

National Strategic Action Plan for Blood Cancer

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In particular we would like to thank:

- Members of the Blood Cancer Taskforce who provided their valuable time, expertise and leadership in the shaping of the National Action Plan
- Members of the seven Blood Cancer Taskforce Working Groups who also contributed their valuable time and expertise in the development of the National Action Plan
- Members of the Patient and Carer Panel who reviewed the draft National Action Plan and shared their ideas for improving blood cancer treatment, care and support, and identified the highest priority actions in the National Action Plan to empower and support people living with blood cancer and their families
- Regionally-based clinicians and blood cancer experts who brought insights and expertise into the specific challenges to the treatment and care of people with blood cancer outside major metropolitan areas, and developed ideas for closing the gap in survival between Australia’s cities and regional areas
- Aboriginal and Torres Strait Islander experts who peer-reviewed the data and recommendations for Aboriginal and Torres Strait Islander people diagnosed with blood cancer.

We acknowledge the Traditional Owners of Country throughout Australia and recognise the continuing connection to lands, waters and communities. We pay our respect to Aboriginal and Torres Strait Islander cultures, and to Elders both past and present.

Diagrams and photos are used with permission and quotes are from real people.

The development of this National Action Plan was supported by funding from the Australian Government Department of Health.



Australian Government
Department of Health

Partnerships for change

As members of the blood cancer and broader cancer community, we recognise the value of this community-led National Action Plan and look forward to working with other members of the blood cancer community on its implementation.



Foreword

In 2020, we stand united for a once-in-a-generation opportunity to reduce the impact of blood cancer. Australia's first National Strategic Action Plan for Blood Cancer is rightly ambitious – our vision 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. It offers a blueprint for change in the lives of people living with blood cancer and reimagines the way treatment and care of blood cancer patients is planned and administered across our country.

This plan is the culmination of the tireless efforts of the Blood Cancer Taskforce, along with the expertise of clinicians, researchers, healthcare professionals and policy experts from around the country, all centred on what people living with blood cancer have truthfully told us about their lived experiences.

The National Action Plan includes recommendations across the entire blood cancer ecosystem: from research, clinical trials, precision medicines, treatment access and reimbursement, through to achieving best practice in diagnosis, treatment and supportive care.

We've looked at the access challenges for Australians living with blood cancer, including those living in regional or remote areas, Aboriginal and Torres Strait Islander communities, and people with diverse and varied cultural and ethnic backgrounds.

The recommendations we've developed as a blood cancer community seek to improve how a person is supported from the point of diagnosis, through their treatment and recovery and adjusting to life beyond treatment – wherever they live in Australia and whatever their background.

There is no one-size-fits-all solution. We are building on existing systems while also recommending new ways of delivering healthcare to people living with blood cancer across the continuum of treatment.

The recommendations will collectively achieve significant and lasting change for people living with blood cancer, their families, carers and the Australian community. These approaches could also be applicable to many other cancers and across the health system as a whole.

While the task in front of us might be daunting, the fundamental principle of the National Action Plan is very simple: every Australian with a blood cancer should have equitable access to the best information, treatment and supportive care.

We know there are many hurdles to achieving our shared vision of zero lives lost to blood cancer by 2035.

We also know that simply doing what we already do, better and more consistently across the country, may prevent 13 per cent of blood cancer mortality and save up to 22,000 lives between now and 2035.

While this plan is firmly fixed in making lasting improvements for people living with blood cancer in 2020, critically, it looks to the future – the future of new and improved treatments and care which are being developed through local and international research.

We believe our person-centred approach will sustain our efforts as we embark on turning this blueprint into lasting action. The leadership and commitment assembled through this National Action Plan will bring a paradigm shift in patient care and brings great hope for change for the more than 110,000 Australians living with a blood cancer today.

As the Leukaemia Foundation's *State of the Nation: Blood Cancer in Australia* report released in 2019 so clearly demonstrated, the economic and personal costs of not acting with urgency are too great to bear. The COVID-19 pandemic has reminded us how economic health and physical health are inextricably linked; it has also shown how quickly change can happen with clear direction, sufficient motivation, unity of purpose and application of resources.

We sincerely thank the Commonwealth of Australia for supporting the Leukaemia Foundation to bring together the blood cancer community to deliver this National Action Plan.

We would like to thank everybody who has contributed to this point, including the Leukaemia Foundation's former CEO Bill Petch, the tireless efforts of Insight Economics, the Taskforce and Working Group members, the Taskforce Secretariat, the other cancer support agencies, the individuals in the community who provide funding to beat blood cancer and the many thousands of people living with blood cancer and their carers who have shared their stories.

We commend the Australian community to work with us to implement this plan and by acting together, we will achieve zero lives lost to blood cancer by 2035.



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Blood Cancer Taskforce Co-Chair
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National Strategic Action Plan for Blood Cancer

Summary statement

Vision:

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.

The National Action Plan provides an evidence-based blueprint to coordinate and accelerate national efforts to improve survival and quality of life outcomes for people diagnosed with blood cancer and to support their carers and families.

This Australia-wide review of the treatment and supportive care landscape is the most comprehensive assessment of the strengths of our health system for people living with blood cancer as well as the areas requiring further development to increase survival rates. While many advances in treatment and care have made some blood cancers chronic conditions, there are still gaps in access to treatment and care across many blood cancers. It has been developed with support from the Federal Government and as a result of the *State of the Nation: Blood Cancer in Australia* report developed by the Leukaemia Foundation and members of the blood cancer community.

The *State of the Nation* report was a first of its kind analysis that identified the challenges and opportunities influencing survival and quality of life for people living with a blood cancer in Australia.

The National Action Plan is a community-led blueprint for change, informed by hundreds of patients, carers and leaders in blood cancer research, diagnosis, treatment and care. This will be the first national consensus, from the blood cancer community, on the blood cancer agenda.

Working together, our vision 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.

Central to this is empowering patients and their families to make choices for their wellbeing, so that:

- Patients and their families know what questions to ask at every stage of their cancer journey
- Patient autonomy and choice is valued and supported
- All patients and especially high-risk patients receive the help they need to equitably access services
- Patients and their families are supported to avoid financial hardship.

Blood cancer is one of the most common, costly and fatal cancers in Australia today. There are no screening programs available for blood cancers and there is no way to prevent a blood cancer through lifestyle change, apart from reducing risk factors for cancer, for example through diet, exercise, reducing obesity and smoking.

New policy initiatives are needed to address the burden of blood cancer mortality. There have been major advances in treatments and care

which have seen significant improvements in survival rates. However, more work is required to ensure all Australians have equitable access to the information, treatments and supportive care which could help them survive their blood cancer.

Blood cancers affect Australians of all ages: they are the most common form of cancer for children and young adults, and a significant cause of death and reduced quality of life among older Australians. Australian Institute of Health and Welfare data estimate that more than 17,300 people will be diagnosed with a blood cancer in 2020 and that there has been a 40 per cent increase in incidence rates over the last 17 years. Modelling from the *State of the Nation* report suggests there are more than 110,000 people living with a blood cancer today and this is projected to increase to almost 275,000 people by 2035.

At the same time, blood cancers and the costs to families and the wider community are not well understood. Blood cancers are among the most costly cancers to treat, requiring the delivery of highly specialised services by specialist haematologists working in both public and private settings. Blood cancers, like other cancers, can also have a significant adverse financial impact on patients and their families, arising from out of pocket costs from diagnostics and services, travel and accommodation, and long-term impacts on employment and household savings.

Survivors face ongoing and often a lifetime of health and financial side effects as a result of their treatments. People living with blood cancer require information and access to supportive care, from diagnosis and throughout their cancer journey to enable informed decision-making, improved quality of life and to avoid financial hardship.

Through coordinated and strategic collaboration between patients, patient organisations, clinicians, researchers, industry and governments, much can be done to improve survival and quality of life for people living with blood cancer. More than 13 per cent of deaths from blood cancers can be prevented today, through the implementation of clinical best practice to remove variations in survival outcomes between metropolitan and regional areas and ensuring consistent evidence-based treatment and care nationally. Furthermore, exciting recent advances in research offer the potential for some blood cancers to be cured in our lifetimes.

The National Action Plan sets out the priority areas, objectives and actions for addressing the challenges of blood cancer to achieve the vision of zero lives lost to blood cancer by 2035.

Priority areas and objectives

Through collaboration with patients and leaders in the blood cancer community, the National Action Plan identifies four major priorities to improve outcomes for people living with blood cancer and their families; these are:

- **Empower patients and their families**
- **Achieve best practice**
- **Accelerate research**
- **Enable access to novel and specialised therapies.**

Within each priority a series of objectives and actions were identified to improve outcomes for people living with blood cancer.

These priority areas are interconnected and coordinated action will often be required across two or more priority areas to maximise impact. There is no one-size-fits-all action. Improvements are recommended from diagnosis through to post-cancer care.

This suite of recommendations will take time to implement and embed into clinical and supportive care practice across the country. As blood cancer diagnoses continue every day, there is no time to waste in implementing these recommendations.



Benefits and outcomes

Implementation of the National Action Plan will address challenges in the treatment and care of people living with blood cancer and will accelerate research for a cure.

The actions recommended by this plan are intended to complement and build on existing initiatives where these are already underway. They will benefit patients and their families by reducing preventable deaths, improving their quality of life as survivors, and maximising their ability to work and participate in social activities.

Significant benefits will also accrue to Australian communities and governments, through improvements in the quality, safety and sustainability of the health system, helping loved ones to live longer and supporting people to live a full life, be that in a working capacity or in a social capacity – for all people, from all walks of life.

The expected outcomes from the implementation of the National Action Plan include:

- Enhancing patient autonomy through their empowerment to make informed decisions along with support for high-risk groups to equitably access quality, safe and best practice supportive care and treatments.
- Reduced mortality from blood cancer.
- Improved quality of life through improved physical functioning, reduced emotional distress and improved social and practical capacity for people living with blood cancer.
- More sustainable healthcare systems, through better targeting of services and capacity for self-management.
- Reduced financial hardship for people living with blood cancers and their families.
- Increased research impact and identification of opportunities to access to clinical trials for patients with blood cancer.
- Equitable access for people with blood cancer living in Australia's regional and remote areas.
- Capitalising on and supporting Australia's reputation for research excellence.
- Higher rates of social and workforce participation for blood cancer survivors who are capable and supported to return to work.
- Growth and upskilling of the blood cancer workforce.

The realisation of these benefits will depend on sustained leadership by the blood cancer community to deliver this National Action Plan.

Plan on a page

VISION: 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.

Empower patients and their families

Achieve best practice

Accelerate research

Enable access to novel and specialised therapies

Empower patients to make informed choices

Action 1.1 Empower patients to navigate the healthcare system

Action 1.2 Develop a Blood Cancer Information Strategy as part of a broader digital health and information strategy for cancer

Action 1.3 Develop key performance indicators for written treatment and survivorship care plans

Action 1.4 Develop complex referral support tools

Enable patient-centred care through patient reported outcomes

Action 1.5 Develop a national system for patient reported outcomes in blood cancer

Empower and support high-risk patient groups

Action 1.6 Address challenges for Aboriginal and Torres Strait Islander people with blood cancer

Action 1.7 Address challenges for Culturally and Linguistically Diverse people with blood cancer

Action 1.8 Address challenges for people with blood cancer living in regional and remote areas

Action 1.9 Meet the needs of patients across their lifespan

Develop national standards for quality and safety

Action 2.1 Develop optimal care pathways and clinical guidelines for all major blood cancer subtypes

Value an accurate diagnosis

Action 2.2 Develop guidelines for diagnostics and review Australia's capacity to meet these guidelines

Action 2.3 Make precision medicine the standard of care

Ensure access to supportive care

Action 2.4 Screen for supportive care needs

Action 2.5 Improve referrals and equitable access to cancer-patient friendly exercise programs

Invest in workforce development

Action 2.6 Invest in clinical capability in both primary and specialist settings

Prevent financial hardship

Action 2.7 Implement reforms to address sources of financial hardship

Identify priority areas for research funding that deliver greater impact

Action 3.1 Identify priority areas for research funding that deliver greater impact through a Blood Cancer Research Program

Harness benefits of real world data

Action 3.2 Improve value and use of real-world data for blood cancer patients

Increase access to clinical trials

Action 4.1 Pilot key performance indicator for discussion of clinical trial options with patients

Harmonise evidence development and regulatory applications

Action 4.2 Increase access to clinical trials in regional and remote areas, including a national approach to prioritising tele-trials

Action 4.3 Establish an Enabling Access Working Group to improve equitable access to novel and specialised therapies

About the National Strategic Action Plan for Blood Cancer

The National Action Plan addresses the urgent need for a coordinated and strategic national response to the challenges of blood cancer.

The intended audiences for the National Action Plan include the Federal and state and territory governments, health service providers, philanthropic and individual funders, clinicians, people living with blood cancer and their carers, researchers and research funders.

Implementation will require national action and partnerships across all sectors and levels of the health system, non-government organisations, the private sector, researchers and academics, and particularly with those individuals our health system serves.

The National Action Plan builds on the recommendations of the *State of the Nation: Blood Cancer in Australia* report that was published by the Leukaemia Foundation in 2019. It also closely aligns with and supports the goals, principles and strategic priority areas of a range of other national and state-wide strategies, action plans and models of cancer care.

The development of the National Action Plan was led by the Leukaemia Foundation with the valuable input of hundreds of dedicated members of the blood cancer community including:

- The 29-person Blood Cancer Taskforce, comprised of patients and the preeminent multidisciplinary experts from across the blood cancer community
- A Patient and Carer Panel of 30 blood cancer patient and carer voices and patient organisations, spanning acute and chronic blood cancers affecting patients of all ages

- The seven expert Working Groups of the Blood Cancer Taskforce, which drew together more than 90 subject matter experts, focussed on achieving best practice in treatment and care, developing optimal care pathways (OCPs) and clinical guidelines, accelerating research, developing a system for patient reported outcomes, improving access to supportive care, improving diagnostics, and enabling access to novel and specialised therapies
- Engagement with 43 experts across the blood cancer community, including Federal, state and territory governments, the majority via one-on-one interviews, with some members of the Federal Department of Health participating in a stakeholder meeting
- Regionally-based clinicians and blood cancer experts, focussed on the specific challenges to the treatment and care of people with blood cancer living outside major metropolitan areas
- Aboriginal and Torres Strait Islander experts, including leading experts from the National Aboriginal Community Controlled Health Organisation, the Menzies School of Health Research, Melbourne University, regional and remote practising clinicians, the Department of Health, and state and territory governments
- 21 written submissions from members of the blood cancer community, including patient groups, pharmaceutical and medical technology industry and the research community.

Development of the National Action Plan was augmented by input from extensive consultation undertaken for the *State of the Nation* report, which included more than 65 individual consultations as well as insights from more than 3,200 people living with blood cancer and their families, through a national Blood Cancer Patient and Carer Survey.



The National Action Plan is supported by three companion documents, which are provided separately. These are: a Review of Evidence for Action, supporting the recommendations of the National Action Plan; a Summary of Cancer Policies outlining relevant initiatives and strategies across Federal, state and territory governments; and a Consultation Summary.

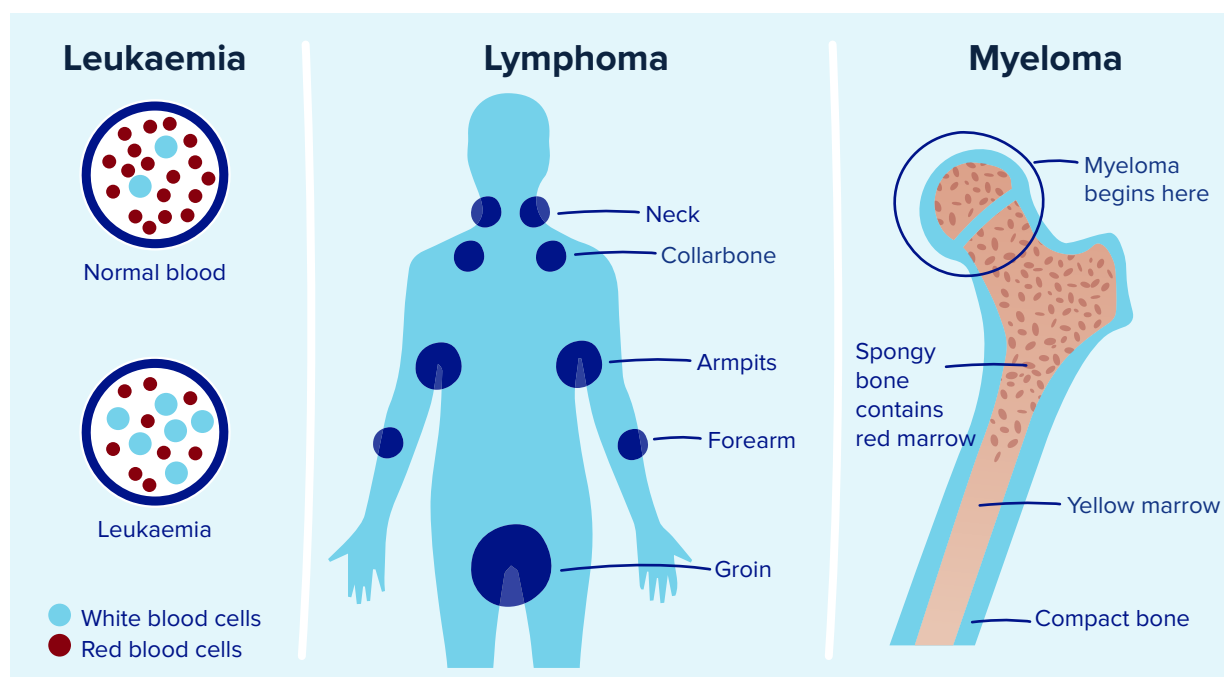
The National Action Plan is intended to guide partners and assist governments, in planning and

directing funding towards policies, programs and reforms. Through engagement and collaboration across the blood cancer community, the National Action Plan aims to reduce preventable deaths, improve quality of life for people living with blood cancer and their families, and bring forward curative therapies.

What is blood cancer?

Blood cancer is a complex set of diseases that can affect anyone at any stage of life. It is the most common form of cancer in children and adolescents.

Blood cancer arises from abnormalities in the blood cells that affect normal blood cell production and function. Typically, blood cancers are grouped into one of three major subtype classifications: leukaemia, lymphoma or myeloma. There are also increasing diagnoses of other types of blood cancers, however, which fall under the category of myelodysplastic syndrome (MDS) and myeloproliferative neoplasms (MPN) (previously called myeloproliferative disorders).



Source: Mayo clinic

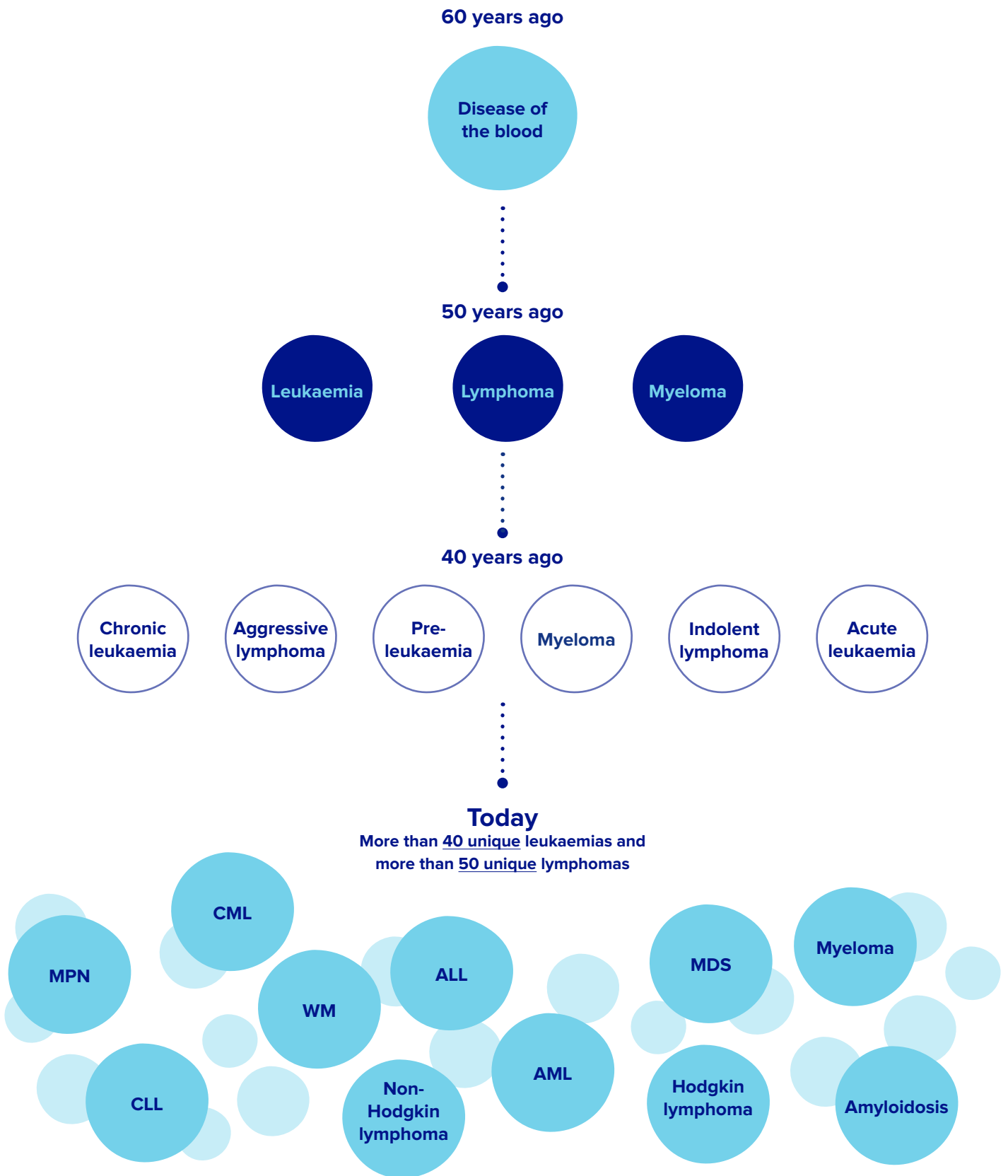
People with blood cancer experience a range of symptoms depending on the type of blood cancer. Some blood cancers develop and progress quickly (acute) and need to be treated as soon as they are diagnosed, whereas others develop more slowly (chronic) and may progress over weeks, months or years.

Treatment depends on the exact type of blood cancer a person is diagnosed with, as well as factors such as their age and general health.

Blood cancers collectively represent one of the most common types of cancer in Australia today, and one of the most common causes of cancer death among Australians, young and old.

Because blood cancers are traditionally reported by major subtypes, however, the incidence and prevalence of blood cancers has not been well understood in Australia. Consequently, the significance of blood cancers as a priority for governments and the health system is often underestimated.

How the understanding of blood cancer has evolved

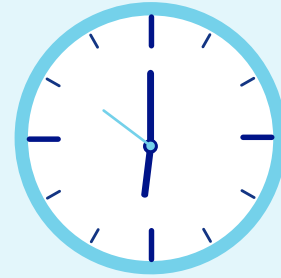


Blood cancer in Australia today

**More than
5,600**

people lose their life every year, making blood cancer one of the biggest causes of cancer death

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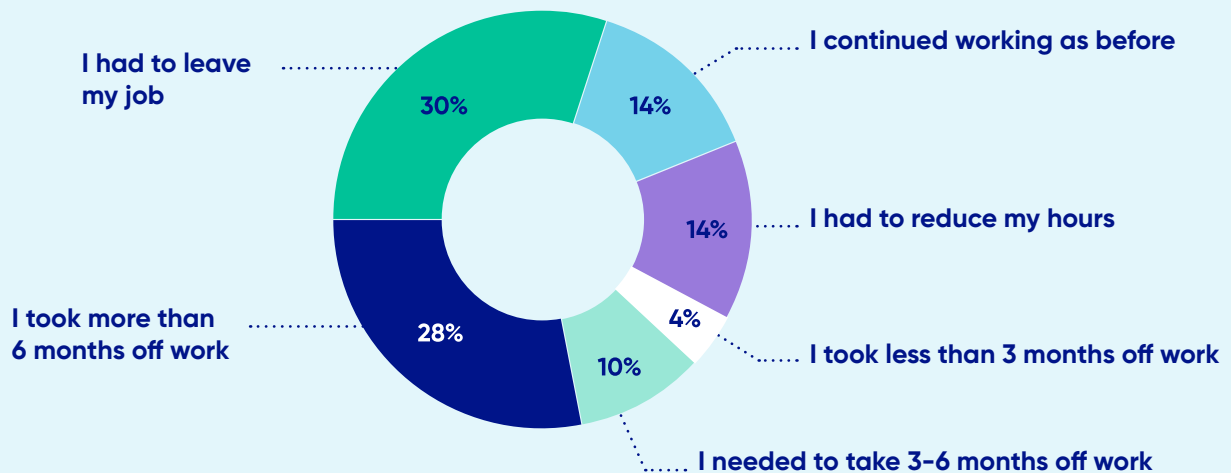
Every 31 minutes a person is newly diagnosed with a blood cancer (that's 17,321 Australians per year)

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More than 110,000 people of all ages are living with a blood cancer today



Survivors may face side effects and late effects impacting ability to return to work and take part in social activities

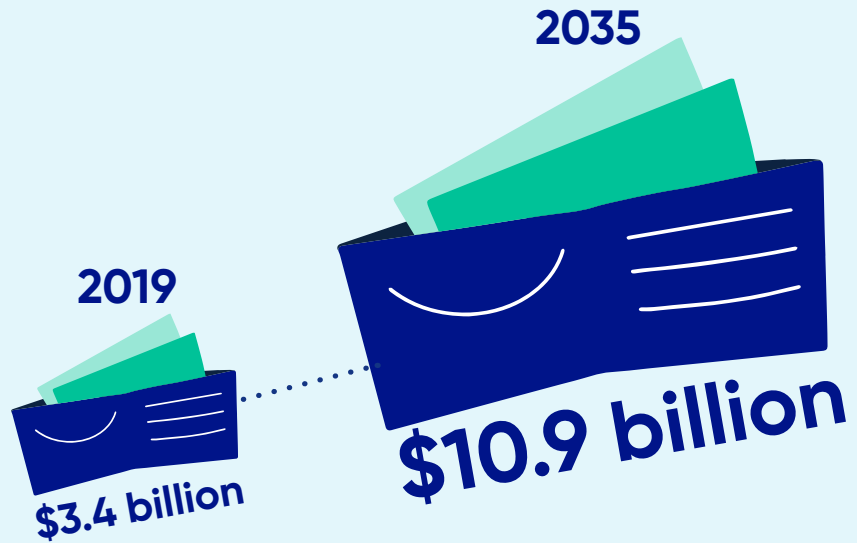


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Source - Australian Institute of Health and Welfare 2020

* Source - State of the Nation: Blood Cancer in Australia report 2019

\$10.9 billion is the expected annual cost to the health system in 2035 to treat and care for people with a blood cancer



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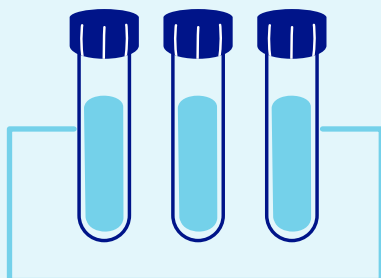
Less than 50% of people had a written care plan

*



Just 1 in 3 people had a supportive care discussion as part of their treatment planning

*



Only 1 in 5 people report having access to a clinical trial

*

22,000 lives that could be saved by 2035 through best practice treatment and care

*

* Source - State of the Nation: Blood Cancer in Australia report 2019

I took control after becoming adrift in the system

The long wait for a diagnosis took its toll on Bronwyn Bisley, but her biggest challenges lay ahead as the information she desperately needed dried up.

After feeling run-down and noticing swelling in her neck, the mother-of-three visited her doctor where a CT scan seemed to show Bronwyn had breast cancer. It was an opinion that set in motion a significant series of events: a referral to an oncologist, more appointments and scans, biopsies and, eventually, surgery.

But breast cancer was eventually ruled out and Bronwyn was instead referred to a haematologist 200km away in Melbourne.

Bronwyn said: “Finally, about three months after my first CT scan scare, my blood cancer diagnosis arrived - by Skype. The haematologist said I would need chemotherapy, six months leave from work and she asked if I had questions. I had absolutely no idea what to ask.

“Then I didn’t see her again for a really long time.”

Bronwyn was unsure about what lay ahead. She faced “distressing” chemotherapy sessions and debilitating side effects, felt like she didn’t have enough information or support, and had to wait two months between seeing her haematologist.

Overwhelmed, Bronwyn took the frightening decision to press pause on her life-saving treatment.

She added: “I didn’t want to be on that factory line for months, having no discussions with my haematologist, being so sick and only feeling worse.”

Bronwyn decided to take control. She dedicated time to get the information she needed. She spoke to experts and friends and eventually travelled to Melbourne, two hours from her hometown, to meet another haematologist.

Feeling empowered and supported, it wasn’t long before Bronwyn was back having more individualised treatment in a way that better managed her side effects. The information she gathered also saw her make positive changes to her lifestyle that helped her recovery.

The 50-year-old from regional Victoria, now back at work, said: “I never experienced those horrendous symptoms or side effects again. I was more informed, and everything became a lot better.

“It would make a huge difference if everyone with blood cancer was given the information, ideas, connections and support they needed right from the get-go.”



“

I didn't want to be on that factory line for months, having no discussions with my haematologist, being so sick and only feeling worse

Bronwyn Bisley, VIC

”

Empower patients and their families

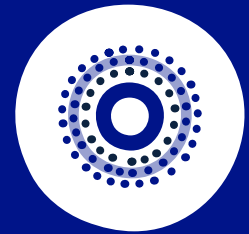
What we hope to achieve



Empower patients and their families to make informed choices



Enable patient-centred care through patient reported outcomes



Empower and support high-risk groups

Why is this important?

Improving survival and quality of life for people living with blood cancer starts with the person diagnosed. Supported by their families, the patient knows their history and treatment goals better than anyone else. The autonomy of the person with blood cancer to make informed decisions for their life is central to the National Action Plan. Obtaining a treatment plan and treatment and care that are best for that person, however, requires their empowerment through information to act.

‘Empowering patients and their families to make informed choices’ was identified by the Patient and Carer Panel as the most important objective in the National Action Plan, with the overwhelming majority saying it should be pursued by the blood cancer community as the highest priority.

While Australians enjoy one of the best healthcare systems in the world, many people find the healthcare system complex and confusing. They may also lack sufficient health and financial literacy to engage with providers and make informed decisions about their treatment and care. These choices will potentially have significant long-term health and financial implications for themselves and their families.

By supporting patients to become more autonomous and to better navigate the healthcare system, enabling the systematic reporting of outcomes and experience, and improving services to high-risk groups, people living with blood cancer will know the right questions to ask and make informed decisions that are best for them and their circumstances.

Empower patients and their families to make informed choices



Action 1.1

Empower patients to navigate the healthcare system

Rationale

One of the most significant barriers to empowering people living with blood cancer is the complexity of the healthcare system. More than one in five people living with blood cancer reports feeling 'completely uncertain' or having 'lots of questions' about their diagnosis, and one in ten about their treatment plan. Patients may not be aware of services available to help them with the carer support or financial planning. Research has shown that patient navigation services can reduce disparities in health outcomes, improve adherence to follow-up care, improve health service sustainability, and improve patient satisfaction.

Implementation

1.1.1 Develop a patient navigation service to assist people living with blood cancer to navigate the healthcare system. Delivery of this service should be considered as part of the Blood Cancer Information Strategy (Action 1.2).

At diagnosis, primary healthcare providers will refer patients to both a haematologist (and/or other specialist) and confirm consent for a referral to a patient navigation service. Consent and referral to a patient navigation service should also be facilitated through specialist services. This will help support patients to know the right questions to ask, connect people with national sources of information about clinical trial opportunities, and connect them to relevant resources to support decision-making or access support.

The patient take-up rates of the referral would determine the size of the patient navigation support service required. The service should factor in the unique needs of high-risk groups and patient life stages to best target support.

Benefits

- Reduced mortality, especially for high-risk groups.
- Improved quality of life.
- Reduced financial hardship.
- Sustainability in health services.

Linked actions for implementation

1.2

2.1

2.4

2.6

Empower patients and their families to make informed choices



Action 1.2

Develop a Blood Cancer Information Strategy as part of a broader digital health and information strategy for cancer

Linked actions for implementation

1.1

1.6

1.7

2.6

Rationale

The provision of evidence-based and trusted sources of information was one of the top priorities identified by patients through the People Living with Blood Cancer Survey. The Survey also identified that Google was the third most frequently cited source of information about their diagnosis and/or treatment and care. This highlights both the high demand for online information and also points to the risks of patients finding and relying on information that may not be reputable or evidence-based.

Technology is also connecting patients around the world, further highlighting differences in care, support, access to medicines and health outcomes.

To enable patient navigation of the complicated issues involved in diagnosis, treatment, choosing a doctor, living with blood cancer, maintaining quality of life, palliative and end of life care, and the myriad of other issues blood cancer patients deal with, an information pathway that guides patients through their journey is a high priority.

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.

An integrated digital health and information strategy for blood cancers, that enhances navigation to these and other trusted and reputable sources of information, is required. This is consistent with the Federal Government's wider strategy for digital health information services.

Developing this strategy for blood cancers can also help guide wider efforts for cancers more broadly.

Implementation

1.2.1 Form an inclusive, patient focussed and cross-organisational working group to develop a Blood Cancer Information Strategy, as part of a broader digital health and information strategy for cancer. The aim is to ensure patients can access the right information, at the right time, which is relevant to their diagnosis and personal situation. This information could include:

- Information about blood cancer sub-types and key questions for patients.
- OCPs, including the OCP for Aboriginal and Torres Strait Islander people with cancer, and Clinical Guidelines by sub-type.
- Information for primary care clinicians, specialists and other healthcare workers.
- Information to support complex referrals to specialists.
- Information about supportive care services for patients and carers, including support for financial planning.
- Connect people to national sources of information about clinical trial opportunities. ►

Empower patients and their families to make informed choices



The working group should include patient organisations, patient advocates, clinicians, researchers and other relevant stakeholders. It will be focussed on the principles and objectives that organisations agree will deliver better outcomes for patients.

This action would be supported by a training and change management strategy delivered to primary healthcare workers and specialists.

Benefits

- Reduced mortality.
- Improved quality of life.

Action 1.3

Develop key performance indicators for written treatment and survivorship care plans

Linked actions for implementation

2.1

2.4

2.6

Rationale

Health key performance indicators (KPIs) are measures that help ensure that services delivered in Australia are effective, appropriate and are achieving good outcomes for patients and the wider community.

The People Living with Blood Cancer Survey found that less than half of patients reported receiving a written care plan, which is inconsistent with clinical best practice and OCPs endorsed by the National Cancer Expert Reference Group. This contributes to poor understanding of diagnosis and treatment options, and may compound the multi-factorial issues faced by blood cancer patients, such as immunosuppression, infections, vaccination, diet and exercise, which can lead to poor survivorship outcomes and low adherence to recommended follow-up care.

By monitoring the provision of written treatment and survivorship care plans, KPIs will serve to promote improvements in clinical practice.

Implementation

1.3.1 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.

1.3.2 The establishment of KPIs would be led by the Australian Commission on Safety and Quality in Health Care and would leverage work already underway by the Commission, in partnership with clinical working groups from each jurisdiction. Once the systems and methods for KPI reporting are developed, training and change management would be delivered to clinicians to support their implementation and incorporate written treatment and survivorship plans into existing practices and processes.

Benefits

- Reduced mortality, especially for high-risk groups.
- Improved quality of life.
- Sustainability in health services.

Empower patients and their families to make informed choices



Action 1.4

Develop complex referral support tools

Linked actions for implementation

1.1

1.2

2.6

Rationale

While some primary and specialist healthcare providers may have experience and expertise in the diagnosis and treatment of blood cancers, many healthcare providers will have limited experience with blood cancers, particularly the rarer subtypes. Stakeholders reported that some primary healthcare providers are well networked, but others lack information to support an appropriate referral. Critically, the initial referral at the primary care level can set into motion a series of events that have a substantial impact on long term health and financial outcomes for the patient and their family. All patients need to consider potential out of pocket costs relating to their care and treatment. Patients with private health insurance need to weigh up the benefits of using the private health system versus any potential out of pocket costs. Supporting patients and their families to make informed decisions at this critical phase is essential.

An opportunity exists to build on recent efforts to improve transparency and empower patients in a supported conversation with their GPs and other primary healthcare providers to select the most appropriate haematologist (and/or other specialist) for them. The Blood Cancer Information Strategy could support information provision to the referring GP/primary healthcare provider and patients on:

- whether the specialist's practice is centred on blood cancers or practices in a group where blood cancers comprise a majority of case volumes;
- opportunities to link up with blood cancer sub-specialists as part of a healthcare team;
- if the centre is accredited in a highly specialised service (where appropriate) and integrated with hospital training systems;
- nationally available resources for consumers regarding private health insurance, out of pocket fees, medical costs and informed financial consent (such as the Department of Health Private Health Insurance Resources and the Medical Costs Finder);
- treatment options in private and public settings.

Combined, this would substantially address market failures and barriers arising from incomplete information and better support clinicians and patients in the early stages of referral.

Implementation

1.4.1 Patient support organisations and blood cancer clinicians nationally to collaborate to develop a positively-oriented service directory where specialists in blood cancer subtypes are more easily identified and expected fees are outlined to support an individual's planning.

Benefits

- Reduced mortality, especially for high-risk groups.
- Sustainability in health services.

Enable patient-centred care through patient reported outcomes



Action 1.5

Develop a national system for patient reported outcomes in blood cancer

Linked actions for implementation

1.8

2.4

Rationale

As the treatment of cancer is transforming many cancers from acute, life-threatening diseases to long-term chronic conditions, patient reported outcomes (PROs) are increasingly recognised as important tools for symptom and adverse event monitoring to enable better patient care, as well as tools to guide investment in research and regulatory decision making.

PROs are particularly important in oncology because while side-effects are common among patients receiving treatment for advanced cancers, research has found they are undetected by clinicians up to half the time.

Studies have shown PROs in an oncology setting can improve patient satisfaction, symptom detection, therapy adherence, clinician-patient communication and patient involvement in care, as well as management of side-effects and utilisation of supportive care. PRO systems have also been shown to reduce presentation to Emergency Departments, and frequency of hospitalisation. In one recent study, overall survival was also extended and health-related quality of life improved.

To successfully bring about change in patient management and clinical practice, PROs must be embedded within existing clinical systems. The context and implementation strategies utilised when introducing PROs into standards of care (including minimal disruption to workflows and burden on staff) are also critical to success.

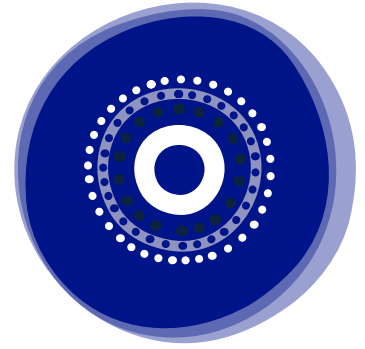
Implementation

1.5.1 Given the above evidence of benefit, and the need for a nationally coordinated approach, the National Action Plan recommends assembling a clinical advisory working group of clinicians and patients by blood cancer subtype to undertake a PROs scoping study:

- Define the principles and objectives of a PRO system.
- Agree a taxonomy for data, standards and methods of collection and analysis.
- Select PRO measures and identify thresholds for clinical action.
- Stock-take of existing clinical systems capabilities by jurisdiction.
- Develop a plan for implementation that ensures embedding in existing systems of care and Electronic Medical Records (EMRs).

Benefits

- Empower patients.
- Patient satisfaction.
- Sustainability in health services.
- Improved quality of life.



Empower and support high-risk patient groups

Action 1.6

Address challenges for Aboriginal and Torres Strait Islander people with blood cancer

Linked actions for implementation



Rationale

In 2008, Australian governments committed to eliminating the life-expectancy gap between Indigenous and non-Indigenous Australians. AIHW data show that cancer contributes to the gap in health outcomes. Survival rates for all cancers combined from 2010 to 2014 was 59.3 per cent for non-Indigenous Australians compared to 48.1 per cent for Indigenous Australians.

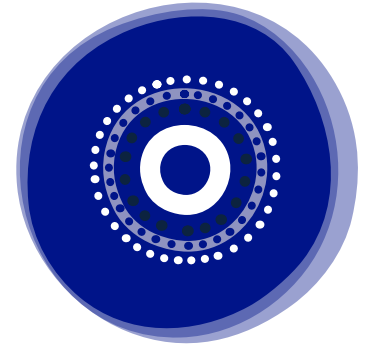
The incidence and prevalence of blood cancers in Aboriginal and Torres Strait Islander communities is likely under-diagnosed and under-reported.

What data are available, however, suggests that Aboriginal and Torres Strait Islander people experience poorer health outcomes for blood cancer than non-Indigenous Australians. Multiple intersecting factors contribute to lower rates of presentation, later diagnoses, lower rates of service utilisation and poorer outcomes. Aboriginal and Torres Strait Islanders are also less likely to be able to find a matched donor in the event that they require an allogeneic stem cell transplant, due to a lack of Aboriginal representation on the Australian Bone Marrow Donor Registry.

Implementation

The key focus to achieve improvements in quality of life for Aboriginal and Torres Strait Islander people is the commitment to improvements in core care needs. In addition to wider efforts to improve cancer service delivery to Aboriginal and Torres Strait Islander people, the National Action Plan recommends specific actions to improve outcomes for Aboriginal and Torres Strait Islander people diagnosed with blood cancers specifically:

- **1.6.1** 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.
- **1.6.2** Work with the Aboriginal and Torres Strait Islander Health Workforce to undertake a gap review of Indigenous Health Workforce expertise in blood cancers to support culturally sensitive care across all healthcare settings (both Indigenous and non-Indigenous).
- **1.6.3** Develop an awareness and education campaign regarding blood cancer signs and symptoms in partnership Community Controlled Health Services.
- **1.6.4** Promote the use of Cancer Australia's OCP for Aboriginal and Torres Strait Islander people with cancer within the blood cancer clinical network, in conjunction with individual OCPs for different blood cancer subtypes.
- **1.6.5** Ensure access for Indigenous people to chemotherapy, emerging therapies and safe and effective stem cell transplants. Work with the Enabling Access Working Group (Action 4.3) and existing reform agendas underway with government and non-government organisations to increase the representation of Aboriginal and Torres Strait Islanders on the Australian Bone Marrow Donor Registry.
- **1.6.6** Leverage existing activities and national reform agendas to improve participation rates of Indigenous cancer patients in clinical trials for blood cancers.
- **1.6.7** Ensure relevance and use of supportive care assessment tool to support Aboriginal and Torres Strait Islander people living with blood cancers. The supportive care assessment tool should be validated for use with Aboriginal and Torres Strait Islanders, consistent with the advice in the OCP for Aboriginal and Torres Strait Islander people with cancer. ►



Empower and support high-risk patient groups

Action 1.7

Address challenges for Culturally and Linguistically Diverse people with blood cancer

Linked actions for implementation

- 1.2
- 1.5
- 2.6
- 4.2
- 4.3

Benefits

- Reduced mortality and improved quality of life especially high-risk groups.
- Investment in regional and remote areas.
- Increased research investment.
- Upskilling and workforce participation.

Rationale

Blood cancer affects people from all cultures and backgrounds, and Australia is becoming more culturally and linguistically diverse. The 2016 Census reported that roughly one in three Australians were born overseas and two thirds of these people were newly arrived having migrated to Australia after 2012. Australians today speak more than 300 languages, follow over 130 religious faiths and approximately one in five humanitarian arrivals are illiterate in their main spoken language.

Barriers to patient engagement and access to the healthcare system may encompass language, cultural practices, religion and other beliefs.

Also, the Australian bone marrow donor pool is predominantly comprised of Caucasian, middle-aged and female donors. As a result, over 80 per cent of Australian unrelated transplants depend on international donors. Some ethnic groups are not well represented in these international donor groups, particularly Aboriginal and Torres Strait Islander, South East Asian, Greek, Lebanese, and Pacific Islander populations, which can result in inequitable access to potentially life-saving bone marrow transplants for some ethnicities.

Implementation

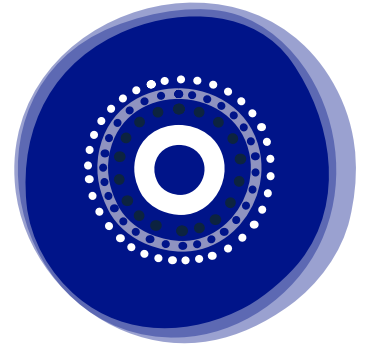
The key focus for Culturally and Linguistically Diverse people living with blood cancer is to reduce barriers to access best practice clinical care.

In addition to wider efforts to improve cancer service delivery to Culturally and Linguistically Diverse people, the following targeted initiatives are recommended to improve the provision of services for people diagnosed with blood cancer from Culturally and Linguistically Diverse backgrounds:

- **1.7.1** Ensure access to bone marrow donors for Australians of all ethnicities.
- **1.7.2** Undertake a stock-take of culturally and linguistically diverse patient needs by hospital to enable prioritisation by location.
- **1.7.3** Provide education and training to translators, cultural advocates, and local cultural organisations in blood cancer OCPs and medical terminology at high priority centres.
- **1.7.4** Explore options for enhanced telemedicine and digital health information services, such as the development of Royal District Nursing Service Talking Books and/or the National Ageing Research Institute Moving Pictures initiatives for blood cancer. This could have benefits for other patient populations, not just those from culturally and linguistically diverse backgrounds.
- **1.7.5** Ensure PRO systems are culturally appropriate and available in languages other than English, and the Blood Cancer Information Strategy considers culturally appropriate and accessible information provision.

Benefits

- Reduced mortality and improved quality of life especially high-risk groups.
- Upskilling and workforce participation.



Empower and support high-risk patient groups

Action 1.8

Address challenges for people with blood cancer living in regional and remote areas

Linked actions for implementation



Rationale

Consistent access to best practice treatment and care has the potential to deliver improved survival outcomes and quality of life for people living with blood cancer. Data shows that we could reduce mortality from blood cancers by 13 per cent by removing variations in survival outcomes nationally, which includes removing variations between metropolitan and regional/remote areas.

State cancer registry data show that survival outcomes at 1-year and 5-years for people living in regional and remote areas are poorer than for metropolitan-based patients. If the metro-regional divide were addressed, approximately five per cent of expected mortality to 2035 (more than 9,300 people) could potentially be avoided.

The causes of this are multiple and intersecting, arising from higher rates of economic disadvantage in regional and remote communities, a lack of specialists, specialist diagnostic and blood cancer subtype services, barriers to travel, lack of supportive care and barriers to clinical trial participation.

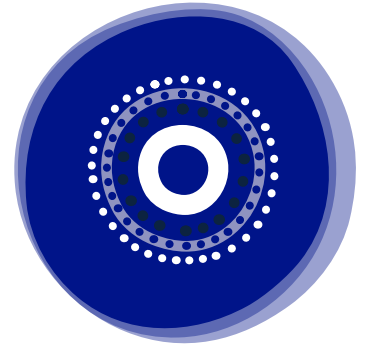
Implementation

Addressing the disparity in survival outcomes for regional and remote patients will require a sustained and sophisticated policy effort, that is complementary to and not duplicative of existing policies, including:

- **1.8.1** Reduce unwarranted variation in treatment and care through development, promotion and implementation of individual OCPs for different blood cancer subtypes, clinical guidelines and accreditation, underpinned by patient navigation services, the Blood Cancer Information Strategy and a workforce change management strategy.
- **1.8.2** Develop guidelines for diagnostics and review Australia's capacity to meet those guidelines, including the availability of specialised diagnostic services for regional and remote patients, and recommend options for improving test accuracy and appropriate guidelines for timeliness for regional and remote patients.
- **1.8.3** Conduct a skills audit of the regional and remote workforce and develop a strategy to enable care closer to home, adoption of telehealth, more effective diagnosis and referral of patients to subtype specialists and increased clinical trial participation in the regions. The skills audit and strategy should be done in consultation with relevant stakeholders and leverage existing work that is underway.
- **1.8.4** Improve opportunities to access clinical trials for blood cancer patients living in regional and remote areas, in particular through contributing to the development of teletrials and the removal of barriers to travel, through advocacy and leveraging work that is already underway through the national reform agenda in clinical trials.
- **1.8.5** Enable patient-centred care through a national system for PROs that can enable improved monitoring of symptoms and adverse events, as well as a more systematic screening and referrals to supportive care.

Benefits

- Reduced mortality and improved quality of life especially high-risk groups.
- Upskilling and workforce participation.



Empower and support high-risk patient groups

Action 1.9

Meet the needs of patients across their lifespan

Linked actions for implementation

1.1

1.2

1.5

2.1

2.6

Rationale

Blood cancers affect people of all ages and are the most frequently diagnosed cancers and causes of cancer death among children, adolescents and young adults. Blood cancers also affect geriatric patients, who are likely to have significant co-morbidity, polypharmacy and frailty that may influence their eligibility for treatment and clinical trial enrolment.

Each of these people living with blood cancer are important and each have unique needs at different phases of their life:

- Blood cancer patients are often immunocompromised as a result of their treatment and as such are highly susceptible to infections. This is of particular concern for individuals who have undergone stem cell transplants, those with comorbidities and or are from high risk patient groups.
- Paediatric patients have high supportive care needs, both during treatment and over the course of their lives as many face a long tail of side effects and late effects from treatment.
- Adolescents and young adults similarly have high supportive care needs over their lifetime and can face unique challenges transitioning from paediatric to adult services. This population typically has a poorer participation in clinical trials.
- Adults with young families or planning families can face substantial social and practical challenges, requiring supportive care services in the form of fertility preservation, psychosocial support and financial planning.
- Geriatric patients often face complex treatment arrangements involving multiple specialists and need for shared care, as well as risks of hardship due to low income. Careful planning and consideration for their caregivers is essential, including an assessment of their capacity to support.
- Patients undergoing palliative and/or end of life care require specific supports, including advanced care planning and other forms of supportive care for the individual and their families (for example financial support, counselling, grief and bereavement, pain management etc.).
- These needs are often compounded where patients reside in regional and remote areas, or where patients come from an Aboriginal and Torres Strait Islander or other culturally and linguistically diverse background.

Implementation

1.9.1 The development and implementation of each action in the National Action Plan should consider the unique needs of patients across their lifespan, including palliative and end of life care. Specific considerations for life stages and circumstances must therefore be included in the OCPs and clinical guidelines, the development of the Blood Cancer Information Strategy and patient navigation services, and a national system for patient reported outcomes. It will also rely on implementation at the workforce level, through training and change management, aimed at improving the understanding of blood cancers, availability of new tools and models for shared care. Consideration should be given to existing work that is already underway in order to complement, not duplicate, efforts to improve outcomes for blood cancer patients.

Benefits

- Reduced mortality and improved quality of life especially of high risk groups.

Same cancer, same drug but our access to treatment was anything but consistent

They're three women all battling an incurable type of blood cancer, but Neda, Nikki and Shirley have felt hardship in very different ways.

Before lenalidomide was listed on the PBS, the breakthrough medicine could cost more than \$194,000 for single course of treatment. But it was an option that could help these three Australians to prolong their disease in remission.

Unable to pay the \$1,000 monthly cost, Neda Masters from Queensland was on the verge of moving to America where she could get affordable access the drug.

The 46-year-old mum said: "We didn't have a choice. Thankfully, my husband had a job lined up but I didn't know what I was going to do if my family couldn't live and work in America with me.

"Getting access to the best treatment was going to come at huge cost. We were unable to make the move to America because of the COVID-19 pandemic. Thankfully, the PBS listing in March means I can access the drug here at an affordable price."

Nikki Wagner from New South Wales could only initially afford three boxes

of lenalidomide, calling them her "princess pills" with each small tablet costing around \$250.

Thankfully, her brother intervened and raised the \$18,000 needed to start maintenance on this drug.

The 56-year-old said: "It cost about \$5,000 for each box of 21 tablets. There was no way we could continue to afford them.

"However, following the initial costs outlaid, I was told I would be getting the drug on compassionate grounds through the drug company. From then on, I was able to get a box for less than \$8, a life-changing discount."

Shirley Irwin was not so lucky. The 71-year-old from Victoria used \$54,000 from savings to pay for her lenalidomide which she took for eight months.

The mother-of-two said: "I've had some difficulty coming to terms with spending the kid's inheritance on this medication. But they assured me, 'we don't want the money, we want you'."



Nikki Wagner, NSW



Shirley Irwin, VIC



Getting access to the best treatment was going to come at huge cost.

Neda Masters, QLD



Achieve best practice

What we hope to achieve



Develop national standards for quality and safety



Value an accurate diagnosis



Ensure access to supportive care



Invest in workforce development



Prevent financial hardship

Why are these actions important?

Ensuring consistent access to best practice treatment and care has the potential to deliver substantial improvements in survival outcomes and quality of life. Data shows that we could reduce mortality from blood cancers by 13 per cent by removing variations in survival outcomes nationally (8 per cent difference between states) and between metropolitan and regional/remote areas (5 per cent difference), based on current survival outcomes between 2018-2035. That translates to preventing more than 22,000 deaths over that period, just by doing things that are already known to work and are available in Australia more consistently.

The Patient and Carer Panel identified both 'Ensuring access to supportive care' and 'Value an accurate diagnosis' as very important objectives in the National Action Plan and should be pursued by the blood cancer community in the grouping of the highest priorities.

There are many challenges to overcoming the barriers to achieving best practice, including incomplete notification of blood cancers to state and territory cancer registries, the rapidly evolving nature of blood cancer, the essential requirement that practitioners have completed specialist training and have the skills to deliver a safe, quality service, and the limited understanding of the importance of supportive care and non-biologic factors. By defining best practice through the development of OCPs and clinical guidelines, improving diagnostic practices, increasing referrals to supportive care, investing in workforce development and implementing reforms to prevent financial hardship, real improvements can be made to the lives of people living with blood cancer and their families today.

Develop national standards for quality and safety



Action 2.1

Develop Optimal Care Pathways and clinical guidelines for all major blood cancer subtypes

Linked actions for implementation

1.2

2.6

Rationale

Ensuring consistent access to treatment and care depends on the definition of clinical best practice. As the review of cancer policies showed, Australia is out of sync with other developed countries in the development and use of clinical guidelines, as well as the requirement of accreditation for highly specialised services, such as bone marrow transplants. Multiple studies have demonstrated that adherence to clinical best practice improves survival outcomes and patient quality of life. Often high-risk patient groups, including geriatric patients, women and regional patients are less likely to receive care that accords with current best practice. Accredited centres for highly specialised services also report superior outcomes for highly specialised services compared with non-accredited centres.

Clinical guidelines bring together the best available evidence to underpin scientifically valid recommendations for the diagnosis and treatment of patients. They are a key mechanism to improve quality and safety in care and reduce variation in survival outcomes.

OCPs make wide ranging evidence-based recommendations for best practice care, from the point of diagnosis, through treatment, survivorship and end-of-life care. OCPs cover a wide range of relevant issues for both patients and clinicians, including opportunities to deliver services and care through integrated and telehealth models, guidance for managing infection control and palliative care, for example. They are important tools for helping clinicians to understand the importance of providing information and supportive care services but are only useful if they are used. To date OCPs have been developed for acute myeloid leukaemia, Hodgkin lymphoma and diffuse large B-cell lymphoma.

Together, clinical guidelines and OCPs can minimise variation and promote best practice care. They are the foundation for achieving best practice and reducing disparities in survival outcomes.

There is a critical need to address gaps in OCPs and clinical guidelines for different blood cancer subtypes. OCPs and clinical guidelines are interdependent and to be effective should be fully integrated into clinical practice.

Implementation

2.1.1 Undertake a stock-take of current OCPs and national/international clinical guidelines to inform and prioritise the adoption or development of new OCPs and clinical guidelines (or update existing OCPs and clinical guidelines) for all major blood cancer subtypes.

2.1.2 Clinical guidelines would need to be updated at agreed intervals and presented at key meetings, such as the annual ALLG meeting, and endorsed by relevant professional colleges. The publication of OCPs and clinical guidelines should be considered in the development of the Blood Cancer Information Strategy, with training and education provided to support their integration and implementation into clinical practice.

2.1.3 Through the guideline development, a limited number of selected, highly specialised services may be identified as requiring high case volumes to ensure safety and quality. It is recommended that these highly specialised services are then required to be accredited via processes that are complementary to and not duplicative of existing accreditation requirements and are in line with international best practice.

Benefits

- Reduced mortality, especially for high-risk groups
- Improved quality of life
- Sustainability in health services

Value an accurate diagnosis



Action 2.2

Develop guidelines for diagnostics and review Australia's capacity to meet these guidelines

Linked actions for implementation

1.8

2.1

2.3

2.6

4.3

Rationale

Access to accurate and timely diagnostics is fundamental to the treatment, care and survival for people living with blood cancer. Early and accurate diagnosis is critical to not only the understanding of what type of blood cancer an individual has, but also to what treatment pathway will offer the best survival and quality of life outcomes. This is at the heart of precision medicine.

Ongoing research has increased our understanding of the complexity of blood cancers, which in turn has resulted in the development of highly specialised and complex diagnostic services to improve diagnosis and inform patient treatment, including the use of targeted medicines.

While a timely and accurate diagnosis is fundamental to quality and safe clinical practice and patient outcomes, major challenges exist in achieving an accurate and timely diagnosis, the delivery of diagnostic services to patients and in the notification of all blood cancers to state cancer registries.

At a population level, under-notification of cases to state cancer registries leads to insufficient depth of reporting and under-reporting. If cancer registries are not notified of cases then this leads to an underestimation of blood cancer incidence. The AIHW has recently created a new grouping 'All blood cancers combined' in its Cancer in Australia dataset, which gives us a greater understanding of blood cancers as a whole, however, issues still remain with notification of cases to cancer registries. This is a key barrier to understanding the true scale and impact of blood cancers in Australia.

At the patient level, international studies show that error rates in blood cancer diagnoses can be high, and can occur more frequently in rare blood cancers. Misdiagnosis leads to inappropriate treatment, contributing to poorer patient outcomes than necessary, as well as inefficiencies and extra costs within the health system.

Timeliness is also a major challenge; complex tests can take several weeks to complete, delaying time to treatment. If a person lives in a regional or remote area, these delays may be further increased. These challenges are not unique to Australia, and other countries have undertaken major reviews of diagnostic services to improve accuracy and timeliness.

Many diagnostics which are now internationally recognised as standard-of-care for patients with blood cancers are additionally not yet listed on the Medicare Benefits Schedule (MBS). This can lead to significant cumulative out-of-pocket costs to patients and/or lower rates of test ordering in some areas, with consequent poorer decision-making. MBS listings occur following an application to the Medical Services Advisory Committee (MSAC) to assess whether a technology is safe, effective and cost effective. These applications can be made by individuals, clinical groups or industry with data to support the listing.

While there are currently opportunities for consumers to engage with the MSAC process, including consumer representation on the committees responsible for considering applications, consumer understanding of and engagement with the process is not as strong as it should be, given the central importance of getting the diagnosis right. As seen for the analogous Pharmaceutical Benefits Scheme (PBS) processes, improved transparency and better integration of the consumer voice in enunciating value improves both the evaluation process and subsequent implementation. Evolution of existing processes is essential to more fully engage consumers and to incorporate their views into decisions that so directly affect their health and healthcare options. ►

Value an accurate diagnosis



Implementation

2.2.1 Review existing international diagnostics guidelines in blood cancer and develop Australian-specific guidelines for minimum and recommended testing requirements for different types of blood cancer in Australian healthcare settings. These guidelines should be integrated with clinical guidelines (Action 2.1).

2.2.2 Following the development of diagnostic guidelines for different types of blood cancer, undertake a wider strategic assessment of blood cancer diagnostics service delivery across Australia. This would include workforce development needs in metropolitan and regional areas, as well as potential options for improving accuracy, timeliness and efficiency in diagnostic services nationally. This strategic assessment should also identify options to address issues with under-notification of cases to state cancer registries.

2.2.3 The Enabling Access Working Group (Action 4.3) should engage with governments, regulators and the blood cancer community to:

- Coordinate evidence to support the development of applications for MBS reimbursement of diagnostics that are standard of care but are not yet listed.
- Continue important reforms to MSAC processes for MBS listings, focusing on greater transparency and the rapid adoption of diagnostics, which have been demonstrated to be cost-effective that direct patients to the most effective therapies. This should include enhancing consumer understanding of and engagement with the MBS listing process, drawing experience from improved consumer engagement in PBS processes.

Benefits

- Reduced mortality, especially for high-risk groups
- Improved access to services for regional and remote patients
- Sustainability in health services

Action 2.3

Make precision medicine the standard of care

Linked actions for implementation

2.2

3.1

4.3

Rationale

Blood cancer has been at the forefront of precision medicine, and as research has advanced, the understanding of the genomic complexity of blood cancers has increased markedly.

Genomic profiling is required for accurate subtype diagnosis and the subsequent treatment of blood cancer patients. Through genomic profiling clinicians can more precisely match patients to targeted therapies. These efforts are critical to the expansion of precision medicine and the realisation of curative therapies.

In Australia today, however, access to genomic diagnostics is limited and privately funded, creating barriers to equitable access and slowing the development of data to inform research efforts.

To support improvements in clinical practice and blood cancer research efforts, precision medicine (with genomic testing as required) should be made the standard of care.

Implementation

2.3.1 The implementation of precision medicine as a standard of care could be developed and funded as part of the Blood Cancer Research Program and supported by a working party focussed on the harmonisation of research efforts and evidence development for regulatory approval across Australia.

Benefits

- Reduced mortality.
- Improved quality of life.
- Sustainability in health services.

Ensure access to supportive care



Action 2.4

Screen for supportive care needs

Linked actions for implementation

1.3

2.1

2.6

Rationale

Supportive care is care given to prevent or treat, as early as possible, the symptoms and side effects of blood cancer and its treatment. Supportive care encompasses the management of issues across a range of physical, emotional, and social domains to improve a patient's quality of life – including psychosocial support, practical, education and career support, nutritional advice, physiotherapy, palliative care and financial support.

Evidence shows that a blood cancer diagnosis and its treatment leads to deterioration of patient's quality of life along a number of different dimensions, and that outcomes may be substantially lower for people living in rural or remote areas, unemployed, female, adolescents and young adults and geriatric patients. Often symptoms do not present alone, but rather a person will experience a side effect, such as fatigue, along with other symptoms such as pain, emotional distress, and sleep disturbance, which is known as a symptom cluster. Studies have shown these effects are inter-related and influence survival, but can be managed effectively through appropriate referrals to supportive care.

Critically, however, both contemporary literature and the Survey of People Living with Blood Cancer showed that supportive care is inconsistently discussed with patients, and symptoms are undetected by clinicians in up to half of all patients. More than one third of Australian patients reported wishing they had received more help to understand the side effects of their treatment and how to manage them.

Implementation

2.4.1 Screening for supportive care must be integrated into clinical guidelines to support their implementation in both primary and specialist healthcare environments. To promote uptake and use, KPIs for supportive care screening should be developed to foster improvements in clinical practice.

2.4.2 OCPs and clinical guidelines for blood cancer should recommend routine screening of patients at key milestones throughout treatment, supported through the introduction of a national system for PROs.

2.4.3 To foster the consistent screening for supportive care in clinical practice, the need for supportive care screening should be included in training and change management strategies and audited over time.

Benefits

- Improved quality of life, especially for high-risk groups.
- Reduced mortality.
- Sustainability in health services.

Ensure access to supportive care



Action 2.5

Improve referrals and equitable access to cancer-patient friendly exercise programs and lifestyle services

Linked actions for implementation

1.5

2.4

2.6

Rationale

Strong evidence is available to show that exercise substantially improves outcomes for patients across a range of dimensions including fatigue, pain, distress, anxiety, depression, declines in bone health, cognitive and cardiovascular function, as well as increased health related quality of life. Exercise improves survival outcomes for people living with blood cancer and is safe, even after undergoing a transplant.

Reflecting this high level of evidence for the importance of exercise to patient outcomes, many Australian and international professional organisations have called for increased physical activity screening and referrals to exercise programs where appropriate, including American Cancer Society, American College of Sports Medicine Roundtable, the Clinical Oncology Society of Australia, Exercise & Sports Science Australia and Cancer Care Ontario. Despite these recommendations, most people living with blood cancer do not engage in exercise at levels required to realise benefits to their health and wellbeing. Reports indicate that 60 to 70 per cent of people with cancer do not meet aerobic exercise guidelines, and 80 to 90 per cent do not meet resistance exercise guidelines. Additionally, the importance of exercise is inconsistently discussed with patients.

These data demonstrate that current strategies to engage people with cancer in exercise are not working. As a result, very few people with cancer are realising the widespread benefits exercise provides to restoring health and wellbeing during and after treatment.

In addition to exercise, there is a wide range of evidence that supports health and wellness benefits of other lifestyle services such as dietetics, wellness programs (including smoking and alcohol cessation) for cancer patients.

Implementation

2.5.1 To improve uptake of exercise recommendations for people living with blood cancer, physical activity levels should be consistently screened as part of a supportive care screening strategy and supported by a national system for patient reported outcomes.

2.5.2 Depending on the outcomes of the patient engagement and understanding of patient goals, clinicians should refer people to a program for cancer patient-friendly exercise and lifestyle services, depending on their individual support requirements. The program should trial referrals to a range of supervised and self-directed programs in both healthcare provider and community settings activity levels and in turn quality of life and survival.

Benefits

- Improved quality of life, especially for high-risk groups.
- Reduced mortality.
- Sustainability in health services.

Invest in workforce development



Action 2.6

Invest in clinical capability in both primary and specialist settings

Rationale

Clinicians are required to stay up to date with the complex scientific evidence involved in accurate diagnoses, which govern the selection of the most appropriate treatment and care. At the same time, significant and rapid advances in blood cancer diagnosis and care have been occurring over the past decade. Ongoing investment in education and training infrastructure is therefore required, to support clinicians and to ensure the currency of clinical capability in primary and specialist settings, including supportive care.

More work needs to be done to improve models of shared care for blood cancer patients between primary and specialist settings, to improve coordination of treatment and supportive care, from diagnosis, through active treatment and survivorship.

Investing in Australia's workforce, in collaboration with the appropriate bodies representing each relevant sector of the workforce, is fundamental to achieving the vision of zero lives lost to blood cancer, including:

- Improving skills for the safe and quality delivery of personalised medicine.
- Improving understanding of blood cancers in primary care settings.
- Improving skills for the safe and quality delivery of shared care.
- Improving skills and training in palliation for haematology patients.
- Developing Australia's regional and remote workforce.
- Improving systems for best practice knowledge sharing and health services delivery across public and private, metropolitan and regional care settings including multidisciplinary teams and telehealth (including tele-trials).

Implementation

2.6.1 Define a service standard, informed by OCPs, clinical and diagnostic guidelines and the research roadmap, to determine workforce needs in primary and specialist settings including supportive care.

Once service standards have been defined, a blood cancer workforce strategy should implement, in partnership with governments and relevant professional colleges:

- **2.6.2** A skills audit of regional and remote workforce requirements.
- **2.6.3** Appropriate training and change management approaches developed with relevant professional bodies in primary care settings, aimed at improving the awareness and understanding of blood cancers, the availability of new tools, and models for shared care (including telehealth).
- **2.6.4** A training and change management strategy aimed at specialist settings, focussed on advances in telehealth, personalised medicine and implications for clinical practice, the roll-out of hospital training, and the use of supportive care and palliative care for people living with blood cancer.

A workforce strategy for blood cancer needs to occur in conjunction with existing structures and activities already implemented or under development by the relevant professional bodies, as well as government and the blood cancer clinical and research community. Key to this will be integration with the National Medical Workforce Strategy currently underway, which will guide long term collaborative medical workforce planning across Australia.

Benefits

- Reduced mortality and improved quality of life especially high risk groups.
- Investment in regional and remote areas.

Linked actions for implementation



Prevent financial hardship



Action 2.7

Implement reforms to address sources of financial hardship

Linked actions for implementation

1.2

1.4

1.5

1.8

2.4

Rationale

A blood cancer diagnosis can have a material adverse impact on household finances, due to the unexpected need to meet out of pocket costs related to treatment, diagnostics, travel and accommodation, as well as the impact to income resulting from a loss of income and/or early retirement for the patient and/or carer.

The Survey of People Living with Blood Cancer found that just over 30 per cent of respondents reported incurring out of pocket costs and approximately one third of respondents required financial assistance as a result of their blood cancer. The survey indicated that patients incurred substantial costs related to travel and accommodation, medicines for supportive care and diagnostic tests. The cumulative impact of these costs to patients and their families, particularly for vulnerable groups with low income or savings, can lead to financial hardship for many households.

Economic disadvantage is a major contributing factor to inequities in survival outcomes between metropolitan and regional areas, with people living in regional areas roughly twice as likely to be socioeconomically disadvantaged (30 per cent of regional and remote patients compared to 13 per cent of metropolitan patients). People living in regional areas were 17 times more likely to report locational and financial barriers to care than people living in metropolitan areas. Economic disadvantage is also a significant issue for other patient populations, particularly high-risk groups (such as Aboriginal and Torres Strait Islanders for example) and for specific blood cancer patient cohorts, such as adolescents and young adults.

Each state and territory operates Patient Assistance Travel Schemes (PATS). These state-based schemes offer some financial support however they vary in magnitude, coverage and administration. In addition, most schemes limit support for people travelling to undertake clinical trials. Currently there is no national scheme or policy that covers travel and related costs for participation in clinical trials however in some instances, costs associated with travel for clinical trials may be covered by the trial-sponsor.

Implementation

In addition to screening for financial distress using a national system for patient reported outcomes in blood cancer, supporting complex referrals for informed financial consent and patient choice, and the development of a Blood Cancer Information Strategy, the National Action Plan recommends the following reforms to prevent financial hardship:

- **2.7.1** Consult with all jurisdictions to reform Patient Assisted Travel Schemes (PATS), including advocating for streamlined administrative processes, greater access to the schemes and support for patients to participate in clinical trials.
- **2.7.2** Review options for the introduction of financial support mechanisms (such as a temporary disability payment) to support people with cancer and other serious illness who require temporary financial support.

Benefits

- Reduced mortality, especially for high-risk groups.
- Improved quality of life.

Personalised cellular therapy gives Hunter a future

A cutting-edge cellular therapy, made possible by breakthrough research, has given seven-year-old Hunter hope for a brighter future.

Hunter was three years old when he was diagnosed with an aggressive blood cancer, and standard chemotherapy and transplant treatments proved unsuccessful.

“We found out Hunter has a very rare chromosomal abnormality in his leukaemic cells,” explained Hunter’s mum, Kate.

“Because of that, I always knew he was going to relapse. I didn’t think it would be as early as he did, but in my hearts of hearts, I knew.”

Blood Cancer Taskforce member Dr Rishi Kotecha is Hunter’s oncologist at Perth’s Children Hospital and advocated for Hunter to receive newly approved CAR T-cell therapy at the Royal Children’s Hospital in Melbourne.

Hunter was just the tenth child in Australia to undergo federally funded, CAR T-cell therapy, only qualifying for the treatment after leukaemia cells were found in both his central nervous system and bone marrow.

“This is unlike any treatment he’s ever had before,” said Kate.

“His T-cells were extracted and sent to America to be re-engineered. We then got them back, and he was given a small 10ml syringe of these new ‘super cells’.

Even though the process of engineering the cells and having them returned is complicated, from Kate’s perspective, it was quite straightforward.

“It was relatively simple, almost too simple, but it put him into remission.”

Hunter’s dad, Dave, is adamant research is the key to making a difference for families struggling with blood cancer.

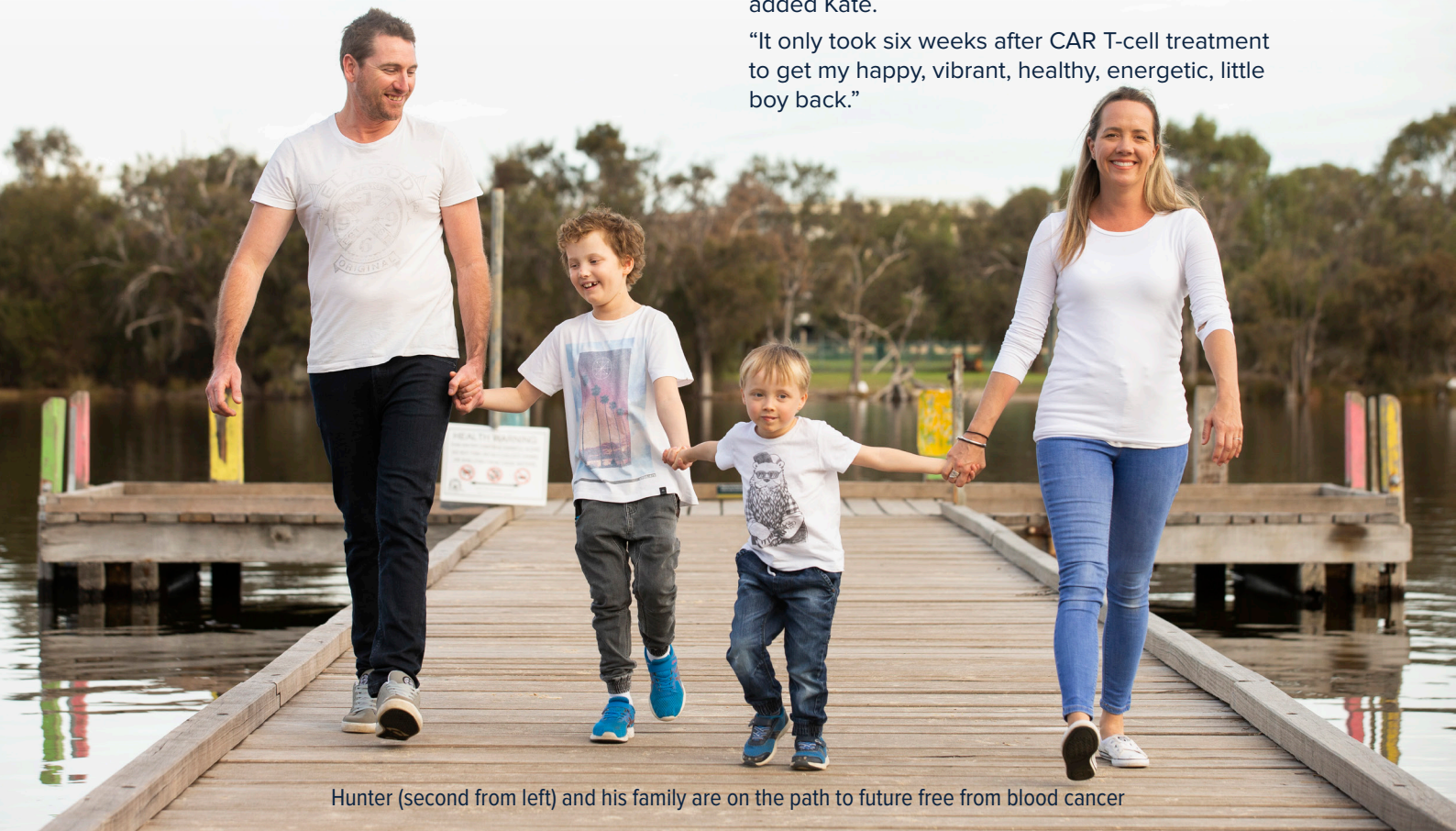
“It’s because of research Hunter has been given another chance,” Dave said.

“It means everything to people like us who have seen our son struggle through these toxic treatments for over half his life.

“The more support we can offer to research and clinical trials, the better.”

“It’s sad Hunter had to go through the trauma of his transplant, because he only started feeling like himself again nine months after the transplant,” added Kate.

“It only took six weeks after CAR T-cell treatment to get my happy, vibrant, healthy, energetic, little boy back.”



Hunter (second from left) and his family are on the path to future free from blood cancer

Accelerate research

What we hope to achieve



Identify priority areas for research funding that deliver greater impact



Harness benefits of real-world data

Why are these actions important?

Recent advances in a range of technologies have brought the possibility of sustained remission for patients with many different types of blood cancers closer than ever. While significant gains have been made, addressing projected mortality and morbidity from blood cancers as a collective will require increased and sustained investment in research. More than 60 per cent of mortality and morbidity from blood cancers is due to an inadequate understanding of the disease and consequent absence of innovative therapies with curative potential. This major problem cannot be solved through the implementation of current best practice. Investment in discovery and fundamentally, new treatment development is paramount.

As our understanding of the genetic basis of blood cancer through research improves, the number of identified blood cancer subtypes is increasing. This “splitting” into smaller and smaller subtypes can challenge traditional approaches to research and creates a new imperative for strategic research collaboration for impact. Alternatively, it can accelerate the development of targeted and curative therapies.

Australia has been a leader in blood cancer research, championing significant improvements in targeted therapies and immunotherapies. Australian researchers and institutions are internationally recognised centres of excellence and have a significant role to play in global collaboration towards cures for blood cancers. However, as an OECD country with a small population, Australia has unique access challenges in realising the full benefits of precision medicine. Leading the way in research and addressing access challenges will enable Australian patients to gain access to life-saving therapies sooner.

The Patient and Carer Panel identified ‘Increasing research funding, funding sources and impact through a Blood Cancer Research Program’ as a very important objective in the National Action Plan and should be pursued by the blood cancer community in the grouping of other high priorities.

Identify priority areas for research funding that deliver greater impact



Action 3.1

Identify priority areas for research funding that deliver greater impact through a Blood Cancer Research Program

Linked actions for implementation

2.3

4.2

4.3

Rationale

Research in blood cancers has made tremendous strides in the past 15 years, with therapies for paediatric cancers delivering cures for many children and the advent of tyrosine kinase inhibitor therapies enabling people with chronic myeloid leukaemia (CML) to live effectively normal lifespans. More recently, the development of novel cellular therapies offers the promise of curative treatment for a range of historically low-survival subtypes.

More needs to be done to build on these successes. Even with the full empowerment of patients, implementation of current clinical best practice, and access to novel therapies, the vision of zero lives lost to blood cancer cannot be realised without new investment in research. In this way, actions to accelerate research breakthroughs by increasing research and funding through a Blood Cancer Research Program are some of the most critical aspects of the National Action Plan.

A survey of blood cancer research found that the major barriers to addressing mortality from blood cancer included inadequate understanding of disease biology and a consequent lack of curative therapies for many specific subtypes. New investment in genomics, microbiota, diagnostics, immunotherapies, targeted therapies and cellular therapies hold the potential to further address the unmet needs of subtypes for which there is currently no cure and where five-year survival is poor.

Realising this vision requires funding through various sources (i.e. the NHMRC, MRFF venture capital and philanthropy), and for the persistent barriers to high impact research to be addressed. The latter include lack of enabling infrastructure, lack of national and international collaboration and consistent patient referrals, and complex governance approvals that prevent good research from getting done.

Australia has demonstrated considerable ability in supporting world-leading research, such as the Centre of Excellence in CML, development of venetoclax, and the Zero Childhood Cancer Program. These home-grown successes include learnings that can inform the design of future research programs.

Implementation

3.1.1 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.

3.1.2 The research initiatives to be prioritised should seek funding through the existing mechanisms operating for the NHMRC and MRFF, and leverage this funding, and/or seek new funding through, venture capital, non-government organisations, philanthropic organisations and public-private partnerships. Where appropriate, representation should be made to government agencies to fund blood cancer priority areas, ensuring funding has the greatest impact.

Benefits

- Reduced mortality and improved quality of life.
- Increased research investment.

Harness benefits of real-world data



Action 3.2

Improve value and use of real-world data for blood cancer patients

Linked actions for implementation

1.5

2.3

3.1

4.3

Rationale

Real-world data is information related to the health status of a person following receipt of healthcare services, that is collected outside the context of clinical trials. Potential sources of real-world data include clinical registries, electronic medical records, and patient reported outcome platforms, as well as health services information such as PBS and MBS data.

The AIHW is currently leading a number of important initiatives that will improve linkages between and access to real world data. In particular, the Cancer and Treatment Linked Analysis Asset (CaT-Link), which is in development is planned to link together data for all cancers, including blood cancers, in the Australian Cancer Database with MBS, PBS, hospitals and deaths data.

Opportunities to leverage various types of real-world data to inform our understanding of the impact of therapies on patient outcomes are expanding significantly. Internationally, governments, pharmaceutical and medical technology industry, researchers and NGOs are collaborating to invest in data management approaches for the systematic reporting of quality real world data. Major examples include the Sentinel and CancerLinQ projects in the US and the HARMONY project in the EU, which are used not only for research but also regulatory approvals by the FDA and EMA, respectively.

There are currently three major blood cancer specific registries in Australia collecting data on patient outcomes nationally:

- The ALLG National Blood Cancer Registry, which collects data for AML, ALL and uncommon lymphomas from participating sites.
- Lymphoma and Related Diseases Registry (LaRDR), which collects data for lymphoma patients from participating sites.
- Myeloma Registry, which collects data for lymphoma patients from participating sites.

These registries collect important and comprehensive data but on a limited number of patients because of funding and infrastructure constraints. Australia does not otherwise have any strategic approach to data collection similar to the collaborations in development in the EU and US. For a small and mature market such as Australia, the integration of Australian patient data with global data sets represents a significant opportunity to support the impact and outcomes of Australian research.

Implementation

3.2.1 The Federal Government has recognised the importance of these datasets with the *National Clinical Quality Registry Strategy*, which seeks to improve the value and sustainability of a range of clinical registries nationally. The Strategy is an opportunity to build data linkage, integration and interoperability capability. Through the implementation of the Strategy, a review should be undertaken to evaluate options to improve the value and sustainability of blood cancer registries and Australian blood cancer patient data by extending the coverage of these registries, leveraging from, and linking to, existing administrative datasets and annotated samples stored at related biobanks, and enabling linkages with international real world data endeavours.

Benefits

- Increased research investment.
- Reduced mortality.
- Improved quality of life.
- Sustainability in health services.

I needed better information about clinical trial options

Matthew Fogarty has spent almost five years regularly travelling to the other side of the world to collect the handful of pills that keep his blood cancer at bay.

After running out of proven, effective treatment options in Australia for his rare type of leukaemia, the 56-year-old stumbled across a clinical trial in America recruiting people to test a drug called ibrutinib, which wasn't available in Australia at the time.

The father-of-three applied for entry to the trial and was accepted. Nearly half a decade later, he has spent more than \$100,000 of his own money travelling from his home in Perth to Washington DC every 12 weeks to pick up his next dose of the life-saving medicine.

"It's been a miracle drug for me and may well have saved my life," he said.

"I believe I'm the only person in the world with this type of blood cancer who has achieved complete remission on ibrutinib. I hope other people like me have an opportunity to try this drug as soon as possible."

Matt says he had access to the treatment options of his choice after he was diagnosed in 2004, but

each time was unable to achieve full remission. He felt his only option left was to try ibrutinib via Australia's compassionate access program. However, his application was declined because "there wasn't enough evidence to prove ibrutinib could successfully treat this type of blood cancer".

He added: "I'm disappointed no one thought to tell me about the clinical trial in the US, or even suggest I look. I discovered it myself on Google and contacted the trial doctors myself. Surely, I could have been given better information about clinical trial options at that time.

"The financial and psychological impact of the relentless international travel has been substantial, and I'm very fortunate to have had the support I needed from my family to get me through it. I realise not everyone is as lucky as I am.

"If there were more clinical trials here in Australia, it would open up access for many more people and potentially make a huge difference to their quality of life."



“

I'm disappointed no one thought to tell me about the clinical trial in the US, or even suggest I look.

Matthew Fogarty, WA

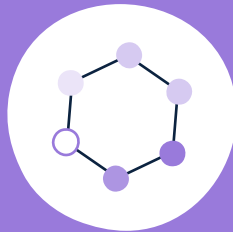
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Enable access to novel and specialised therapies

What we hope to achieve



Increase access to clinical trials



Harmonise evidence development and regulatory applications

Why are these actions important?

Being at the forefront of precision medicine brings new challenges for traditional models of therapy development and regulatory approval. As patient populations become smaller, due to more defined disease subtypes, there may be poorer financial returns from research and development into new therapies. This can, in turn, decrease market incentives for companies to invest in new therapies and could lead to delays in evidence development and public access to novel and specialised therapies.

This is particularly acute with respect to evidence development and public funding for novel diagnostics. Many novel diagnostics remain unfunded, even though they are used as the standard of care in developed markets, as developing the required evidence base may be time-consuming, complex or expensive (or a combination of all three). This will be compounded for new therapies that require a mix of state and federal funding (for example, CAR T-cell therapies). Blood cancer patients, clinicians, and governments alike will, therefore, benefit from a coordinated strategy for evidence development nationally.

Patient participation in clinical trials in Australia remains low, and although there are many possible reasons for this, it may be due in some part to a lack of discussion of clinical trial options with patients and/or assumptions that patients will not travel for care. There is also a need for clinical trials with more pragmatic entry criteria and greater use of novel trial designs, coupled with diagnostic testing for targeted therapies.

The Patient and Carer Panel identified 'Increasing access to trials' for these patients as a very important objective in the National Action Plan, and it should be pursued by the blood cancer community as one of the highest priorities.

The Government is focussed on revitalising the clinical trials agenda, which includes increasing Australian patient participation in clinical trials. This is part of a broader national reform agenda, which can be leveraged for the benefit of blood cancer patients.

Clinical trials and research are integral to achieving both best practice and best outcomes for patients. Improving clinical trial participation is essential to increase access to novel therapies, and in turn, patient outcomes.

Increase access to clinical trials



Action 4.1

Pilot key performance indicator for discussion of clinical trial options with patients

Linked actions for implementation

1.3

2.1

2.6

3.1

4.2

Rationale

Research has shown that the systematic enrolment of patients in clinical trials is one of the single most important actions to reduce the number of lives lost to blood cancer. For example, between 1975 and 1995, the systematic enrolment of paediatric patients in clinical trials saw 5-year survival rates improve by roughly 50 per cent.

Despite the demonstrated benefits of clinical trials, patient participation in blood cancer clinical trials in Australia remains low, with some data indicating less than seven per cent of patients enrolling in clinical trials.

Low rates of clinical trial participation can also affect clinical trial outcomes, with trials closing where they are unable to recruit patients, which has long term implications for Australian research excellence and investment.

There is currently significant work being undertaken at a national level on a clinical trials agenda. The Australian Commission on Safety and Quality in Health Care is actively engaged in the national reform agenda and a pilot of the Clinical Trials Governance Framework, which will see clinical trials requirements incorporated into hospital and health service accreditation processes, is due to commence shortly. This will include requirements for consistent key performance indicators (KPIs) in relation to all clinical trials.

KPIs in clinical trial environments often focus on measuring participation and enrollment. The survey of People Living with Blood Cancer however indicated that the most common reason as to why people with blood cancer do not participate in trials is because it is not suggested by their specialist. This is consistent with international research, which found that while more than 70 per cent of cancer patients are inclined or very willing to participate in clinical trials, less than five per cent of adult patients are enrolled in a trial.

Implementation

4.1.1 The National Action Plan recommends a pilot study to examine the implementation of a KPI for a clinician-led discussion regarding enrolment in clinical trials if and where available and appropriate. A KPI for a clinical trials discussion could be piloted in blood cancers (or a subset of blood cancer patients). The results generated may have wider application for cancer patients more broadly and on a national level. The aim is to increase active consideration of clinical trials in treatment planning and empower patients to have greater engagement and understanding of their clinical trial options.

4.1.2 The establishment of a KPI for consideration of available clinical trial options with patients would leverage existing national clinical trial reform agendas and be led by the Australian Commission on Safety and Quality in Health Care as part of their existing program of work. Once the systems and methods for KPI reporting are developed, these would be embedded in blood cancer OCPs and clinical guidelines, and there would be training and change management delivered to clinicians to support their implementation.

Benefits

- Reduced mortality.
- Increased investment.

Increase access to clinical trials



Action 4.2

Increase access to clinical trials in regional and remote areas, including a national approach to prioritising tele-trials

Linked actions for implementation

1.3 4.1

1.8

2.1

2.6

3.1

Rationale

Data show there is very significant latent demand for regional clinical trials and tele-trials. Addressing barriers to clinical trials participation by rural and remote patients has the potential to substantially address the disparity in survival outcomes.

To date, however, access to clinical trials in regional areas have been rate-limited by the following factors:

- Immature regional cancer centre services.
- A significant under-estimation of the workforce requirements at the regional trial sites to enable the safe and effective roll-out of tele-trial models.
- High regional workforce turnover.
- The use of tele-trials not being incorporated into available clinical guidelines and/or service frameworks.
- Administrative inefficiencies associated with ethics and governance approvals for each site.
- Lack of incentives for industry to establish tele-trial sites.

Implementation

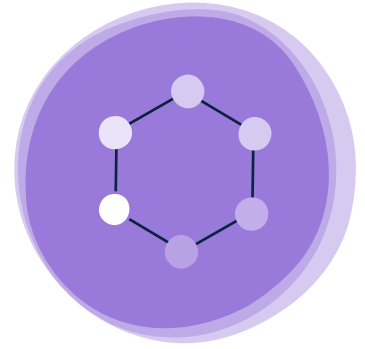
The National Action Plan recommends building on existing work being undertaken at the state/territory and federal level (including the regional and remote clinical trials infrastructure program) to promote and support patient participation in regional clinical trials and tele-trials through:

- **4.2.1** Ensuring that blood cancer OCPs and clinical guidelines document the importance of discussing clinical trial research options with patients, including those living in regional and remote areas.
- **4.2.2** A national approach to blood cancer research supported by the Blood Cancer Research Program, with regional trial sites pre-approved for ethics and governance to streamline trial opening, leveraging work already underway through the national reform agenda in clinical trials.
- **4.2.3** A skills audit of regional and remote workforce requirements (including the primary care workforce) and an infrastructure audit of facilities to enable clinical trial participation at these sites.

Benefits

- Reduced mortality, especially for high-risk groups.
- Increased investment in regional and remote areas.

Harmonise evidence development and regulatory applications



Action 4.3

Establish an Enabling Access Working Group to improve equitable access to novel and specialised therapies

Linked actions for implementation

2.1

2.2

3.1

3.2

4.1

Rationale

The landscape for the registration and subsidisation of new medicines, diagnostics and services in Australia is highly complex. If a therapy is not publicly funded (either through a PBS or MBS listing), patients must either privately fund access to their treatment, seek access through a clinical trial, compassionate access or Special Access Scheme, or forego the therapy.

Listing a new medicine and diagnostic on the PBS or MBS may be hampered by a lack of evidence and/or cost-effectiveness. This is exacerbated for rare cancer patient populations, where the stratification of diseases into ever smaller patient populations increases the challenges for generating evidence and obtaining public subsidy for precision medicines.

Lack of evidence to support registration can also have the unintended consequence of increasing use of 'off-label' prescribing (i.e., using a medicine outside of its registered indication(s) as approved by the Therapeutic Goods Administration), the outcomes of which are not always reported to relevant clinical registries. This can delay or prevent further evidence development to support listings to a broader group of patients.

The currently rapidly-evolving technology landscape for blood cancers presents challenges for patients, governments, service providers, researchers, clinicians and industry - in what is an already complex regulatory, funding, and research landscape. There are also risks to equitable access to traditional transplant and novel cellular therapies, that could benefit from a coordinated and transparent national strategy.

Implementation

4.3.1 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 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.

Benefits

- Reduced mortality.
- Improved quality of life.

Implementation with the blood cancer community

The successful implementation of the National Strategic Action Plan for Blood Cancer will depend on sustained collaboration and leadership by partners in the blood cancer community.

The National Action Plan sets out an ambitious agenda for change.

Implementing the recommendations will require ongoing coordination and commitments from across the blood cancer community, including the cancer charities, and will require a multi-phase reform agenda over many years.

To support implementation and to ensure coordination with all members of the blood cancer community, a number of fundamental activities are recommended.

Focus on actions that will have the greatest immediate impact on blood cancer mortality and access to new treatments as the first step in implementation

While the recommendations should be taken holistically and work together to reduce blood cancer mortality, priority should be given to those recommendations that can have the most immediate impact, by addressing preventable deaths and improving equitable access to new treatments.

Our research shows that we could reduce deaths by 13 per cent and save 22,000 lives by 2035 through nationally consistent implementation of best practice treatment and care for blood cancer patients, using therapies that are already available in Australia today. This is where we should focus in the first instance as it will have the most immediate impact to reduce deaths.

Addressing preventable deaths will be achieved through:

- Actions within the **Empower Patients and their Families** priority area, to ensure access to appropriate information and that patients are empowered to be actively involved and supported in their diagnosis, treatment and care (including support for high-risk patient populations)
- Actions within the **Achieve Best Practice** priority area, focussing on ensuring an accurate diagnosis and national standards for safety and quality.
- Actions within the **Accelerate Research** priority area, in particular developing the Research Roadmap to support blood cancer researchers and pave the way for ongoing new discovery.
- Actions within the **Enable Access to Novel and Specialised Therapies** priority area to increase clinical trial participation, and supporting the activities of the Enabling Access Working Group to develop a short-list of clinically important medicines and diagnostics that do not yet have public subsidy and where they may be barriers to evidence development. This should include addressing gaps in genomic testing for blood cancers and working collaboratively with key partners to develop PBAC submissions for currently unlisted targeted therapies for rare blood cancers.

Determining how all the recommendations in the National Action Plan are developed, refined and prioritised is a critical part of the implementation work of the Blood Cancer Taskforce, in partnership with governments and the blood cancer community. All these partners have a shared responsibility for health outcomes according to their role and capacity within the healthcare system.

Through this collaborative framework, the blood cancer community should prioritise those actions that apply specifically to blood cancer, while appreciating that there are a significant number of actions that will also apply to cancers more broadly.

Extend the term of the Blood Cancer Taskforce

Coordination and oversight of the National Action Plan, alongside community-led actions, will reduce barriers to participation and lead to more successful outcomes.

It is recommended that the Blood Cancer Taskforce is extended for a time-limited period, to support coordination of the blood cancer community and implementation of actions in this National Action Plan. This approach is in line with the review of Australian and international cancer policies and the approach taken for other policy reform agendas.

The Leukaemia Foundation would continue to support the Blood Cancer Taskforce, and Taskforce membership would continue to include representatives from the leading cancer charities providing services to people living with blood cancer.

Work with key partners in the blood cancer community to develop actions and plans for implementation

Ongoing development of actions recommended by the National Action Plan and their subsequent implementation will require the collaboration and leadership of a wide range of partners in the blood cancer community. These partners include:

- Patients, carers and families
- Blood cancer specialists
- Primary healthcare providers
- Patient support organisations including blood cancer charities

- Blood cancer research community
- All levels of government
- Non-government organisations
- Public-private partnerships
- Public and private healthcare providers and private health insurers
- Pharmaceutical and medical devices industry
- Donor and investor communities.

The Blood Cancer Taskforce would work with key partners from across the blood cancer community to further refine, develop and prioritise actions for implementation.

Summary of actions and steps for implementation

PRIORITY AREA: EMPOWER PATIENTS AND THEIR FAMILIES

OBJECTIVE: Empower patients to make informed choices		
Action	Implementation	Timeframe
1.1 Empower patients to navigate the healthcare system	<p>1.1.1 Develop a patient navigation service to assist people living with blood cancer to navigate the healthcare system. Delivery of this service should be considered as part of the Blood Cancer Information Strategy (Action 1.2).</p> <p>At diagnosis, primary healthcare providers will refer patients to both a haematologist (and/or other specialist) and confirm consent for a referral to a patient navigation service. Consent and referral to a patient navigation service should also be facilitated through specialist services. This will help support patients to know the right questions to ask, connect people with national sources of information about clinical trial opportunities, and connect them to relevant resources to support decision-making or access support.</p> <p>The patient take-up rates of the referral would determine the size of the patient navigation support service required. The service should factor in the unique needs of high-risk groups and patient life stages to best target support.</p>	1-2 years
1.2 Develop a Blood Cancer Information Strategy as part of a broader digital health and information strategy for cancer	<p>1.2.1 Form an inclusive, patient focussed and cross-organisational working group to develop a Blood Cancer Information Strategy, as part of a broader digital health and information strategy for cancer. The aim is to ensure patients can access the right information, at the right time, which is relevant to their diagnosis and personal situation. This information could include:</p> <ul style="list-style-type: none"> • Information for primary care clinicians, specialists and other healthcare workers • Information to support complex referrals to specialists • Information about supportive care services for patients and carers, including support for financial planning • Connect people to national sources of information about clinical trial opportunities. <p>The working group should include patient organisations, patient advocates, clinicians, researchers and other relevant stakeholders. It will be focussed on the principles and objectives that organisations agree will deliver better outcomes for patients. This action would be supported by a training and change management strategy delivered to primary healthcare workers and specialists.</p>	1 year
1.3 Develop KPIs for written treatment and survivorship care plans	<p>1.3.1 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.</p> <p>1.3.2 The establishment of KPIs would be led by the Australian Commission on Safety and Quality in Health Care and would leverage work already underway by the Commission, in partnership with clinical working groups from each jurisdiction. Once the systems and methods for KPI reporting are developed, training and change management would be delivered to clinicians to support their implementation and incorporate written treatment and survivorship plans into existing practices and processes.</p>	1-2 years
1.4 Develop complex referral support tools	<p>1.4.1 Patient support organisations and blood cancer clinicians nationally to collaborate to develop a positively-oriented service directory where specialists in blood cancer subtypes are more easily identified and expected fees are outlined to support an individual's planning.</p>	2-3 years

OBJECTIVE: Enable patient-centred care through patient reported outcomes		
Action	Implementation	Timeframe
1.5 Develop a national system for PROs in blood cancer	<p>1.5.1 Given the above evidence of benefit, and the need for a nationally coordinated approach, the National Action Plan recommends assembling a clinical advisory working group of clinicians and patients by blood cancer subtype to undertake a PROs scoping study:</p> <ul style="list-style-type: none"> • Define the principles and objectives of a PRO system • Agree a taxonomy for data, standards and methods of collection and analysis • Select PRO measures and identify thresholds for clinical action • Stock-take of existing clinical systems capabilities by jurisdiction • Develop a plan for implementation that ensures embedding in existing systems of care and Electronic Medical Records (EMRs). 	2-3 years
OBJECTIVE: Empower and support high-risk patient groups		
Action	Implementation	Timeframe
1.6 Address challenges for Aboriginal and Torres Strait Islander people with blood cancer	<p>1.6.1 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.</p> <p>1.6.2 Work with the Aboriginal and Torres Strait Islander Health Workforce to undertake a gap review of Indigenous Health Workforce expertise in blood cancers to support culturally sensitive care across all healthcare settings (both Indigenous and non-Indigenous).</p> <p>1.6.3 Develop an awareness and education campaign regarding blood cancer signs and symptoms in partnership Community Controlled Health Services.</p> <p>1.6.4 Promote the use of Cancer Australia's OCP for Aboriginal and Torres Strait Islander people with cancer within the blood cancer clinical network, in conjunction with individual OCPs for different blood cancer subtypes.</p> <p>1.6.5 Ensure access for Indigenous people to chemotherapy, emerging therapies and safe and effective stem cell transplants. Work with the Enabling Access Working Group (Action 4.3) and existing reform agendas underway with government and non-government organisations to increase the representation of Aboriginal and Torres Strait Islanders on the Australian Bone Marrow Donor Registry.</p> <p>1.6.6 Leverage existing activities and national reform agendas to improve participation rates of Indigenous cancer patients in clinical trials for blood cancers.</p> <p>1.6.7 Ensure relevance and use of supportive care assessment tool to support Aboriginal and Torres Strait Islander people living with blood cancers. The supportive care assessment tool should be validated for use with Aboriginal and Torres Strait Islanders, consistent with the advice in the OCP for Aboriginal and Torres Strait Islander people with cancer.</p>	3-5 years
1.7 Address challenges for Culturally and Linguistically Diverse people with blood cancer	<p>1.7.1 Ensure access to bone marrow donors for Australians of all ethnicities.</p> <p>1.7.2 Undertake a stock-take of culturally and linguistically diverse patient needs by hospital to enable prioritisation by location.</p> <p>1.7.3 Provide education and training to translators, cultural advocates, and local cultural organisations in blood cancer OCPs and medical terminology at high priority centres.</p> <p>1.7.4 Explore options for enhanced telemedicine and digital health information services, such as the development of Royal District Nursing Service Talking Books and/or the National Ageing Research Institute Moving Pictures initiatives for blood cancer. This could have benefits for other patient populations, not just those from culturally and linguistically diverse backgrounds.</p> <p>1.7.5 Ensure PRO systems are culturally appropriate and available in languages other than English, and the Blood Cancer Information Strategy considers culturally appropriate and accessible information provision.</p>	1-2 years

<p>1.8 Address challenges for people with blood cancer living in regional and remote areas</p>	<p>1.8.1 Reduce unwarranted variation in treatment and care through development, promotion and implementation of individual OCPs for different blood cancer subtypes, clinical guidelines and accreditation, underpinned by patient navigation services, Blood Cancer Information Strategy and a workforce change management strategy.</p> <p>1.8.2 Develop guidelines for diagnostics and review Australia's capacity to meet those guidelines, including the availability of specialised diagnostic services for regional and remote patients, and recommend options for improving test accuracy and appropriate guidelines for timeliness for regional and remote patients.</p> <p>1.8.3 Conduct a skills audit of the regional and remote workforce and develop a strategy to enable care closer to home, adoption of tele-health, more effective diagnosis and referral of patients to subtype specialists and increased clinical trial participation in the regions. The skills audit and strategy should be done in consultation with relevant stakeholders and leverage existing work that is underway.</p> <p>1.8.4 Improve opportunities to access clinical trials for blood cancer patients living in regional and remote areas, in particular through contributing to the tele-trials and the removal of barriers to travel, through advocacy and leveraging work that is already underway through the national reform agenda in clinical trials.</p> <p>1.8.5 Enable patient-centred care through a national system for PROs that can enable improved monitoring of symptoms and adverse events, as well as a more systematic screening and referrals to supportive care.</p>	<p>3-5 years</p>
<p>1.9 Meet the needs of patients across their lifespan</p>	<p>1.9.1 The development and implementation of each action in the National Action Plan should consider the unique needs of patients across their lifespan, including palliative and end of life care. Specific considerations for life stages and circumstances must therefore be included in the OCPs and clinical guidelines, the development of the Blood Cancer Information Strategy and patient navigation services, and a national system for PROs. It will also rely on implementation at the workforce level, through training and change management, aimed at improving the understanding of blood cancers, availability of new tools and models for shared care. Consideration should be given to existing work that is already underway in order to complement, not duplicate, efforts to improve outcomes for blood cancer patients.</p>	<p>3-5 years</p>

PRIORITY AREA: ACHIEVE BEST PRACTICE

<p>OBJECTIVE: Develop national standards for quality and safety</p>		
<p>Action</p>	<p>Implementation</p>	<p>Timeframe</p>
<p>2.1 Develop OCPs and clinical guidelines for all major blood cancer subtypes</p>	<p>2.1.1 Undertake a stock-take of current OCPs and national/international clinical guidelines to inform and prioritise the adoption or development of new OCPs and clinical guidelines (or update existing OCPs and clinical guidelines) for all major blood cancer subtypes.</p> <p>2.1.2 Clinical guidelines would need to be updated at agreed intervals and presented at key meetings, such as the annual ALLG meeting, and endorsed by relevant professional colleges. The publication of OCPs and clinical guidelines should be considered in the development of the Blood Cancer Information Strategy, with training and education provided to support their integration and implementation into clinical practice.</p> <p>2.1.3 Through the guideline development, a limited number of selected, highly specialised services may be identified as requiring high case volumes to ensure safety and quality. It is recommended that these highly specialised services are then required to be accredited via processes that are complementary to and not duplicative of existing accreditation requirements and are in line with international best practice.</p>	<p>1 year</p>

OBJECTIVE: Value an accurate diagnosis		
Action	Implementation	Timeframe
2.2 Develop guidelines for diagnostics and review Australia's capacity to meet these guidelines	<p>2.2.1 Review existing international diagnostics guidelines in blood cancer and develop Australian-specific guidelines for minimum and recommended testing requirements for different types of blood cancer in Australian healthcare settings. These guidelines should be integrated with clinical guidelines (Action 2.1).</p> <p>2.2.2 Following the development of diagnostic guidelines for different types of blood cancer, undertake a wider strategic assessment of blood cancer diagnostics service delivery across Australia. This would include workforce development needs in metropolitan and regional areas, as well as potential options for improving accuracy, timeliness and efficiency in diagnostic services nationally. This strategic assessment should also identify options to address issues with under-notification of cases to state cancer registries.</p> <p>2.2.3 The Enabling Access Working Group (Action 4.3) should engage with governments, regulators and the blood cancer community to:</p> <ol style="list-style-type: none"> Coordinate evidence to support the development of applications for MBS reimbursement of diagnostics that are standard of care but are not yet listed Continue important reforms to MSAC processes for MBS listings, focusing on greater transparency and the rapid adoption of diagnostics, which have been demonstrated to be cost-effective that direct patients to the most effective therapies. This should include enhancing consumer understanding of and engagement with the MBS listing process, drawing experience from improved consumer engagement in PBS processes. 	1 year
2.3 Make precision medicine the standard of care	2.3.1 The implementation of precision medicine as a standard of care could be developed and funded as part of the Blood Cancer Research Program and supported by a working party focussed on the harmonisation of research efforts and evidence development for regulatory approval across Australia.	2-3 years
OBJECTIVE: Ensure access to supportive care		
Action	Implementation	Timeframe
2.4 Screen for supportive care needs	<p>2.4.1 Screening for supportive care must be integrated into clinical guidelines to support their implementation in both primary and specialist healthcare environments. To promote uptake and use, KPIs for supportive care screening should be developed to foster improvements in clinical practice.</p> <p>2.4.2 OCPs and clinical guidelines for blood cancer should recommend routine screening of patients at key milestones throughout treatment, supported through the introduction of a national system for PROs.</p> <p>2.4.3 To foster the consistent screening for supportive care in clinical practice, the need for supportive care screening should be included in training and change management strategies and audited over time.</p>	1-2 years
2.5 Improve referrals and equitable access to cancer patient-friendly exercise programs and lifestyle services	<p>2.5.1 To improve uptake of exercise recommendations for people living with blood cancer, physical activity levels should be consistently screened as part of a supportive care screening strategy and supported by a national system for PROs.</p> <p>2.5.2 Depending on the outcomes of the patient engagement and understanding of patient goals, clinicians should refer people to a program for cancer patient-friendly exercise and lifestyle services, depending on their individual support requirements. The program should trial referrals to a range of supervised and self-directed programs in both health care provider and community settings activity levels and in turn quality of life and survival.</p>	3-5 years

OBJECTIVE: Invest in workforce development		
Action	Implementation	Timeframe
2.6 Invest in clinical capability in both primary and specialist settings	<p>2.6.1 Define a service standard, informed by OCPs, clinical and diagnostic guidelines and the research roadmap, to determine workforce needs in primary and specialist settings including supportive care.</p> <p>2.6.2 A skills audit of regional and remote workforce requirements.</p> <p>2.6.3 Appropriate training and change management approaches developed with relevant professional bodies in primary care settings, aimed at improving the awareness and understanding of blood cancers, the availability of new tools, and models for shared care (including telehealth).</p> <p>2.6.4 A training and change management strategy aimed at specialist settings, focused on advances in tele-health, personalised medicine and implications for clinical practice, the roll-out of hospital training, and the use of supportive care and palliative care for people living with blood cancer.</p>	3-5 years
OBJECTIVE: Prevent financial hardship		
Action	Implementation	Timeframe
2.7 Implement reforms to address sources of financial hardship	<p>In addition to screening for financial distress using a national system for PROs in blood cancer, supporting complex referrals for informed financial consent and patient choice, and the development of a Blood Cancer Information Strategy, the National Action Plan recommends the following reforms to prevent financial hardship:</p> <p>2.7.1 Consult with all jurisdictions to reform PATS, including advocating for streamlined administrative processes, greater access to the schemes and support for patients to participate in clinical trials.</p> <p>2.7.2 Review options for the introduction of financial support mechanisms (such as a temporary disability payment) to support people with cancer and other serious illness who require temporary financial support.</p>	3-5 years

PRIORITY AREA: ACCELERATE RESEARCH

OBJECTIVE: Identify priority areas for research funding that deliver greater impact		
Action	Implementation	Timeframe
3.1 Identify priority areas for research funding that deliver greater impact through a Blood Cancer Research Program	<p>3.1.1 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.</p> <p>3.1.2. The research initiatives to be prioritised should seek funding through the existing mechanisms operating for the NHMRC and MRFF, and leverage this funding, and/or seek new funding through venture capital, non-government organisations, philanthropic organisations and public-private partnerships. Where appropriate, representation should be made to government agencies to fund blood cancer priority areas, ensuring funding has the greatest impact.</p>	3-5 years
OBJECTIVE: Harness benefits of real world data		
Action	Implementation	Timeframe
3.2 Improve value and use of real world data for blood cancer patients	<p>3.2.1 The Federal Government has recognised the importance of these datasets with the <i>National Clinical Quality Registry Strategy</i>, which seeks to improve the value and sustainability of a range of clinical registries nationally. The Strategy is an opportunity to build data linkage, integration and interoperability capability. Through the implementation of the Strategy, a review should be undertaken to evaluate options to improve the value and sustainability of blood cancer registries and Australian blood cancer patient data by extending the coverage of these registries, leveraging from, and linking to, existing administrative datasets and annotated samples stored at related biobanks, and enabling linkages with international real world data endeavours.</p>	3-5 years

PRIORITY AREA: ENABLE ACCESS TO NOVEL AND SPECIALISED THERAPIES

OBJECTIVE: Increase access to clinical trials		
Action	Implementation	Timeframe
4.1 Pilot key performance indicator for discussion of clinical trial options with patients	<p>4.1.1 The National Action Plan recommends commissioning a pilot study to examine the implementation of a KPI for a clinician-led discussion regarding enrolment in clinical trials if and where available and appropriate. A KPI for a clinical trials discussion could be piloted in blood cancers (or a subset of blood cancer patients). The results generated may have wider application for cancer patients more broadly and on a national level. The aim is to increase active consideration of clinical trials in treatment planning and empower patients to have greater engagement and understanding of their clinical trial options.</p> <p>4.1.2 The establishment of a KPI for a discussion of available clinical trial options with patients would leverage existing national clinical trial reform agendas and be led by the Australian Commission on Safety and Quality in Health Care as part of their existing program of work. Once the systems and methods for KPI reporting are developed, these would be embedded in blood cancer OCPs and clinical guidelines and there would be training and change management delivered to clinicians to support their implementation.</p>	1-2 years
4.2 Increase access to clinical trials in regional and remote areas, including a national approach to prioritising tele-trials	<p>4.2.1 Ensuring that blood cancer OCPs and clinical guidelines document the importance of discussing clinical trial research options with patients, including those living in regional and remote areas.</p> <p>4.2.2 A national approach to blood cancer research supported by the Blood Cancer Research Program, with regional trial sites pre-approved for ethics and governance to streamline trial opening, leveraging work already underway through the national reform agenda in clinical trials.</p> <p>4.2.3 A skills audit of regional and remote workforce requirements (including the primary care workforce) and an infrastructure audit of facilities to enable clinical trial participation at these sites.</p>	2-4 years
OBJECTIVE: Harmonise evidence development and regulatory applications		
Action	Implementation	Timeframe
4.3 Establish an Enabling Access Working Group to improve equitable access to novel and specialised therapies	<p>4.3.1 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:</p> <ul style="list-style-type: none"> • 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 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. 	3-5 years

COVID-19 Addendum to the National Strategic Action Plan for Blood Cancer

The severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) outbreak, which caused the coronavirus disease 2019 (COVID-19) pandemic in the beginning of 2020, has had unprecedented impacts on global health systems, economies, communities and individuals.

At the time of writing, the number of Australians who have contracted the virus is much lower than many other countries thanks to measures put in place by governments (including quarantine measures, testing, contact tracing, and isolation of contacts and social distancing measures, and community education and support programs), working alongside the efforts of individuals, businesses, organisations and local communities.

The impact of COVID-19 is nevertheless severe, changing the way we live and interact, the way we work, and the way we deliver services. It reminds us how economic health and physical health are inextricably linked – and how quickly things can change with direction, motivation, unity of purpose and resources.

This addendum was developed as the Blood Cancer Taskforce was nearing completion of its work, in order to highlight the significant effect COVID-19 will continue to have in Australia in the context of blood cancers and the actions outlined in the National Action Plan. The prioritisation of actions, which decreases the mortality burden of blood cancer, is accentuated in both the current COVID-19 and ongoing post-COVID-19 environments.

The response to the pandemic has shown the capacity and willingness of both government and non-government organisations to respond flexibly and innovatively to a health crisis. It also provides a unique opportunity to consider and reconfigure what truly patient-centred health services and support programs look like for people living with blood cancer and the wider cancer community.

COVID-19 and the blood cancer community

The COVID-19 pandemic demonstrated critical need for freely, readily available, clear, and evidence-based information not only for the public and people affected by cancer but also for health professionals and researchers. The Federal and state governments created several general

COVID-19 campaigns and resources (including the Coronavirus and COVID-Safe apps and COVID-19 information web pages) but also developed cancer specific resources to provide information for people affected by cancer (Cancer Australia's Information Hub).

Modelling on the impact of COVID-19 in Australia and how the health system would respond was key to Australia's success in containing the pandemic and keeping COVID-19 infections and deaths low.

Overseas evidence showed that people with a cancer diagnosis are more vulnerable to COVID-19 and people living with blood cancer are among the most vulnerable, having a higher risk of moderate and severe complications or death from COVID-19 compared to those without cancer.

The immunocompromised status of many patients with a blood cancer necessitates additional precautions to avoid COVID-19 infection. This may impact their ability to access timely cancer care, treatment, or services at hospitals and other treating centres, and may also lead to increased anxiety, social isolation and negative effects on their mental health.

The current COVID-19 crisis has highlighted the importance of getting new treatment options onto the PBS, as there are a number of new therapies that are less immunosuppressive, reducing the risk of infection, which may require less hospital contact (i.e., if delivery is through oral rather than IV treatment).

The capacity of the healthcare sector to adapt to these circumstances and respond to these increased patient needs is critical. This includes less face-to-face contact for diagnosis and treatment (for example, through telehealth), offering support services virtually (such as counselling and psychosocial support), and the ongoing provision of clear and consistent information to empower patients to make informed decisions about their health and healthcare in a very challenging environment.

In response to the COVID-19 pandemic, the Federal government developed a framework, which provided an overview of cancer management under different phases of the pandemic and in relation to health system capacity. The framework, based on the OCPs

for people with cancer, explored system-wide approaches to cancer management during the COVID-19 pandemic, across the cancer pathway from prevention and early detection through to survivorship and end-of-life care (Cancer Australia's *Cancer care in the time of COVID-19: A conceptual framework for the management of cancer during a pandemic*).

The pandemic has led to new COVID-19 related research priorities being rapidly developed. Australia has been leading in certain areas of COVID-19 research (i.e., development of animal models and vaccines), while our international partnerships have also allowed us to collaborate and adopt best clinical practice in Australia. The pandemic also reinforced how important international collaboration and clinical trials are for the rapid translation of research into clinical practice. There are clearly opportunities to harness the momentum of these international collaborations for the ongoing benefit of blood cancers and other disease areas.

There are a number of recommendations in the National Action Plan that, therefore, have a heightened significance for blood cancer patients in the context of the COVID-19 pandemic, namely:

- Helping patients **navigate the health system** and facilitating access to evidence-based, credible and reputable information, through the creation of digital health and information tools for patients, caregivers and clinicians, such as through online patient navigation services and collaborative models for joined-up online information portals or gateways as part of the Blood Cancer Information Strategy (Action 1.1, Action 1.2).
- The expansion and **strengthening of telehealth services**, including teletrials, can be a significant driver in helping the blood cancer community implement best practice reforms to ensure patients can access the best possible treatment and care, no matter where they live (Action 1.8, Action 4.2).
- Written treatment and survivorship **care plans that are dynamic and responsive** to the individual needs of the patient, helping them understand their diagnosis and treatment, particularly when they may be seeing their clinicians less frequently and are reducing face-to-face contact with healthcare professionals (Action 1.3).
- Developing **Patient Reported Outcome systems for blood cancers**, to assist with remote monitoring of patients and reduce hospitalisation rates (Action 1.5).

- Addressing **access challenges** for people with blood cancer living in regional and remote areas (Action 1.8), which are heightened when travel restrictions mean there are additional barriers to accessing the best possible information, treatment and care.
- Ensuring patients are not falling through the cracks when there may be other pressures on the health system, by facilitating **national consistency and best practice** care through optimal care pathways and clinical guidelines (Action 2.1) and consistent screening and referrals to supportive care (Action 2.4).
- Under-notification and ensuring an accurate diagnosis were already challenges for blood cancers. It is now likely to be heightened in the COVID-19 environment with reports of fewer presentations to health professionals and decreases in cancer diagnosis more generally. Addressing historical and ongoing **issues with data and notification**, therefore, remains a pressing issue to address (Action 2.2).
- Continuing vital research in blood cancer (Action 3.1), including patient participation in clinical trials, particularly through tele-trial models given the heightened risks to patients during the pandemic (Action 4.2).
- Ensuring our most vulnerable patient populations do not face further barriers to accessing the healthcare system and are supported to access the best possible information, treatment and care suited to their age, unique needs and circumstances, including people living in regional or remote areas, Aboriginal and Torres Strait Islanders and people with culturally and linguistically diverse backgrounds (Action 1.6, Action 1.7, Action 1.9 and Action 1.9).

COVID-19 and the supply of optimal stem cell donors for Australian patients

The pandemic has also shed light on issues that have been developing for some time on the size and suitability of Australia's stem cell donor pool. In the context of the blood cancer community, one of the more significant impacts of COVID-19 was the effective cessation of the importation of live viable matched donor stem cells and a move to cryopreservation of these cells from all international donors.

Bone marrow and blood stem cell transplants are used to treat a range of diseases, the majority of which are haematological diseases such as

leukaemia, lymphoma, myeloma, amyloidosis and aplastic anaemia.

Around 2000 stem cell transplants are carried out in Australia each year. While the majority of these use the patient's own stem cells (autologous transplant), around 600 will need stem cells donated from a genetically matched stem cell donor (allogeneic transplant). In some instances, the donor may be a family member, however, where no related donor is available, a search of Australian and overseas registries is conducted to search for a suitably matched, unrelated stem cell donor.

Today in Australia, the vast majority of unrelated stem cell donations are sourced from overseas. The pool of Australian registered stem cell donors does not fit the profile of donors preferred by clinicians, nor is it fully representative of the ethnic diversity of the Australian population.

Finding the best possible matched stem cell donor is critical for patients. The more compatible the donor-patient match, the less likely there will be rejection or severe Graft versus Host Disease (GvHD). GvHD occurs when the transplanted donor immune cells begin attacking the recipient's organ tissues, often leading to irreversible damage and life-long symptoms for the patient. It can have enormous ongoing costs for the patient and for the health system, and it can be fatal.

As outlined in Action 4.3 in the National Action Plan, there is a need to optimise the supply of suitably matched stem cell donors for Australian and international patients. Our overreliance on international donors is an historical and ongoing issue, however it has been brought into sharp relief as a result of the COVID-19 crisis and the inability to continue to transport live cells in a timely manner.

The sector has come together to find short-term solutions to this issue, including the cryopreservation of international stem cell donations, however, ongoing and longer-term solutions must be found.

Optimising the supply of stem cells is vitally important and includes strengthening Australia's own donor pool. While we will always require access to overseas donors, there are clear and compelling reasons to have more diversity in the Australian pool of registered donors and greater diversity within it. Of particular concern is the poor representation of Aboriginal and Torres Strait Islanders in the Australian Donor Registry. For Aboriginal and Torres Strait Islanders with blood cancer, bolstering Australia's donor pool is a matter of life or death, as international donors cannot be relied on for these patients.

COVID-19 and blood cancer research

A number of issues stemming from COVID-19 (for example, risks to patients, hospital preparedness and reprioritisation, logistics, laboratory closures and supply chain issues) have impacted clinical trial activity, resulting in some trials being stopped, delayed or paused. Many associated correlative studies have also been paused, due to logistics issues around courier shipments of specimens from hospitals to research laboratories.

In addition, the closure of research laboratories and/or physical distancing measures implemented in laboratories will impact outcomes and timelines for research publications and presentations in the immediate future.

These interruptions have resulted in delays to research and clinical trial reporting, which will have downstream effects on publication of important results.

Universities are expected to have revenue shortfalls, which is likely to result in large cuts to research funding. In addition, many research centres are dependent on their own fundraising campaigns and this will be challenging to attain in the immediate future.

External charitable organisations who provide vital funding are expected to have reduced or no capacity to fund research in the next 12-24 months.

Limited funding opportunities, in particular, will create significant challenges for the research workforce in the short to medium term, with junior and early-to-mid career researchers being among the most impacted.

COVID-19 and the Australian cancer community

The COVID-19 pandemic has forced a dramatic shift in how critical health and support services are delivered. This is perhaps most apparent in the rapid investment and expansion of telehealth.

Increased take-up of telehealth, including teletrials, can have a significant and lasting benefit for facilitating more equitable access to health services, which is a critical issue for all cancer communities – not to mention people accessing the health system more broadly.

More work needs to be done to build on this foundation of telehealth for cancer care to support more remote models of working, including bolstering engagement between primary and specialist settings to enable more effective shared care arrangements for patients across the treatment continuum, particularly between treatments and after treatment ends.

There is also an opportunity for innovating the telehealth delivery nurse-led care and allied health services beyond the hospital environment and especially for survivorship care, the needs of which are not currently met by what is reimbursable through the MBS.

If we are to take any silver linings from a situation as devastating as the COVID-19 pandemic, it can be to leverage interventions that have already occurred in response to the pandemic, which can now be continued and/or amplified (like telehealth) so that they continue to be of significant benefit to patients and the Australian community.

In the cancer charities sector, the pandemic has prompted an important opportunity for greater alignment and collaboration through the Cancer Charities CEO Forum and Support Service Group. Led by the Cancer Council of Australia, for the first time the major Australian cancer charities are formally collaborating on a regular basis to ensure a rapid response to patient needs and alignment of information and services across the sector during this time.

The formation of the Cancer Charities CEO Forum and Support Service Group is an opportunity to explore greater collaboration and efficiencies across the sector in both the COVID-19 and post-COVID-19 environment, for example through shared service delivery, shared resources and finding areas of commonality across cancers more broadly to advocate for future reforms.

The economic effects of the COVID-19 pandemic have and will continue to shift how projects are prioritised and funding is made available to deliver services to the community. As a result, the capacity of the blood cancer community to resource and fund new projects towards delivering the National Action Plan agenda may be diminished, particularly in the immediate future as many organisations rely on donations. This heightens the need for a partnership approach and appropriate support from governments. Collaboration in the sector is more important now than ever before.

The formation of the National Cabinet has enabled greater speed and flexibility in health-related decision-making across the country and across jurisdictions. Greater coordination across the cancer support organisations and alignment with government strategies and priorities will lead to more efficient service delivery to patients in need.

Indeed, given the impact of the pandemic on cancer patients more broadly, those

organisations providing cancer services must redouble efforts to work together in a much more cohesive and considered way to ensure the best outcomes for patients.

It is also an important and opportune time for policymakers and the cancer community to collaborate on reforms that will benefit cancer patients more broadly, particularly the high-mortality cancers, which includes blood cancer.

There are a number of recommendations in the National Action Plan that are presented with evidence for their benefit in blood cancers, that would benefit the wider cancer community and may already be underway in some form and/or to varying degrees across different parts of the cancer community. For example:

- Online patient navigation services and collaborative models for joined-up online information, as part of a broader digital health and information strategy for cancer.
- Reforms to better integrate the consumer voice in MBS decision-making and the evolution of existing PBS and MBS processes to more fully engage consumers and incorporate their views into decisions that directly affect their health and healthcare options.
- Written treatment and survivorship care plans, OCPs and clinical guidelines, combined with consistent screening and referrals to supportive care.
- Empowering and supporting high-risk patient groups, Aboriginal and Torres Strait Islanders, and people from culturally and linguistically diverse backgrounds.
- Achieving best practice in the delivery of treatment and care across Australia to reduce disparities in survival outcomes based on where someone lives, particularly in regional and remote areas.

These and many other issues presented in the National Action Plan – including increasing research impact, greater and more equitable access to clinical trials, minimising financial hardship and supporting people with best practice treatment and care regardless of their age or circumstance – are areas where policymakers and the cancer community can come together to improve outcomes for all cancer patients.

Blood Cancer Taskforce

Taskforce member	Affiliated organisations
Professor Sanchia Aranda AM	Cancer Council Australia
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Dr John Bashford	Icon Group; Private Cancer Physicians of Australia
A/Professor Kate Burbury	Peter MacCallum Cancer Centre
Dr Joe Collins AM	Lions Club International
Dr Michael Dickinson	Lymphoma Australia, Chair Medical Subcommittee
Dr Chris Fraser	Australian and New Zealand Children's Haematology/Oncology Group
Professor Maher Gandhi	Mater Research Institute
Professor David Gottlieb	Westmead Hospital
Barbara Hartigan	Leukaemia Foundation Patient Support
Dr Carrie Hillyard AM (co-chair)	Leukaemia Foundation
Professor Tim Hughes	South Australian Health and Medical Research Institute
Dr Paul Jackson	Cancer Australia
Professor David Joske	Solaris Health WA
Melanie Kelly	Insight Economics
A/Professor Rishi Kotecha	Perth Children's Hospital; Australian and New Zealand Children's Haematology/Oncology Group
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Professor Paula Marilton	Princess Alexandra Hospital
Dr Robert Menz	Royal Australian College of General Practitioners
A/Professor Peter Mollee	Australasian Leukaemia & Lymphoma Group
Carmel O'Kane	Cancer Nurses Society of Australia
Bill Petch (former co-chair)*	<i>Leukaemia Foundation</i>
Professor Miles Prince AM	Snowdome Foundation; Myeloma Australia; Epworth Hospital
Professor Andrew Roberts AM	Walter and Eliza Hall Institute of Medical Research
Professor John Seymour AM (co-chair)	Peter MacCallum Cancer Centre & Royal Melbourne Hospital
Deborah Sims	Blood cancer survivor
Delaine Smith	Australasian Leukaemia & Lymphoma Group
Elizabeth de Somer	Medicines Australia
Dr Will Stevenson**	<i>Past President, Haematology Society of Australia and New Zealand</i>
Richard Vines	Rare Cancers Australia
Dr Meg Wall	Monash Pathology; Haematology Society of Australia and New Zealand Council

* Dr Carrie Hillyard replaced Bill Petch as Leukaemia Foundation co-chair in June 2020

**Dr Will Stevenson departed the Taskforce when his term as HSANZ President expired

List of acronyms

ACSQHC	Australian Commission on Safety and Quality in Health Care
AIHW	Australian Institute of Health and Welfare
ALLG	Australasian Leukaemia & Lymphoma Group
ALL	Acute lymphoblastic leukaemia
AML	Acute myeloid leukaemia
CAR T-cell	Chimeric antigen receptor T-cell
CaT-Link	Cancer and Treatment Linked Analysis Asset
CEO	Chief Executive Officer
CLL	Chronic lymphocytic leukemia
CML	Chronic myeloid leukaemia
COVID-19	Coronavirus disease 2019
CT	Computed tomography
EMA	European Medicines Agency
EMR	Electronic Medical Record
FDA	Food and Drug Administration
GP	General practitioner
GvHD	Graft versus Host Disease
HSANZ	Haematological Society of Australia and New Zealand
KPI	Key performance indicator
LaRDR	Lymphoma and Related Diseases Registry
MBS	Medicare Benefits Schedule
MDS	Myelodysplastic syndromes
MPN	Myeloproliferative neoplasms
MRFF	Medical Research Future Fund
MSAC	Medical Services Advisory Committee
NGO	Non-government organisation
NHL	Non-Hodgkin lymphoma
NHMRC	National Health and Medical Research Council
OCP	Optimal care pathway
OECD	Organisation for Economic Co-operation and Development
PATS	Patient Assisted Transport Schemes
PBAC	Pharmaceutical Benefits Advisory Committee
PBS	Pharmaceutical Benefits Scheme
PRO	Patient reported outcome
WD	Waldenström's macroglobulinemia

