

Written feedback | NSW Cancer Plan Discussion Paper

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Introduction

On behalf of the Cancer Institute NSW, we thank you for your ongoing support to improving cancer control in NSW.

We are pleased to share with you the accompanying discussion paper for your review and comment. The discussion paper has been developed based on research and consultations to date, and provides background information and key questions for consideration that will shape the development of the next Plan.

The paper is structured according to eight domains, with key questions for consideration under each domain. We invite you to consider those domains that are most relevant to your work or expertise.

We welcome your response to these questions. Please send the completed template to cancerplan@nousgroup.com.au by 9 November 2020.

Should you have any questions or comments, please don't hesitate to contact Michael Stewart, Senior Consultant, Nous (Michael.Stewart@nousgroup.com.au / 8378 8936) or Jenny Miu, Evaluation and Planning Coordinator NSW Cancer Plan, Cancer Institute NSW (Jenny.Miu@health.nsw.gov.au / 8374 3604)

Written feedback

Topic / Question	Notes
What should be the vision and high-level goals for the next NSW Cancer Plan? Why?	<p>The Leukaemia Foundation considers it vital to include blood cancers as a major area of focus for the next NSW Cancer Plan. We also consider that patient-centricity is foundational to achieving all other goals.</p> <p>Blood cancer arises from abnormalities that affect normal blood cell production and function. Typically, blood cancers are grouped into one of three major sub-type classifications: leukaemia, lymphoma or myeloma. When combined, blood cancers are among the most frequently occurring types of cancer, and one of the most significant causes of cancer death.</p> <p>Based on the most recent data, more than 17,300 people are diagnosed with a blood cancer each year in Australia (17,321 projected in 2020), making blood cancer the second most commonly diagnosed cancer in Australia today. The latest AIHW data (2016) also show blood cancers kill more Australians than breast cancer, prostate cancer or colorectal cancer.</p> <p>AIHW data show that in 2016 in NSW, 4,725 people were diagnosed with a blood cancer, and 1,692 people died. Standardised for population, with 17.6 deaths per 100,000, that figure is higher than the national figure, at 17.4 per 100,000, despite a lower than average incidence rate (52.5 cases per 100,000 in NSW, compared to 55.8 cases per 100,000 across the country).</p> <p>Blood cancers represent fully 10 per cent of all cancers and two per cent of Australia's total disease burden, and the nature of blood cancers means that preventative interventions such as screening are not effective. Early and accurate diagnosis is critical for treatment, however diagnosis can be delayed, sometimes fatally, due to lack of understanding of blood cancers and their complexity. People are also more likely to die of blood cancer if they live in a regional/remote area, and there are survival differences between states.</p> <p>Analysis of state cancer registry data in the Leukaemia Foundation's <i>State of the Nation: Blood Cancer in Australia</i> (2018) report (available at: https://www.leukaemia.org.au/wp-content/uploads/2020/06/State-of-the-Nation-Blood-Cancer-in-Australia_Leukaemia-Foundation.pdf) indicated that if current best practice survival rates achieved in Australia today were realised nationally, without any variation</p>

between metropolitan and regional patients, or between states, the number of deaths predicted by the blood cancer model would be substantially reduced; for example:

- If the metropolitan/regional divide were addressed, approximately five per cent of deaths (more than 9,300 people between 2018-2035) could potentially be avoided (see Figure 4.3 in the *State of the Nation* report p. 85 'Address the metro-regional divide').
- In addition, if other variations in survival outcomes by state and territory were addressed, a further eight per cent of mortality could be reduced, yielding a cumulative 13 per cent improvement on expected mortality based on current survival outcomes between 2018 and 2035 (see Figure 4.4 in the *State of the Nation* report p. 85 'Consistent best practice').

The National Strategic Action Plan for Blood Cancer, released on 27 September 2020 (available at: <https://www.leukaemia.org.au/national-action-plan/>), provides an evidence-based blueprint to coordinate and accelerate national efforts to improve survival and quality of life for people diagnosed with blood cancer and to support their carers and families. It sets out the necessary 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, 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 was developed with members of the blood cancer community and led by the Blood Cancer Taskforce – an expert group including leading clinicians, research, patients and patient advocates (information on the Taskforce is available at: <https://www.leukaemia.org.au/how-we-can-help/advocacy-and-policy/blood-cancer-taskforce-2/>). 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:

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

A key feature of the National Action Plan is that it is patient-centric. It builds on work undertaken by the Leukaemia Foundation's *State of the Nation* report, which included a Survey of People Living with Blood Cancer, with feedback from more than 3,200 people living with blood cancer and their carers.

The Leukaemia Foundation is the only national organisation that represents all Australians living with blood cancer. We provide practical and emotional support to Australians diagnosed with a blood cancer at no cost, thanks to the generosity of the community through our fundraising efforts. We believe that any reform must involve patients at every step of the way, which is why the first priority of the National Action Plan was actions that seek to empower patients.

These actions include 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.

The National Action Plan has been developed to be relevant and applicable across all Australian jurisdictions. The Leukaemia Foundation, in its capacity as the secretariat for the Blood Cancer Taskforce, is aiming to advance the recommendations of the National Action Plan in partnership with the blood cancer community and governments at the Federal and state level. The concepts and recommendations presented in the following sections may thus be suitable for implementation or piloting in NSW, and then scaled for impact across other jurisdictions.

There are 8 domains listed below. Please only focus on the domains that are most relevant to your work.

Consider the questions listed as guidance but feel free to include any detail you feel is relevant to help the advancement of cancer control in the selected domains you respond to.

Prevention

- Which prevention activities should be prioritised and why?
- What is required to ensure cancer prevention activities are well coordinated across NSW?

N/A - The preventative targets identified in the discussion paper as having the highest potential for impact - smoking cessation and tobacco control, sun protective behaviours, alcohol consumption, healthy eating, exercise and healthy lifestyles, chronic infection and vaccination – sadly are not specifically relevant to the blood cancer context. 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 more generally (for example, through diet, exercise, reducing obesity and smoking etc.).

For blood cancers, different health initiatives are required due to the nature of the blood cancers themselves: it is access to accurate and timely diagnostics that is fundamental to the treatment, care and survival for people living with blood cancer, where timely and accurate diagnosis leads to the

treatment pathway and specialist care that will offer the best survival and quality of life outcomes for patients.

In the absence of specific prevention programs and programs for early screening/detection, public policy initiatives are required that focus on achieving nationally consistent best practice treatment and care including early and accurate diagnosis and access to precision medicine, access to new treatments and ongoing advances in research for a cure.

Screening and early detection

- What will have the greatest impact on early detection of cancers?
- Should certain groups be targeted in cancer screening efforts? If so, which groups?
- What is required to support the role of primary care providers, including GPs, to detect cancers early and enable timely referral to diagnosis and treatment?

People with blood cancers typically present to a general practitioner in a primary care setting with symptoms of unexplained fatigue, bone or joint pain, unexplained lumps, and unexplained bruising or bleeding.

The non-specific nature of these symptoms may delay presentation to a GP and subsequent testing, and this delay makes it critical that patients have access to timely and accurate diagnosis when they do present for testing. This is even more relevant now than it has been in the past; as research has increased our understanding of blood cancers, it has enabled increasingly precise diagnoses and therefore treatment pathways that offer the best survival and quality of life outcomes. These diagnostic tools have themselves become highly specialised and complex, as have medicines which can now be granularly targeted to a specific patient and their specific cancer.

While blood cancers benefit from technological advances that deepen the precision by which specific subtyping classifications can be detected, there will likely be increasing challenges with generating the traditional forms of data necessary for economic evaluation of technologies and therapeutic interventions. At the same time, as research yields breakthroughs and new curative therapies, so we anticipate the Australian population will continue to expect timely access to these new and novel agents.

While a timely and accurate diagnosis is foundational to quality and safe clinical practice, major challenges exist in the delivery of diagnostic services for blood cancers that are defined as minimum standards of care ('must haves') by international disease guidelines.

International studies show that the diagnostic error rate in blood cancers (or discordance between initial diagnosis and expert review) can be high. Timeliness also remains a major challenge within diagnostic

delivery, while simultaneously being increasingly recognised as a critical quality issue that must be improved to meet minimum standards.

The National Action Plan makes the following recommendations on diagnosis:

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.

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: a. Coordinate evidence to support the development of applications for MBS reimbursement of diagnostics that are standard of care but are not yet listed. b. 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.

Cancer treatment and support

While new discoveries are critically important to improving the survival rates of people living with blood cancer, a considerable difference can be made by ensuring consistent access to best practice treatment and care – what is already funded and performed. Data shows that we could reduce mortality from blood cancers by 13 per cent by removing variations in survival outcomes nationally (8 per cent

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- What improvements or developments in cancer treatment and service delivery will provide the greatest and most equitable outcomes?
 - How does the cancer system need to change to ensure cancer care is better integrated across service providers and financially sustainable?
 - What's needed to improve quality of life for people with cancer, including people receiving palliative care and at end of life?

difference between states) and between metropolitan and regional/remote areas (5 per cent difference), based on current survival outcomes between 2018-2035.

The Blood Cancer Taskforce identified that actions that seek to remove the 13 per cent variation in survival outcomes and address preventable deaths through actions that will realise consistent and equitable access to best practice treatment and care for all Australians. There are, however, systemic challenges that must be overcome to achieve this including: inconsistent notification of blood cancers to state and territory cancer registries, the rapidly evolving nature of blood cancer which stratifies cancer subtypes and therefore their treatments, 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.

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. Accredited centres for highly specialised services report superior outcomes for highly specialised services compared with non-accredited centres. Financial equity is an additional and not inconsiderable factor and a lack of ability to pay may have adverse consequences: if a medicine, device, or service is not PBS or MBS listed, Australian patients must either privately fund, seek compassionate access via a clinical trial, or forego the therapy. In practice, this means it will likely be out of reach for most Australians, and clinicians have been reported not discussing options with patients if therapies are not publicly subsidised.

The National Action Plan makes a number of recommendations that go to the issue of cancer treatment and care (in addition to those already mentioned):

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.

1.5.1 Assemble 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

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- 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).

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 nongovernment organisations to increase the representation of Aboriginal and Torres Strait Islanders on the Australian Bone Marrow Donor Registry.

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.

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.

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.

1.8.4 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.

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.

2.1.3 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.

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.

2.4.1 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.

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.

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.

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.

4.3.1 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.

Equity and priority populations

As noted in the National Action Plan, often high-risk patient groups are less likely to receive care that accords with current best practice.

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- What are the priority populations that should be a focus for the next Plan? Why?
 - What will have the greatest impact in reducing inequity in access and outcomes for these populations?
 - How can the cancer care system, and cancer services, empower priority populations?

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.

Blood cancer affects people from all cultures and backgrounds, and Australia is becoming more culturally and linguistically diverse, but access to best practice treatment is not consistent across all sections of the population. Barriers to patient engagement and access to the healthcare system may encompass language, cultural practices, religion and other beliefs: 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. Differences in language and cultural background can hamper access to healthcare and understanding of treatments.

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 – except for Aboriginal and Torres Strait Islander people with blood cancer, who are both less likely to be able to find a matched donor in the event that they require an allogenic stem cell transplant and also have no international donor options. Other ethnic groups not well represented in these international donor groups include 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.

There are specific intersecting challenges for Aboriginal and Torres Strait Islander people which contribute to lower rates of presentation, later diagnoses, lower rates of service utilisation and poorer outcomes. 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.

Many of the issues that affect Aboriginal and Torres Strait Islander people intersect with issues that affect people living in remote and regional areas: 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.

The National Action Plan makes recommendations (in addition to those already mentioned) towards considering patients both across their lifespan and makes specific recommendations around addressing challenges for people with blood cancer from Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities, including:

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.

1.6.3 Develop an awareness and education campaign regarding blood cancer signs and symptoms in partnership Community Controlled Health Services.

1.6.6 Leverage existing activities and national reform agendas to improve participation rates of Indigenous cancer patients in clinical trials for blood cancers.

1.7.1 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.

Patient empowerment and experience

- What is most important to those who experience cancer, their families and carers?
- What is required to ensure that the NSW cancer system and services deliver consistently exceptional patient experience across the entire cancer care journey?

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.

One of the most significant barriers to empowering people living with blood cancer is the complexity of the healthcare system. In the Survey of People Living with Blood Cancer, more than one in five people reported feeling 'completely uncertain' or having 'lots of questions' about their diagnosis, and one in

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- What is required to empower patients to shape the cancer system and cancer care?

ten about their treatment plan. Patients may not be aware of services available to help them with the carer support or financial planning.

Unsurprisingly, provision of evidence-based and trusted sources of information was one of the top priorities identified by patients through the Survey of People Living with Blood Cancer. 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.

The Survey of People Living with Blood Cancer also 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 multifactorial 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.

While all of the actions in the National Action Plan have been considered from a patient perspective, the following are of particular relevance on this topic:

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

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.

1.8.5 Enable patient-centred care through a national system for PROs that can enable improved monitoring of symptoms and adverse effect as well as a more systematic screening and referrals to supportive care.

Ensuring that the health workforce is developed in lockstep with advances in blood cancer research, care and treatment is key to ensuring those patients receive best practice care – at the primary level as well as the specialist level.

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.

The National Action Plan makes a number of recommendations regarding workforce development and upskilling that support its other recommendations, including:

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).

1.8.3 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.

Cancer workforce and experience

- Should the cancer workforce and experience be a focus for the next Plan? Why?
- What is needed to ensure we have an accessible and high quality cancer care workforce to meet the current and future needs of NSW?
- Where should efforts be focused to enhance the experiences of the cancer care workforce?
- Which system stakeholders are responsible for leading workforce development and experience for the NSW cancer system?

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.

2.6.1 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, and other Cancer Plans across the country, including the NSW Cancer Plan in development.

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.

System alignment and integration

- How can health, cancer and other care systems be better aligned and integrated?

See response to cancer treatment and support, which encompasses system integration as a necessary part of ensuing best practice treatment and care.

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- What will have the greatest impact on strengthening the linkages between the NSW public cancer system and private cancer service providers?
 - What will have the greatest impact on strengthening linkages between primary and secondary and tertiary care?
 - How can the system better coordinate treatment, care and support along each stage of the cancer pathway?
 - In what parts of the cancer control system and through what mechanisms can accountability for outcomes be improved?
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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.

Research, data and technology

- What aspects of research should be prioritised to have the most impact on cancer outcomes? What is required to enable this?
- What aspects of data and technology should be prioritised to have the most impact on cancer outcomes? What is required to enable this?
- How can virtual care models be further embedded and sustained in the delivery of integrated cancer services?

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.

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.

Access to clinical trials is often limited by more than simply knowing that they are an option. Particularly for patients in rural and regional areas, the distances and cost involved in participating in trials may be prohibitive. Data show there is significant latent demand for regional clinical trials and tele-trials; to date, access to clinical trials in regional areas has been rate-limited by immature regional cancer centre services, under-estimation of the workforce requirements at regional trial sites to enable the safe and effective roll-out of tele-trial models, high regional workforce turnover, and administrative inefficiencies

associated with ethics and governance approvals for each site. Compounding this is the lack of incentives for the pharmaceutical and clinical trial sectors to establish tele-trial sites.

The National Action Plan makes a number of key recommendations around research, some of which fall under cancer treatment (access to clinical trials), but otherwise include:

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.

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.

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.
