians enjoy one of the best health care systems in the world, with health outcomes among the world's best across a range of conditions, including cancer. At the same time, Australia's health care system is also highly complex, founded on a federated model of service delivery, involving a complex mix of Federal, State and private funding. This can result in inconsistent access to clinical best practice nationally, with some patients at risk of unequal access to treatment and care.

State Cancer Registry data shows variation in survival by jurisdiction and regional area. For example, State Cancer Registry data show that survival outcomes at 1-year and 5-years for people living in rural and remote areas is poorer than for metropolitan based patients (Figure 2.1).

Figure 2.1: 1-year, 5-year survival outcomes for blood cancer patients, benchmarked against metro counterparts

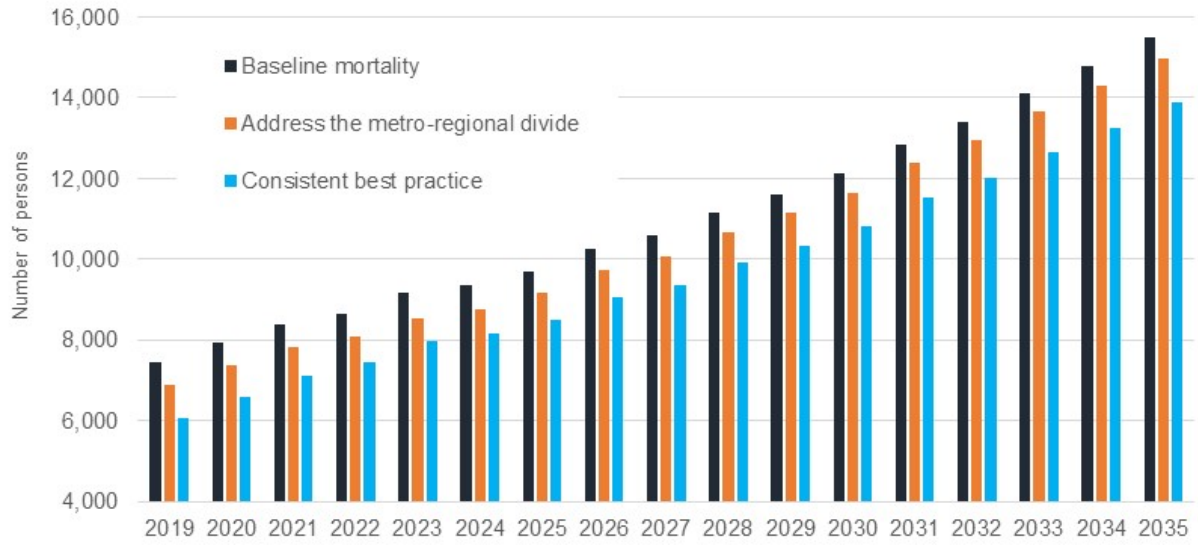


Source: State cancer registry data for blood cancers

If these variations were eliminated deaths from blood cancer would reduce by 13 per cent (Figure 2.2).[14]

[14] Leukaemia Foundation, 2019, State of the Nation: Blood Cancer in Australia, prepared by Insight Economics, accessed at: https://www.leukaemia.org.au/about-us/mylifecounts/stateofthenation/..

Figure 2.2: Reduction in deaths from blood cancer if best practice in Australia consistently implemented



Source: Leukaemia Foundation, 2019, *State of the Nation: Blood Cancer in Australia*, prepared by Insight Economics, accessed at: https://www.leukaemia.org.au/about-us/mylifecounts/stateofthenation/. Note the "Baseline" projections, "Address the Metro-Regional Divide" projections and "Consistent Best Practice" projections are based on AIHW and State cancer registry data using technologies currently in use in Australia.

Importantly, this estimate of benefit not a stakeholder derived estimate.

The potential improvement in survival was derived from analysis of State Cancer Registry data taking into account both gender and age factors. A series of 16 discrete models were developed for eight blood cancer sub-types for each gender. Base case incidence and mortality for each blood cancer sub-type was built up from five-year age cohorts for males and males based on historical trends which were projected forward. To estimate the benefit of reduced variation in clinical care, a scenario was run in each of the 16 models where the optimal survival outcome a particular age and gender cohort within a particular blood cancer sub-type was applied to that age and gender cohort nationally. This analysis was done in a stepped manner: first, eliminating regional variation observed (Figure 2.1) and then eliminating differences between states and territories. In total, a 13 per cent improvement in survival based on already available and funded technologies as estimated.

Blood cancer differs from other solid tumours in that these variation is not explained by delays in presentation; it is explained by variation in clinical practice across regions which is likely to be a function of training and expertise in blood cancer diagnosis and treatment nationally, particularly as the science of blood cancer rapidly advances.

These data are consistent with other research that shows variation from clinical best practice leads to potentially preventable death. For example, an Australian study published in 2019 evaluated survival outcomes for 1,442 patients with diffuse large B-Cell lymphoma, which is an aggressive form of non-Hodgkin lymphoma, over two time periods and found that compliance with clinical best practice treatment guidelines was associated with a 40 per cent lower risk of death.[15] In addition, the analysis found that high-risk groups were less likely to receive treatment that complied with the current guidelines for lymphoma:

- Geriatric patients (people aged >80 years) were 62 per cent less likely to receive treatment that complied with guidelines

[15] Wong Doo, N., White, V. M., Martin, K., Bassett, J. K., Prince, M. P., Harrison, S. J., Jefford, M., Winship, I., Millar, J., Milne, R. L., Seymour, J. F., and Giles, G. G., 2019, "The Use of Optimal Treatment for DLBCL is Improving in All Age Groups and Is a Key Factor in Overall Survival, but Non-Clinical Factors Influence Treatment", *Cancers*, vol 11, 928, doi:10.3390/cancers11070928.

- Women were 32 per cent less likely to receive treatment that complied with guidelines
- Regional and remote patients were 37 per cent less likely to receive treatment that complied with guidelines.[16]

Similarly, another Australian analysis found non-adherence to international guidelines for treatment of transplant-eligible myeloma patients, and that adherence to treatment guidelines depended on referral patterns and treatment settings. For example, patients referred to medical oncologists and private care settings were less likely to be recommended transplant than patients referred to haematologists or public care settings.[17]

Non-adherence to clinical best practice in leukaemias is also reported, resulting in both preventable death as well as increased treatment-emergent adverse events and hospitalisations (Box 2.1).

Box 2.1: Health and economic benefits of increased uptake of clinical best practice

By 2025, there will be roughly 840 patients diagnosed with AML aged 75 years or older; by 2035 this is expected to have grown to more than 1,800 patients each year.

Recent data has established the use of azacitidine to improve survival and reduce hospitalisation compared with conventional care regiments (CCR), being either induction chemotherapy, low-dose cytarabine, or supportive care only. Azacitidine increased median overall survival by 3.8 months vs current commonly used AML treatments (10.4 vs 6.5 months; P = .1009).

In addition hospitalisations of AML patients was less likely, with shorter hospital stays. In the azacitidine and CCR arms, 165 patients (69.9%) and 157 patients (66.8%), respectively, were hospitalized for a TEAE. Rates of hospitalization for TEAEs per patient-year of drug exposure in the azacitidine and CCR arms were 1.96 and 2.39, respectively (relative risk, 0.82; 95% CI, 0.70-0.960; P = .0083). Times spent in the hospital for TEAEs were 28.5 days and 38.3 days per patient-year of drug exposure in the azacitidine and CCR arms, respectively (relative risk, 0.74; 95% CI, 0.71-0.78; P < .0001).

Applying the improvements in survival to future AML patients aged 75 and older reveals both health gains as well as avoided hospitalisation costs, depending on current rates of uptake:

- Between 1,100 to 3,800 additional years of life gained
- Between $2.5 million and $10.2 million in avoided hospital costs
- Net benefit cost ratio of 1.1.

Source: Dombret, H., Seymour, J. F., Butrym, A., Wierzbowska, A., Selleslag, D., Jang, J. H., Kumar, R., Cavenagh, J., Schuh, A. C., Candoni, A., Récher, C., Sandhu, I., Bernal del Castillo, T., Al-Ali, H. K., Martinelli, G., Falantes, J., Noppeney, R., Stone, R. M., Minden, M. D., McIntyre, H., … Döhner, H. (2015). International phase 3 study of azacitidine vs conventional care regimens in older patients with newly diagnosed AML with >30% blasts. Blood, 126(3), 291–299. https://doi.org/10.1182/blood-2015-01-621664Seymour, J. F., Döhner, H., Butrym, A., Wierzbowska, A., Selleslag, D., Jang, J. H., Kumar, R., Cavenagh, J., Schuh, A. C., Candoni, A., Récher, C., Sandhu, I., Del Castillo, T. B., Al-Ali, H. K., Falantes, J., Stone, R. M., Minden, M. D., Weaver, J., Songer, S., Beach, C. L., … Dombret, H. (2017). Azacitidine improves clinical outcomes in older patients with acute myeloid leukaemia with myelodysplasia-related changes compared with conventional care regimens. BMC cancer, 17(1), 852. https://doi.org/10.1186/s12885-017-3803-6. Key assumptions: 1 year survival for azacitidine assumed to be 46 per cent compared to 32 per cent for CCR, and year 2 survival for azacitidine assumed to be 18 per cent compared to 5 per cent for CCR. Costs of azacitidine per patient assumed to be $11,778 per eviQ cost estimates; CCR assumed to be $815 per patient with 50 per cent of patients administered low dose cytarbine at $520 per patient (eviQ), and $1,100 for standard induction chemotherapy (eviQ). Probabilty of hospitalisation for azacitidine 1.96 and 2.39 for azaciditine. ALOS 28.5 days for aza at $2,418 per day per NHCDC for major leukaemia admission, ALOS for CCR 38.3 days.

[16] Wong Doo, N., White, V. M., Martin, K., Bassett, J. K., Prince, M. P., Harrison, S. J., Jefford, M., Winship, I., Millar, J., Milne, R. L., Seymour, J. F., and Giles, G. G., 2019, "The Use of Optimal Treatment for DLBCL is Improving in All Age Groups and Is a Key Factor in Overall Survival, but Non-Clinical Factors Influence Treatment", *Cancers*, vol 11, 928, doi:10.3390/cancers11070928.

[17] Wong Doo, N, Coory, M, White, V, et al, 2014, Low Uptake of Upfront Autologous Transplantation for Myeloma in a Jurisdiction With Universal Health Care Coverage: A Population-Based Patterns of Care Study in Australia, Lymphoma, Myleoma, and Meukemia, 14(1):61-67, doi: 10.1016/j.clml.2013.09.01

Combined, these real world case study examples across lymphoma, myeloma and AML align strongly with the State Cancer Registry data that show there is variation in clinical practice which leads to preventable death.

Added to this, there are also relatively high rates of revision in the diagnosis of blood cancers; international studies have estimated routine rates of revision ranging from 17.8 per cent to 55 per cent.[18] Genomic testing is reported by stakeholders and patients to be inconsistently undertaken, leading to risks of inaccurate diagnosis and treatment planning.[19]

The National Strategic Action Plan articulates a long-term strategy for improving the consistent implementation of best practice nationally through series of reforms and concerted action by blood cancer stakeholders through the development and implementation of the Action Plan. Key actions set out by the National Strategic Action Plan include:

- Reducing variation in treatment and care through the development of national standards for quality and safety—specifically, optimal care pathways and treatment guidelines by disease sub-type
- Improving the accuracy of diagnosis through the development of guidelines for quality in pathology, reviewing pathology services nationally, and making emerging genetic and genomic testing part of the standard of care
- Improving patient quality of life outcomes by making consistent screening for supportive care referrals part of the standard of care, enhancing survivorship support, and increasing offerings of cancer-friendly rehabilitation and physiology
- Investing in workforce development—in particular in the areas of the regional and remote workforce, personalised medicine, palliative care, and training of GPs and community pharmacists
- Preventing financial hardship through policy reform in a number of areas—reforms to PATS programs and welfare support, including the introduction of temporary disability support.

The first step of this strategy is the articulation of diagnostic and clinical best practice for the major blood cancer sub-types, which is the core enabling infrastructure needed to support the development of a quality framework for blood cancers and workforce training for the sector.

Establishing optimal diagnostic and treatment guidelines are critical, because the health and economic payoffs from reform are large. Assuming a progressive implementation of the National Strategic Action Plan from 2021 and phased realisation of benefits beginning from 2022, ramping up to consistent clinical best practice by 2025, would see more than 25,000 years of life saved. Valued at $50,000 per year of life gained, this would translate into direct benefits of more than $704 million in $NPV_{1.5\%}$ terms over the 2022-2035 period.

While many blood cancer patients are no longer of working age, a significant number of survivors would be expected to return to work. Based on the survey of people living with blood cancer in the *State of the Nation in Blood Cancer* report Patient and Carer survey[20]

[18] National Institute for Health and Clinical Excellence, Addendum to Haematological Cancers: improving outcomes (update), Service Guidance Addendum, Methods, evidence and recommendations, May 2016; Abimanyi-Ochom, J., Mudiyanselage, S.B., Catchpool, M., Firipis, M., et al, 2019, Strategies to reduce diagnostic errors: a systematic review, *BMC Medical Informatics and Decision Making,* 19:174; Bowen, J.M., Prry, A.M., Laurini, J.A., Smith, L.M., et al, 2014, Lymphoma diagnosis at an academic centre: rate of revision and impact on patient care, *British Journal of Haematology*, 166:202-208, doi: 10.1111/bjh.12880; Report of the Independent Cancer Taskforce, 2015, *Achieving World Class Cancer Outcomes. A Strategy for England 2015-202*0. http://www. cancerresearchuk. org/ sites/ default/ files/ achieving_ worldclass_ cancer_ outcomes_-_ a_ strategy_ for_england_ 2015- 2020. pdf

[19] Leukaemia Foundation, 2019, State of the Nation: Blood Cancer in Australia, prepared by Insight Economics, accessed at: https://www.leukaemia.org.au/about-us/mylifecounts/stateofthenation/..

[20] Leukaemia Foundation, 2019, State of the Nation in Blood Cancer, available at: https://www.leukaemia.org.au/wp-content/uploads/2020/06/State-of-the-Nation-Blood-Cancer-in-Australia_Leukaemia-Foundation.pdf

which was very consistent with extensive systematic literature reviews and research on labour force participation by cancer survivors,[21] was assumed that:

- 40 per cent of people living with blood cancer were already retired at diagnosis, and would not return to the workforce
- 40 per cent of persons that were working prior to their diagnosis and treatment would not return to the workforce as a blood cancer survivor.

On balance, it was expected that 36 per cent of survivors would re-join the labour force.

Increased population growth and increased labour force participation from improved survival and the avoidance of preventable death would therefore also be expected to generate social and economic returns to the community.

Modelling the increase in population and labour force participation using a CGE model of the Australian economy[22] showed that the realisation of best practice nationally would be expected to create $735 million in additional economic output in $NPV_{1.5\%}$ terms. As economic output expands, so too, will government revenues, with more than $21 million in additional tax revenue expected per annum over the 2025-2040 period.

While the realisation of these improvements will depend on subsequent action from across the blood cancer community, these investments on contingent on Actions 2.1 and 2.2 being funded.

Health and economic outcomes from Actions 2.1 and 2.2:

- **More than 25,000 years of life gained through the increased adherence to clinical best practice, valued at $704 million in $NPV_{1.5\%}$ terms ($50,000 per QALY gained)**
- **Increased workforce participation with more than 511 Australians returning to work on average per annum, or more than 11,000 additional FTE over the 2025-2040 period**
- **An increase in GDP of $735 million in $NPV_{1.5\%}$ terms over the 2025-2040 horizon arising from increased population and labour force participation**
- **An increase in government revenues by $21 million per annum on average over the 2025-2040 horizon, associated with expanded economic output**

2.3 Impacts of investment in Blood Cancer Research (Action 3.1)

Extensive academic research has shown that medical research generally, and cancer research specifically, delivers significant improvements in both health and economic prosperity. Investment in cancer research directly produces:

- *Health gains*, in the form of improved survival and improvements in quality of life
- *Investment effects*, in the form of leveraging investment and activity into an economy that would not have otherwise occurred
- *Jobs creation*, including in particular highly skilled jobs

[21] de Boer, A, Taskila, T, Ojajärvi, A, van Dijk, FJH, and Verbeek, JHAM, 2009, Cancer Survivors and Unemployment: A Meta-analysis and Meta-regression, JAMA, 301(7):753–762, doi: 10.1001/jama.2009.187; Insight, 2019, Return to work after cancer: a key health outcome, accessed at: https://insightplus.mja.com.au/2019/6/return-to-work-after-cancer-a-key-health-outcome/; Mehnert, A. 2011, Employment and work-related issues in cancer survivors, Crit Rev Oncol Hematol., 77(2):109-30, doi: 10.1016/j.critrevonc.2010.01.004; Spelten, ER, Sprangers, MA, Verbeek, JH, 2002, Factors reported to influence the return to work of cancer survivors: a literature review, Psycho-oncology. 11(2):124-31, doi: 10.1002/pon.585; Taskila T, and Lindbohm ML, 2007, Factors affecting cancer survivors' employment and work ability, Acta Oncol., 46(4):446-51, doi: 10.1080/02841860701355048.

[22] Modelling undertaken using the MMRF Model operated by Centre of Policy Studies at Victoria University.

- *Productivity spillovers,* arising from the spillover of knowledge from disease area into the treatment of other cancers and chronic health conditions through open, networked research communities.

These direct effects then have wider multiplier effects throughout the economy, often leading to a significant return on investment.

For example, a 2012 RAND study commissioned by Cancer Research UK found that public and charitable investments in cancer research generated a 40 per cent per annum return for every dollar invested in perpetuity,[23] while a 2008 study of the returns on cancer research in Australia similarly found a return of $2.34 in health gains alone (ignoring other investment or spillover effects) for every dollar expended on cancer research.[24]

Wider studies of the benefits of medical research have similarly identified significant returns on investment from medical research, including a recent 2017 study by the Australian Commission on Safety and Quality in Health Care found that Australian investigator-led clinical trials delivered a return of $5.80 for every dollar invested[25] and a study for the Association of Australian Medical Research Institute (AAMRI) in 2018 that estimated a return of $3.90 for every dollar invested in medical research.[26]

Health gains expected from blood cancer research investments

A consistent approach to the valuation of the health impacts of investments in cancer research involves a multi-step process:

- Quantify the improvements in health outcomes that have been achieved over a particular period or are expected in the future. This can be done using either a 'bottom up' case study approach or through a 'top down' evaluation of observed changes in survival over time.
- Determine the proportion of improvements in health outcomes observed or expected that are attributable to academic research, as distinct from policies or interventions for the prevention, screening and early detection of cancer (e.g., breast screen programs, skin checks, screening for colorectal cancer or cervical cancer)
- Determine the proportion of benefit attributable to a selected jurisdiction or funder, in this case the share of benefit attributable to the Australian blood cancer research community.

This approach has been implemented to inform an expectation for improvements in health outcomes resulting from investment in blood cancer research.

Step 1: Determine improvements in health outcomes in blood cancer

As a result of sustained investment in cancer research, overall survival has improved dramatically across all blood cancers since 1975, both globally and in Australia, and continue to improve as a result of advances in research.

- From 2001 to 2016 alone, 5-year survival rates globally improved by 22 per cent across all leukaemias, 38 per cent for Hodgkin Lymphoma, 44 per cent for myeloma, and 14 per cent across all types of Non-Hodgkin Lymphomas (SEER data).
- Long term survival rates have also improved dramatically, with ten-year survival rates globally increasing by 97 per cent for people diagnosed with leukaemia, 29 per

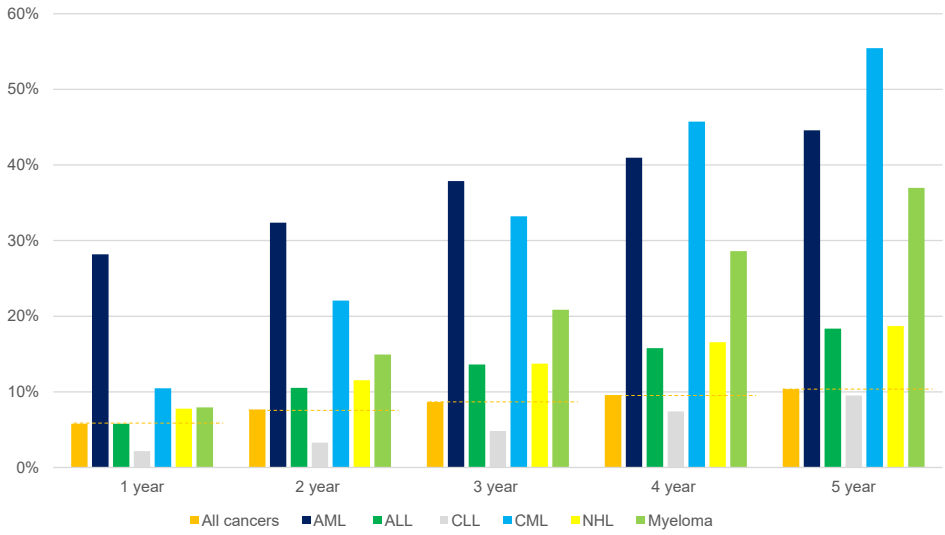
[23] RAND, Medical Research: What's It Worth?, BMC Medicine, 2012
[24] CINSW, 2008, Health Returns on Cancer Research Investments
[25] Australian Clinical Trials Alliance, 2017, Economic evaluation of investigator-initiated clinical trials conducted by networks
[26] KPMG, 2018, Economic Impact of Medical Research in Australia, accessed at: https://aamri.org.au/wp-content/uploads/2018/10/Economic-Impact-of-Medical-Research-exec-summary.pdf

cent for people diagnosed with Hodgkin Lymphoma, 50 per cent for people diagnosed with myeloma, and 47 per cent for people diagnosed with Non-Hodgkin Lymphoma (Cancer Research UK and SEER data).

- The improvements among children and adolescents diagnosed with blood cancers have been the most significant. In 1975, the proportion of cured AML patients was less than 6 per cent across all age groups with a median survival time for 'uncured' patients on only 6 months. By 2000, the proportion of AML patients cured had risen to 68 per cent for children and 32 per cent for adolescents (but remained at 8 per cent for adults and 4 per cent for elderly patients).

These improvements in survival data globally have been similarly observed in Australia. AIHW data shows that the health gains realised in blood cancer have significantly outstripped the gains observed across all cancers (Figure 2.3).

Figure 2.3: Benchmarking improvements in relative survival at 1-year, 2-years, 3-years, 4-years, and 5-years from diagnosis from 1997-2001 to 2012-2016 for all cancers and blood cancers



Source: Insight Economics analysis of AIHW, 2020, Australian Institute of Health and Welfare (AIHW) 2020 Cancer Data in Australia; Canberra: AIHW. <https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/>.

Step 2: Determine the contribution of research to health outcomes compared to other policy interventions

Generally, the contribution of cancer research to observed health gains is estimated to be in the order of 50 per cent.[27] The balance of improvement in health outcomes is estimated to be attributed to changes in clinical practice, including the introduction of prevention and screening interventions which have delivered significant health gains to patients and the wider community. As noted in a Cancer Institute NSW review of the benefits of cancer research:[28]

> *Not all the gains in cancer wellbeing are due to our own R&D. The methodology estimates the proportion due to research as opposed to other factors (e.g., public health programs such as 'Slip Slop Slap', 'Quit Smoking' campaigns, the Cervical Screening Program, BreastScreen and so on). …*
>
> *This proportion is estimated to as 50% (30% to 70%) for cancer R&D.*

[27] See for example: CINSW, 2008, The Health Returns on Cancer Research Investments; KPMG, 2018, Economic Impact of Medical Research in Australia, accessed at: https://aamri.org.au/wp-content/uploads/2018/10/Economic-Impact-of-Medical-Research-exec-summary.pdf; National Health and Medical Research Council, 2014, Measuring Up 2013, accessed at: Measuring up 2013 | NHMRC; National Health and Medical Research Council, 2019, Measuring Up 2018, accessed at: https://www.nhmrc.gov.au/about-us/publications/measuring-2018.

[28] CINSW, 2008, The Health Returns on Investment in Cancer Research

An assumption of 50 per cent attribution of impact to medical research was also adopted by the NHMRC in its successive evaluations of the value of NHMRC funded research.[29]

Unlike many other cancers, however, for which survival outcomes have been improved through prevention, screening and early detection interventions, it is not currently possible to prevent or screen for blood cancers. As a result, a greater proportion of the health gain observed in blood cancer survival is directly attributable to cancer research. Having said this, not all the gain is attributable to academic research. Other major contributions to improvements in survival include policies for service centralisation and centre volumes for highly specialised services,[30] compliance with clinical best practice[31] and accreditation of bone marrow transplant centres.[32] Based on literature, it was assumed the benefits of these policies and service models has been in the order of 15 per cent of the health gains observed over the 2000-2020 period.

By implication, research is assumed to account for 85 per cent of the health gains observed over this time period.

Step 3: Determine the contribution of Australia's blood cancer research community to research outcomes

Cancer research, particularly blood cancer research, is a globally collaborative effort. Nevertheless, once the contribution of research to improvements in observed health outcomes has been estimated, it is then necessary to determine the share of global research effort that may be attributable to a particular jurisdiction and/or funder. To quantify the contribution of a particular jurisdiction to global research efforts, the generally accepted approach is to undertake citation analysis which can measure research impact.

Importantly, within the world of research not all publications are equal. Extensive analysis of research paper impact is undertaken by a range of organisations to determine the impact of research globally which are synthesized into evaluations of journal and research impact.

Australian medical research is generally assumed to 'punch above its weight' in the evaluation of research impact. For example, in Cancer Institute NSW's evaluation of investment in cancer research it was estimated that Australian cancer researchers account for 2.5 per cent of total research impact (compared with a share of the world's population of only 0.3 per cent). Similarly, the NHMRC has recently estimated a contribution of 3.14 per

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[29]

[30] Huntington, S.F., Hoag, J.R., Zhu W., Wang R., et al, 2018, Oncologist volume and outcomes in older adults diagnosed with diffuse large B cell lymphoma, Cancer 2018 Nov 1; 124(21):4211-4220. Doi: 10.1002/cncr.31688. Lecuyer, L., Chevret, S., Guidet, B., Aegerter,P., et al, 2008, Case volume and mortality in haematological patients with acute respiratory failure, Eur Respir J 2008; 32: 748–754. Azoulay E., Pène F., Darmon M., et al, 2015, Managing critically Ill hematology patients: Time to think differently, Blood Reviews, 29:359–367; Lecuyer, L., Chevret, S., Guidet, B., Aegerter,P., et al, 2008, Case volume and mortality in haematological patients with acute respiratory failure, Eur Respir J 2008; 32: 748–754.

[31] Wong Doo, N., White, V. M., Martin, K., Bassett, J. K., Prince, M. P., Harrison, S. J., Jefford, M., Winship, I., Millar, J., Milne, R. L., Seymour, J. F., and Giles, G. G., 2019, "The Use of Optimal Treatment for DLBCL is Improving in All Age Groups and Is a Key Factor in Overall Survival, but Non-Clinical Factors Influence Treatment", *Cancers*, vol 11, 928, doi:10.3390/cancers11070928. Komajda, M., Lapuerta, P., Hermans, N., et al. 2005, Adherence to guidelines is a predictor of outcome in chronic heart failure: the MAHLER survey, *Eur Heart J.*, 26(16):1653-1659.
National Institute for Clinical Excellence, National Health Service, 2016, *Guidance on Cancer Services, Improving Outcomes in Haematological Cancers*, The Manual, accessed at: https://www.nice.org.uk/guidance/ng47/evidence, p 7.

[32] Caunday, O., Agulles, O., McGrath, E., Empereur, F., et al, 2013, Implementation of JACIE accreditation results in the establishment of new indictors that unevenly monitor processes contributing to the delivery of hematopoietic SCT, *Bone Marrow Transplantation*, 48:604-609, doi: 10.1038/bmt.2012.181. Gratwohl, A., Brand, R., Neiderwieser, D., Baldomero, H., Chabannon, C. et al, 2011, Introduction of a Quality Management system and outcome after hematopoietic stem cell transplantation, *J Clin Oncol*, 29:1980-6, doi: 10.1200/JCO.2010.30.4121
Angelucci, E., Matthes-Martin, S,, Baronciani, D., Bernaudin, F., et al, 2014, Hematopoietic stem cell transplantation in thalassemia major and sickle cell disease: indications and management recommendations from an international expert panel, *Haematologica*, 99(5):811-20. doi: 10.3324/haematol.2013.099747. Anthias, C., O'Donnell, P.V., Kiefer, D.M., et al, 2016, European Group for Blood and Marrow Transplantation Centers with FACT-JACIE Accreditation Have Significantly Better Compliance with Related Donor Care Standards, *Biol Blood Marrow Transplant*, 22:514e519.

cent (2008), 3.09 per cent (2013), and 3.6 per cent (2018) based on bibliometric analysis of medical research in its *Measuring Up* reports.[33]

For this evaluation data from Scopus, which is a global abstract and citation database used to evaluate academic research performance,[34] was obtained for the 2010-2020 period and evaluated to determine the impact of Australia's blood cancer research community on blood cancer research globally. This analysis showed that over the past 20 years the impact of Australia's blood cancer community has consistently delivered a higher impact by a factor of two (Table 2.1).

Table 2.1: Australian share of publications, including high impact publications, 2010-2020

Citation analysis	All Australian medical research	Leukaemia	Lymphoma	Myeloma
Share of citations - all publications	3.1%-3.6%	6.3%	6.3%	5.2%
Share of citations - top quartile of publications		6.7%	5.6%	5.5%
Share of citations - publications with impact factor >10 (Top 2% of publications)		5.5%	5.8%	4.7%

Source: Scopus, NHMRC Measuring Up reports 2018, 2013, 2008

Moreover, Australian researchers have also accounted for an overweight share of clinical trials in blood cancer globally, even with its small population representing only 0.3 per cent of the world's population and around one per cent of reported blood cancer globally, noting that incidence tends to be under-reported in low- and middle- income countries (Table 2.2)

Table 2.2: Australian share of global clinical trials, 2000-2020 and 2015-2020

Disease	Share of global population	2000-2020	2015-2020
Leukaemia	1.3%	8%	11%
Lymphoma	1.3%	9%	11%
Myeloma	0.9%	3%	10%

Source: Clinicaltrials.gov; Australian 2018 incidence compared to global 2018 incidence as reported by World Cancer Research Fund, accessed at: https://www.wcrf.org/dietandcancer/cancer-trends/worldwide-cancer-data.

Thus, blood cancer research globally has delivered outsized improvements in survival and Australian researchers have accounted for a substantially higher share of high impact knowledge creation than the average for all medical research in Australia.

Taken together, these data show that investment in Australian blood cancer research likely delivered excellent value for money over the 2015-2020 period. For the purposes of this report, it was estimated that Australia's contribution to advances in blood cancer research has been in the order of six per cent.

Putting it all together: value of health gains from investment in blood cancer research

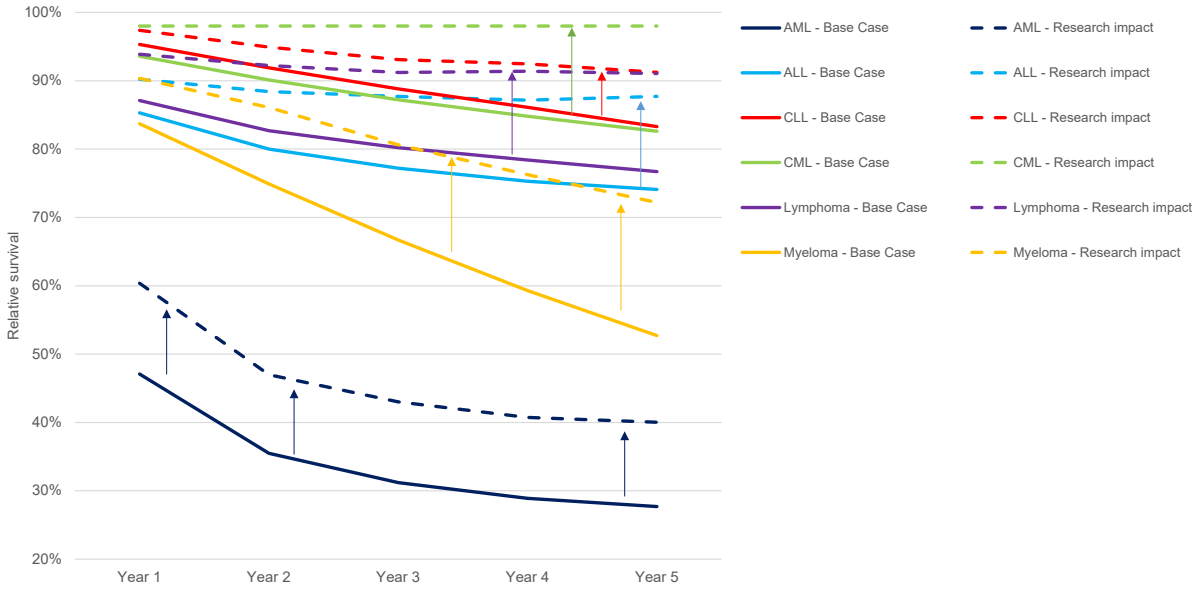
On average there is a 15-year lag between research investment and benefits realisation, with roughly seven years between research award and publication and a further seven between research publication and change in clinical practice. Applying the historical improvements in survival observed from the 1997-2001 period to the 2012-2016 period forward for each blood

[33] NHMRC, 2019, Measuring Up 2018, accessed at: https://www.nhmrc.gov.au/about-us/publications/measuring-2018; NHMRC, 2014, Measuring Up 2013, accessed at: Measuring up 2013 | NHMRC

[34] See Scopus overview at https://www.elsevier.com/solutions/scopus?dgcid=RN_AGCM_Sourced_300005030.

cancer sub-type yields expected five-year survival curve improvement for each of the blood cancer sub-types (Figure 2.4).

Figure 2.4: Expected improvements in research holding investment and improvements in survival constant



Source: Analysis of AIHW relative survival curves for selected blood cancer sub-types 1997-2001, 2012-2016.

Applying these improvements to projected incidence over the 2030-2040 horizon would see the gain of 186,000 additional life years; of this, 85 per cent of these gains could be expected to be realised as a result of academic research, with Australia's blood cancer community accounting for at least six per cent of this total. On net, Australia's research community could be expected to see an additional 9,500 in additional years of life gained over the 2030-2040 period. Valued at $50,000 per QALY gained, this would generate more than $233 million in benefit for the community in $NPV_{1.5\%}$ terms and a return on government investment in blood cancer research in terms of health gains alone of $2.60 for every dollar invested (Benefit Cost Ratio of 3.6).

Investment gains from investment in blood cancer research

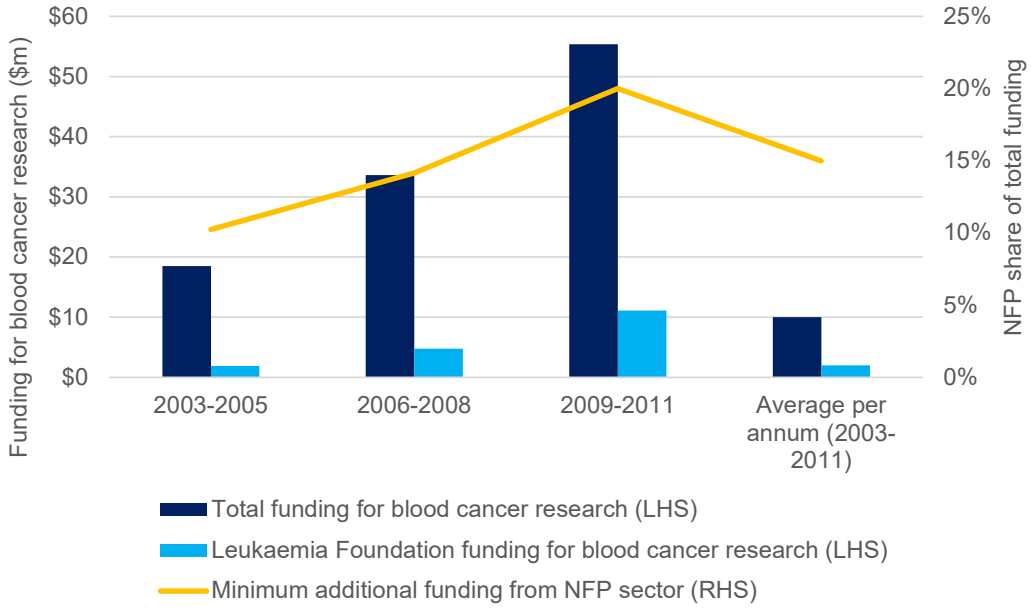
Successive Cancer Australia research audits show that government investment in blood cancer research can be an important catalyst for additional private sector investment in Australia that may not otherwise be expected to occur, and which can accelerate and increase the impact of blood cancer research in Australia.

Historical data show the Leukaemia Foundation accounted for 15 per cent of all research funding in Australia over the 2003-2011 period (Figure 2.5). Importantly, this is the minimum additional leverage estimate, as other important charities focused on research, such as the Snowdome Foundation and Australian Cancer Councils, as well as other international research organisations have also invested in Australia's high impact blood cancer research community.

Cancer Australia estimates that overall Australian governments account for 66 per cent of total funding, which would imply Australian governments have invested around $7 million in blood cancer research historically.[35]

[35] Funder data are not evaluated at a tumour type level in Cancer Australia research audits to date.

Figure 2.5: Investment in blood cancer research



Source: Cancer Australia, 2014, Cancer Research in Australia, An overview of funding to cancer research projects and research programs in Australia 2006 to 2011 accessed at: https://www.canceraustralia.gov.au/sites/default/files/publications/cancer-research-australia-overview-funding-cancer-research-projects-and-research-programs-australia/pdf/cancer-research-in-australia-full-report.pdf and Leukaemia Foundation research data.

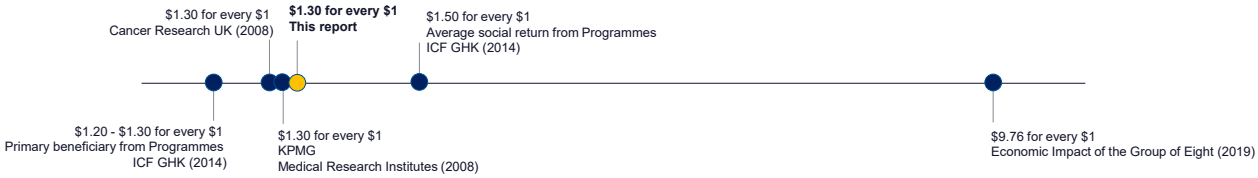
Thus, the private sector invests between 17.6 cents and 30 cents for every dollar the government invests. The development of a research roadmap, which aims to organise the sector around high value, high impact projects, would be expected to lift additional private sector investment compared to what would otherwise be the case.

Knowledge and productivity spillovers gains from investment in blood cancer research

In addition to realised health gains, investment in cancer research has a high spillover effect into the wider economy. This is particularly evident in blood cancer; advances in the understanding of genomics and personalised medicine, such breakthroughs in the development of targeted therapies for CML or CAR-T therapies for a range of blood cancers, have spilled over into research and treatment of other cancers and chronic conditions.

Knowledge and productivity spillovers can be challenging to quantify and vary depending on the nature of the innovation system. Open, strongly networked research ecosystems are the foundation of productivity spillovers. The valuation of spillovers ranges from returns of 20 per cent per annum, to a recent study of Australia's Group of Eight universities which assumed a productivity factor of $9.76 for every dollar invested (Figure 2.6).

Figure 2.6: Benchmarking productivity spillover assumptions – cancer and medical research studies



Source: Australian Commission on Quality and Safety in Health Care, 2017, Economic evaluation of investigator-initiated clinical trials conducted by networks; KPMG, 2018, Economic Impact of Medical Research in Australia, accessed at: Economic Impact of Medical Research in Australia (aamri.org.au); London Economics, 2019, Economic Impact of the Group of Eight Universities, accessed at: The economic impact of Group of Eight universities – Group of Eight (go8.edu.au).

Australian governments and the not-for-profit sector have supported the development of a highly networked, collaborative research network across Australia, manifest in the formation of the Blood Cancer Taskforce and Australia's significant research impact globally.

At a minimum, the productivity spillover return from investment in blood cancer research would be expected to be $1.30 for every $1 invested. Given the highly networked nature and track record for knowledge breakthroughs in genomics and personalised medicine, there is a strong case to be made that an investment in blood cancer research would be expected to exceed the average spillover rate.

Investing in a research roadmap would enable the potential for productivity and knowledge spillovers to be maximised, increasing the return beyond $1.30 for every $1 invested.

Total minimum return on investment in blood cancer research

The blood cancer research community has called for the development of a research roadmap to maximise the outcomes from blood cancer research, to ensure a high return on investment for every dollar invested.

Based on the expected health gains, investment gains, and productivity spillover gains as well as jobs creation in a knowledge intense industry, the minimum return on investment would be expected to be $3.46 for every dollar invested based on historical trends (BCR 4.5). The research roadmap would seek to improve on this return through strategic collaboration across Australia and with international researchers as appropriate.

Health and Economics from Action 3.1.1:

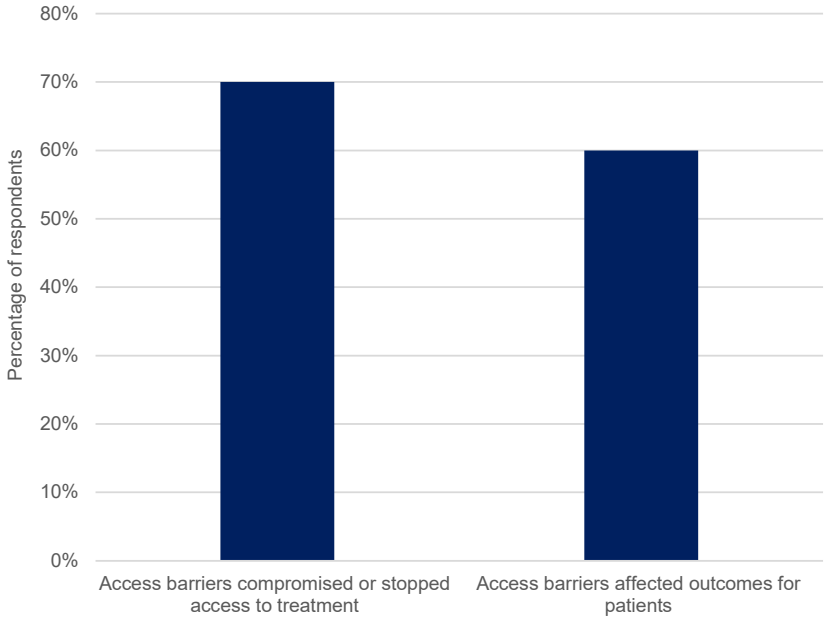
- **Additional private sector research funding of 17.6 cents to 30 cents for every $1 invested by governments**
- **Return on investment from health gains alone of $2.61 (BCR 3.6)**
- **Productivity spillovers of at least $1.30 for every $1 invested**
- **Highly skilled medical research jobs creation**
- **Total return on investment of $3.46 for every $1 invested (BCR 4.8) in blood cancer research**

2.4 Impacts of improving access to novel and specialised therapies (Action 4.3)

Blood cancer patients face significant access challenges for novel and specialised therapies arising from:

- A lack of market incentives to seek TGA registration of indications for rare blood cancer sub-types and/or PBS reimbursement, due to small patient populations, leading to significant off-label prescribing of therapies that are standard of care in blood cancer resulting in a failure to develop evidence to support registration and listing for rare indications
- Inconsistent availability to PBS listed medicines across Australian jurisdictions and hospitals due to high in-patient costs; for example, 70 per cent of ALLG and HSANZ members reported access barriers for high cost PBS funded therapies (Figure 2.7).

Figure 2.7: Access barriers for PBS-listed medicines



Source: ALLG and HSANZ Survey of ALLG and HSANZ membership 2019: Access to high cost PBAC approved drugs

Access to novel and specialised therapies is therefore a complex problem to fully resolve, requiring reforms aimed at:

- Improved regulation of off-label drug use
- Improved data capture of off-label drug use to support evidence development for TGA registration and PBS listing
- Addressing regulatory settings to allow for streamlined registration of additional indications for rare blood cancer sub-types by the TGA and price agreements for rare indications by the PBAC
- Funding model reform to reduce inter-jurisdictional inequity in access to PBS funded medicines
- Funding clinical trials aimed at developing evidence to support listing for novel therapies and diagnostics.

To address this multi-layered issue, the Action 4.3 of the National Strategic Action Plan proposes a systematic and formalised approach to identifying pathways for evidence development and access for an agreed shortlist of therapies in partnership with Australian Governments.

Addressing these inequities through a more transparent and regulated approach will yield improvements in survival as well as improvements in equity of access to quality and safe care across Australia. As shown in the below case studies, the therapies identified by the National Strategic Action Plan are clinically important but commercially small, leading to significant risks of access delays for patients and their families.

- *Case study: ALK Inhibitors in ALK+ve lymphoma* — Less than 1 per cent of all lymphomas are ALK+ve lymphomas, with less than 110 cases expected to be diagnosed in 2025 in both paediatric (10-15 per cent of all NHLs) and adult populations (1-2 per cent of all NHL).[36] In adult populations, around 20 per cent to

[36] van der Krogt, J, Vanden Bempt, M, Finalet Ferreiro, J, Mentens, N, et al, 2017, Anaplastic lymphoma kinase-positive anaplastic large cell lymphoma with the variant RNF213-, ATIC- and TPM3-ALK fusions is characterized by copy number gain

30 per cent of patients (roughly 20 patients per year) will be relapsed/refractory to treatment, with no standard treatment for these patients currently established. While hematopoietic stem cell transplant may be performed, the prognosis for these patients is poor.

At the same time, new research has emerged in the past 10 years demonstrating that ALK is a druggable target for cancer therapy. Clinical use of ALK inhibitors for 'ALK-rearranged' lung cancers has remarkably improved patient survival in the past decade and early trials in blood cancer have showed similar promise. For example, a literature review found complete remission and partial remission was achieved in 75 per cent of paediatric patients.[37] Similarly, overall survival at three years was reported to be 86 per cent in a Children's Oncology Group study of crizotinib in paediatric populations.[38] Early trial data for adult cohorts have shown a similar outcomes; a French program established in 2014 to avoid off-label use and allow for a nationwide access to crizotinib found complete or partial response was achieved for 67 per cent of patients in both paediatric and adult populations.[39]

Access to ALK inhibitors in Australia, however, is inconsistent and inequitable, arising from a lack of market incentives to seek TGA registration and PBS reimbursement for such a small patient population.

- *Case study: MRD testing in AML* — Patients diagnosed with AML are treated with chemotherapy if they are considered fit enough for treatment, with the goal of inducing complete remission, which is defined as a normal appearing bone marrow biopsy (<5% leukemic cells) and normal circulating blood counts. However, even when the patient is in complete remission, low levels of leukaemia cells may persist that are likely to have chemotherapy-resistance and stem cell properties. This minimal residual disease (MRD) can re-initiate AML within weeks to months; it is estimated more than 50 per cent of patients relapse, of which only 11 per cent survive after 5 years.[40]

  If, however, clinicians can pinpoint when a patient's MRD begins progressing towards the rapid expansion to relapse, pre-emptive therapies can be taken with better patient outcome.[41] A potentially curative therapy for AML is hematopoietic stem cell transplant, but these transplants are typically reserved for patients at high risk of disease relapse, because while hematopoietic stem cell transplant lowers relapse risk, it is associated with a high treatment mortality. MRD analysis allows clinicians to delay transplant for patients that are MRD negative and initiate transplant rapidly for patients with MRD positive results.[42] Since 2018, the European Leukaemia Network and the US FDA have both recommended expanding the application of MRD in AML.[43]

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of the rearranged ALK gene. Haematologica 2017;102(9):1605-1616; doi: 10.3324/haematol.2016.146571; and Sekimizu, M., Osumi, T, Fukano, R, Koga, Y, et al, 2018, A Phase I/II Study of Crizotinib for Recurrent or Refractory Anaplastic Lymphoma Kinase-Positive Anaplastic Large Cell Lymphoma and a Phase I Study of Crizotinib for Recurrent or Refractory Neuroblastoma: Study Protocol for a Multicenter Single-arm Open-label Trial

[37] Theilen, TM, Soerensen, J, Bochennek, K, Becker, M, et al, 2018, Crizotinib in ALK+ inflammatory myofibroblastic tumors—Current experience and future perspectives, Paediatric Blood and Cancer, doi: 10.1002/pbc.26920

[38] Mossé, YP, Lim, MS, Voss, SD, Wilner, K, et al, 2013, Safety and activity of crizotinib for paediatric patients with refractory solid tumours or anaplastic large-cell lymphoma: a Children's Oncology Group phase 1 consortium study, The Lancet Oncology, 14(6):472-480, doi: 10.1016/S1470-2045(13)70095-0.

[39] Brugières, L, Houot, R, Cozic, N, De La Fouchardière, C, et al, 2017, Crizotinib in Advanced ALK+ Anaplastic Large Cell Lymphoma in Children and Adults: Results of the Acs© Phase II Trial. Blood 2017; 130 (Supplement 1): 2831. doi: 10.1182/blood.V130.Suppl_1.2831.2831.

[40] Voso, MT, Ottone, T, Lavorgna, S, Venditti, A, et al, 2019, MRD in AML: The Role of New Techniques, Frontiers in Oncology doi: 10.3389/fonc.2019.00655

[41] Ibid

[42] Ibid, and Press, RD, Eickelberg, G, Froman, A, et al. Next-generation sequencing-defined minimal residual disease before stem cell transplantation predicts acute myeloid leukemia relapse. Am J Hematol. 2019; 94: 902– 912, doi: 10.1002/ajh.25514.

[43] Freeman, SD, and Hourigan, C, 2019, MRD evaluation of AML in clinical practice: are we there yet?. Hematology Am Soc Hematol Educ Program 2019; 2019 (1): 557–569. doi: 10.1182/hematology.2019000060

The use of MRD in AML is an example of a therapy that requires clinical trial funding or a registry-based approach to support evidence development for MBS listing and equitable access nationally.

- *Case study: Bortozemib and daratumumab for amyloidosis* — Roughly 15 per cent of persons diagnosed with myeloma are affected with amyloidosis; in 2025, this will translate to approximately 440 patients being diagnosed with amyloidosis. Recent research breakthroughs have seen treatment options for amyloidosis expand rapidly, including therapies used in combination with novel agents such as bortozemib and/or daratumumab.

  As noted in the current treatment guidelines for AL amyloidosis developed by the Myeloma Foundation, bortezomib-based regimens are the preferred front-line therapy for amyloidosis, with multiple studies demonstrating superior haematological response and progression free survival compared to historical chemotherapy regimens.[44]

  More recently, studies have shown the incorporation of daratumumab further improves outcomes for patients; the percentage of amyloidosis patients who had a complete response was significantly higher for patients receiving daratumumab than in the control group: 53.3 per cent vs. 18.1 per cent (relative risk ratio, 2.9; 95% confidence interval [CI], 2.1 to 4.1; P<0.001).[45]

  Neither of these novel agents are indicated or reimbursed for amyloidosis in Australia today, however.

- *Case study: BRAF inhibitors for hairy cell leukaemia* — Hairy cell leukemia is a relatively rare type leukaemia, accounting for approximately two per cent of all leukaemia diagnoses each year (around 200 patients) and occurring in men more frequently at a rate of 4-5:1. While hairy cell leukaemia often initially responds well to chemotherapy, up to 50 per cent of patients are expected to relapse, often multiple times, becoming progressively less sensitive to these treatments over time. Recently, the BRAF-V600E kinase has been identified as targetable mutation, opening the way for new treatment options for these patients. Early studies have found that in relapsed/refractory patients complete or partial remission was observed in 96 per cent of patients (CR = 35%) and 100% of patients (CR = 42%) in an Italian trial (n = 25 patients) and a US trial (n = 24 patients), respectively. At a median follow-up of 23 months, the median relapse-free survival in the Italian trial was 19 months in patients who had achieved CR and 6 months in those who had obtained PR; the median treatment-free survival in these cases was 25 and 18 months, respectively. In the US study, the progression-free survival and the overall survival at 1 year were 73% and 91%, respectively.[46]

  Currently, BRAF inhibitors are used successfully in the treatment of melanoma; BRAF inhibitors, however, are not registered and PBS reimbursed in Australia for hairy cell leukaemia. Given the small patient population, the risk of off-label use without evidence development and significant delays to reimbursement are significant.

- *Case study: Molecular diagnostics* — Critically, the molecular diagnostics required to diagnose ALK+ve lymphomas and hairy cell leukaemias are not MBS listed, and

[44] Myeloma Australia, 2019, Clinical Practice Guideline Systemic AL amyloidosis, accessed at: https://myeloma.org.au/wp-content/uploads/2019/10/MSAG_ATG_oct19.pdf

[45] Kastritis, E, Palladini, G, Minnema, MC, Wechlekar, AD, et al, 2021, Daratumumab-Based Treatment for Immunoglobulin Light-Chain Amyloidosis, N Engl J Med 2021; 385:46-58
DOI: 10.1056/NEJMoa2028631

[46] This summary is based on analysis and data reported in: Falini, D., Tiacci, E, 2019, New treatment options in hairy cell leukemia with focus on BRAF inhibitors, doi: 10.1002/hon.2594

therefore inconsistently used, leading to risks of inaccurate diagnoses for blood cancer patients and inappropriate treatments.

The use of molecular diagnostics is an example of a technology that requires clinical trial funding or a registry-based approach to support evidence development for MBS listing and equitable access nationally – and in turn, improve health outcomes through better diagnosis and treatment of these rare blood cancers.

Health and Economics from Action 4.3:

- **More equitable access to novel therapies, with enhanced regulatory transparency and evidence development for rare blood cancer sub-types**
- **Improvements in survival through access to novel therapies**

2.5 Impacts of empowering patients through improved information (Action 1.2)

One of the most significant barriers to the empowerment of people living with blood cancer is the complexity of the Australian healthcare and welfare systems. Patients and their families can feel overwhelmed by a cancer diagnosis, and lack effective tools for finding timely, personalised information to support informed conversations. At the same time, significant decisions are made at this time that can have real consequences for their long-term health and financial wellbeing. It starts with the selection of their specialist, the understanding of their diagnosis and treatment options, and progresses through to how to get the right supportive care for themselves and their families that help them to not just survive, but also live well.

The Survey of People Living with Blood Cancer undertaken as part of the *State of the Nation* report,[47] to which more than 3,200 patients from across Australia responded found that:

- One of five people living with blood cancer report feeling 'completely uncertain' or having 'lots of questions' about their diagnosis
- More than 10 per cent report having 'a lot of questions' or 'feeling completely uncertain' about their treatment plan
- Less than half of patients reported receiving a written care plan, which is inconsistent with recommended clinical best practice and OCP recommendations
- More than a third of respondents indicated that no supportive care was discussed at treatment planning (Figure 2.5).

Reflecting patient uncertainty and questions about their blood cancer, more than one in four patients reported they wished they had more information at treatment planning about the following services:

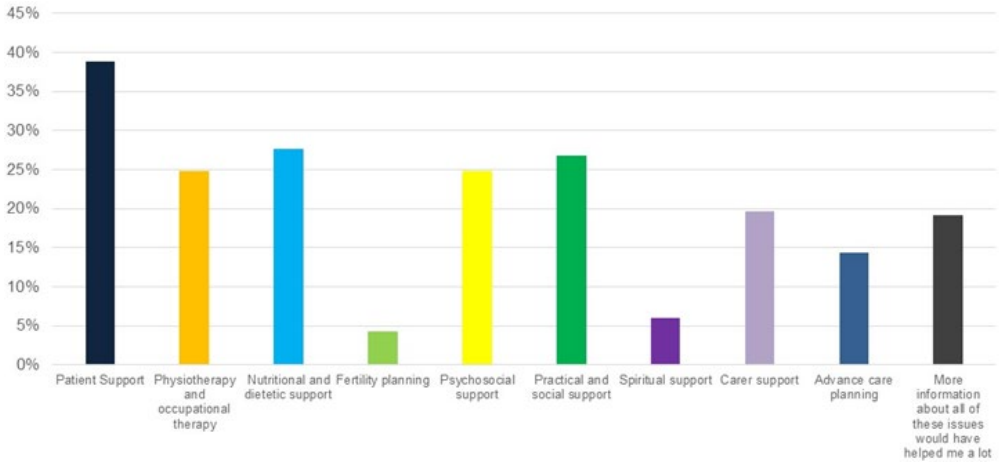
- Patient support services, which can support patients to better navigate the health care system)
- Nutritional and dietetic support
- Practical and social support
- Psychosocial support

[47] Leukaemia Foundation, 2019, *State of the Nation: Blood Cancer in Australia*, prepared by Insight Economics, accessed at: https://www.leukaemia.org.au

- Physiotherapy and occupational therapy.

One in five indicated they wish they had received more information about the whole range of supportive care services.

Figure 2.1: In hindsight, what do you wish had been discussed at treatment planning?



Source: Leukaemia Foundation, 2019, State of the Nation: Blood Cancer in Australia, prepared by Insight Economics, accessed at: https://www.leukaemia.org.au Survey of People Living with Blood Cancer, see Appendix B in that report.

The Survey of People Living with Blood Cancer also found that Google was the third most frequently cited source of information, following their haematologist (#1) and the Leukaemia Foundation (#2).[48] These data highlight the high latent demand for health-related information, particularly in the context of increasing consumer expectations for patient-centred care.[49] They also point to risks of patients finding and relying on unreliable information or seeking out services that are not evidence-based. More needs to be done to help people navigate to information that they and their clinicians can trust.

There are a number of trusted sources of information for blood cancer patients and clinicians, including Federal, state and territory departments of health and agencies such as Cancer Australia – as well as patient organisations like Cancer Council, Leukaemia Foundation, Lymphoma Australia, Myeloma Australia, MPN Alliance, WMozzies, Australian Amyloidosis Network, Rare Cancers and Canteen, among others.

Credible patient organisations that are focused on specific diseases can be a critical link to evidence-based information. They may also provide access to tools and resources that can be used to inform treatment and care, for both patients and clinicians.

The development of standard templates for written treatment and survivorship care plans, alongside the digital information strategy for cancer being developed through the Australian Cancer Plan will enable greater consistency and clarity of information provided to patient carers and their families across Australia.

[48] Leukaemia Foundation, 2019, *State of the Nation: Blood Cancer in Australia*, prepared by Insight Economics, accessed at: https://www.leukaemia.org.au/about-us/mylifecounts/stateofthenation/. p 49.
[49] See for example: CHF, 2018, *White Paper Shifting Gears: Consumers Transforming Health* accessed at: https://chf.org.au/sites/default/files/181125_shifting_gears_-_consumers_transforming_health.pdf and Productivity Commission, 2019, *Shifting the Dial: 5-Year Productivity Review*, accessed at: https://www.pc.gov.au/inquiries/completed/productivity-review/report/productivity-review.pdf.

Health and Economics from Action 1.2:

- **Reduced inconsistencies and incomplete information to blood cancer patients and their carers through written treatment and survivorship care plan templates.**

2.6 Impacts of empowering patients through improved information about blood cancer in Aboriginal and Torres Strait Island cohorts (Action 1.6.1)

In 2008, the significant disparities in health and wellbeing outcomes between Aboriginal and Torres Strait Islander people and the wider Australian community were quantified and established as a major policy priority for Australian governments. In that year the *Closing the Gap Strategy* was developed, with the goal of achieving health equity between Indigenous and non-Indigenous Australians by 2030.

AIHW data show that cancer contributes to the gap in health outcomes. For example, survival rates across all cancers are lower for Indigenous Australians compared to non-Indigenous Australians;[50] the survival rates for all cancers combined from 2010-2014 was 59.3 per cent for non-Indigenous Australians compared to 48.1 per cent for Indigenous Australians.

From a blood cancer perspective, there are very limited public data available to inform policy development. Stakeholder consultations indicated the challenges associated with reporting of blood cancers generally is likely to be exacerbated for Indigenous Australians, because incidence rates for rare diseases in small populations can vary substantially from one period to another, leading to potential statistical instability. Data on the incidence of all cancers, including blood cancers, are collected by state cancer registries and collated in the Australian Cancer Database. Not all state cancer registries report cancer incidence and mortality for Indigenous Australians, and there are variations between the reporting of incidence and mortality across these registries. The AIHW analyses data submitted to the Australian Cancer Database and reports on the highest incidence cancers for Indigenous Australians.

Publicly reported data from the AIHW on the incidence and survival rates of blood cancers in Aboriginal and Torres Strait Islander communities is largely currently limited to lymphoma:[51]

- *Incidence* — There were 52 cases of NHL per year reported in 2019, with an incidence rate per 100,000 which is 10 per cent lower than for non-Indigenous populations. Data are not publicly reported for other sub-types.
- *Prevalence* — Reported prevalence of 230 people with NHL. No information is reported for other blood cancer sub-types.
- *Survival rates* — Five-year survival rate for lymphoma is lower in Aboriginal and Torres Strait Islander populations (62.9 per cent) than that of non-Indigenous populations (64.7 per cent).

Putting effort into understanding the true incidence, prevalence and survival of blood cancers is likely to see these rates increase. No data for Aboriginal and Torres Strait Islander populations are currently reported for leukaemias, myeloma, or other blood cancers (MDS, MPN). This under-diagnosis and under-reporting is consistent with WHO cancer statistics, which shows that regions marked by lower socioeconomic advantage tend to report lower

[50] AIHW, 2019, *Cancer in Australia*, https://www.aihw.gov.au/reports/cancer/cancer-in-australia-2019/contents/table-of-contents
[51] Haigh, M., Burns, J., Potter, C., Elwell, M., Hollows, M., Mundy, J., Taylor, E., Thompson, S., 2018, *Review of cancer among Aboriginal and Torres Strait Islander people*. Australian Indigenous Health Bulletin, 18(3). Retrieved from: http://healthbulletin.org.au/articles/review-of-cancer-2018/; AIHW, 2019, *Cancer in Australia,* https://www.aihw.gov.au/reports/cancer/cancer-in-australia-2019/contents/table-of-contents.

rates of incidence and prevalence than wealthier countries.[52] The high risks of under-diagnosis and under-reporting were also strongly supported by Aboriginal and Torres Strait Islander experts consulted as part of the National Strategic Action Plan development, as well as written submissions.

What data are available, however, suggests that Aboriginal and Torres Strait Islander people experience poorer health outcomes for blood cancer than non-Indigenous Australians. Available data report Aboriginal and Torres Strait Islander cohorts are:

- 20 per cent less likely across all cancers to attend the GP compared to non-Indigenous patients[53]
- More likely to be diagnosed at more advanced stage of cancer[54]
- Less likely to be hospitalised for the treatment of their cancer. Rates of hospitalisation for Aboriginal and Torres Strait Islanders was:[55]
  - 20 per cent less likely across all cancers
  - 60 per cent less likely in NHL
  - 40 per cent less likely in ALL.

  The probability of formal hospitalisation decreased with remoteness: Aboriginal and Torres Strait Islander people are 30 per cent less likely to be hospitalised if the person resided in outer regional, remote and very remote areas[56]
- Less likely to be able to find a matched donor if they require an allogenic stem cell transplant, with the AMBDR reporting a lack of Aboriginal representation in donor registry[57]
- More likely to have more co-morbidities:[58]
  - 67 per cent more than one co-morbidity
  - 33 per cent three or more co-morbidities
- Less likely to participate in clinical trials. One the one hand, co-morbidity can render a patient ineligible for clinical trial participation; however, larger issues have been identified to include barriers arising from governance, patient motivation, service delivery and capacity[59]
- More likely to face transport challenges. Land is central to wellbeing for Aboriginal and Torres Strait Islander peoples, as is the centrality of family and kinship. The ability to see children or bring children to specialist centres, and return travel to communities was reported to strongly influence engagement with the healthcare

[52] WHO, 2019, *World Cancer Report*.
[53] Haigh, M., Burns, J., Potter, C., Elwell, M., Hollows, M., Mundy, J., Taylor, E., Thompson, S., 2018, *Review of cancer among Aboriginal and Torres Strait Islander people*. Australian Indigenous HealthBulletin, 18(3). Retrieved from: http://healthbulletin.org.au/articles/review-of-cancer-2018
[54] Diaz 2015 – add formal citation
[55] Haigh, M., Burns, J., Potter, C., Elwell, M., Hollows, M., Mundy, J., Taylor, E., Thompson, S., 2018, *Review of cancer among Aboriginal and Torres Strait Islander people*. Australian Indigenous HealthBulletin, 18(3). Retrieved from: http://healthbulletin.org.au/articles/review-of-cancer-2018
[56] *Ibid*.
[57] ABDMR submission to the National Strategic Action Plan.
[58] Australian Government, 2017, National Strategic Framework for Chronic Conditions, accessed at: https://www1.health.gov.au/internet/main/publishing.nsf/Content/nsfcc.
[59] Facilitators and barriers to implementation of a pragmatic clinical trial in Aboriginal health services
Hueming Liu, Tracey-Lea Laba, Luciana Massi, Stephen Jan, Tim Usherwood, Anushka Patel, Noel E Hayman, Alan Cass, Anne-Marie Eades, Chris Lawrence and David P Peiris Med J Aust 2015; 203 (1): 24-27. || doi: 10.5694/mja14.00581

system.[60] Multiple stakeholders indicated there are challenges in some cases in accessing Patient Assisted Travel Scheme (PATS) funding to enable the return to country between treatment intervals.

- More likely to under-report pain, resulting in under-utilisation of palliative care.[61]

'Closing the Gap' will require significant improvements in a range of chronic diseases, including cancer. Lung and liver cancer are serious concerns for the community, diagnosed at two times the rate of non-Indigenous populations per 100,000. At the same time, blood cancers are likely under-reported and under-diagnosed, and more data is needed to understand true incidence.

Investment in an epidemiological study would be expected to close data gaps with respect to blood cancer sub-types and help inform a targeted strategy towards these patient cohorts.

Health and Economics from Action 1.6.1:

- **Data to inform cost effective health service planning for Aboriginal and Torres Strait Islander cohorts**

2.7 Conclusion: no regrets, high return investment

Phase 1 initiatives are core enabling infrastructure for the realisation of the vision of the National Strategic Action Plan.

While the full realisation of the benefits is dependent on the complete implementation of the National Strategic Action Plan, they are represent the first step towards significant improvements in quality, safety, and equitable access in blood cancer treatment in Australia.

Economic benefits in the form of more than $800 million in additional years of life and GDP growth of nearly $1 billion over the 2025-2040 period substantially exceed funding requirements.

Compared to the required project cost of $3.7 million (See Chapter 3 and Appendix B for detailed project costings) this constitutes a no-regrets investment, with returns significantly in excess of the costs of implementation and which is mindful of the wider fiscal context of government.

While this investment is modest in the context of total government expenditure on both blood cancer treatment and research, it substantially exceeds the not-for-profits' capacity to fund independently, particularly against the backdrop of persistent pandemic trading conditions. This funding will support the realisation of the National Strategic Action Plan for Blood Cancer vision, which is critical to implementing a national reform effort given Australia's federated health system.

[60] Optimal Care Pathway for Aboriginal and Torres Strait Islander people accessed at: https://www.cancer.org.au/content/ocp/Optimal_care_pathways_Aboriginal and Torres Strait Islander_Report_August_2018.PDF

[61] *Ibid.*

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Chapter 3

Costs and implementation planning

The Blood Cancer Taskforce has developed detailed project implementation plans and costs, informed by an assessment of implementation options and risks.

Appendix B provides detailed project descriptions, including proposed timing, costs and risks to be managed. This chapter presents the summary of the costs and key project governance approach.

3.1 Funding requirements

The expected total cost of Phase 1 over the first three years is $3.7 million in real $2020 dollars (Table 3.1).

Table 3.2 summary of costs by key cost component. In addition to specific Action Plan projects, the costings also provide for administrative support through the Blood Cancer Secretariat. is costed independent of projects. The project costing does not include:

- Blood Cancer Taskforce member time in Taskforce meetings
- Project Steering Committee member time meetings
- Australian Governments (Federal and State) representative time on Project Steering Committees meetings.

The in-kind costs of senior blood cancer leader time to support the operation of the Blood Cancer Taskforce and oversight of proposed projects was estimated to be in the order of $460,000 over the forward estimates, which is on top of the time already donated for the development of the National Strategic Action Plan and Blood Cancer Taskforce to date.

Table 3.1: Phase 1 Funding Requirements

	Total	MYEFO21	2022-23	2023-24	2024-25	2025-26	2026-27
Essential standard setting projects (Govt funding)	**$2,769,897**	**$713,115**	**$1,028,391**	**$1,028,392**	**$0**	**$0**	**$0**
Oversight, leadership and coordination							
Extend the Blood Cancer Taskforce (expires Dec 2021)	$147,324	$29,465	$58,930	$58,930	-	-	-
Quality standards for blood cancer diagnosis, treatment and care							
Action 1.3.1 Written care plan templates	$282,862	$282,862		-	-	-	-
Action 2.1.1 & 2.2.1 clinical and diagnostic guidelines	$764,640	$127,440	$318,600	$318,600	-	-	-
Action 2.1.1 Additional OCPs (est. 5 additional subtypes)	$167,483	$28,750	$69,366	$69,367	-	-	-
Address challenges for patient access to novel and specialised therapies							
Action 4.3.1 Enabling Access Working Group	$1,107,588	$184,598	$461,495	$461,495	-	-	-
Personnel support (contingent on size and scale of funded projects)							
Leukaemia Foundation personnel support (x1 FTE @ $120k p/a)	$300,000	$60,000	$120,000	$120,000	-	-	-

	Total		2022-23	2023-24	2024-25	2025-26	2026-27
Research projects (potential non-govt funding)	**$913,343**		**$669,436**	**$243,907**	**$0**	**$0**	**$0**
Action 3.1.1 Blood Cancer Research Roadmap	$181,623	-	$181,623	-	-	-	
Action 1.6.1 Epidemiological study in Indigenous people	$731,720	-	$487,813	$243,907	-	-	-

Total package	**$3,683,240**

Table 3.2: Costing by project

Essential standard setting projects (Govt funding)	
Extend the Blood Cancer Taskforce and secretariat	
Project Management (15% PMO fee)	$8,840
Taskforce Secretariat (0.25 FTE project manager)	$28,590
Travel Costs	$16,500
Audit	$5,000
ANNUAL COST	**$58,930**
Written care plan templates	
Project Lead (5% of total cost)	$11,786
Project Management (15% PMO)	$35,358
Project Team (project manager and consultant)	$235,718
TOTAL COST	**$282,862**
Improved access to therapies	
Project Lead (5%)	$46,150
Management Costs (15%)	$138,448
Senior Project Manager + Consultant	$372,077
Access to Novel Therapies	$408,206
Access to Cellular Therapies	$142,706
TOTAL COST	**$1,107,588**
Clinical and diagnostic guidelines (estimate up to 6 disease areas)	
Project Lead Oversight (5% admin fee)	$31,860
Project Management (15% PMO fee)	$95,580
Content development (Medical writer + Clinical Lead)	$631,800
Professional editing (estimate)	$5,400
TOTAL COST	**$764,640**
Additional OCPs (x5)	
Project Lead Oversight (5% admin fee)	$7,190
Project Management (15% PMO fee)	$21,560
Consumer Guide ($90ph*45 hrs)*5	$20,250
OCP, QRG and Content development (Medical writer)*5	$70,875
Professional editing	$4,500
Graphic design	$13,108
Translation of Consumer Guides	$30,000
TOTAL COST	**$167,483**
Research projects (potential non-govt funding)	
Blood Cancer Research Roadmap Project costs	
Project Lead (5% admin fee)	$2,088
Project Management (15% PMO fee)	$6,264
Project Team (Project Director, Manager and Analyst)	$41,760
Research Roadmap consultancy costs	$115,000
10% Contingency	$16,511
TOTAL COST	**$181,623**
Epidemiological Study of Blood Cancer in Indigenous People	
Project Lead (5% admin fee)	$27,717
Project Management (15% PMO fee)	$83,150
Research Roadmap consultancy costs	$554,333
Contingency 10%	$66,520
TOTAL COST	**$731,720**

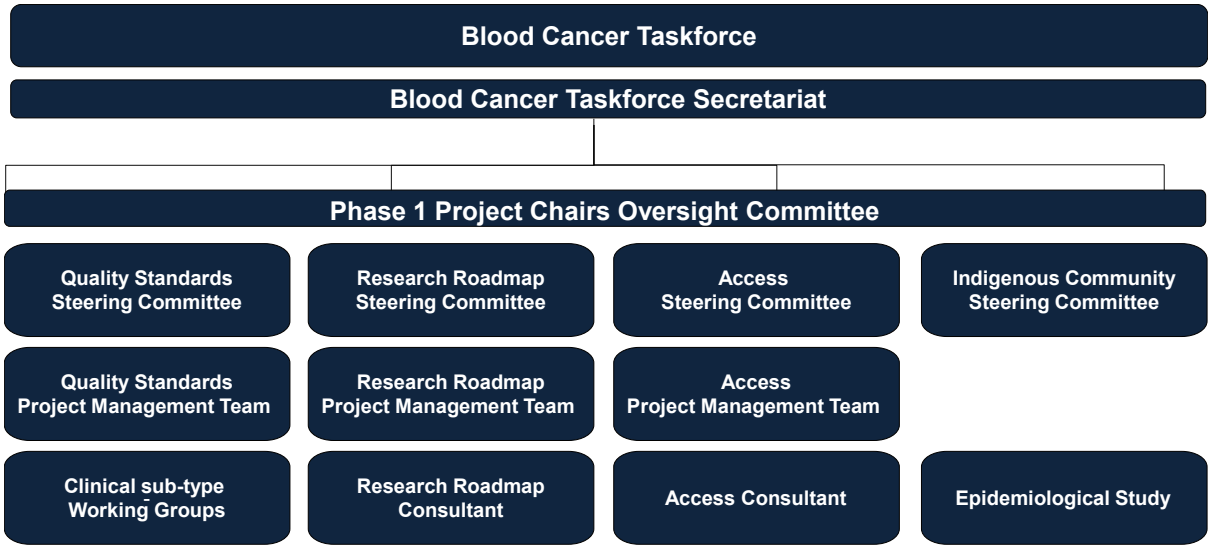
3.2 Project governance

Project Governance will be devolved to Project Steering Committees, which will identify Project Lead organisations and Project Teams, to allow for maximum blood cancer community collaboration and specialist skills to be brought to each project.

Project Teams will report monthly to the Oversight Committee to ensure effective integration of approach across each project, supported by the Secretariat, which would have responsibility for reporting to the Taskforce and Department of Health.

Project management costs and content development costs have been included for each project except Action 1.6.1 (Epidemiological study of blood cancer in Aboriginal and Torres Strait Islander populations), which was costed based on benchmarked grants analysis.

Figure 3.1: Proposed Project governance



Appendix A

Consultation Process

A.1 Blood Cancer Taskforce

Taskforce member	Affiliated organisation
Professor Sanchia Aranda AM	Cancer Council Australia
Dr Sharon Avery	Cairns Base Hospital
Dr John Bashford	Icon Group & PCPA
A/Professor Kate Burbury	Peter MacCallum Cancer Centre
Dr Joe Collins	Lions Club International
Dr Michael Dickinson	Lymphoma Australia, Chair Medical Subcommittee
Dr Chris Fraser	ANZCHOG
Professor Maher Gandhi	Mater Research Institute
Professor David Gottlieb	Westmead Hospital
Barbie Hartigan	Leukaemia Foundation Patient Support
Professor Tim Hughes	SAHMRI
Dr Paul Jackson	Cancer Australia
Professor David Joske	Solaris Health WA
Melanie Kelly	Insight Economics
A/Professor Rishi Kotecha	Curtin University
A/Professor Steven Lane	QIMR Berghofer
Professor Paula Marlton	Princess Alexandra Hospital
Dr Robert Menz	RACGP
A/Professor Peter Mollee	Australasian Leukaemia & Lymphoma Group
Carmel O'Kane	Cancer Nurses Society of Australia
Bill Petch (co-chair)	Leukaemia Foundation
Professor Miles Prince AM	Snowdome Foundation; Myeloma Australia, Epworth Hospital
Professor Andrew Roberts	Walter and Eliza Hall Institute

Taskforce member	Affiliated organisation
Professor John Seymour AM (co-chair)	Peter MacCallum Cancer Centre & Royal Melbourne Hospital
Deborah Sims	Blood Cancer Survivor
Dr Delaine Smith	Australasian Leukaemia & Lymphoma Group
Elizabeth de Somer	Medicines Australia
Dr Will Stevenson	Haematology Society of Australia & New Zealand
Richard Vines	Rare Cancers Australia
Dr Meg Wall	HSANZ Council

A.2 Working Group members

Working Group member	Affiliated organisation
Achieving Best Practice	
Professor John Seymour AM (Lead)	Peter MacCallum Cancer Centre & Royal Melbourne Hospital
Professor Sanchia Aranda AM	Cancer Council Australia
Dr John Bashford	Icon Group & PCPA
A/Professor Kate Burbury	Peter MacCallum Cancer Centre
Dr Joe Collins	Lions Club International
Professor David Currow	*Cancer Institute NSW*
Dr Michael Dickinson	Peter MacCallum Cancer Centre/Lymphoma Australia
Professor Maher Gandhi	Mater Research Institute
Barbie Hartigan	Leukaemia Foundation Patient Support
Professor David Joske	Solaris Health WA
Dr Robert Menz	RACGP
Bill Petch	Leukaemia Foundation
Sam Soggee	*HSANZ Nurses Committee*
Dr Will Stevenson	Haematology Society of Australia & New Zealand
Optimal Care Pathways/Treatment guidelines	
Professor John Seymour AM (Lead)	Peter MacCallum Cancer Centre & Royal Melbourne Hospital
Dr Emma Cohen	*Austin Health*
A/Professor Ilona Cunningham	*Head of Haematology, Concord Hospital*
Dr Michael Dickinson	Lymphoma Australia, Chair Medical Subcommittee

Working Group member	Affiliated organisation
Dr Shaun Fleming	*Alfred Hospital & Epworth Hospital*
Dr Simon Gibbs	*Monash*
Dr Nada Hamad	*Kinghorn Cancer Centre*
Dr Devendra Hiwase	*SA Health*
Professor Joy Ho	*RPA*
Professor Tim Hughes	SAHMRI
Professor Maarten Ijzerman	*UniMelb*
Dr Louise Imlay-Gilespie	*RHC*
Dr Robert Menz	RACGP
A/Professor Peter Mollee	Australasian Leukaemia & Lymphoma Group
Dr David Ross	*SA Pathology*
Deborah Sims	Blood Cancer Survivor
Danielle Spence	*Cancer Council VIC*
Dr Will Stevenson	Haematology Society of Australia & New Zealand
Professor Con Tam	*St Vincent's Private Hospital & Peter MacCallum Cancer Centre*
A/Professor Andrew Wei	*Monash*
Patient Reported Outcomes	
Professor Sanchia Aranda AM (Lead)	Cancer Council Australia
Linda Brown	Cancer Symptom Trials, UTS
Sue Evans	Cancer Council VIC
Professor Afaf Girgis	UNSW
A/Professor Karla Gough	Peter MacCallum Cancer Centre
Professor Maarten Ijzerman	UniMelb
Professor David Joske	Solaris Health WA
Shelley Rushton	Cancer Institute NSW
Dr Delaine Smith	Australasian Leukaemia & Lymphoma Group
Supportive Care	
Professor David Joske (Lead)	Solaris Health WA
A/Professor Anna Boltong	VCCC
A/Professor Prue Cormie	Ex-Med Cancer
Professor Elizabeth Eakin	University of Queensland
Professor Mei Krishnasamy	VCCC & UniMelb

Working Group member	Affiliated organisation
Professor Sandi Hayes	QUT
Nicole Kinnane	ACSC
Katherine Lane	Cancer Council VIC
Dr Kylie Mason	Peter MacCallum Cancer Centre
Dr Robert Menz	RACGP
Deborah Sims	Blood Cancer Survivor
Andrew Smith	Leukaemia Foundation
Trish Wilson	Bloomhill Cancer Centre
D/Professor Patsy Yates	QUT
Diagnostics	
Professor Maher Gandhi (Lead)	Mater Research Institute
Dr Piers Blombery	Peter MacCallum Cancer Centre
A/Professor Sue Branford	Centre for Cancer Biology
Jana Chromicka	MA industry representative - Sanofi
Dr Peter Diamond	Leukaemia Foundation
Professor Wendy Erber	UWA
Jill Finlayson	PathWest
Kelly Griffiths	MA industry representative - ViiV/GSK
Professor Maarten Ijzerman	UniMelb
Professor Harry Iland	RPA
A/Professor Bryone Kuss	Flinders Medical
Professor Miles Prince AM	Snowdome Foundation; Myeloma Australia, Epworth Hospital
Dr Archna Sharma	UTAS
Dr Will Stevenson	Haematology Society of Australia & New Zealand
A/Professor Jenny Turner	Douglass Hanly Moir
Dr Bronwyn Williams	QLD Health
Dr Helen Wordsworth	RCPA & Sullivan Nicolaides
Accelerating Research	
Professor Andrew Roberts (Lead)	Walter and Eliza Hall Institute
Dr Saraid Billiards	MRFF
Suzie Bratuskins	Snowdome Foundation
Dr Graham Brown	Foursight Associates

Working Group member	Affiliated organisation
Miriam Dexter	Snowdome Foundation
Dr Peter Diamond	Leukaemia Foundation
Professor David Gottlieb	Westmead Hospital
Professor Michele Haber	CCIA
Professor Joy Ho	RPA
Dr Paul Jackson	Cancer Australia
A/Professor Rishi Kotecha	Curtin University
A/Professor Steven Lane	QIMR Berghofer
A/Professor Zoe McQuilten	Monash
A/Professor Peter Mollee	Australasian Leukaemia & Lymphoma Group
Dr Delaine Smith	Australasian Leukaemia & Lymphoma Group
Dr Masha Somi	MRFF
Professor Judith Trotman	Concord Hospital
A/Professor Andrew Wei	Monash
Professor Deborah White	SAHMRI
Enabling Access	
Dr Delaine Smith (Lead)	Australasian Leukaemia & Lymphoma Group
Dr Tara Cochrane	Haematologist, Gold Coast
Dr Michael Dickinson	Lymphoma Australia, Chair Medical Subcommittee
Dr Chris Fraser	ANZCHOG
Professor Maher Gandhi	Mater Research Institute
Dr Jim Griffiths	Haematologist, PCPA
Dr Carolyn Grove	Haematologist, Sir Charles Gairdner Hospital, PathWest
Dr Eliza Hawkes	ONJ
Dr Georgina Hodges	Haematologist, Townsville – Icon Cancer Centre
Petrina Keogh	Medicines Australia
Peter Komocki	Medicines Australia
A/Professor Steven Lane	QIMR Berghofer
Dr Robert Menz	RACGP
Ashley McInnes	Patient and advocate
Sharon Millman	Lymphoma Australia
A/Professor Peter Mollee	Australasian Leukaemia & Lymphoma Group

Working Group member	Affiliated organisation
Professor Hamish Scott	SA Genomics, SAHMRI
Deborah Sims	Blood Cancer Survivor
A/Professor Ferenc Szabo	Haematologist, Darwin
Megan Varlow	Cancer Council Australia
Richard Vines	Rare Cancers Australia
Hayley Williams	Haematology Cancer Care Coordinator, Darwin
Professor John Zalcberg	ACTA

Appendix B

Detailed project assumptions

B.1 Blood Cancer Taskforce Secretariat

Role requirements

The Blood Cancer Taskforce Secretariat will:

- In Q1 and Q2 of 2021, the Blood Cancer Secretariat will work with the Blood Cancer Taskforce and Australian Governments to support the formation of:
  - Phase 1 Project Steering Committees
  - Phase 1 Project Management Teams
- Over the course of 2021, the Blood Cancer Secretariat will engage with all Project Management Teams to get a monthly update on project status and report to the Project Steering Committee Chairs to ensure alignment of projects, these reports will be circulated to the Taskforce Chairs meeting.
- Prepare progress reports to the Blood Cancer Taskforce

FTE requirements

It is assumed that performing the above secretariat functions will require 0.5 FTE during the establishment phase (Q1 and Q2 2021) then 0.25 FTE of a Project Manager and 0.25 FTE of a Project Analyst's time over the first three years of National Strategic Action Plan implementation.

Other costs: Taskforce expenses

- Assume one in-person meeting per year requiring 30 members to travel, at average cost of $535 per member.
- External audit of LF management for OCP, Taskforce and implementation projects of $5,000.00
- Consultant fees for Stage 1 implementation plan costings of $33,000.00
- Additional consultant fees (including Stage 2 implementation plan) $50,000.00
- Phase 1 implementation support $126,625.00

Funding

Year 1 costs funded.

B.2 Actions 2.1 and 2.2: OCPs and treatment guidelines, including diagnostic guidelines

Project description from the National Strategic Action Plan

Address gaps in OCPs and treatment guidelines for different blood cancer subtypes. OCPs and treatment guidelines are interdependent and to be effective should be fully integrated into clinical practice.

Project Objective Statement

- Develop additional OCPs for major blood cancer sub-types not already developed by the Cancer Council, adopting the same format as the updated OCPs to be launched in 2021. To be confirmed by the Steering Committee, in Phase 1 this will include: an additional Lymphoma OCP, ALL, CML, CLL, Myeloma.
- Develop Australian-specific treatment guidelines for major sub-types leveraging existing international and Australian treatment guidelines.(CML, CLL, DLBCL, Follicular, Myeloma, Paediatric ALL)
- As part of the Australian-specific treatment guidelines, ensure the development of Australian diagnostic guidelines (Action 2.2.1).

Key project assumptions

- OCP project already funded with scope to include: an additional Lymphoma OCP, ALL, CML, CLL, Myeloma
- Subsequent phases to cover AML (adult and paed) and MDS, MPNS
- Diagnostic guidelines to be developed as part of clinical guideline development
- Neither OCPs nor Guidelines to be developed from scratch – starting point for OCPs is the Cancer Council/NCERG OCPs and starting point for guidelines is ESMO/ELN

Potential funding and governance options

- Taskforce to have responsibility for OCP and guideline development, but ongoing governance model to be determined by Project Steering Committee as part of Phase 1 Project implementation
- Australian Federal government provided seed funding ($300k for OCPs committed), with Federal and State governments potential to support implementation and funding of guidelines
- NGOs to co-fund where needed to support development of both OCPs and guidelines as needed.

Key implementation activities

1 Establish a Project Steering Committee and sub-type clinical and patient advisory groups to oversee development of OCPs and treatment guidelines:

1.1 Project Steering Committee to involve one clinical lead and one patient from clinical and patient advisory groups, as well as Australian Governments representatives

1.2 One jurisdiction or organisation to be nominated to be the lead for project (Project Lead)

2 Project Steering Committee confirms the scope, objectives and approach of clinical and diagnostic guidelines for inclusion in Phase 1 project

2.1 Scope: CLL, CML, DLBCL, Follicular Lymphoma, Myeloma, Paediatric ALL

2.2 Objectives: Establish minimum standards for diagnostics and treatment by sub-type, with guidance on clinical best practice based on international evidence (regardless of public subsidy/private funding considerations, though these may be noted within the guidelines)

2.3 Approach: ESMO / ELN treatment guidelines to be the starting point. Plan for publication with key journals (MJA, IJM)

3 Project Lead establishes Project Team, comprised of Project Manager and Analyst, plus medical writer support (or fully outsources to a contractor)

4 Format for treatment guidelines agreed among Project Steering Committee

4.1 Project Team reviews updated ESMO, ELN, NCCN, WHO, NICE and relevant Australian clinical and diagnostic guidelines (e.g., Myeloma Australia) for proposed structure, and develops draft structure for Project Steering Committee review and approval

4.2 Draft options for clinical guideline structure are distributed to sub-type clinical and patient advisory groups for comment

4.3 Format for treatment guidelines are finalised with the Project Steering Committee

5 Project Team then develops content for clinical and diagnostic guidelines, following principle of ESMO as starting point. Project Team to review ESMO, ELN, NCCN, WHO, NICE and relevant Australian treatment guidelines, including diagnostic guidelines, by sub-type to develop draft guideline content. Working with sub-type clinical team, draft recommendations for Australian specific treatment guidelines are developed, including draft diagnostic guidelines

6 Draft guidelines presented to Project Steering Committee and refined where necessary

7 Revised guidelines presented at ALLG meeting

8 Guidelines are endorsed by HSANZ

9 Training and change management for guidelines rolled out nationally through professional colleges.

Key risks to be managed

- Project implementation: Poor coordination with minimum standards/templates and Blood Cancer Digital Health Information Strategy work, leading to ineffective execution (confusion around requirements) and/or inefficiencies (excess costs, delays in timing)
    - Overall risk rating: High (Consequence = Major, Likelihood = Very LIkely)
    - Mitigation strategy: Monthly reporting to Blood Cancer Secretariat and Phase 1 Project Chairs Oversight Committee to ensure project alignment
    - Residual risk rating: Medium (Consequence = Moderate, Likelihood = Low)
    - Cost implications: In kind project management time

- Benefits realisation: Lack of buy-in and training by clinicians leads to poor uptake and use
    - Overall risk rating: High (Consequence = Extreme, Likelihood = Very likely)
    - Mitigation strategy: Planning for implementation with colleges to support national rollout, possibly through change management and training program supporting communication of treatment guidelines, diagnostics and templates across settings and jurisdictions
    - Residual risk rating: Medium (Consequence = Major, Likelihood = Low)
    - Cost implications: Cost of change management strategy to GPs and specialists
- Political: Lack of buy-in and/or sustained support from State governments to implement nationally, leading to continued inconsistent information
    - Overall risk rating: High (Consequence = Extreme, Likelihood = Very likely)
    - Mitigation strategy: Project Steering Committee comprised of Australian governments and professional bodies, colleges
    - Residual risk rating: Medium (Consequence = Major, Likelihood = Low)
    - Cost implications: Additional time for operation of Project Steering Committee with high levels of inclusion
- Legal / insurance: Potential risks to clinicians and providers if minimum standards not met
    - Overall risk rating: Significant (Consequence = Major, Likelihood = Possible)
    - Mitigation strategy: Seek legal advice regarding medicolegal risks
    - Residual risk rating: Low (Consequence = Minor, Likelihood = Low)
    - Cost implications: Unknown
- Financial / political: If guidelines recommend therapies that lack public funding, may not be endorsed by government or could lead to perceptions of a two-tiered health system
    - Overall risk rating: High (Consequence = Major, Likelihood = Possible)
    - Mitigation strategy: Language and format to be agreed with Australian Governments through Project Steering Committee
    - Residual risk rating: Medium (Consequence = Moderate, Likelihood = Low)
    - Cost implications: Time to agree approach ahead of guideline development
- Social / benefits: OCPs and Guidelines fail to take into account at-risk group requirements
    - Overall risk rating: High (Consequence = Major, Likelihood = Possible)
    - Mitigation strategy: Ensure patient input to guidelines from all sub-types, at-risk groups (e.g., ATSI, CALD, rural and remote, geriatric, paediatric) and life stages
    - Residual risk rating: Medium (Consequence = Moderate, Likelihood = Low)
    - Cost implications: Additional time and funding to meaningfully engage with all patient cohorts

- Social / benefits: Disagreement among clinical leads regarding recommended standard of care (e.g., Paed ALL)
    - Overall risk rating: High (Consequence = Major, Likelihood = Possible)
    - Mitigation strategy: Phased approach to agree scope, objectives and approach, and inclusive representation in clinical advisory groups
    - Residual risk rating: Medium (Consequence = Moderate, Likelihood = Low)
    - Cost implications: Additional time and funding for Steering Committee and clinical advisory group members

B.3 Action 1.3.1: Minimum standards and templates for written treatment and survivorship care plans

Project description from the National Strategic Action Plan

- Develop minimum standards or 'template' for written treatment and survivorship care plans, for both acute and chronic blood cancers.
- Treatment and survivorship plans would be dynamic, and remain relevant to the patient at different stages of their diagnosis and treatment and include guidance on supportive care considerations such as managing immunosuppression, community sourced infection, vaccination, diet, exercise, palliative care and any other psycho-social supportive care needs.

Project Objective Statement

- Ensure a nationally consistent, minimum standard approach to written communications to patients for treatment and survivorship planning, to ensure equity of access to information, treatment plans and supportive care services

Key project assumptions

- Proposed approach must work within federated model, allowing for clinical system variation
- Assumes standards/templates are developed in parallel to development of OCPs and treatment guidelines
- Assumes primary and tertiary setting implementation
- Assumes simultaneous implementation across settings / geographies
- Assume auditing excluded in this scope as dependent on KPIs Action 1.3.2

Potential funding and governance options

- Co-development of standards and templates by Taskforce and Governments
- Australian Federal and State governments will have responsibility for implementation funding

Key implementation activities

1 Establish a Project Steering Committee

1.1 Project Steering Committee to involve all Australian Governments (Federal and State), all professional colleges and associations (RACGP, AMA, HSANZ, PCPA) and patient groups (Leukaemia Foundation, Myeloma Australia, Lymphoma Australia, Cancer Council, Rare Cancers)

1.2 One jurisdiction to be identified as lead for project (Project Lead), which will commit a Project Team, comprised of a Project Manager and Analyst to deliver project

2 Project Team hosts a workshop to agree objectives for the templates/standards with the Project Steering Committee (or engages a consultant to do this)

2.1 Project Team conducts patient and clinician survey and stakeholder consultations to inform objectives

2.2 Draft objectives presented to and refined/agreed with the Project Steering Committee

3 Project Team conducts a review of jurisdictional approaches to written treatment plans, taking into account infrastructure constraints and current policy settings (or engages a consultant to do this)

4 Project Team identifies gaps by jurisdiction relative to agreed objectives and develops draft options

5 Project Team prepares draft standards/templates and presents options to the Project Steering Committee.

5.1 Options are assessed against agreed objectives and feasibility of implementation by jurisdiction using a scorecard method.

5.2 The preferred standard / template and plan for implementation is agreed.

6 Australian governments, clinicians and blood cancer NGOs implement minimum standards/templates and roll out change management strategy to support uptake by clinicians.

Key risks to be managed

- Project implementation: Poor coordination with OCPs, treatment guidelines and diagnostic guidelines leading to ineffective execution (confusion around requirements) and/or inefficiencies (excess costs, delays in timing)
    - Overall risk rating: High (Consequence = Extreme, Likelihood = Possible)
    - Mitigation strategy: Project Team to engage with Quality Standards Project Management Team and Taskforce Oversight Committee on quarterly basis
    - Residual risk rating: Medium (Consequence = Major, Likelihood = Low)
    - Cost implications: Project management time to engage with Quality Standards Project Steering Committee and Project Team
- Benefits realisation: Lack of buy-in and training regarding benefits and use of templates leads to poor uptake and use
    - Overall risk rating: High (Consequence = Extreme, Likelihood = Very likely)
    - Mitigation strategy: Change management and training program rolled out supporting treatment guidelines, diagnostics and templates
    - Residual risk rating: Medium (Consequence = Major, Likelihood = Low)
    - Cost implications: Change management strategy to GPs and specialists

- Political: Lack of buy-in and/or sustained support from governments to implement nationally leading to continued inconsistent information
    - Overall risk rating: High (Consequence = Extreme, Likelihood = Very likely)
    - Mitigation strategy: Project Steering Committee comprised of Australian governments and professional bodies
    - Residual risk rating: Medium (Consequence = Major, Likelihood = Low)
    - Cost implications: Additional time for operation of / participation in Project Steering Committee with high levels of inclusion across State and territory govts
- Legal / insurance: Potential risks to clinicians and providers if minimum standards not met
    - Overall risk rating: Medium (Consequence = Moderate, Likelihood = Neutral)
    - Mitigation strategy: Seek legal advice regarding medicolegal risks
    - Residual risk rating: Low (Consequence = Minor, Likelihood = Low)
    - Cost implications: Unknown
- Technological / financial: If implementation requires modification of clinical systems, this could create significant financial costs and may not be possible where software owned / operated by international firms
    - Overall risk rating: High (Consequence = Major, Likelihood = Possible)
    - Mitigation strategy: Goal would be to flexibly set standards and allow jurisdictions to meet standards without modification of clinical systems
    - Residual risk rating: Medium (Consequence = Major, Likelihood = Low)
    - Cost implications: None, assume implementation will be required to work with existing systems
- Social / benefits: Templates and standards fail to take into account at-risk group requirements
    - Overall risk rating: High (Consequence = Major, Likelihood = Possible)
    - Mitigation strategy: Ensure patient input to standards and templates from all sub-types, at-risk groups (e.g., ATSI, CALD, rural and remote, geriatric, paediatric) and life stages
    - Residual risk rating: Medium (Consequence = Moderate, Likelihood = Low)
    - Cost implications: Additional time and funding to meaningfully engage with all patient cohorts.

B.4 Action 3.1: Research Roadmap

Project description from the National Strategic Action Plan

- Develop a Research Roadmap for blood cancers, with a virtual network of Australian research partners organised around disease goals or technology strengths and with business models for streamlining and augmenting collaboration across research nodes of excellence nationally and internationally.

Project Objective Statement

- Finalise a Blood Cancer Research Roadmap leveraging and refining the priorities set out in the National Strategic Action Plan with very targeted stakeholder consultation as needed, which sets out a clear list of potential research projects (extending from basic to clinical research) against each priority to support high impact research.

Potential funding and governance options

- Taskforce-led roadmap development
- PPP funding model, with Australian Government funding through MRFF, NHMRC, supported by NGOs

Key implementation activities

1 Establish Project Steering Committee

1.1 Project Steering Committee to involve membership of Leukaemia Foundation, Lymphoma Australia, Myeloma Australia, Snowdome, Cancer Australia, Australian Government research leads, clinical leads for each sub-type, patients

1.2 One jurisdiction or organisation to be identified as the lead organisation for the project (Project Lead), which will identify a Project Manager and analyst support (Project Team) to oversee project on behalf of the Steering Committee

2 The Project Lead will identify a Project Manager to oversee the finalisation of the Research Roadmap

3 The Project Steering Committee, with support of the Project Team, will develop an RFT for Research Roadmap. RFT should seek:

3.1 Agreement and refinement of research priorities as developed in the National Strategic Action Plan

3.2 Consultation with researchers to identify specific project opportunities against these research priorities.

4 Go to market with RFT, review Vendor responses, select preferred bidder

5 Finalise Research Roadmap

6 Report to the Taskforce and Governments (Dept of Health, CoAG)

Key risks to be managed

- Political: Lack of buy-in and/or sustained support from government and Blood Cancer community support for implementation of Roadmap recommendations
    - Overall risk rating: Significant (Consequence = Major, Likelihood = Neutral)
    - Mitigation strategy: Project steering committee comprised of NGOs and Government, shared funding model
    - Residual risk rating: Medium (Consequence = Major, Likelihood = Unlikely)
    - Cost implications: Additional time for Project Steering Committee members, time to engage widely with clinicians and patients to develop Roadmap
- Political: stakeholder fatigue

  - Overall risk rating: High (Consequence = Major, Likelihood = Very likely)
  - Mitigation strategy: Priorities identified in NAP to form basis of research roadmap with Steering Committee to identify any gaps, consultant to engage in one-on-one approach to researchers with respect to opportunities against these priorities
  - Residual risk rating: Medium (Consequence = Major, Likelihood = Unlikely)
  - Cost implications: None, but consultancies to be highly targeted, with goal of Roadmap being finalised mid-year
- Procurement and contractual: contract selection and consultant performance / management
  - Overall risk rating: Significant (Consequence = Major, Likelihood = Possible)
  - Mitigation strategy: RFT development, Steering Committee composition to be robust
  - Residual risk rating: Medium (Consequence = Major, Likelihood = Unlikely)
  - Cost implications: Minimal, time to develop RFT and conduct vendor selection

Key cost assumptions

- Blended daily rate of consultant project management teams applied to estimated project days, assuming 0.1 FTE Senior Director time, 0.5 FTE Project Manager time and 1 FTE Project Analyst time per day. Hourly rates assume Senior Director $500/hour, Project Manager $385/hour, and Project Analyst $200/hour.
- Indicative days per task shown below.

B.5 Action 4.3: Improve access to novel and specialised therapies

Project description from the National Strategic Action Plan

- A multidisciplinary Enabling Access Working Group should be established, including consumers, to work across the blood cancer community and address challenges for patient access to novel and specialised therapies. The Working Group would have three specific tasks:
  - Develop a short-list of clinically important medicines and diagnostics that do not have public subsidy and where there are market barriers to evidence development. Work with the Federal Government and the blood cancer community to coordinate an approach to evidence development for each therapy, which could include funding investigator-led clinical trials, or coordination of research and regulatory applications, including provisional registration, which may require participation in a registry to enable access to a novel therapy.
  - Commission a review of access to novel and specialised therapies by state and territory to identify disparities in access to standard of care therapies and develop a plan to improve equity of access nationally.
  - Engage with Government to develop a strategy to optimise the supply of suitable stem cell donors for Australian and international patients and to

ensure equity of access to cellular and emerging therapies, including CAR T-cells for all Australians.

- The Enabling Access Working Group would consider and complement work that is already underway to improve access to new therapies and diagnostics, including projects to be delivered through the MRFF, for example, the Health System Preparedness for Cancer and Paediatric Healthcare Initiative.

Project Objective Statement

- Create a plan for improving national, equitable access to clinically important technologies that are not publicly funded (Task 1)
- Create a plan for reducing inequities to standard of care diagnostics and therapies as defined by the treatment guidelines across jurisdictions and public-private settings (Tasks 2 and 3).

Key implementation activities

1 Establish Project Steering Committee, Project Lead and Project Team

1.1 Project Steering Committee to involve Australian Governments (Federal and State), MSAC, PBAC, LF, LA, MA, ALLG, HSANZ, ANCHOG, clinical leads for each sub-type, including pediatric cancers, and patient representatives for each sub-type, including at-risk cohorts

1.2 Steering Committee members to each execute an NDA

1.3 Steering Committee to identify a Project Lead to lead the management of the project, which would identify or engage a Project Manager and Analyst (Project Team) to operationalize the project on behalf of the Steering Committee

Task 1 – Shortlist of products

1 Project Team to develop:

1.1 Criteria for product prioritisation (e.g., unmet need, alternative therapies, patient population, clinical importance with reference to treatment guidelines)

1.2 A short-list of products

1.3 A list of options for improving access through existing or potential programs, which could include funding for investigator led trials, funding regulatory application, or registry requirements.

The draft short-list and plan would be presented to the Steering Committee for discussion and agreement. Funding for implementation of the agreed plan could be provided by government, NGOs, or partnership model, on a case by case basis as appropriate.

Task 2 – Review of Access to Novel and Specialised Therapies

1 Following completion of treatment guidelines (including diagnostic guidelines), or based on an agreed scope of work by the Project Steering Committee if the Guidelines project is delayed, the Project Steering Committee should review standard of care therapies and determine the scope of a Review of Access to Selected Novel and Specialised Therapies by

state and territory, across public and private settings. The RFT for the Review would seek:

1.1 Identify funding arrangements by state and territory for novel and specialised therapies in scope across public and private settings

1.2 Evaluate the utilisation of novel and specialised therapies in scope by jurisdiction and setting

1.3 Identify options for improving access by jurisdiction and setting to selected therapies.

2 Go to market with RFT for Access to Selected Novel and Specialised Therapies, review Vendor responses, select preferred bidder

2.1 **Option for Project Steering Committee to go to market with Task 2 and Task 3 projects simultaneously and review responses to determine potential efficiencies, effectiveness of completing projects together.*

3 Conduct Review of Access to Selected Novel and Specialised Therapies

3.1 Project Steering Committee to report to the Taskforce on the outcome of the project.

Task 3 – Review of Access to Cellular Therapies

1 In parallel to implementation step 3 above, the Project Steering Committee would also work with Project Team to develop an RFT for Review of Access to Cellular Therapies. The RFT should seek:

1.1 Horizon scan of cellular therapies

1.2 Develop estimate of future demand for cellular therapies by sub-type by state and territory

1.3 Review access to cellular therapies by jurisdiction and by setting (potentially leveraging other access review)

1.4 Develop and publish plan for improving equity of access to cellular therapies nationally.

2 Go to market with RFT for Review of Access to Cellular Therapies, review Vendor responses, select preferred bidder

3 Conduct Review of Access to Cellular Therapies

3.1 Project Steering Committee to report to the Taskforce.

Key risks to be managed

- Political: Lack of buy-in from stakeholders or disagreement for shortlisted products
    - Overall risk rating: High (Consequence = Extreme, Likelihood = Very likely)
    - Mitigation strategy: Project Steering Committee to be comprised of NGOs and Government, with co-development of criteria for product prioritisation, and goal of co-developing a plan for each product
    - Residual risk rating: Significant (Consequence = Major, Likelihood = Possible)

    - Cost implications: Additional time for Project Steering Committee members, time to engage widely with clinicians and patients to develop criteria and shortlist

- Benefits realisation: Inability to implement plan and/or review findings due to costs
    - Overall risk rating: High (Consequence = Extreme, Likelihood = Very likely)
    - Mitigation strategy: Project Team and Steering Committee to establish criteria and agree threshold/evidence guidelines for various planning pathways
    - Residual risk rating: Significant (Consequence = Major, Likelihood = Possible)
    - Cost implications: Additional time for Project Steering Committee to establish criteria and threshold/evidence guidelines for various planning pathways
- Benefits realisation: Patients views not meaningfully included in assessment of products
    - Overall risk rating: Significant (Consequence = Major, Likelihood = Likely)
    - Mitigation strategy: Project Steering Committee to include patient perspectives, patient surveys and consultations where appropriate
    - Residual risk rating: Medium (Consequence = Moderate, Likelihood = Unlikely)
    - Cost implications: Additional time to engage widely with patients
- Procurement and contractual: Vendors lack highly specialised skills required for Reviews of Access to Novel Therapies, Cellular Therapies
    - Overall risk rating: Significant (Consequence = Extreme, Likelihood = Possible)
    - Mitigation strategy: Competitive process to RFT developed with input from Project Steering Committee
    - Residual risk rating: Medium (Consequence = Major, Likelihood = Unlikely)
    - Cost implications: Minimal, time to develop RFT and conduct vendor selection
- Political: Conflicts of interest and confidentiality risks
    - Overall risk rating: High (Consequence = Major, Likelihood = Very likely)
    - Mitigation strategy: Project Steering Committee members to execute NDA, agree to Steering Committee guidelines
    - Residual risk rating: Medium (Consequence = Major, Likelihood = Unlikely)
    - Cost implications: Legal costs by LF and Australian Government to draft and ratify these.

B.6 Action 1.6.1: Epidemiological study of blood cancer in Aboriginal and Torres Strait Islander people

Project description from the National Strategic Action Plan

- In consultation with organisations managing current data collection systems (e.g., hospitals, state cancer registries, AIHW), commission an epidemiological and health services implementation research study to better understand limitations, improve data collection and statistics on blood cancers and to enable culturally sensitive care that improves primary health attendance and hospitalisation rates.

Project Objective Statement

- Identify limitations to data collection and analysis for Aboriginal and Torres Strait Islander people with blood cancer
- Recommend options for addressing data limitations to enable better data collection and investment

Key implementation activities

1 Establish Project Steering Committee

1.1 Project Steering Committee to involve membership of Community Controlled Health Services, Cancer Australia, AIHW, State Cancer Registries, NGOs

1.2 Project Steering Committee may form an advisory group of local Aboriginal and Torres Strait Islander groups

1.3 One jurisdiction or organisation to be identified as the lead organisation for the project (Project Lead), which will identify a Project Manager and analyst support (Project Team) to oversee project on behalf of the Steering Committee

2 The Project Steering Committee, with support of the Project Team, will develop an RFT for the study. RFT should seek:

2.1 Understand data limitations by jurisdiction and geography

2.2 Identify options to improve data collection and statistics on blood cancers and to enable culturally sensitive care that improves primary health attendance and hospitalisation rates

2.3 Make recommendations for investment and policy change.

3 Go to market with RFT, review Vendor responses, select preferred bidder

4 Conduct study

5 Report to the Taskforce and Australian Governments.

Key risks to be managed

- Political: Lack of sufficient Aboriginal leadership and input in study
    - Overall risk rating: Significant (Consequence = Major, Likelihood = Neutral)
    - Mitigation strategy: Engage with Community Controlled Health Services

  - Residual risk rating: Medium (Consequence = Major, Likelihood = Unlikely)
  - Cost implications: Additional time for Project Steering Committee members, time to engage widely with clinicians and patients to develop Roadmap
- Procurement and contractual: contract selection and consultant performance / management
  - Overall risk rating: Medium (Consequence = Major, Likelihood = Low)
  - Mitigation strategy: RFT development, Steering Committee composition to be robust
  - Residual risk rating: Medium (Consequence = Major, Likelihood = Unlikely)
  - Cost implications: Minimal, time to develop RFT and conduct vendor selection.

Key cost assumptions

- Epidemiological study would cost the average of recent epidemiological studies, with scope to be refined by research lead (See Cost Study).
- Taskforce looking for a research partner to lead grant application, with Taskforce endorsement, letters of support

Appendix C

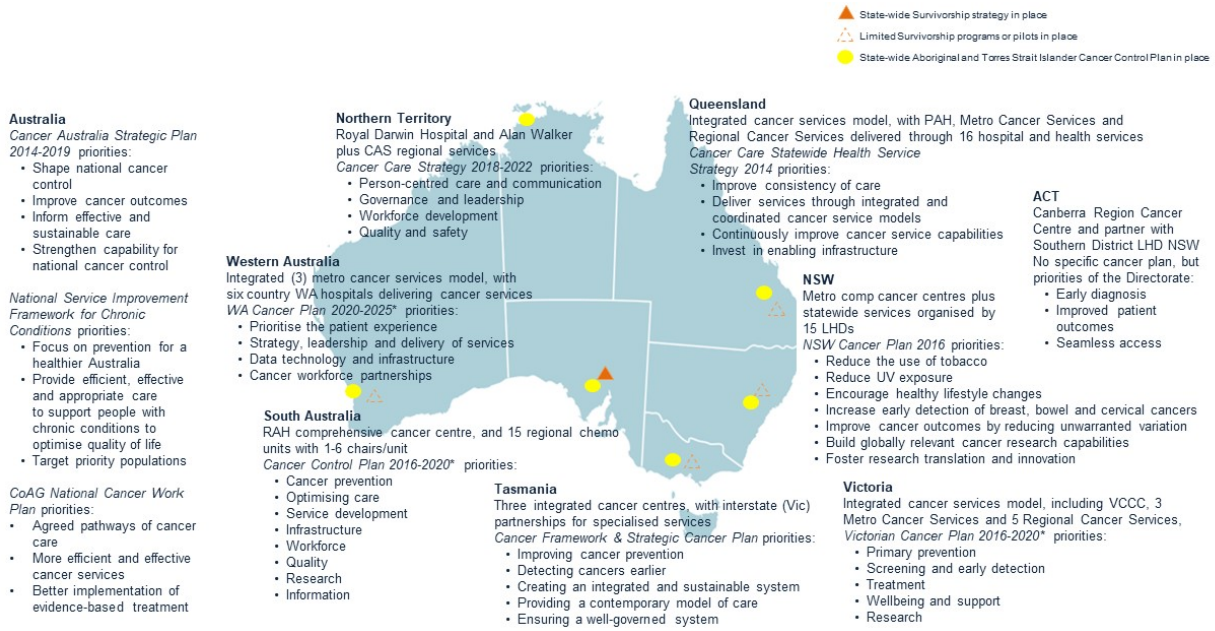
Strategic alignment with cancer policies

C.1 Overview of strategic alignment

The stocktake of cancer and related policies highlights the significant effort governments in State and Territory, National and international jurisdictions to significantly reduce the incidence, prevalence, mortality and burden of cancer for patients and their families. At all levels of government policies have been enacted to improve prevention and screening, early detection, accurate diagnosis, safe and quality service delivery and access to supportive care. Over time, governments have enacted policies to better orient their health services to better meet the needs of chronic disease and are increasingly grappling with new challenges and opportunities presented by precision medicine paradigms. Governments at all levels are investing in cancer research programs with the goal of ending mortality from cancer, and at an international level, are seeking to harness the potential of real-world evidence and 'smart data' to accelerate research productivity for evidence development.

Within Australia, a review of State and Territory cancer policies shows significant investment in the development of integrated metropolitan and regional cancer services, with care closer to home increasingly enabled through 'hub and spoke' cancer service structures (Figure 1). Moreover, all States and Territories, as well as Federal Cancer policies, identify policies specifically aimed at meeting the needs of priority groups, including in particular patients from Aboriginal and Torres Strait Islander communities.

Figure C.1: Overview of key Federal, State and Territory Cancer Policy Priorities and Service Structures



The stocktake of cancer policy priorities reveals a very significant emphasis and effort on prevention, screening and early detection, and often a number of actions within this focused

on specific cancers with a high reported incidence, including breast cancer, lung cancer, and colorectal cancer. These are clearly important priorities for the improved control of cancer in the community, but these strategies do not directly benefit people living with blood cancer today and actions to better control blood cancer mortality are not identified in any cancer policy—even though the combined incidence of blood cancers is similar to that of other high-incidence cancers, with higher costs of care and lower survival rates.

In addition to prevention and early detection, however, the other consistent, major focus of cancer policies priorities at Federal, State and Territory levels is on improving quality and safety in care through more consistent treatment and care, including reducing unwarranted variation. This is strongly aligned to the National Strategic Action Plan for Blood Cancer, which recommends the development of National, Integrated, Digitally-Enabled Optimal Care Pathways and Treatment guidelines by blood cancer sub-type. Moreover, the review highlights that from an international perspective Australia is out of synch with international best practice for the development and maintenance of disease based treatment guidelines.

In Australia at a Federal level, there is an increasing focus on identifying opportunities and policies that address challenges common to all chronic diseases, including cancer, with the goals of improving service efficiency and effectiveness. Similarly, the Australian Government is putting substantial investment in creating 'one stop shop' fronts for services online and many in development at national level, such as the Carer Gateway or Mental Health Gateway. This is aligned to the National Strategic Action Plan for Blood Cancer which also seeks to develop a national Blood Cancer Gateway to empower patients and clinicians with relevant information.

Many cancer policies within Australia have been in place for some time and many are undergoing a refresh. Increasingly, a number of cancer policies updates are putting greater emphasis on enabling meaningful patient-centred care. This is observed in the development of policy innovations such as patient navigation services, patient reported outcomes, and systems for the implementation of precision medicine. These policy innovations are highly aligned to the National Strategic Action Plan for Blood Cancer.

Governance arrangements to better coordinate policy implementation across a complex service environment and geography was also highlighted as important component to planning. Many State and Territory cancer policies, as well as Federal strategies, allocated responsibility for the implementation of actions by priority to organisations that were best placed to manage the outcomes and risks from policy implementation; some cancer plans also organised priorities and actions into short, medium and long term planning horizons and identified indicators for monitoring performance over time.

Ultimately, the stocktake of cancer policies systematically identifies the strong alignment of the National Strategic Action Plan for Blood Cancer with broader cancer and chronic disease strategies; recommended policy reforms have the potential to benefit a wide range of people diagnosed with cancer in addition to people living with blood cancer. The National Strategic Action Plan for Blood Cancer also calls for investment in research for blood cancer and a real world evidence pilot program in line with international research investment plans with the goal of accelerating the work of Australian research centres of excellence in a world of personalised medicine.

C.1 Jurisdictional summary tables

Table C.1: Summary of Cancer Policy Alignment with the National Strategic Action Plan for Blood Cancer

	Aus	NSW	VIC*	Qld	WA*	SA	Tas	NT	ACT	WHO	Eng	US	Can
Approach to long term goals / vision of plan													
Long term goals for mortality reduction, survival improvements	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑
Quality of life improvements		☑	☑	☑			☑						☑
Reduce outcome variation between metro and regional, priority groups	☑		☑	☑	☑			☑		☑		☑	
Improve prevention	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑
Patient experience			☑	☑									☑
Governance													
Explicit allocation of responsibility by Priorities, Actions across governments and disease community	☑	☑	☑	☑	☑						☑		☑
Structures for regular publication of disease treatment guidelines in place											☑	☑	☑
Performance monitoring													
Explicit targets?			☑	☑	☑					☑	☑	☑	
KPI frameworks		☑	☑	☑						☑	☑		☑

	Aus	NSW	VIC*	Qld	WA*	SA	Tas	NT	ACT	WHO	Eng	US	Can
Empowering Patients													
Enhanced notification process													
Patient navigation / care coordinator	☑				☑			☑			☑		☑
One-stop shop for information	☑				☑								
Referral tools					☑								
Written care plans				☑	☑								
Patient reported outcomes		☑	☑		☑								
Empower and support priority groups	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑
Achieving Best Practice													
OCPs and treatment guidelines	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑
Models of care and policies to target inequities for priority groups	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑
Accreditation and credentialing or sub-type specialist input to MDTs				☑		☑	☑				☑		
Guidelines / policies for improving quality in diagnostics				☑	☑		☑				☑		
KPIs for clinical trials				☑							☑		
Precision medicine (genomics) as standard of care				☑							☑		

	Aus	NSW	VIC*	Qld	WA*	SA	Tas	NT	ACT	WHO	Eng	US	Can
Screen for supportive care needs										☑	☑	☑	☑
Survivorship strategies, including rehabilitation	☑	☑	☑	☑	☑	☑		☑					
Mental health support	☑	☑	☑	☑	☑	☑		☑					
Palliative care		☑	☑	☑	☑	☑	☑	☑					
Workforce development	☑	☑	☑	☑	☑	☑	☑	☑			☑		
Rural and remote services & workforce policies				☑		☑		☑					
Service directions for partnerships w/ private providers, NGOs, interstate				☑			☑					☑	
Tools to address information barriers to insurance, provider purchases	☑				☑								
Preventing financial hardship												☑	
Enabling Access to Novel and Specialised Therapies													
Address market failures to evidence development											☑		
Streamline regulatory processes											☑		
Increase access to precision medicine (genomics+)	☑	☑	☑	☑	☑					☑	☑	☑	☑
Access to emerging cellular therapies										☑	☑	☑	☑

	Aus	NSW	VIC*	Qld	WA*	SA	Tas	NT	ACT	WHO	Eng	US	Can
Supply of bone marrow donors													
Accelerate Research													
Roadmap for Research	☑	☑	☑		☑	☑	☑			☑	☑	☑	☑
Increase research in genomics	☑	☑	☑		☑	☑				☑	☑	☑	☑
Workforce development	☑	☑	☑	☑	☑	☑							
Increase access to clinical trials	☑	☑	☑	☑	☑	☑		☑					
Increase international collaboration	☑	☑	☑		☑								
Real world evidence / big data											☑		☑

Appendix D

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