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TE AHO O TE KAHU CANCER CONTROL AGENCY

CANCER SERVICES PLANNING

# The Model of Care for Transplant & Cellular Therapy Services in Aotearoa, New Zealand

December 2023

# FOREWORD



On behalf of the Stem Cell Transplant Project team at Te Aho o Te Kahu, it gives me great pleasure to present this Model of Care for Stem Cell Transplant and Cellular Therapy Services in Aotearoa, New Zealand.

Blood cancer affects an increasing number of people and whānau in Aotearoa each year and comprises over 20% of all cancer cases. Whilst the treatment of blood cancer is improving rapidly, a significant proportion of people will need a stem cell transplant as part of their therapy. All these people can benefit from a stem cell transplant, achieving much better outcomes and in a significant number, a long-term cure.

Recognising the important role of stem cell transplantation and the urgent need for cellular therapy treatment in cancer care, Te Aho o Te Kahu established a project to specifically look at how transplant services were delivered and how they could be improved. The work that followed involved extensive stakeholder consultation and numerous site visits to providers. The healthcare professionals and support services that deliver Haematopoietic Stem Cell Transplant (HSCT) services are passionate and committed. However, services need to be expanded so all people who could benefit from an HSCT can receive this in a timely and efficient way.

In addition new cellular therapies, such as Chimeric Antigen Receptor (CAR) T-Cell therapy, are becoming an important part of treating blood cancer and need to be adopted more widely. Within the context of the health reforms, the time seemed right for the coming together of a national, co-ordinated, equitable and high-quality stem cell transplant and cellular therapy service.

This Model of Care explores all areas related to the provision of HSCT services. The model is ambitious for the future but very achievable, and has the potential to deliver significant improvement for people and whānau with blood cancer. Our hope is that this model will provide a framework for commissioners, funders, managers, and clinicians to deliver high quality and equitable care across Aotearoa.

We would like to acknowledge all stakeholders involved in this project particularly those who are working in the HSCT units, the New Zealand Blood Service and those non-government organisations who support and advocate for whānau. We also acknowledge those whānau living with blood cancer, and those who have lost loved ones to blood cancer. We have listened to your stories, and sincerely hope that through this document services will continue to develop and improve, better meeting the needs of those who follow you on that blood cancer journey in the years to come.

Dr. Humphrey Pullon, MBChB, FRACP, FRCPA
Specialist Haematologist and Clinical Advisor to Te Aho o Te Kahu


IN CONFIDENCE, NOT GOVERNMENT POLICY

# ACKNOWLEDGEMENTS

This work has been a truly collective effort and reflects a shared ambition across stakeholders that all people and whānau will have access to high quality, sustainable and equitable transplant and cellular therapy services.

We would like to acknowledge the generosity of all who contributed to informing the content and context for the model.

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# PURPOSE OF THIS DOCUMENT

There is an urgent need to improve access to stem cell transplant in Aotearoa, as well as to set a more sustainable and equitable course for the future

The purpose of this document is to describe the attributes of optimal service design for Transplant and Cellular Therapy (TCT). Consolidating these attributes into a national model of care establishes an agreed position on the delivery of equitable, high-quality and effective TCT care in Aotearoa, and forms the basis from which future planning and ongoing quality improvement can occur.

Transplant and Cellular Therapies are highly specialised treatments for blood cancer, which also have applications for other cancers and non-malignant conditions. Haematopoietic Stem Cell Transplant (HSCT) repopulates the bone marrow stem cells after initial chemotherapy, radiation or immunotherapy and in allogeneic transplant this resets the immune system and restores healthy bone marrow function. These treatments often offer a cure for people when all other options have been exhausted.

Expanding clinical applications, improved supportive therapy and overall population growth has meant demand for HSCT has increased markedly in the last decade. HSCT providers have been unable to keep pace with this demand due to chronic resource constraints and insufficient investment. This has left these services no longer fit for purpose and ill-equipped for the future.

Additionally, progress in research, clinical application and manufacturing of immune cell therapies is accelerating. These important new treatments will increase the demands on existing services and strengthens the case to optimise these services now, in alignment with an agreed model of care.

The term 'model of care' has different interpretations but fundamentally describes how health services are delivered. Depending on the context, a model of care can be as broad as an end-to-end operating model that shapes how services are designed and delivered, or as specific as a single treatment care plan.

In this case the model of care describes how services, from a whole of system perspective, should be designed and delivered. Therefore, the model includes attributes of current practice which already reflect optimal care, attributes which are opportunities to evolve current practice as well as some entirely new ways of working.

There are differences between current practice and the model, and while this document does not outline the detail of how to move from the current to proposed future state, a summary of known areas of substantive difference has been included for context (See Implications of the New Model on page 6).

It is also acknowledged that developing the model has not occurred in isolation and that the next stage of implementation planning will need to include and maintain momentum on current sector projects. This includes the business cases completed in 2022/23 for additional staff and infrastructure upgrades at hospitals delivering TCT, the planning for the implementation of CAR T-cell therapy and the work of Te Aho o Te Kahu (the Cancer Control Agency) in Cancer Services Planning for Systemic Anti-Cancer Treatment and Optimal Cancer Care Pathways.

# STRUCTURE OF THIS DOCUMENT

This document outlines the key attributes of optimal service delivery and, alongside a yet to be developed implementation plan, is intended to guide providers on how to evolve and enhance TCT and HSCT services. The model also has enduring value as a quality tool, and can be used to assess service delivery to inform ongoing quality improvement and more timely strategic planning.

The model is presented across eight operational and clinical categories. Each section includes an overarching narrative that describes the intent and rationale for the attributes, and then a list of the attributes that demonstrate optimal care relevant to the category.

The attributes in the model reflect a **whole-of-service** perspective. This offers the opportunity to be innovative about aspects of care, but in a way that is mindful of the need for all aspects of a service to be high functioning for improvement to occur. The model also reflects a **whole-of-system** approach recognising the current and potential contribution of all organisations involved in delivering TCT services, including external providers such as the New Zealand Blood Service, kaupapa Māori providers and non-government organisations.

This model is primarily about the delivery of transplant and cellular therapies but, where sensible to do so, includes attributes that are relevant to broader aspects of clinical haematology services. Examples include leadership and governance arrangements across Clinical Haematology as a whole, the future of CAR T-cell therapy and the use of HSCT to treat multiple sclerosis and other autoimmune conditions.

Each attribute in the model is framed as belonging to **'the provider.'** In this document this term represents **all parties** involved in optimal delivery of TCT services. This includes decision makers, commissioners, planners, and service leadership, as well as those involved in day-to-day operation of services. It also includes the contribution of others outside the hospital, as referenced above.

Framing the attributes in this way has been deliberate and intended to **foster shared accountability.** Using the term 'provider' as a collective also reflects that the model is written from the perspective of people and whānau, who view the system as one entity, and their journey within it as a continuous set of experiences. Taking this whānau centred approach to developing the model, along with expert clinical advice and research, has offered a comprehensive understanding of optimal TCT services. This understanding has then been translated into what the provider (in its broadest definition) **needs to do** to deliver this optimal and seamless pathway for people and whānau with blood cancer.

It is accepted that in some cases further delineation of specific individual accountabilities may be appropriate, such as determining accountability for investment decisions, and this level of specificity would be part of continuous quality improvement or other investment planning.

# DEVELOPING THE MODEL OF CARE

Changing how services are designed can be highly impactful in addressing inequities, with the right approach and priority (Gurney et al 2019).

This model of care describes a system that ensures services are high quality and sustainable. It is a synthesis of the voices of those who best understand TCT – from people and whānau who experience treatment, through to those who deliver care both within and external to hospital services, and those tasked with safeguarding the system.

Writing this model has been part of a programme of work undertaken by Te Aho o Te Kahu to develop and provide strategic advice that will drive improvement in the delivery, efficacy, and equity of cancer treatments within the reformed health system. Phase One of this Cancer Services Planning programme was about understanding the current state and high-level vision for cancer treatment and included extensive stakeholder engagement across the sector. The findings from this work included recommendations for radiation oncology, systemic anti-cancer therapies, complex cancer surgery and HSCT. These recommendations are detailed in the He Mahere Ratonga Mate Pukupuku – Cancer Services Planning report, which is published on the Te Aho o Te Kahu website (Te Aho o Te Kahu 2022).

Phase Two of the programme is about making meaningful progress on delivering these Phase One recommendations. This is currently underway and includes developing future facing and comprehensive models of care for all cancer treatments. The intent is to then use these models to assess where improvement is needed, and to work with health system partners to develop agreed plans for how improvement will occur.

For the TCT model of care this phase of work has included:

- Establishment of a Te Aho o Te Kahu project team to drive the work inclusive of an overarching focus on eliminating inequity, prioritising accessibility and acceptability and meeting obligations under Te Tiriti o Waitangi. (See Acknowledgements section for team membership).
- Continued development of the Phase One findings, including a detailed equity analysis, further literature review and development of national dataset and service continuance (recovery) programme.
- A national workshop with stakeholders from all TCT providers, consumers, advocates, and Māori leadership to test initial ideas in June 2022.
- Regular meetings with clinical leadership, the establishment of a national nursing network and site visits to all TCT providers (August 2022 – October 2022).
- Testing of a first draft of the model of care (April – August 2023).
- A detailed gap analysis of current and future state, and an implementation plan (to be determined).

## Te Tiriti o Waitangi and the Model's Development

As a Crown agency, Te Aho o Te Kahu is acutely aware of its' obligations and aspirations under Te Tiriti o Waitangi. This model has been developed with Te Tiriti o Waitangi at the forefront of thinking which includes how the model functions to address bias and discrimination, how to balance leadership between providers and Māori communities, and how to share decision-making and resources, and for providers to be accountable for Māori health equity. To ensure Te Tiriti principles were consistently considered and prioritised, the following framework has been applied.

| Te Tiriti o Waitangi Principles | The attributes in this Model of Care will enable commissioners and service providers to… |
|---|---|
| Tino Rangatiratanga<br>Provides for Māori self-determination and Mana Motuhake in the design, delivery, and monitoring of health and disability services | Provide Māori whānau with the information and resources they need to exercise Tino Rangatiratanga over their treatment journey.<br>Ensure services are designed sustainably and in partnership with appointed equity champions and Māori consumer representatives. |
| Equity<br>Requires the Crown to commit to achieving equitable health outcomes for Māori | Put in place a range of priorities and resources to ensure that Māori have equitable access to services.<br>Support the inclusion of indigenous remedies with westernised treatments where appropriate. |
| Active Protection<br>Requires the Crown to act, to the fullest extent practicable, to achieve equitable outcomes for Māori. This includes ensuring that it, its agents, and its Treaty partner are well informed on the extent, and nature, of both Māori health outcomes and efforts to achieve Māori health equity | Be informed by key strategic documents and programmes focused on equitable health outcomes for Māori, including:<br>- Government response to Hauora Manaaki Ki Aotearoa Whānui - The Health and Disability System Review<br>- Government response to Komiti Whiriwhiri Take Māori - Māori Affairs Committee inquiry into Health Inequities<br>- Whakamaua: Māori Health Action Plan 2020 - 2025<br>- He Pūrongo Mate Pukupuku o Aotearoa 2020 - The State of Cancer in New Zealand 2020<br>- Te Pae Tata – Interim New Zealand Health Plan 2022<br>- He Korowai Oranga: The Māori Health Strategy 2022 |
| Options<br>To provide for kaupapa Māori health services and to ensure that all healthcare services are provided in culturally appropriate ways that recognise and support the expression of hauora Māori models of care. | Strengthen relationships with kaupapa Māori health providers, who in turn can support people and whānau to receive treatments in a mana enhancing manner.<br>Incorporate insights and opinions from Kaupapa Māori health providers, Māori health professionals and Māori whānau to understand cultural sensitivity and opportunities for improvement.<br>Recognise that kaupapa Māori health providers have a meaningful influence which they naturally incorporate in their daily work routines.<br>Support all people working in TCT and cancer treatment services to develop their knowledge of and ability to deliver culturally safe care. This includes: |

| Te Tiriti o Waitangi Principles | The attributes in this Model of Care will enable commissioners and service providers to… |
|---|---|
| | - Embedding cultural protocols and priorities into service designs<br>- Ensuring all staff members are familiar and comfortable with key concepts such as tapu, noa and tikanga practices<br>- Ensuring staff understand and can apply various Māori health models (Te Whare Tapa Wha, Te Wheke, Te Pae Mahutonga, and Te Waka o Meihana)<br>- Recognising and supporting any whānau Māori who may be disconnected from their cultural roots. |
| Partnership<br>The principle of partnership, which requires the Crown and Māori to work in partnership in the governance, design, delivery, and monitoring of health and disability services. Māori must be co-designers, with the Crown, of the primary health system for Māori. | Partner with Māori (including Hei Āhuru Mōwai, clinicians, health providers and whānau) to develop a robust clinical and operational governance structure for clinical haematology that is consistent with:<br>- Te Pae Tata, Interim New Zealand Health Plan 2022<br>- He Korowai Oranga: The Māori Health Strategy 2022<br>- Whakamaua: The Māori Health Action Plan 2020 - 2025<br>- He Mahere Ratonga Mate Pukupuku o Aotearoa 2020 |

Table 1: Project Framework

## An Equity-led and Whānau Centred Model of Care

There are many drivers of inequity. These factors can be at a societal level (e.g., social determinants of health) or more directly related to cancer treatment and care (e.g., the design of cancer services). While the TCT model of care is limited in its ability to affect the broader factors, there is good evidence that a focus on factors such as service design and delivery can address inequities (Gurney et al 2019).

In developing the attributes of the TCT model there has been a deliberate focus on how to improve the accessibility, availability, acceptability, and standardisation of service delivery at each step. Each attribute has been tested for its influence in addressing inequity and how it reflects a whānau centred approach.

The following questions have been developed to guide the analysis:

1. Who is most affected by this issue/work, and how are they affected?
2. Are Māori needs and aspirations identified?
3. How will this work improve the experience of people and their whānau?
4. What Māori and Pacific health gains will come from this work?
5. Will this work develop or progress kaupapa Māori initiatives?
6. How do the wider determinants of health impact on this work?
7. How are Māori, Pacific peoples and tāngata whaikaha involved in planning and decision-making?
8. How will this work contribute to more equitable cancer outcomes for Māori, Pacific peoples and/or tāngata whaikaha?
9. What unintended consequences might arise? Who is going to endure the most? Are there risks for widening the equity gap? How could these be mitigated?

# IMPLICATIONS OF THE NEW MODEL

The following implications describe known areas of substantive difference between the new model and the current state, and are informed by previous reports, interviews / workshops with stakeholders and site visits.

Some of the attributes listed in this document simply confirm the continuation of current practice, with the caveat that investment is required where **current practice** reflects optimal care but **current resources** are insufficient to deliver this care consistently. Other attributes are an evolution of current practice or describe entirely new ways of working.

The implications have been identified to provide context and are only an outline of the steps needed to transform TCT services. Formal change management plans, where investment or significant changes to operational structure is indicated, will be the next phase of this work. However not all implications will require this level of formality. There are several attributes that reflect opportunities for change that are within the delegation of TCT providers, individually and collectively, and could be introduced as part of continuous quality improvement.

## Implications for HSCT Leadership and Governance

- Establishing a new leadership and governance framework consistent with the evolving governance and operating model for the reformed healthcare system.
- Establishing and appointing national TCT clinical, quality and equity leadership roles to support this framework.
- Implementing a regional approach to service delivery, noting this will impact differently across the providers (See Section 2. Service Distribution).

## Implications for Service Distribution

- Investment to support the development of new (additional) autologous sites.
- Evolution of a regional service model, particularly for the Northern, Central and Southern regions where there will be multiple sites of autologous HSCT.
- Implementation of outpatient autologous transplant pathways for Northern and Te Manawa Taki regions.
- Introduction of CAR T-cell therapy as per national planning.

## Implications for Service Delivery

- Strengthening of the shared care model between TCT providers and referring clinical haematology sites.
- Changes to infrastructure and process at Waikato Hospital and Auckland City Hospital to support an ambulatory autologous HSCT pathway.
- Improvements to travel and accommodation support.
- Implementation of a national business continuance strategy to manage disruption.
- Adoption of national assessment of needs guidance.

- Strengthening of cultural competence and safety across the pathway, supported by the national Equity Lead for TCT (to be appointed).
- Agreeing new processes to ensure and demonstrate equitable access to TCT services, including review of MDM processes and referral management.
- Adoption of wait time indicators across all TCT providers.
- Adoption of non-deferable bed management practices for all TCT admissions.

## Implications for Workforce

- Assessment across all workforce groups and investment to align with recommended workforce establishments.
- Working across providers to establish a single integrated team.
- Alignment with goals and strategies of the Te Whatu Ora Workforce taskforce.
- Development of new national roles for a Clinical Director, Equity Lead and Quality Manager of Transplant and Cellular Therapy.
- Ongoing investment in Care Capacity and Demand Management (CCDM) to support full implementation in all relevant clinical areas and professions.
- Strengthening of cultural competence training and ongoing review.
- Increasing the workforce profile to better reflect the community served.

## Implications for TCT Facility

- Review and redesign of the physical environment at all five sites to increase capacity, enhance the acceptability and accessibility of facilities.
- Steps needed to meet accepted standards set by the Foundation for the Accreditation of Cellular Therapies (FACT), the Health and Disability Service and the Australasian Health Facility Guidelines.

## Implications for Performance and Planning

- Adherence to nationally agreed wait times (see Sections on Service Delivery and Workforce for detail).
- Improvement in system wide capability to proactively identify and address inequity, guided by equity-led leadership and governance arrangements.
- Transition to electronic (paper-light) systems making full use of existing or planned technology solutions for non-surgical cancer treatment including electronic prescribing for HSCT regimens.
- Development of a national clinical and service informatics plan for HSCT / TCT.
- Establishment of wait list management systems that provide visibility at local, regional, and national levels.
- Enhancement of dedicated TCT data management capability (workforce).
- Improvement to data collection and processes that align with data standards.

## Implications for Safety and Quality

- Evolution of existing quality management practices and systems to align with a national / regional system of service delivery.
- Evolution of existing quality management practices and systems to align with Te Ao Māori Health Quality and Safety Commission framework.
- Ongoing investment in FACT accreditation status for all Allogeneic HSCT providers.
- Alignment with FACT accreditation standards for all Autologous HSCT providers.
- Dedicated Quality Management roles for all sites functionally reporting through to national leadership for quality.

## Implications for Research and Clinical Trials

- Cost to fund cooperative clinical trials (may be offset with industry-based trials).
- Cost to support people and whānau through clinical trials (may be offset with industry-based trials).
- Development of public awareness to clinical research and trials.
- Ongoing development of the senior cross-agency working group to consider implementations of the Enhancing Aotearoa New Zealand Clinical Trials recommendations by Manatū Hauora, Te Whatu Ora, and Te Aka Whai Ora.

# CURRENT STATE OF TCT SERVICES

There are three main types of blood cancer (leukaemia, lymphoma, and myeloma). Collectively these cancers account for 10.4% of all cancers registered with around 7-8 people diagnosed every day. An estimated 21,000 people live with a blood cancer or related condition in Aotearoa. Most blood cancers, if left untreated, lead to severe illness and premature loss of life.

Blood cancer mortality rates in Aotearoa are improving, but there are significant inequities in outcomes. The age standardised incidence of blood cancers is higher in Māori than non-Māori, and cancer specific mortality is higher for Māori for myeloma, leukaemia, and lymphoma (Ministry of Health 2021). Māori and Pacific peoples with multiple myeloma develop the disease younger, are less likely to receive first line treatment or stem cell transplant and have inferior survival rates (Moore et al 2022; Soeberg et al 2012).

Blood cancers are treated by clinical haematology services which care for people with a range of malignant and non-malignant haematological conditions. All major hospitals in Aotearoa have some form of access to specialist haematology services. Table 1. describes how these services are organised.

| Levels | Service Activities | Hospital |
|---|---|---|
| 1 | Systemic therapy administration and visiting clinical haematology clinics | Ashburton<br>Blenheim<br>Balclutha (systemic therapy administration only)<br>Dunstan (systemic therapy administration only)<br>Gisborne<br>Greymouth<br>Hawke's Bay<br>Kaitaia<br>Keneperu<br>New Plymouth / Hawera<br>Oamaru (systemic therapy administration only)<br>Rotorua<br>Southland<br>Thames<br>Timaru<br>Wairarapa<br>Whakatāne<br>Whanganui (visiting clinic only) |
| 2 | The services provided at level one and on-site clinical haematology team, access to General Medicine inpatient beds | Tauranga<br>Nelson<br>Whangarei |
| 3 | The services provided at level two and clinical haematology inpatient beds | North Shore<br>Middlemore |
| 4 | The services provided at level three and acute leukaemia care | Dunedin |
| 5 | The services provided at level four and autologous transplantation | Palmerston North<br>Waikato |
| 6 | The services provided at level five and allogeneic transplantation | Auckland City<br>Christchurch<br>Wellington Regional |

Table 2: Clinical Haematology Delineation

This delineation framework is a work in progress and has been developed following a review of international delineation frameworks (NSW 2021), and by consensus with the National Haematology Work Group. It has been included in this model of care to acknowledge that TCT services need to be integrated within the full scope of clinical haematology services in Aotearoa. This framework also forms the basis of the facility and infrastructure requirements per site (See Section 5).

In Aotearoa, TCT services provide HSCT. HSCT is a procedure which repopulates the body with healthy haematopoietic stem cells after blood cancer treatment. Before a transplant occurs, chemotherapy and sometimes radiation therapy, are given to destroy cancer cells. This conditioning treatment also prepares the body to start again with new cells. Once completed, new healthy haematopoietic stem cells are infused, and they commence rebuilding the body's blood and immune system, which is vital to survival.

There are two types of HSCT. Autologous transplant is the infusion of a person's own stem cells (which have been removed prior to conditioning) and allogeneic transplant is where healthy stem cells from another person are infused to take over the bone marrow function in the recipient. The pathways for both types of transplants are outlined in detail on pages 14-15 of this document.

## Service Delivery Model

Around 370 stem cell transplants occur in Aotearoa each year. This number is small compared to other cancer treatments; however, the pathway is complex, resource-intense and can take many months to complete. People can require ongoing significant medical treatment for years following HSCT. The low volume and high acuity of transplant services necessitates that there are only a limited number of sites to ensure clinical quality, safety, and stability.

The current configuration is for three allogeneic providers (based at Auckland City, Wellington, and Christchurch Hospitals) and (with the addition of Waikato and Palmerston North Hospitals) five autologous providers. See Figure 1.

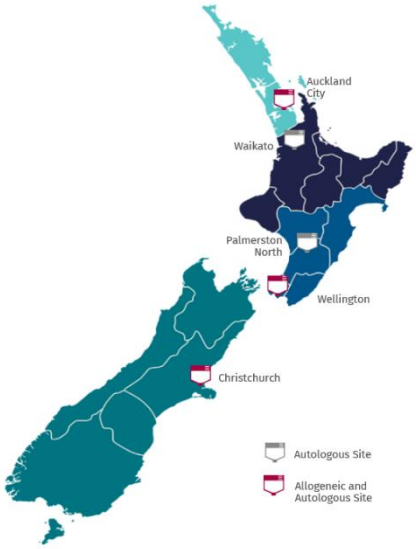



Figure 1: Current TCT sites

Notwithstanding a strong collegial network, and adherence to the same international standards of care, the providers are independent from each other, reflecting the autonomous nature of the previous District Health Board model of health care delivery.

The providers are also quite different in size. For example, the Auckland City Hospital catchment provides allogeneic transplant for 50 percent of the New Zealand population. This is not necessarily problematic if providers are resourced to meet demand, however it does mean that individual centres can have quite different challenges (and opportunities) related to scale.

## Demand for HSCT

Within Aotearoa, the demand for HSCT has continued to increase. In 2011, and again in 2018, national service planning exercises were undertaken to project the expected increase in HSCT demand. This national service planning exercise has been updated using data sourced from the Australia and New Zealand Transplant and Cellular Therapy Registry Data Summary 2021. Through linear regression modelling, the volume of HSCT per annum has been modelled against the national population.

Figure 2 forecasts the annual volumes for HSCT assuming middle growth rates (displayed in the dashed line). The projected growth range, including high and low growth scenarios, is displayed in the blue lines.

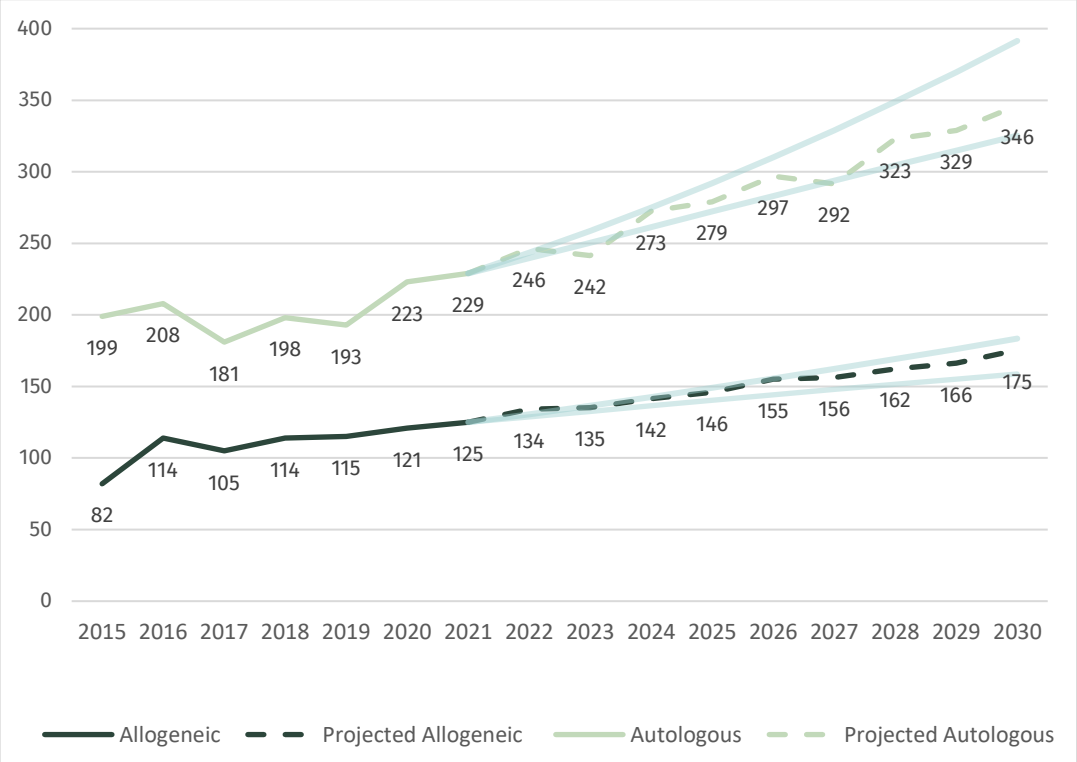



Figure 2: Forecast HSCT Volumes 2015 – 2030

By the year 2030, allogeneic HSCT volumes are projected to increase by 40% while autologous HSCT volumes are forecast to increase by 51% (based on the middle growth rate displayed in Figure 2).

Additional to this analysis, the introduction of CAR T-cell therapy will further increase projected demand. Modelling, based on The New Zealand Cancer Registry and international indications, indicates CAR T-cell therapy will be accessed by 150 adults per year. This modelling is for CAR T-cell therapy.

## Inequities and Service Delivery Issues

How services are designed and operate is a key contributor in whether people and whānau face unnecessary barriers to getting the care they need and the outcomes they should achieve. Across all aspects of cancer care these barriers create inequities.

There are alarming inequities when comparing the effects of the colonisation, racism, and social determinates on Māori against non-Māori. Because of this, Māori are directly impacted by socioeconomic inequalities (Ministry of Social Development 2006). Māori experience longer and slower pathways through health care, have hospitalisation rates that are disproportionately low, yet represent high in disease and mortality rates, are more likely to live in rural areas where access to services and treatment can be problematic and less likely to receive appropriate levels of care in screening (Ellison-Loschmann and Pearce 2006; Stevens et al 2008; Pitama et al 2012)

These barriers to care also disproportionately impact Pacific peoples, as well as those living in socioeconomically deprived communities particularly rural areas, those living with mental illness, disabled peoples and the SOGIESC-diverse (sexual orientation, gender identity and expression, and sex characteristics) community.

People who are unable to access transplant services when they need them, rely on less effective treatments and consequently experience inadequate symptom control and poorer outcomes including avoidable mortality and suffering, and reduced quality of life.

Insufficient, inequitable, and inadequate access to HSCT is a longstanding issue for Aotearoa (Ministry of Health 2018). Over the last two decades there has been variable and inadequate investment to support sustainable service provision and mitigate risks for HSCT providers and whānau. This insufficient service development has meant the current state falls short of a modern TCT service, despite the best endeavours of staff. This has led to missed opportunities to improve and innovate and which has introduced variation in access, operating models, quality management approaches and how services collaborate.

The need to improve cancer service design and delivery was reinforced at the Te Aho o Te Kahu Community Hui held in 2021. The aim of these Hui was simple - to hear the stories and experiences of whānau Māori, so that their voices could help shape the future direction of cancer care. Rongohia Te Reo, Whatua He Oranga - The Voices of Whānau Māori Affected by Cancer report was released in 2023 summarising the themes and insights from the hui. Aspirations identified by whānau Māori included:

- Reorientating services to meet the needs of Māori.
- Developing a system that accommodates kaupapa Māori concepts, so Māori are supported to undertake and complete treatment.
- Ensuring support is available for both the person and their whānau.
- System mechanisms are developed that encompass Te Ao Māori and Mātauranga Māori concepts and made available to people and whānau.
- Addressing racism.

While there is sound rationale for the smaller number of HSCT provider sites, this does mean that many people live some distance from their treatment facility and face significant challenges when travelling to access treatment (See Sections 2 Service Distribution for detail). For HSCT this is compounded by the length and complexity of the treatment programme, which extends from weeks to months away from home.

Service delivery and access issues exist for all providers. Most have inadequate facilities, as well as infrastructure and resource constraints. Wait times exceed recommended guidance and service sustainability planning is inadequate.

In 2011 a Bone Marrow Transplant Service Improvement Plan was developed by the Ministry of Health and the National Haematology Work Group. The plan was endorsed by the then Cancer Treatment Advisory Group and Cancer Control Steering Group. The plan was intended to be a starting point for increasing capacity and improving the delivery of transplant services.

The recommendations were to retain the current configuration of services and to undertake four principal areas of service improvement:

- Development of national clinical indications, consistent with best practice.
- Addressing capacity issues, physical resources and specialist staffing.
- International accreditation of services and facilities.
- Improving waiting times (Ministry of Health 2011).

In 2018, the plan was revisited and found that there had been significant medical advances since 2011. These changes included expanded access to transplant, making it available for older people, as well as greater donor availability which increased demand for transplant and increased intervention rates (Ministry of Health 2018). This update recommended that the District Health Boards discuss the implications of these projected demands with their local and regional haematology teams to plan for current and future service delivery. While some discussions were progressed, the plan was largely not acted on and access issues persist.

In 2021, in response to growing wait lists, a national working group was implemented to monitor waiting times, coordinate patient flow, and develop a recovery program. This oversight remains in place and is integrated across a continuum of improvement as part of the model of care development in this document.

# CURRENT HSCT PATHWAYS

## Allogeneic HSCT Pathway

| | |
|---|---|
| Induction  | Before transplant, some people will undergo induction therapy to control their disease. This could take weeks or several months. Others do not require induction therapy and are ready to proceed to transplant as soon as their stem cell donor is ready. |
| Referral  | People needing a transplant will be under the care of a primary haematologist. They will have had other treatment before being referred to a transplant team. Sometimes, but not always, this primary haematologist will also be part of this transplant team. All transplant centres have a multi-disciplinary meeting to determine eligibility for transplant based on international guidelines and best practice. |
| Provision of stem cells  | Before a person can have an allogeneic transplant, a stem cell donor must be identified. A donor is identified by human leukocyte antigen typing of eligible family members and those on local and international unrelated donor registries. Once identified, the most suitable potential donor undergoes further medical screening. The donor then undergoes stem cell mobilisation and collection. Stem cells are collected by the New Zealand Blood Service or an international stem cell registry, using a process called apheresis. Apheresis separates white blood cells directly from the blood of the donor. The collected cells are then prepared in a specialist laboratory, to make them ready for transplantation. The cells may be cryopreserved and stored before transplant. This step may take between 1 to 3 months. |
| Work-up  | In the weeks leading up to transplant, often at the same time as the donor screening, there are many tests and procedures to undergo as part of the pre-transplant work-up, such as imaging, regular blood tests and central venous access device insertion. This step can take one to four months depending on donor availability. |
| Conditioning  | Once ready-to-go for transplant, conditioning therapy is needed. Conditioning therapy helps to destroy any cancer cells that may be in the person's body and to make room in the bone marrow for the new healthy stem cells. Conditioning therapy may include chemotherapy, total body irradiation, immunotherapy or a combination of the three. |
| Transplant  | Infusion of the stem cells occurs in a specialist inpatient unit. Once in the bloodstream, the stem cells make their way to the bone marrow. It takes 10 - 28 days for the stem cells to engraft and begin to repopulate the bone marrow. There is considerable risk of infection, bleeding, organ dysfunction, the possibility of graft rejection, and graft versus host disease during this time. Close monitoring is essential. Most people spend 4 - 8 weeks in hospital but some people will spend up to 3 months. |
| Post-Transplant  | After discharge from hospital, the person and whānau remains linked to the transplant centre for at least the first 100 days. This means staying close to the transplant centre and being supported by whānau members or friends who can watch out for any signs of declining health and support a return to the hospital. For those who live further than 30 minutes from the transplant centre, accommodation is required close to the hospital campus. People can return home between 3 months and 6 months post-transplant where they will be supervised jointly with their primary haematologist. Around one half of people develop graft-versus-host disease or another transplant-related complication following HSCT. These people and whānau will remain at the transplant centre for longer. |

# Autologous HSCT Pathway

| | |
|---|---|
| Induction treatment  | Before transplant, people will undergo induction therapy. For those with myeloma, around four cycles of induction therapy, taking around four months, are required. For those with lymphoma, two to three cycles of induction therapy, taking around two months, are often required. |
| Referral  | People needing an autologous transplant will be under the care of a primary haematologist. They will have had other treatment before being referred to a transplant team. Sometimes, but not always, this primary haematologist will also be part of this transplant team. There is a nationally agreed acceptance and prioritisation criteria that determines whether a transplant is a beneficial and suitable option for people with myeloma or lymphoma. All transplant centres have a multi-disciplinary meeting, or designated TCT meeting, to confirm the recommendation for stem cell transplant. |
| Provision of Stem Cells  | Before a person can have an autologous transplant, stem cells must be collected or harvested. This process involves people having systemic treatment (chemotherapy and/or granulocyte colony-stimulating factor injections) that push or mobilise the stem cells from the bone marrow into the blood so they can be collected by apheresis, by the New Zealand Blood Service. These cells are then prepared in a specialist facility to make them ready for transplantation. The cells may be cryopreserved and stored before transplant or transplanted as fresh cells as part of a clinical trial. Once the cells are collected people are ready-to-go and shortly proceed to transplant in 2 - 4 weeks. |
| Conditioning  | After this preparatory work, a course of high dose conditioning therapy is needed. This treatment helps to destroy any cancer cells that may be in the body. Conditioning therapy may include chemotherapy, total body irradiation, or a combination of the two. When used, chemotherapy conditioning therapy is ideally given in an ambulatory care unit adjacent to or within the transplant unit. |
| Transplant  | Infusion of the stem cells ideally occurs in an ambulatory care setting adjacent to or within the transplant unit with close monitoring. Once in the bloodstream, the stem cells make their way to the bone marrow. It takes between ten and eighteen days for the stem cells to engraft and begin to repopulate the bone marrow. |
| Post-Transplant  | Close monitoring continues at least until the stem cells have engrafted and have repopulated the bone marrow. There is a high risk of infection during this time meaning established pathways for rapid re-admission are essential. This means staying close to the transplant centre and being supported by whānau members or friends who can watch out for any signs of declining health and support a return to the hospital. During this time, admission to hospital is almost universal, typically for 7-10 days. For those who live further than 30 minutes' drive from the transplant centre, accommodation is required close to the hospital campus. After two to four weeks, if all is well, a return home and discharge to the care of their primary haematology team for ongoing monitoring to ensure continued engraftment and successful control of the blood cancer will occur. |

TE AHO O TE KAHU CANCER CONTROL AGENCY

# THE ATTRIBUTES OF OPTIMAL SERVICE DELIVERY

# 1. LEADERSHIP AND GOVERNANCE

Transplant and Cellular Therapy providers will establish and sustain leadership and governance arrangements that empower clinicians and other service leaders to improve, and be held accountable for, the quality and safety of TCT services.

The right leadership and governance arrangements are a critical enabler to ensure that TCT services always act in the best interests of people and whānau. Therefore, this section focuses on establishing new structures and leadership positions that will better support TCT providers to improve performance, maintain stability, ensure sustainability, and unlock innovation. It is likely that these descriptions will evolve as the national strategic and service networks are established.

Consistent with Te Pae Tata the approach includes the development of national strategic and service networks, and regional hospital and specialist networks. He Mahere Ratonga Mate Pukupuku recommends a networked leadership structure to drive improvement (Te Aho o Te Kahu 2022). This is consistent with the priority of the health reforms to establish structural arrangements that unify and simplify the healthcare system, including a standardised operating model of nationally led planning and regional service delivery.

Both Te Pae Tata and He Mahere Ratonga Mate Pukupuku propose three levels of leadership for robust clinical / operational governance. These levels are designed to connect strategic thinking with frontline expertise, integrating policy into practice.

These three levels of leadership inform the following attributes and are:

- National **strategic leadership** to drive planning and decision making for all people, including determining priorities and approaches to how services are delivered and monitoring improvements
- **Technical leadership** to focus on quality and consistency of care for all people, and to manage the integration of policy into practice. This level of leadership requires TCT subject matter expertise and lived experience
- **Operational leadership** that takes responsibility for the delivery and maintenance of a robust and resilient model of care, through effective operational management at regional services and local sites.

## Attributes

1.1 All providers are to set a course for action that embeds a Tiriti-dynamic system, eliminates inequities in health outcomes for Māori, and delivers on the aspiration of Pae Ora 2022.

1.2 All providers will support growing Māori leadership, which in turn provides an avenue to Te Ao Māori and Mātauranga Māori concepts.

1.3 Te Aho o Te Kahu, Te Aka Whai Ora, Te Whatu Ora, and the New Zealand Blood Service will work in partnership to establish TCT as a **single national coordinated system of treatment** that is delivered at multiple sites.

## Leadership Structures

The following attributes describe the TCT leadership and governance structure. This is summarised in the following chart.

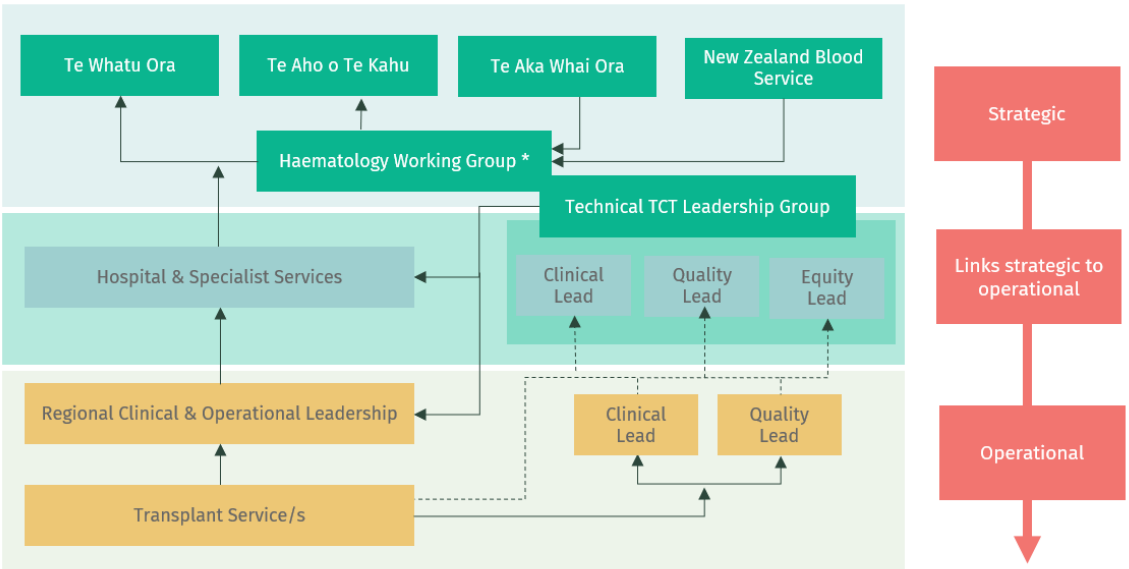



Figure 3: Leadership Structure

1.4 All levels of TCT leadership will have access to the necessary infrastructure and information to support effective clinical and operational governance, including sufficient time and administrative support to execute duties to their fullest extent.

1.5 All TCT leadership roles will have the delegated authority, and executive support, to address unwarranted variation between services and sites.

*To undertake meaningful change and improve the TCT pathway, all leadership roles will have the delegated authority to make change and influence the wider health care system to achieve effective results.*

1.6 Te Whatu Ora will establish and maintain effective **Service Delivery Leadership and Management** structures for TCT services**.** These arrangements will take responsibility for the delivery of a robust and resilient model of care for TCT (See Sections 2 – 8 for detail).

*It is noted that these structures may span TCT, clinical haematology and non-surgical cancer services as one system.*

1.7 Te Aho o Te Kahu, Te Aka Whai Ora, Te Whatu Ora, and the New Zealand Blood Service will work in partnership to ensure that there is dedicated and effective **Clinical Haematology strategic leadership** to drive national planning to support the TCT Technical Leadership Group in monitoring performance and integrating policy into practice.

1.8 Te Aho o Te Kahu, Te Aka Whai Ora, Te Whatu Ora, and the New Zealand Blood Service will work in partnership to establish a **TCT Technical Leadership** Group to inform national strategy, monitor service delivery and link policy with operation. This group will include clinical experts, TCT clinical, quality, and operational leaders, Māori cancer leadership, people with lived experience of TCT and non-government organisations (NGO) who support people and whānau undergoing TCT.

*How these Leadership Groups align with the existing Te Aho o Te Kahu National Haematology Work Group, and the yet to be established Te Whatu Ora Clinical Networks, will be the subject of implementation planning. There is potential for a new technical leadership group to evolve from the existing TCT Special Interest Group.*

1.9 Te Whatu Ora will establish national operational **Clinical, Quality and Equity TCT Leadership Roles** to oversee treatment delivery and outcomes.

*Reflecting the complexity of TCT service delivery and the priority to eliminate inequities both strategically and in real time, the function of these roles is to take the lead in continuous quality improvement, service development, and equity of access and outcome.*

*Once established, the roles will work within relevant strategic and service networks, monitor national TCT performance and outcomes, including equity accountability measures (yet to be developed) and connect with TCT providers to maintain safety, quality, and improved outcomes.*

*These new roles are additional to existing service roles and will span the functions of strategic and technical leadership from a national perspective. The scope, size and detail of these roles will be determined through the implementation planning phase, but at a minimum will be 0.5 FTE.*

1.20 All **TCT sites** will appoint **local leadership** as per FACT accreditation:

- Each site will have a designated Clinical Programme Director (0.2 FTE for combined sites and 0.1 to 0.15 FTE for autologous only sites)
- Each site will have a designated Quality Manager (FTE TBC).

# 2. SERVICE DISTRIBUTION

Transplant and Cellular Therapy providers will be distributed to ensure clinical quality, safety, and stability. This distribution is to be enhanced by well-defined pathways, support for accommodation and transport, and shared care that ensure continuity of care and equity of access.

The complexity and high acuity of TCT means that there needs to be a careful balance between the number and location of provider sites, and having sufficient scale to ensure clinical quality, safety, and sustainability. The current distribution of three allogeneic and five autologous provider sites was last reviewed in 2018 (Ministry of Health 2018). While considered appropriate at that time, the projected growth for HSCT and the potential implementation of CAR T-cell therapy, necessitates new planning for how to increase capacity to meet need.

One proposed opportunity is to build this capacity and capability by not only investing in existing provider sites but also to expand the number of autologous provider sites in the Northern and Southern regions (See Figure 4).

Creating new sites offers benefits beyond simply creating new capacity. For some areas this will mean treatment closer to home, but it is also an opportunity for existing providers to make progress with broader work to develop and enhance regional Clinical Haematology Services.

While new sites are signalled in the following attributes, it is accepted that each region will need to consider how implementing this integrates within current and planned operating models for regional Clinical Haematology Services. This is particularly relevant for the Northern Region where a future model of care for all cancer services is under development.

All investment will be subject to business case development.




Figure 4: Potential future TCT distribution

It is also acknowledged that these future arrangements, even with new sites, will not fully mitigate the impact of being away from home for most people who access TCT. As described, physically establishing services closer to home is not a viable mitigation and therefore the geographic barriers need to be alleviated through the provision of excellent whānau centred support pathways, whānau centred funded accommodation and seamless partnerships between whānau, local services and the transplant provider. This approach is detailed in Section 3. Service Delivery.

It is also noted that all sites, including those yet to be established, are experiencing facility constraints. Any proposed changes to service distribution does not mitigate these risks, and business cases for facility redevelopment and upgrades need to progress as planned.

## Attributes

2.1 TCT services will be delivered by four (4) regional providers, across a network of up to eight (8) sites. Services will be delivered in partnership with the New Zealand Blood Service.

2.2 These regional TCT services will be included within the overarching structure and leadership arrangements for non-surgical cancer treatment in each region. Population catchments for the regional providers are unchanged from existing non-surgical cancer treatment service boundaries.

2.3 Allogeneic transplant will be provided by three (3) regional services, across three (3) sites. These sites are Auckland City, Wellington Regional and Christchurch Hospitals.

2.4 The three (3) allogeneic transplant providers will operate as one specialist network, delivering an agreed national pathway. The details of this pathway are subject to implementation planning but will include national and regional structures that clearly evidence equitable access to transplant. This includes consideration of a single point of entry, a national multi-disciplinary meeting, and a national wait list.

2.5 Autologous transplant will be provided by all four regional services, across up to eight (8) sites. It is proposed that these sites are located at North Shore, Auckland City, Middlemore, Waikato, Palmerston North, Wellington Regional, Christchurch and Dunedin Hospitals.

2.6 The four providers will operate regional autologous transplant services in line with nationally agreed protocols. The details of this pathway are subject to implementation planning but will include at a minimum a regional single point of entry, multi-disciplinary meeting and wait list.

2.7 Each site will demonstrate the appropriate infrastructure, physical space, and specifications to deliver transplant and cellular therapy services (See Section 5 for facility and technology requirements).

2.8 New sites, additional to those listed, will be subject to a national approval process requiring full compliance to specified service delivery criteria.

2.9 All providers will have a comprehensive suite of strategies to support whānau who need to travel for TCT (See Section 3. Service Delivery).

The distribution by region is summarised in Table 3. Any changes to current arrangements as a consequence of the recommendations, are detailed in the Implications of the New Model section on page 6.

| TCT Providers | Role | Site/s |
|---|---|---|
| Northern TCT Service | Allogeneic Transplant Provider for Northern and Te Manawa Taki region | Auckland City Hospital |
| | Autologous Transplant Provider for the Northern region | Auckland City Hospital<br>North Shore Hospital<br>Middlemore Hospital |
| Te Manawa Taki TCT Service | Autologous Transplant Provider for Te Manawa Taki region excluding the Taranaki district | Waikato Hospital |
| Central Region TCT Service | Allogeneic Transplant Provider for the Central region, Taranaki district and Nelson Marlborough case-by-case | Wellington Regional Hospital |
| | Autologous Transplant Provider for the Central region, Taranaki district and Nelson Marlborough case-by-case | Wellington Regional Hospital<br>Palmerston North Hospital |
| | CAR T-cell provider (currently available via clinical trial) | Wellington Regional Hospital |
| Te Waipounamu TCT Service | Allogeneic Transplant Provider for Te Waipounamu region | Christchurch Hospital |
| | Autologous Transplant Provider for Te Waipounamu region | Christchurch Hospital<br>Dunedin Hospital |

Table 3: Service distribution

# 3. SERVICE DELIVERY

Transplant and Cellular Therapy providers will prioritise accessibility, acceptability, and sustainability in service design, ensuring all people and whānau experience high quality and safe care that is centred on their needs.

*"Kia Ora my name is Vonda Nepia and I'm a Leukaemia Survivor.*

*In August 2020, I was diagnosed with AML Acute Myeloid Leukaemia. I want to share with you my approach to wellness and how I became empowered to create my own holistic treatment plan in Hospital.*

*My treatment plan was mainly guided by Mason Durie's Te whare Tapa whā Holistic Wellbeing Model which commonly focuses on the Four main sides of the whare - Wairua (Spiritual wellness), Hinengaro (Mental wellness), Tinana (Physical wellness), whānau (Family & Social wellness).*

*One more important key to my recovery was the inclusion of a fifth dimension Whenua (Land and Identity wellness).*

*So why did I come to the realisation that I wanted to use this model? About a few weeks before I was diagnosed, I was working as a primary school teacher. COVID restrictions had eased, schools reopened, and students returned back to the classroom.*

*The Ministry of Education (MOE) was concerned about the effects COVID had on our students and their whānau so teaching staff were encouraged to prioritise a focus on our students' holistic wellbeing rather than get straight back into curriculum subjects. Hence MOE encouraged the use of Mason Durie's Te whāre Tapa whā Holistic Wellbeing Model. This tool was used to help students reintegrate into school.*

*So, when chemotherapy started, and life began to feel very fragile. I needed help as I was giving up the will to live. A nurse walked into my room and found me sobbing, immediately she comforted me and asked if I needed someone to talk to. Shortly she returned with a wellness checklist. As I filled this in, I noticed it too was organised into Te whare Tapa whā headings. The psychologist nurse visited me and asked how she could help me? So, I asked her to print off a Te whare Tapa whā diagram, bring me two A3 pieces of paper, cello tape, and blue tack.*

*I joined the two A3 pieces of paper with cello tape then stuck the Te whare Tapa whā diagram in the middle. I then went about labelling each of the 5 sides of the whare: with my colourful pens. I titled it "Vonda's Treatment Plan."*

*I knew I had to get honest with myself and organise all the chaos swimming around in my head. So, I used the model to organise my feelings, secrets, and worries. After a few days I had added most of my thoughts to it. I then hung my poster on the wall for all to see.*

*My treatment plan became an empowering tool. Together with hospital staff and my whānau we would discuss resources and support to address the various issues I had. I felt like I was getting back on the right track!*

*Almost 3 years on, I am still utilising this holistic wellbeing model to ensure I balance my lifestyle and stay focused on where I am heading with my new gift of life. My dream is that there is a poster in every room, in every hospital that will encourage patients, whānau and staff to engage in conversations collectively to find solutions to their wellbeing.*

*Tihei Mauri Ora!"*

The attributes in this section were developed in partnership with consumers, caregivers, whānau and those delivering care, drawing on their collective experience and wisdom as to what currently works well and what it would take for care to be more accessible and acceptable. These attributes should be considered in conjunction with Section 4. Workforce Profile and Section 5. Facility and Technology.

# Attributes

## Overall Service Delivery

3.1 All providers will uphold the Health and Disability Code of Rights including ensuing that all people and whānau are treated with respect, dignity, and independence, in a manner free from discrimination, coercion, harassment and exploitation.

3.2 All providers will operate within a model of shared care, forming partnerships with referring providers, including the primary haematology providers, other specialist services and primary care providers as relevant.

*These pathways will enable people and whānau to remain connected to home, from all dimensions of Te Whare Tapa Wha, regardless of physical location throughout the transplant journey.*

3.3 All providers will deliver TCT within nationally agreed and clinically relevant timeframes (See Section 6. Performance and Planning).

3.4 All providers will adopt an ambulatory care pathway for autologous HSCT where clinically appropriate.

*An ambulatory pathway autologous HSCT is the preferred as it supports the people and whānau undergoing transplant and the health system.*

3.5 All providers will support people and whānau to travel away from home, through access to funded travel and accommodation that avoids unnecessary financial hardship relative to individual circumstances.

*This recommendation works in conjunction with a national approach to improve access to national travel and accommodation support.*

3.6 All providers will have access to electronic clinical records and test results that are required to provide safe and high-quality care.

3.7 All providers will have access to electronic booking and scheduling systems that are required to ensure people have timely appointment bookings.

3.8 All providers will ensure scheduling systems or processes include consideration of complexities of the appointment type, the staffing model and flow of the area.

3.9 All providers will have mechanisms and relationships specifically designed to alleviate and/or eliminate the drivers of inequities. This may include but is not limited to:

- access to primary care or community healthcare services in the management of an individual's co-existing health conditions
- comprehensive adequate and upfront funding for accommodation and travel expenses
- prehabilitation and rehabilitation services
- spiritual and cultural support services
- advance care planning
- palliative care services.

3.10 All **treatment providers** will adopt and adhere to a nationally agreed Business Continuance Plan or equivalent terminology. This approach is to mitigate the impact of planned and unplanned disrupted service provision. Recovery actions, within the plan, will give precedence to Māori, Pacific and those underserved by the healthcare system. This includes prioritising these groups in each priority band when reducing or restarting services.

*To support business continuance, people may receive treatment in hospitals outside of their region of domicile. The movement of collected stem cells between regions requires providers to work closely with the New Zealand Blood Service. New Zealand Blood Service have a suite of internal policies to guide this process. Part of this strategy will be the suspension of services at a site until clinical risks are mitigated.*

3.11 All **stem cell processing providers** will adhere to a national business continuance strategy to mitigate the impact of disrupted service provision. This will include details around cell harvesting, manipulation, storage, and distribution for each facility in the event of service disruption.

3.12 All providers will have access to the equipment required along the TCT pathway to provide safe and high-quality care.

3.13 All providers will provide tailored education for people and whānau on blood test results relevant to TCT. All providers will ensure people are informed of their blood test results and how fluctuations may impact their wellbeing.

## Pre-Stem Cell Transplant

3.14 All providers will offer transplant as per nationally agreed clinical indications and informed by best practice.

*Practice is to be guided by international best practice and, where they exist, guidelines from recognised organisations and professional bodies such as the American Society for Transplantation and Cellular Therapy, the European Society for Blood and Marrow Transplantation Handbook and American Association of Blood Banks. Noting also that chronological age should not form the basis for eligibility (Ministry of Health 2018).*

3.15 All providers will adhere to nationally agreed equity led protocols in relation to evaluating pre-transplant performance status.

3.16 All providers will offer a face-to-face discussion, either in person or via telehealth services, for all people and whānau as part of the decision-making process to determine whether transplant is an appropriate option.

3.17 All providers will have mechanisms for people and whānau who are declined (by the provider) for transplant to access a second opinion.

3.18 All providers will have mechanisms to support people and whānau who personally decline transplant, to have the opportunity to review that decision and be reconsidered as / if required.

3.19 All providers will transparently embed equity led responses that reflect understanding of barriers to attending appointments and the actions needed to support whānau to engage with health services.

3.20 All providers will provide written and / or electronic confirmation, on receipt of referral, to the referring primary haematology team. This confirmation will include a summary of the next steps.

3.21 All providers will ensure equitable access to allogeneic transplant.

*Establishing the mechanisms to ensure equitable access is subject to further discussion but is a priority for implementation planning. Strategies to ensure equitable access extend beyond capacity to treat and include acceptance criteria, national quality audit of referrals not accepted / not referred and the opportunity to use multi-disciplinary meetings as a tool for standardisation.*

3.22 All providers will register all transplant referrals onto a national wait list.

*The intent of this attribute is to provide visibility and transparency over national patient flow, rather than management of access which will remain the responsibility of individual sites. A visible national wait list also supports business continuance activities (see Attribute 3.10).*

3.23 All providers will present all transplant referrals for multidisciplinary review.

3.24 All providers will have mechanisms to support the referring haematologist to present the person referred at multi-disciplinary meetings.

3.25 All providers will have pathways to ensure the person being presented at multi-disciplinary meeting is informed of the outcome of the meeting.

3.26 All providers will provide education and support for people and whānau, including those donating stem cells. TCT educational material will be available in a range of languages, formats to support different learning styles, such as information sheets, verbal discussion and videos or images.

3.27 All providers will undertake a comprehensive pre-TCT assessment of needs for all people referred for transplant, including donors as appropriate.

*The assessment of needs will support all providers to develop an individualised care plan, specifying how and to what extent the identified needs will be met (See guidance following page - Assessment of Needs).*

3.28 All providers will ensure all people undergoing TCT have access to comprehensive pre-habilitation services.

*Interventions targeted at improving physical and / or mental health should start in advance of cancer treatment (Macmillan Cancer Support 2020).*

3.29 All providers will ensure, where applicable, all people undergoing allogeneic transplant have access to specialist gynaecological review pre-treatment.

3.30 All providers will ensure all people undergoing TCT have a nutritional assessment and nutritional care plan developed pre-treatment.

3.31 All providers will ensure all people undergoing transplant will have access to specialist psychology services and psychiatry services where appropriate (or agreed alternative in response to the needs of people and whānau).

3.32 All providers will ensure all people undergoing transplant will have access to specialist social work services (or agreed alternative in response to the needs of people and whānau).

3.33 All providers will ensure all people referred for transplant have access to the wrap around support provided by Leukaemia & Blood Cancer New Zealand.

3.34 All providers will ensure all people undergoing allogeneic transplant will have access to specialist palliative care advice pre transplant. People undergoing autologous transplant may be offered access to specialist palliative care advice from referral on a case-by-case basis.

3.35 All providers will ensure all people have the opportunity to develop an Advance Care Plan, noting that this service can be provided by community as well as hospital services.

## Assessment of Needs

The purpose of assessing needs is to ensure people and whānau receive the wrap around support they require. The quality of this wrap around care is an essential component of how services are designed, delivered, and improved. All people and whānau, including cell donors, should have a formal assessment of needs prior to commencing the HSCT pathway. This assessment should then be reassessed throughout treatment recognising that needs may change. A range of professionals can carry out the assessment of needs for people and whānau throughout the TCT pathway.

Assessing needs must include assessment of the following components:

- Social situation including the social support available, living situation for the person undergoing TCT, access to transport and any travel or accommodation requirements
- Requirement for interpretation services
- Education for whānau identified to support and recognise when a person's clinical condition is deteriorating, and urgent care is required
- Taha hinengaro or mental and emotional health needs
- Taha wairua or spiritual health needs
- Complementary treatments (such as rongoā Māori) that are being accessed
- Financial situation including assessing for financial hardship and advising on eligibility for financial assistance (Gulliver 2016).

Responding to the needs of people and whānau must take a whole of system approach, recognising the role of kaupapa Māori and other non-governmental organisations play in support and advocacy.

Prioritisation of the level of support provided may be required to achieve the best outcomes within constrained resources. When this is the case, the recommended approach is that providers prioritise the needs of Māori and Pacific peoples, as well those living in socioeconomically deprived and rural communities, those living with mental illness, disabled peoples and people who are SOGIESC-diverse.

### The Individual Care Plan

An individual care plan should be developed following the assessment of needs. The individual care plan will:

- set objectives and goals of care which identify what is important to the person and include a range of options from active treatment, follow-up after treatment and surveillance to Advance Care Planning and palliative care. Objectives and goals will focus on shared decision making
- ensure the person and whānau have sufficient support to provide genuine informed consent to treatment
- identifying what services, they require and how they will be accessed
- how and when reviews of the care plan will occur.

Where needs are identified, providers will refer the person undergoing TCT and their whānau to appropriate services based on their locality.

## Provision of Stem Cells

3.36 All providers will have 24/7 access to a peripheral blood stem cell apheresis.

3.37 All providers will work with the New Zealand Blood Service apheresis service to ensure the safe service planning and timely delivery of care.

3.38 All providers undertaking stem cell collection will base stem cell collection targets, including minimum CD34+ cell yield to proceed to transplant, on international standards, such as the European Society for Blood and Marrow Transplantation Handbook, and as agreed by the New Zealand Blood Service.

3.39 All providers undertaking stem cell collection will be guided by peripheral blood CD34+ cell count. The collection process should proceed when there are ≥20 CD34+ cells/μL. When there are between 10 and 20 CD34+ cells/μL, stem cell collection should be discussed with a Transfusion Medicine Specialist. Where required, individual collection plans can be agreed.

3.40 All providers will have access to the New Zealand Bone Marrow Donor Registry to enable access to matched-unrelated stem cell donors (from New Zealand or international registries).

3.41 All stem cell processing and storage providers will ensure all stem cell product specifications meet international guidelines, such as the European Bone Marrow Transplant Society guidelines and FACT accreditation standards.

3.42 All stem cell processing facilities will have a Haematopoietic Stem Cell Stability Programme, aligned with international best practice. This programme will address initial, periodic and pre-release graft assessment methodology.

3.43 All stem cell processing facilities will implement clinically appropriate criteria for the release of a product for transplant.

3.44 All stem cell processing facilities will ensure that fresh and cryopreserved stem cells are transported in a temperature controlled and monitored environment, in accordance with FACT accreditation standards.

3.45 All stem cell processing facilities will be operated by appropriately trained staff, including scientists, technicians, and medical professionals. The facilities will be guided by standard operating procedures that detail all aspects of stem cell processing and cryopreservation performed at the facility.

3.46 All stem cell processing facilities will have a designated laboratory, appropriately equipped for the processing of stem cell products, according to the quality standards of the New Zealand Blood Service and the clinical requirements of the provider.

## During Stem Cell Transplant

3.47 All providers will implement a bed management policy where admissions for TCT are non-deferrable.

3.48 All providers will maintain a minimum number of resourced transplant beds to ensure ongoing sustainability to meet demand.

3.49 All providers will have agreed pathways for access to mobilisation and conditioning systemic anti-cancer treatment regimens and total body irradiation. This includes access to adequate compounding facilities as required for regimens with short stability times.

3.50 All providers will have pathways for the timely management of severe adverse (medical) events. This includes, but is not limited to, timely access to specialist advice, medications, and emergency medical equipment.

3.51 All providers will have mechanisms and pathways for the rapid escalation of care, increased intensity of monitoring and relevant work up to address complications that may occur during stem cell transplant. This includes, but is not limited to, timely communication pathways with clinical staff, the intensive care unit and pharmacy department.

*Medical assessment should be undertaken in alignment with the Early Warning Score timeframes. When the need to escalate care in the inpatient setting does not trigger prompt medical assessment through the Early Warning Score, anecdotal evidence suggests a timeframe of medical assessment within 20 minutes of identification of this need.*

3.52 All providers will adhere to nationally agreed criteria for re-admission and fast track pathways for people post-transplant presenting acutely.

3.53 All providers will assess people presenting acutely for neutropenic sepsis and other specific TCT related complications. These are medical emergencies and management includes afterhours medical cover and weekend review.

3.54 All providers will have mechanisms to meet the nutritional needs of people going through transplant. Nutritional options will minimise risks of foodborne illnesses and include sufficient variety to ensure people can eat well while managing side effects.

3.55 All providers will ensure that where autologous stem cell transplantation is provided as an outpatient, people and whānau can access the transplant hospital within 30 minutes.

3.56 All providers will prioritise Māori to exercise Mana Motuhake and Mana Māori, allowing whānau to undertake Ritenga Māori (customary rituals) during all facets of TCT.

3.57 All providers will have cultural practices respecting tikanga in the removal and return of stem cells (See guidance below).

### Guidance for Tikanga in TCT

The concept of Tapu and Noa are used to describe animate and inanimate conditions relating to one's body. Tapu denotes a level of cultural respect that must be adhered to, whereas Noa is free from such practices. Things that are Tapu are kept separate from things that are Noa. This tikanga guidance supports the concept of the human body being Tapu. Throughout the TCT pathway, tikanga should be guided by the preferences of person undergoing TCT and their whānau or kaumatua. This applies to those donating and receiving cells.

Consider the following for tangata whenua and whānau:

- Discuss how whānau might wish to lead the tikanga process. This may include having access to kaumatua who can lead this on their behalf
- If whānau wish staff to lead, then seek and follow advice that enables appropriate tikanga processes to be undertaken
- Ensure there is time and privacy for karakia. Karakia are incantations and prayers that are used to increase the spiritual goodwill of a gathering, to increase the likelihood of a favourable outcome. Karakia can be led by whānau or staff
- Ensure in every step of the pathway whānau are informed and consulted
- Respect if wishes change
- Prior to the disposal of any bodily fluids or parts, consultation with the person or whānau must occur to allow whānau to self-determine how this is to be done.

3.58 All providers will establish connections with Indigenous Practitioners (such as rongoā) and ensure treatment strategies incorporate Māori health frameworks where people and whānau would wish for this to occur.

3.59 All providers will offer tailored education, and ongoing support, for support person/s at referral, and throughout the transplant process.

*All people undergoing TCT require a support person/s who can partner in their care for the duration of treatment, this level of support includes:*

- *being an independent adult in good health*
- *ability to identify potential complications and act in response*
- *protecting against sources of infection*
- *knowing how and when to access medical attention.*

3.60 Where no support person is available, all providers will have mechanisms to ensure that the absence of support is not a barrier to access.

*It is expected that this will be the exception and solutions will be locally tailored but may include referral to community support services, extended inpatient stays or arrangements with residential care facilities.*

3.61 All providers will ensure all people and whānau have access to the wrap around care identified through the assessment of their needs during transplant. Wrap around care will support advanced planning for people and whānau to leave hospital and return home.

## Post Stem Cell Transplant

3.62 All people undergoing transplant will have a survivorship plan including access to services that support the reinstatement of good health and management of potential late effects with a strong focus on the impact of chronic graft versus host disease for people following allogeneic transplant. This includes but is not limited to access to physiotherapy, ophthalmology, gynaecology, occupational therapy, psychological and social support within the region of domicile.

3.63 All providers will repatriate people back to their area of domicile as soon as clinically safe, following stem cell transplant, and with appropriate planning to ensure continuity of care.

3.64 All providers will have access to district nursing services to support the people to discharge from hospital, and return home, as soon as clinically safe.

*District nursing services can bridge the step home for people and whānau. While clinically well, people may require medications, blood tests and support for central venous devices that have been inserted as part of the treatment pathway. District nursing services can facilitate this care and ensure people and whānau return to their homes as soon as clinically safe and appropriate.*

3.65 All providers will have access to and the safe administration of extracorporeal photopheresis if required for the treatment of acute and chronic graft versus host disease following allogeneic HSCT.

*While extracorporeal photopheresis is currently unavailable locally, there are business cases in development by the New Zealand Blood Service to establish extracorporeal photopheresis in New Zealand.*

*The New Zealand Blood Service has provided the following to describe extracorporeal photopheresis:*

Extracorporeal photopheresis is an apheresis-based therapy available at more than two hundred centres worldwide. During extracorporeal photopheresis, whole blood is collected via a cannula in a vein, and the white blood cells are separated from the red blood cells and plasma by centrifugation. Then, the white cells are exposed to ultraviolet A (UVA) light in a separate chamber and returned to the patient. The process reduces harmful immune responses that may lead to ill health, through mechanisms that are not fully understood. Current international guidelines recommend its use for treating children and adults with acute and chronic Graft versus Host disease that has not responded to treatment with steroids.

National guidelines for the use of extracorporeal photopheresis will be established and clear referral pathways will be developed considering the local differences between the transplant centres. Extracorporeal photopheresis for people with acute Graft versus Host disease will usually be undertaken in the hospital setting, but some people with chronic Graft versus Host disease may benefit from longer term extracorporeal photopheresis as an outpatient. New Zealand Blood Service Transfusion Medicine Specialists will work with transplant centre clinical teams to determine the appropriate treatment pathway case by case.

3.66 All providers will have mechanisms to ensure people and whānau are able to contact the provider in a timely manner following discharge.

3.67 All providers will have mechanisms to provide follow up assessments post discharge at a frequency tailored to the needs of the person and their whānau.

3.68 All allogeneic transplant providers will have a late effects management programme. People who have received allogeneic HSCT will be reviewed at least once and then as clinically indicated through this programme to address and manage late effects of allogeneic transplant.

3.69 All providers will have access to vaccination for people following TCT. This will include, but is not limited to, systems to recall people when appropriate for vaccination and education for the person and whānau on the importance of revaccination.

## Accessibility of Services

3.70 All providers will ensure the voices of Māori and those most likely to suffer harm because of known inequities, are integral within service design and ongoing service improvement. This includes but is not limited to Māori and Pacific peoples, as well those living in socioeconomically deprived communities, those living with mental illness, disabled peoples, those living in rural areas and people who are SOGIESC-diverse.

3.71 All providers will implement strategies to ensure services are mana enhancing, enabling and inclusive for the disabled community in Aotearoa.

*Te Aho o Te Kahu has commenced a programme of work, in partnership with the disabled community, to build understanding on how cancer services for disabled people in Aotearoa can improve. This work will inform TCT providers, alongside existing local understanding, in how to deliver better services for people and whānau living with blood cancer and disability.*

3.72 All providers will have processes and pathways that prioritises local connection. This includes developing and sustaining relationships with local support services supported by technology and telehealth for people and whānau to have continued access while receiving treatment away from home.

3.73 All providers will offer outreach consulting, either in person and/or via telehealth, to enable care closer to home and reduce travel burden.

*While access to telehealth for ongoing follow up is crucial to reducing the travel burden for people and whānau not all people are able to set up or have access to devices. How to meet this need will be considered in implementation planning.*

3.74 All providers will communicate effectively and respectfully through a range of media that supports various levels of literacy including multiple languages, video, audio, and social media.

3.75 All providers will ensure people are informed of appointments and bookings in a timely manner, recognising the burden on people and whānau in preparing for a treatment date. All providers will offer contemporary booking and notification systems such as text reminders.

3.76 All providers will demonstrate a person and whānau centred approach in all operational processes, such as the scheduling of appointments with consideration to an individual's circumstance, health status, access to travel.

3.77 All providers will have pathways with primary care providers ensuring these providers remain up to date with the care being provided, such as the ability to access blood test results in real time.

3.78 All providers will have communication pathways ensuring people and whānau remain up to date with the treatment pathway.

## Wider System Linkages and Relationships

3.79 All providers will form collaborative and cooperative alliances with relevant non-government organisations, partnering with these organisations in the delivery of the model of care to maximise the support available to people and whānau, and to avoid duplication of services.

3.80 All providers will have established pathways that seamlessly integrate care for people and whānau with allied health, scientific and technical services.

3.81 All providers will show leadership by providing targeted education about TCT to their wider networks, including to clinical and community teams in districts remote from treatment centres.

3.82 All providers will have relationships with local accommodation providers and non-government organisations who can tailor holistic support for people and whānau travelling away from home. This includes but is not limited to:

- local connections and wayfinding advice that eases the burden of being away from home, such as discounted access to grocery stores, transport, pharmacy, and entertainment services
- facilities that welcome children, including relationships with local schools and/or child health services to facilitate ongoing education and wellbeing
- facilities for washing and drying laundry
- accommodation options require single rooms, or double room suites, to support appropriate levels of isolation, restricted areas for eating and food preparation.

3.83 All providers require access to the 24/7 expertise of other sub-speciality services in the delivery of TCT services for the following:

- access to complex multi-system life support
- access to nuclear medicine facilities
- access to interventional radiology procedures
- access to 24-hour diagnostic radiology
- access to 24-hour comprehensive pathology services, including microbiology and virology, with the ability to provide results urgently.
- access to infectious diseases services
- access to radiation oncology service
- access to operating suite, anaesthesia, and recovery for those undergoing complex major surgical procedures
- access to clinical haematology pharmacy specialty services with sterile manufacturing facilities and cytotoxic drugs where necessary
- access to palliative care service
- CD34+ enumeration services within 60 minutes
- access to additional interventional radiology procedures for complex major surgical procedures
- 24-hour availability of irradiated blood products or equivalent.

*There is known variation in Palmerston North Hospital for CD34+ enumeration. This variation is acknowledged, and an early surrogate measure of human progenitor cell count is used to inform stem cell collection while awaiting CD34+ enumeration. While this is an acceptable surrogate measure, it is not the standard of care. Future HSCT sites will align with CD34+ enumeration timeframes to guide stem cell collection.*

3.84 Where systemic anti-cancer therapy, or radiation therapy, is required as part of the transplant pathway, all providers will meet the relevant model of care attributes, national standards and legislative requirements while incorporating the needs of the TCT service.

3.85 All providers will have pathways to support the transition of care for adolescent and young adults from paediatric providers to adult providers. Pathways will include people in need of long-term surveillance monitoring, people with treatment-related late effects who require ongoing monitoring and people who have a relapsed, secondary, or primary malignancy diagnosed in the paediatric setting.

# 4. WORKFORCE PROFILE

Transplant and Cellular Therapy providers will have an appropriately resourced, well supported, and valued workforce, with a wide range of skills and experiences, including cultural competence.

The foundation of an effective and safe TCT service is a clear understanding of the workforce functions needed to support people and whānau experiencing TCT treatment. This includes the right levels of resourcing to deliver these functions and the right mechanisms to ensure the workforce has the required knowledge, skills, ongoing training, and support. Additionally, the workforce needs to operate as an integrated and cohesive team, regardless of employer, to ensure people and whānau experience the best possible outcomes.

While the majority of the TCT workforce is employed by Te Whatu Ora or the New Zealand Blood Service, there are established partnerships and alliances (such as with, Leukaemia & Blood Cancer New Zealand and accommodation providers) which fulfil vital functions in supporting people and whānau undergoing treatment and are therefore part of the TCT workforce.

New relationships, particularly with kaupapa Māori, Pacific and other providers, are strongly encouraged as part of service delivery going forward. These partnerships are not necessarily contractual relationships but can simply reflect alliances between organisations working towards common goals.

The attributes in this section span establishing, recruiting, retaining, and developing a healthy, sustainable, and high functioning workforce. This section is divided into attributes that support the workforce, supplemented by best practice requirements for each professional group.

The attributes include recommended full time equivalent ratios for staffing groups, where able to be supported by research and align with nationally agreed methodologies and mechanisms for workforce profiles where these exist, such as the Care Capacity Demand Management (CCDM) programme. Where providers do not use nationally agreed methodologies and mechanisms it is expected that they are moving towards this.

It is also noted that providers are currently experiencing significant workforce shortages. The business cases for increased staffing, which have been prepared by providers in 2022/23, are consistent with the attributes in this section and need to progress as planned.

# All Workforce

4.1 All providers will create, and maintain, a supportive environment for all staff, including but not limited to agreed workloads, support to take leave, adequate supervision and safe communication, opportunities to learn and develop.

4.2 All providers will employ directly, or have access to, an established workforce that is appropriate in size and skill to safely meet planned capacity, including leave cover. This workforce establishment will reflect all roles / disciplines across the multidisciplinary team and include mechanisms to ensure the cover of planned absence (See following sections for recommended establishments by workforce type).

4.3 All providers will proactively recruit to new and existing vacancies to ensure continuity of service provision. Recruitment is to begin at the earliest possible opportunity, acknowledging long lead in times particularly for specialist roles.

4.4 All providers will enact an intentional workforce strategy to proactively increase their Māori and Pacific workforce at all levels of leadership and service provision, ensuring that the workforce is representative of the community served.

4.5 All providers will engage the workforce in service planning, ensuring that any change is clearly road mapped and transparent.

4.6 All providers will work in partnership with kaupapa Māori, community, and non-government providers in building the TCT workforce; taking opportunities to be forward thinking and innovative in how, and to who, work is allocated, operating as one team wrapped around people and whānau.

4.7 All providers will annually forecast and plan for workforce needs in relation to meeting ongoing demand and act on these forecasts in a timely manner.

4.8 All providers will have systems and processes to ensure the workforce has the appropriate skills, certifications, and knowledge to fulfil their roles and responsibilities on an ongoing basis.

4.9 All providers will ensure staff receive a comprehensive induction programme at the commencement of employment that covers the essential components of transplant and cellular therapies, relative to their role. Where required, induction programmes will include a supernumerary period for new staff.

4.10 All providers will be able to demonstrate clear pathways for career progression, across all disciplines, from novice through to expert practitioners.

4.11 All providers will build into the staffing establishment dedicated time for continuing professional development and ongoing staff training in alignment with service requirements and as specified in collective agreements. Ongoing training includes a combination of in-house and virtual training, attendance at local and international conferences or workshops and formal study. Providers are encouraged to collaboratively work with partners in offering training.

4.12 All providers will have processes for staff to access employee assistance and support.

4.13 All providers will support staff experiencing grief, recognising the close relationships formed between whānau and staff in TCT services. Support can be tailored to local services but should include at a minimum bereavement debriefing and the opportunity to attend funerals and tangi where able.

4.14 All providers will ensure their workforce is culturally safe and competent through mandatory cultural safety training. This will be readily available and embedded in both orientation programmes and ongoing training programmes.

*Through the 2021 Community Hui, whānau and Māori working in the wider cancer sector agreed that the number of Māori being trained and supported to take up specialist roles in cancer care needs to increase. Many whānau mentioned concerns that the cultural training seemed inadequate and were seeking a higher level of capability in terms of the cultural support they were receiving, and reassurances that this would be delivered in a way that was tika (Te Aho o Te Kahu 2023).*

4.15 All providers will proactively and innovatively look to build for the future by identifying roles and opportunities for trainees, new graduates, and other workforces' entry schemes.

4.16 All providers will fully support staff who are precepting and mentoring students and trainees, providing preceptorship training and allocated time to undertake this critical role.

4.17 All providers will support and strengthen their region through implementing regional workforce training and providing opportunities for training days, or short-term secondment, at other sites within the region for the purpose of upskilling.

# Medical Workforce

The medical workforce is led by Clinical Haematologists who specialise in the treatment of blood conditions. These Senior Medical Officer (SMO) roles have a range of duties across the spectrum of haematological conditions, as well as having varying commitments to departmental leadership, teaching, and research.

There is a paucity of benchmarking relating to HSCT providers. In 2015 the Australasian Bone Marrow Transplant Recipient Registry (ABMTRR) invited 46 HSCT providers in Australia and Aotearoa to participate in a study to describe the number of transplants performed annually per full time equivalent (FTE) SMO. The study found a median of 14.2 transplants per SMO FTE for combined autologous and allogeneic providers, 6.6 transplants per SMO FTE for autologous only providers and 10.6 transplants per SMO FTE combined (Nivison-Smith et al 2017).

A similar survey of 108 HSCT providers in the United States found that larger units were more likely to have sub-speciality teams and less additional duties, so each SMO could carry a larger caseload. Smaller units had lower numbers per SMO but much larger generalist caseloads (Majhail et al 2015). Translating the insights from this study to Aotearoa would indicate 11-12 transplants per SMO FTE per year for all providers except Auckland City Hospital, which given its size, and a fully operational subspecialisation model, could manage a ratio of 21 transplants per SMO FTE per year.

An SMO dedicates only a proportion of their time to transplant activities, with the remainder spent on other aspects of clinical haematology care. How workloads are assigned is relative to service size and types of transplants offered, but also recognises that given the high acuity of transplant care it is not recommended that this occupies all duties within a fulltime position.

The ABMTRR study assessed this division of duties and found that a fulltime SMO, at an allogeneic and autologous provider, would spend around 50% of their time dedicated to HSCT. For smaller autologous only sites this was closer to 15%. The remaining hours were used for general haematology, research, and admin not related to HSCT. See Figure 5.

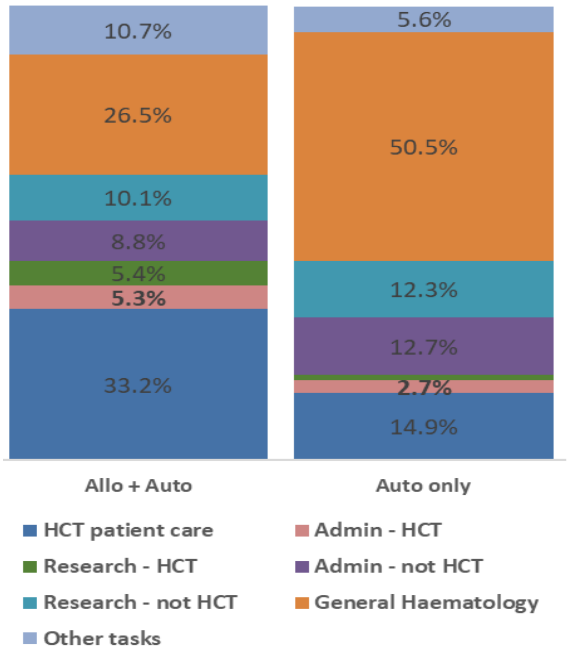



Figure 5: Work breakdown (Nivison-Smith et al 2017).

There are however several caveats in using either study in the New Zealand context. Job mix does vary across the providers with different requirements for outreach clinics (where SMO's travel) and the early repatriation of people post allogenic transplant for care by an autologous centre which is not accounted for in the international benchmarks. The small size of some services also creates anomalies in the calculations and a minimum head count per site should also be considered to ensure the provision of on-call rostering, staff well-being and ongoing professional development (Ministry of Health 2011).

The HSCT medical workforce also includes resident medical officers. Offering roles across the medical training continuum are not only essential to manage the range of duties needed in the inpatient and outpatient HSCT settings, but also ensures ongoing sustainability of the workforce. The number of resident medical officers for inpatient and outpatient settings will be relative to the service size and the requirements for 24/7 acute care. There are nationally agreed methodologies to determine roster rotations and therefore the required resident medical officers FTEs.

The numbers of medical specialist clinical haematology training positions are determined by the Royal Australasian College of Physicians and are assigned to providers across New Zealand, including those centres not offering HSCT. An HSCT Senior Registrar Fellowship position, specialising in HSCT, is currently available at Auckland City Hospital.

All HSCT providers rely on the 24/7 expertise of other medical sub-speciality services. It is acknowledged that these specialist areas will also have workforce needs. Specific modelling of these requirements is outside of the scope of this document. Nonetheless, all HSCT units must have access to the following medical specialities:

Transfusion Medicine Specialists | Intensive Care | Gastroenterology | Neurology Endocrinology | Infectious Diseases | Palliative Care | Gynaecology | Rheumatology Dermatology | Rehabilitation Medicine | Urology | Oral Medicine | Specialist Dentistry

### Medical Workforce Attributes additional to All Workforce

4.18 The national medical leadership role (see Section 1) will be a minimum of 0.5 FTE, with the appointee required to maintain TCT clinical practice, or a mixture of clinical practice and research.

4.19 All providers will appoint an on-site TCT medical specialist lead. These roles will be 0.2 FTE at combined sites and 0.1 to 0.15 FTE at autologous only sites.

4.20 All providers will employ a 24/7 clinical haematology medical team consisting of senior medical officers and resident medical officers.

4.21 All providers will, at a minimum, have an establishment of senior medical officer within the recommended range.

*Further work is needed to agree a national benchmark for senior medical officer FTE. (See narrative above).*

4.22 All providers will have access to a suitably skilled senior medical officer and resident medical officer workforce that enables the provision of prompt after-hours medical evaluation and treatment.

4.23 All providers will actively support the medical training pipeline by offering rotations for resident medical officers through clinical haematology, across inpatient, day-stay and outpatient rotations.

4.24 Allogeneic transplant providers will offer TCT Fellowships for Senior Registrars to train in HSCT medicine.

# Nursing Workforce

The intent of the following attributes is to acknowledge the importance of a fit-for-purpose nursing workforce. A sustainable and flexible critical mass of nurses, fully working their scope of practice, is essential to improving outcomes. This approach aligns with, and builds on, the nursing initiatives underway by Te Whatu Ora Workforce Taskforce including The Nursing Pipeline Programme, the Real Nurses Campaign, and the 2023/24 Health Workforce Plan.

Nursing has an essential role in the TCT continuum from pre-transplant through to ongoing follow up (European Society for Blood and Marrow Transplantation 2019). The TCT nursing workforce includes a range of roles across inpatient and ambulatory clinical areas, as well as specialist apheresis nurses at the New Zealand Blood Service.

While there is limited research related to the optimal nursing establishments for TCT providers, it is accepted that there shall be adequate nursing levels to manage the severity and acuity of the clinical status across all TCT settings.

In 2011, the Ministry of Health Bone Marrow Transplant Services in New Zealand for Adults – Service Improvement Plan made recommendations for nursing ratios. For senior nursing, the recommendation was 1.0 FTE clinical nurse specialist (or equivalent role) for every 30 new transplants per year (Ministry of Health 2011). While international evidence in this area remains sparse, sector engagement through this process reaffirmed that the ratio remains appropriate.

The 2011 Plan also recommended 1.0 FTE nurse per 2-3 inpatients per shift. While this recommendation was based on best practice at the time, the acuity and severity of the needs of people receiving inpatient TCT can vary considerably and change dramatically over the course of even a single shift, which introduces complexity in assessing optimal nursing ratios. This is not unique to TCT and to ensure that inpatient units were staffed safely for expected and actual clinical need, the CCDM programme was developed (Safe Staffing and Care Capacity Demand Management: Effective Implementation Accord 2018). Using CCDM data sets, staffing methodologies and variance response management practices is now the recognised mechanism to ensuring safe staffing levels. This includes supporting inpatient units to have the capacity to meet the needs of people and whānau in real time, while also providing data to annually review and plan staffing levels for the future.

While the 1 nurse to 2-3 inpatients from the 2011 Plan is a useful baseline, HSCT inpatient units must be able to be move to 1:1 (or even 2:1) care if acuity and severity require. Therefore, it is important to evolve this standard ratio, within the context of the CCDM programme. This includes evolving CCDM methodology and consideration of the workforce skill mix to ensure calculations and variance response strategies more accurately reflect and respond to the realities of caring for people and whānau undergoing HSCT.

## Nursing Workforce Attributes additional to All Workforce

4.25 In areas where available, all providers will fully implement Care Capacity and Demand Management (CCDM) for nursing. This includes undertaking staffing methodology calculations, or FTE calculations, recruitment to FTE requirements and implementation of variance response management protocols (Safe Staffing Healthy Workplaces Aotearoa 2023).

*CCDM is fully implemented within many inpatient areas in hospitals in Aotearoa. In 2021, implementation for inpatient areas varied from 42% through to 100% across the regions (Safe Staffing Healthy Workplaces Aotearoa 2023). More recently, the CCDM programme has begun adaptation for, and implementation in, ambulatory nursing areas.*

4.26 In areas where CCDM FTE calculations have not been agreed and implemented, providers will inform safe staffing levels through agreement of the staffing needed to provide safe and effective clinical care with consideration of the staffing skill mix and relevant benchmarks.

4.27 All providers with CCDM implemented will ensure the workforce has regular training on accurate CCDM predicting and reporting. Services will work with the hospital CCDM Coordinator (or equivalent role) to ensure CCDM accurately reflects the complexity of transplant inpatients.

4.28 All inpatient areas will have a designated nurse in charge of each shift. Staffing methodology calculations and real time calculations should include the non-clinical time that this role requires.

4.29 All providers will support nursing entry into the TCT workforce through proactively providing student nursing clinical placements in all inpatient areas. Where appropriate, providers will support student nursing clinical placements across outpatient transplant and cellular therapy areas and wider clinical haematology areas.

4.30 All providers will have designated senior nursing roles to support the transplant pathway, clinical teams and manage coordination of transplant programmes.

4.31 All providers will have a minimum of 1.0 FTE nurse practitioner. The nurse practitioner will work within the clinical haematology team to provide care for people accessing TCT. Providers will support nurse practitioner candidates undertaking the training and registration requirements to develop this role.

4.32 All providers will have a nurse educator/s to support the training and development of the TCT nursing workforce. Within regional services, the nurse educator role/s may be developed into a regional position/s to provide consistent TCT training and development across the region.

4.33 All providers will have TCT senior specialist nursing roles, such as clinical nurse specialists, to provide nursing care and expertise in the direct delivery of care to people and whānau on the transplant pathway. Senior specialist nursing roles will be at a minimum of 1.0 FTE per a maximum of 30 new transplants per annum (Ministry of Health 2011). This ratio is subject to ongoing review and change. Additional FTE may be required to support the early repatriation of people who have had HSCT under shared care arrangements, to support the work up of people who are do not progress to transplant and in regions where people face significant barriers to accessing care – such as travel burdens.

4.34 All apheresis service providers will ensure they have sufficient, suitably qualified, and trained staff to perform stem cell collection, including contingency plans in the event of service disruption.

4.35 All providers will identify positions for new graduate registered nurses and proactively recruit to these positions. All providers will have new graduate positions that provide exposure to inpatient and outpatient Clinical Haematology areas.

4.36 All providers will support the nursing workforce to attend preceptorship training to facilitate precepting student nurses and nurses entering TCT.

4.37 All providers will ensure areas have a suitable skill mix to provide safe TCT. The skill mix of the nursing workforce should be considered when developing rosters for TCT areas.

# Allied Health Workforce

The risks to wellbeing for people having TCT are significant, which means that an integrated system of support is essential to ensure optimal outcomes and quality of life. These support functions include:

- Pre-habilitation and preparatory functions that ensure people can maintain health status, manage wellbeing and plan for the impact of the pathway ahead
- Access to optimal nutritional advice and intervention through all stages of the pathway
- Access to specialist and non-specialist supportive care to assess needs and set goals for social, cultural, spiritual, and emotional wellbeing
- Access to pharmacist-led care to support people and whānau to manage medication, review and assess health status and provide ongoing education
- Access to specialist pharmacist guidance and intervention to ensure high quality and safe dispensing, administration, and management of medications
- Access to comprehensive post treatment follow up and rehabilitation programmes. Potential interventions include supervised exercise programmes
- Psychological support, support with medication, fatigue management, sexual education and support, body images, back to work support and quality of life improvement.

Allied health professionals are well placed to meet these needs. In Aotearoa, this spans over 43 different professions such as social workers, psychologists, physiologists, dietitians, laboratory technicians and scientists. Specifically, to this model, TCT providers rely on access to high quality and safe blood services which are delivered by Allied Health professionals. The requirement for these workforces is discussed in Appendix 1: The role and function of the New Zealand Blood Service.

Each profession has a degree or post graduate level qualification, is regulated via legislation or professional body, and has its own distinct specialised body of knowledge and skills (Ministry of Health 2021b).

Allied Health specialists, especially when working as an integrated team, are highly impactful in improving outcomes and experience for people and whānau. He Mahere Ratonga Mate Pukupuku recognised this impact and made a strong recommendation for the allied health workforce for people with cancer to be strengthened (Te Aho o Te Kahu 2022). The following attributes draw on this finding, as well as best practice and professional body guidance to outline the roles and functions of the allied health professions involved in the delivery of TCT.

The CCDM programme is also evolving for Allied Health workforces and, like nursing, will be the accepted methodology to ensure services have the capacity to meet the needs of the people and whānau. TCT leadership will work with the CCDM programme to provide the level of understanding needed to ensure the methodology is fit for purpose in the TCT pathway.

## Allied Health Workforce Attributes additional to All Workforce

4.38 All providers will have access to dedicated allied health roles, with appropriate training and education to assist in the provision of pre-transplant, recipient evaluation, treatment, and post-transplant follow-up and care.

4.39 All providers will have a designated expert allied health professional to provide expert care, local coordination of the allied health workforce and develop allied health TCT processes and pathways.

4.40 All providers will employ a minimum of 1.0 FTE pharmacist, with advanced specialty level training, for every 15 inpatient haematology and stem cell transplant beds (New Zealand Hospital Pharmacists' Association 2019). This is in addition to pharmacist resourcing required for non-clinical tasks, such as drug protocol management and medication dispensing.

4.41 All providers will employ a minimum of 1.0 FTE pharmacist, with advanced specialty level training, for every 22 same day admission clinical haematology and stem cell transplant treatment spaces (New Zealand Hospital Pharmacists' Association 2019). This is in addition to pharmacist resourcing required for non-clinical tasks, such as drug protocol management and medication dispensing.

4.42 All providers will support the pharmacist training pipeline through proactively providing student pharmacist clinical placements in all TCT areas and alongside pharmacists with advanced specialty level training in haematology and TCT.

4.43 All providers will employ pharmacy technicians and pharmacy assistants as part of the pharmacy workforce.

*In areas where pharmacy technicians and pharmacy assistants are part of the pharmacy workforce, pharmacists have increased time to deliver clinical services (New Zealand Hospital Pharmacists' Association 2019).*

4.44 All providers will have access to psychologists. The FTE shall be adequate for the size and complexity of the provider. CCDM calculations are available in some regions to guide FTE establishments.

4.45 All providers will have access to social workers. The FTE shall be adequate for the size and complexity of the provider and shall include a minimum of one role specialising in transplant. CCDM calculations are available in some regions to inform FTE requirements.

4.46 All providers will have access to physiotherapist support. The FTE shall be adequate for the size and complexity of the provider and shall include a minimum of one role. CCDM calculations are available in some regions to inform FTE requirements.

4.47 All providers will support entry into the TCT workforce for allied health through proactively providing student clinical placements in all inpatient areas, outpatient areas and wider clinical haematology areas where appropriate.

4.48 All providers will have access to occupational therapists. The FTE shall be adequate for the size and complexity of the provider and shall include a minimum of one designated role. CCDM calculations are available in some regions to inform FTE requirements.

4.49 All cancer treatment providers will have access to 1.0 FTE dietitian per 120 people with cancer, noting this calculation is for all people with cancer with varying acuity (New Zealand Institute of Economic Research 2021). TCT specialised dieticians will require much smaller caseloads. CCDM calculations are available in some regions to inform FTE requirements.

4.50 All providers will have access to staff for stem cell and bone marrow collection: The number of trained collection personnel shall be adequate for the number of procedures performed and shall include a minimum of two designated trained individuals with an identified trained backup individual to maintain sufficient coverage. (See Appendix 1: The role and function of the New Zealand Blood Service).

# Quality and Safety Workforce

Quality management is an essential component of TCT. The quality and safety workforce utilise quality management tools to ensure that people, whānau and the TCT workforce, whom all form part of a quality programme, interacts in the most effective way to provide the most effective care.

The quality and safety workforce use robust project management processes to drive a culture of innovation, transformation, and continuous quality improvement. They ensure that key performance indicators are developed and then gathered and reported on.

To achieve FACT accreditation, providers must self-assess against, and align with, over 500 standards. These standards are comprehensive and developed for an international audience. The quality manager role is a senior technical advisory role that bridges the gap between the FACT accreditation standards and the local context in which they are applied. Within the FACT accreditation, it is the role of the quality manager to establish and maintain systems to review, modify and approve policies and standard operating procedures. The quality manager must analyse requirements of FACT standards and translate these into standard procedures and processes to meet those standards.

The quality and safety workforce builds crucial relationships as part of their role to support the alignment with international standards and local quality improvement.

The quality and safety workforce create the quality framework to ensure that the quality standards are ethnicity driven and bridge and embed the directives from Te Whatu Ora and Te Aka Whai Ora into the international driven quality framework. At an international level, they advocate and promote the relationship between Te Ao Māori, Te Tiriti o Waitangi and the application of international quality standards within Aotearoa.

## Quality and Safety Workforce Attributes additional to All Workforce

4.51 All providers will employ a quality manager to establish and maintain the quality model and to monitor compliance across the service. The site quality manager will form part of the national leadership team (See Section 1. Leadership and Governance).

*The quality manager will utilise quality management tools to ensure that people, whānau and the TCT Workforce, whom all form part of the quality programme, interacts to provide the best journey possible for people and whānau. They will provide guidance and leadership in the implementation of appropriate quality and safety systems to achieve the best outcomes in clinical quality and service improvement. The quality manager will be required to critically drive quality assurance and compliance standards related to TCT across the region and local area. The quality manager is the subject matter expert in the requirements to achieve and maintain compliance to FACT accreditation and is critical for the health sector in the delivery of FACT accreditation.*

4.52 All providers will ensure the FTE of the quality team is appropriate for the size and complexity of the provider.

4.53 All providers will have effective communication and liaison between TCT workforce, New Zealand Blood Service, participating laboratories, and ancillary supplemental staff through the quality manager.

4.54 The quality manager will lead and provide guidance in clinical risk management processes including incident investigation, complaint review and risk identification and mitigation and legal compliance for all providers.

4.55 All providers will seek leadership and advice from the quality and safety workforce on the solutions to capture, understand and produce options to improve programme tracking and monitoring, and project start-ups as part of the wider TCT programme.

4.56 All providers will ensure the quality manager has the delegated authority to work across hospital services to support FACT accreditation.

4.57 All providers will consider a quality officer role (or equivalent) to support the quality manager at an FTE adequate for the size and complexity of the provider (Aliurf et al 2021).

## Data Management Workforce

Within healthcare there are numerous types of data. In TCT the data management workforce is primarily focused on TCT research registry data. The purpose of the international registries is to collect and analyse data for research and development of new and improved transplant procedures to improve TCT outcomes. Research registries support the international and local research community to undertake observational research in TCT. Through research, advancements or refinements in the delivery of TCT can be developed. The data management workforce ensures accurate TCT data is submitted to research registries in accordance with the registry requirements. The TCT registries have specific requirements, data forms and auditing processes that the data management workforce must inherently understand and adapt to.

### Data Management Workforce Attributes additional to All Workforce

4.58 All providers will employ dedicated data manager/s (or equivalent), sufficient to collect and maintain complete and accurate data necessary to attain / maintain accreditation status, and to manage production planning.

4.59 All providers will employ dedicated research registry coordinator/s (or equivalent) with TCT subject matter expertise, to contribute to international TCT research registries. Within regional services across multiple sites, this may be further developed into a regional position.

# Other Workforce Attributes

4.60 All providers involved in TCT delivery will include relevant priorities and opportunities outlined in the Kaiāwhina Workforce Plan 2020-2025 to develop, connect, and accelerate new ways of working for kaiāwhina.

4.61 All providers involved in TCT delivery will include relevant priorities and opportunities outlined in the He Anga Whakaahuru, the Supportive Care Framework, to develop connect and accelerate new ways of working for kaiāwhina (Central Cancer Network 2016).

4.62 All providers will employ a dedicated and sufficient kaiāwhina carer workforce to support the delivery of inpatient and outpatient services, such as health care assistants, care assistants or support workers. In areas with CCDM fully implemented, kaiāwhina carer roles will be recruited to meet CCDM FTE calculations.

4.63 All providers will have access to kaitiaki, and equivalent cultural support workers, to support the cultural needs of people and whānau undergoing transplant.

4.64 All providers will have access to spiritual care staff, to support the spiritual and/or religious needs of people and whānau undergoing transplant.

4.65 All providers will have a dedicated and sufficient housekeeping workforce to ensure the environment is free from infection risk, safe for people, whānau and staff. Housekeeping staff play a critical role in supporting efficiency, restocking and equipment servicing, and releasing time for clinical care.

4.66 All providers will have processes and staff time to educate and connect support people caring directly for whānau throughout the transplant process (See Section 3. Service Delivery).

4.67 All providers will have dedicated operational management, where appropriate across all clinical haematology, with sufficient capacity to focus on the needs of the service (See Section 1. Leadership and Governance).

4.68 All providers will have dedicated administrative staff to support patient flow through all aspects of the pathway and the timely scheduling of appointments.

4.69 All providers will have dedicated administrative staff to support clinical staff and operational leadership in their duties.


IN CONFIDENCE, NOT GOVERNMENT POLICY

# 5. FACILITY

Transplant and Cellular Therapy providers will have physical spaces, and access to ancillary services, that facilitates the delivery of acceptable, whānau centred and high-quality care.

He Mahere Ratonga Mate Pukupuku, Cancer Services Planning Report found that most treatment facilities are insufficient to support the delivery of cancer services (Te Aho o Te Kahu 2022). The following attributes are therefore designed to ensure people and whānau can access safe care in supportive physical environments, including that there is sufficient physical capacity to meet demand. The attributes also require that physical spaces promote staff wellbeing.

Appropriate facility design for TCT providers is multifactorial and should consider:

- The relationship between facility design and managing infectious complications from transplant. Infectious complications from transplant can be life-threatening and while some prophylactic medications are available, limiting exposure through protective isolation is essential to decrease risk following transplant (European Society for Blood & Marrow Transplantation 2019)
- Ngā Parewa, the Health and Disability Service Standards which requires that all facility design be culturally appropriate and designed in partnership with those who have lived experience of using the system (Ministry of Health 2021a)
- The FACT accreditation standards and guidance for minimum facility requirements. Alignment with these standards, either through formal FACT accreditation or self-assessment of facilities against the standards, has been shown to support the optimisation of resources and safe care (European Society for Blood and Marrow Transplantation 2019).

Alongside a review of SMO FTE, the 2015 ABMTRR study also invited providers in Australia and Aotearoa to describe the number of transplants performed annually per inpatient bed. 35% of sites had dedicated TCT beds, while the remainder relied on access to the broader pool of beds in the facility. The study looked at the number of transplants performed annually across the sites compared with the number of beds and this translated to 7.9 autologous / allogeneic transplants per inpatient bed and 10.2 autologous transplants per inpatient bed at autologous only sites (Nivison-Smith et al 2017). Outpatient autologous HSCT was not part of this study but would reduce required bed establishments for those hospitals offering this treatment option. The following table is provided as a guide if compared to the 2022 transplant volumes:

| Current sites | Auckland | Hamilton | Palm Nth | Wellington | Christchurch |
|---|---|---|---|---|---|
| 2022 volumes | 136 | 49 | 30 | 56 | 83 |
| Transplants per inpatient bed | 7.9 | 10.2 | 10.2 | 7.9 | 7.9 |
| Required inpatient beds | 17.2 | 4.8 | 2.9 | 7.1 | 10.5 |

Table 4: Extrapolation per region of number of transplant beds (Nivison-Smith 2017)

It is also noted that many TCT providers in Aotearoa have facility planning / business case development underway. These plans have been shared and are consistent with the attributes described in this section.

# Attributes

5.1 All providers will meet the facility and infrastructure standards detailed in the current FACT-JACIE International Standards.

5.2 All providers will use the Australasian Health Facility Guidelines and Supplementary Aotearoa New Zealand Design Guidance, as the primary reference guide for briefing and designing health facility projects. Defining the needs of clinical haematology services in alignment with Guidelines is the subject of Implementation Planning.

*Alignment with the guidelines is intended to encourage standardisation and provide consistency of design and project reporting across health projects without restricting innovation (Te Whatu Ora 2022b).*

5.3 All providers will plan, ensuring durability over time while providing initial flexibility of designed spaces, and adaptability.

5.4 All providers will incorporate a cultural narrative process in any planned refurbishment or new build of facilities, this process recognises the historical relationship between the services' location and the mana whenua, describing the unique characteristics of the place and its people and building mutual understanding of heritage, tradition, and spiritual connections.

5.5 All providers will consult with mana whenua in all planned refurbishments or new build of facilities.

5.6 All providers will have mechanisms that ensure the voices of whānau are integral within facility design and ongoing facility improvement.

5.7 All providers will have mechanisms that ensure the voices of the workforce are integral within facility design and ongoing facility improvement.

5.8 All providers will have décor that reflects the community using these facilities to ensure that services feel safe and welcoming.

*Through the 2021 Community Hui, whānau and Māori shared examples of how they feel unwelcome and disrespected when accessing health services (Te Aho o Te Kahu 2023). Through fostering a welcoming environment, providers can build trust and support people and whānau to feel safe. The use of local pūrakau, or narratives, in facility décor can help with this. In Tauranga Hospital, the story of Mount Maunganui is displayed on the walls to improve the comfort and hospitality of the facilities.*

5.9 All providers will have access to local accommodation to support ambulatory treatment pathways for people and whānau travelling away from home. Local accommodation will include single rooms, or double room suites, to support appropriate levels of isolation, restricted areas for eating and food preparation. (See Section 3. Service Delivery).

5.10 All providers will ensure sites are physically accessible for all people and particularly considering the needs of tāngata whaikaha. This includes, but is not limited to, dedicated free parking.

5.11 All providers will offer all staff healthy, well-maintained, and practical work areas and facilities, which are within reasonable proximity and span not only clinical work areas but adequate spaces for non-clinical administration work and breaks.

## Inpatient Units

5.12 All providers will have a designated inpatient unit, with prioritised access to a sufficient and dedicated number of beds matching anticipated TCT demand. The unit may be within a larger inpatient setting if TCT inpatient rooms and associated facilities are co-located and designed to minimise airborne microbial contamination.

5.13 All providers will have access to sufficient single and hepa-filtered inpatient rooms to meet anticipated demand. Noting that anticipated demand includes the need to accommodate outpatients who potentially require acute admission.

*Actual bed numbers per site will be subject to implementation planning*.

5.14 All providers will ensure inpatient units facilitate whānau to stay overnight and to come together as a whānau when supporting care.

5.15 All providers will have private spaces that can be used for consultation, medical reviews and discussions separate to inpatient bedspaces if preferred by those accessing TCT services and whānau.

5.16 All providers will have an establishment of inpatient beds sufficient to provide inpatient care, as required, during the TCT pathway.

## Outpatient Facilities

5.16. All providers will have designated day stay treatment and procedural facilities that:

- have sufficient treatment spaces for the catchment of the population, as per population to treatment space ratio's to be determined
- are architecturally planned to ensure healthcare providers have good visual access and the ability to monitor people during treatment while also promoting privacy for people where possible
- allow for isolation; at a minimum of one single room should be available for every four treatment spaces
- provide separate (dedicated) areas for apheresis, stem cell returns and the storage of equipment this requires
- have access to resuscitation equipment and medical gases

- have waiting, consultation and treatment rooms that are of sufficient size to enable whānau involvement in care
- are suitably sized to permit screen curtains being closed as required
- have call alarms and emergency call facilities available in all areas where people may be receiving treatment, this includes bathroom facilities
- have appropriate storage solutions to ensure the treatment area promotes safe mobility for people, whānau and staff.

5.17. All providers will have designated outpatient consulting areas that:

- provide for private consultation and physical examination of people, with adequate space for a support person or whānau to be present
- provide acoustic privacy, ensuring conversations cannot be heard outside of the room, to support confidentiality
- include spaces that are of sufficient size to enable whānau involvement
- are consistent at all providers including at outreach clinic sites
- are enabled for telehealth
- have access to resuscitation equipment.

5.18. All providers undertaking stem cell harvesting will have designated areas for apheresis. This area will be in an appropriate location with adequate space and design to minimise the risk of contamination or infection. This area must have ready access to resuscitation equipment and medical gases. The area must fulfil the quality requirements for the use and storage of apheresis equipment and consumables, to meet the requirements of the New Zealand Blood Service.

# 6. PERFORMANCE AND PLANNING

Transplant and Cellular Therapy providers will have effective monitoring and planning processes that ensure timely, coordinated, and equitable care.

Monitoring performance, and using this information to learn and improve, is fundamental to sustainable service provision. This level of ongoing attention to performance and analysis of outcomes occurs at the micro and macro levels.

The Health and Disability System Review found that the system needed far greater tools to not only be well informed, but to have the capability to interpret this information, respond decisively to emerging trends and threats, and understand where to direct future action (Health and Disability System Review 2020).

Similarly, He Mahere Ratonga Mate Pukupuku found that across cancer services the current mechanisms were insufficient to support the delivery of services, including inadequate information systems for collecting data, sharing data and telecommunications (Te Aho o Te Kahu 2022).

Access to real time and robust data is also critical in being able to take action to mitigate inequities. The Planned Care Reset and Restore report stated that it is imperative that all services perform prospective data analysis to allow identification of health inequities and to track progress on addressing health inequities in each service, district, and region (Te Aka Whai Ora & Te Whatu Ora 2022a).

For TCT providers inadequate forward planning has resulted in nationwide capacity constraints and increasing wait times. This lack of planning has been hindered, in part, through inadequate access to information infrastructure to drive innovation and improvement. Going forward providers must be enabled by systems that allow effective minimum data set collection and the tools to meet mandatory requirements for day-to-day operation, accreditation, and future planning.

As part of this approach, it is also important to note that the use of whānau data in the design, development and delivery of health care services is a privilege. Information is a taonga and TCT providers are obligated to apply appropriate safeguards to protect this data from misuse. Recognising the rights and interests of Māori in the collection, ownership, and application of data. Guidance is provided in Appendix 2. Te Aho o Te Kahu Position Statement on Collection of Cancer Data.

The attributes in this section step through the performance measures and mechanisms that are needed for continuous improvement. The attributes span operational measures, such as timely access to services through to population-based indicators such as clinical outcomes and intervention rates.

Additionally, Te Aho o Te Kahu will continue to develop, implement, and monitor a Cancer Information Plan to ensure quality system-level data and information is available for sound decision making.

# Attributes

## All Performance and Planning

6.1 All providers will have access to integrated information technology solutions that support everyday operations, inclusive of activities of continuous quality improvement, and enables mandatory reporting and regulatory functions to be met. These solutions will meet relevant requirements relating to HISO/FIHR/SNOMED data standards.

6.2 All providers will have access to designated personnel to collect and maintain accurate and timely clinical and associated service data. These personnel may work across multiple sites.

6.3 All providers will adhere to the requirements of appropriate legislation and relevant professional and sector standards with regards to the management of clinical records and health information privacy.

6.4 All providers will align with data capturing and reporting mechanisms that meet Māori data sovereignty requirements and support Māori needs and aspirations.

6.5 All providers will ensure the appropriate informed consent is obtained for the collection, use and storage of data.

6.6 All providers will ensure their health information systems capture, and continuously improve, ethnicity data.

6.7 All providers will have service continuance processes, including pre-emptive training and testing, should critical systems fail.

6.8 All providers will establish monitoring mechanisms (red flags) that ensure they are well informed in real time about existing or potential inequities for individual people, and the service.

6.9 All providers will have the capability to interpret these inequities, respond decisively and implement solutions in a timely manner.

6.10 All providers will maintain records on the next steps for people that were referred but who did not meet the threshold criteria, to enable equity analysis to be undertaken.

## Monitoring Access to Services

6.11 All providers will have access to scheduling capability that encompass all required datapoints of the transplant pathway, is able to manage (and retain history) of changes in any one pathway and include production planning capability so wait times can be proactively identified and monitored.

6.12 All providers will have nationally consistent processes to routinely examine patient flow and assess, address and report on excessive wait times for Māori, Pacific and other groups disadvantaged by the healthcare system.

6.13 All providers will establish mechanisms to manage and report against patient flow metrics for TCT services that are delivered at each site, and as a consolidated national dataset.

6.14 All providers will ensure people receive their transplant within agreed timeframes based on disease type, risk of progression or relapse and donor availability (as relevant).

| Description | Timeframe |
|---|---|
| Commencement of conditioning therapy prior to an autologous transplant | Within 4-6 weeks of stem cell collection or being 'ready to transplant' |
| Commencement of conditioning therapy prior to an allogeneic transplant | Within 4 weeks of being 'ready to transplant' |

Table 5: Required timeframes.

6.15 All providers will ensure people requiring their first autologous HSCT for Myeloma will receive this within six months from the date of the first treatment administered for their disease (as well as adhering to the wait times in Table 5 above).

6.16 All allogeneic transplant providers will contribute to, and participate in, a national wait list to provide clarity around unit demand / capacity.

6.17 All autologous transplant providers will contribute to, and participate in, a regional wait list to provide clarity around unit demand / capacity.

6.18 All providers will adhere to a national service continuance strategy which proactively and promptly acts on adverse performance, or unexpected threats that constrain access to treatment.

6.19 In addition, all providers will review the extent to which any interruption or constraint of expected service delivery has disproportionately affected Māori, Pacific or those underserved by the health care system and act promptly to remedy these inequities.

## Planning for the Future

6.20 All providers will use demand and capacity modelling to inform future growth and guide business cases for expansion of services.

6.21 All providers will include the New Zealand Blood Service in planning activity to support the seamless development of future service expansion.

6.22 All providers will work collaboratively with the New Zealand Bone Marrow Donor Registry, in relevant cases, to ensure appropriate service planning.

6.23 All providers will monitor and report on intervention rates against nationally agreed intervention rates for HSCT per million people.

6.24 All providers will model projected demand against these intervention rates and population served, rather than historic volumes.

6.25 All providers will be able to access information on workforce turnover, vacancy rate and length of vacancies to assist service planning.

6.26 As a function of National Strategic Leadership all providers will participate in an annual review of service performance and needs. This analysis will inform an annual plan.

6.27 All providers will be able to contribute to and feedback on updates to the Model of Care document as reviewed by the TCT Technical Leadership Group.

*'The Model of Care for Transplant & Cellular Therapies in Aotearoa, New Zealand' is a living document with ownership sitting with the providers. The TCT Technical Leadership Group will maintain this document to ensure it continues to reflect optimal TCT services within Aotearoa. The frequency of updates and pathway for providers to contribute feedback will be determined by the TCT Leadership Group once established.*

# 7. QUALITY AND SAFETY

Transplant and Cellular Therapy providers will demonstrate a commitment to quality management recognising that a culture of safety and quality is paramount in the delivery of care and the detection and mitigation of risk.

A culture of safety and quality is paramount in the delivery of TCT (Aljurf et al 2021). Within TCT, people, whānau and the workforce are the quality program. Quality management processes monitor the interaction of these - with safety, wellbeing, equity, and experience of people, whānau and the workforce at the heart of this.

The provision of TCT involves collaboration between multiple providers, from donor registries through to clinical services. These multiple moving parts mean that ensuring treatment services remain of high quality can be challenging. The safety and quality attributes in this section have been developed to support providers to operate within this complex treatment pathway.

The Foundation for the Accreditation of Cellular Therapy (FACT) and its European partner organisation the Joint Accreditation Committee ISCT-Europe & EBMT JACIE, set international standards for safety and quality for TCT providers. Through undertaking this accreditation process, or assessing against the FACT standards, providers provide optimum care in line with auditable standards (Aljuf et al 2021). Research has found that FACT accredited TCT sites have increased safety for both people undergoing TCT and those donating stem cells (Keynon and Babic 2018). FACT accreditation also provides greater access to international stem cell donor registries and therefore increases the likelihood of finding suitable unrelated matched donors for people requiring allogeneic HSCT.

FACT accreditation is a three yearly cycle of on-site inspections combined with annual reporting of outcomes. This ensures services are regularly audited against the minimum requirements and are continually meeting these standards. While only mandatory of providers of allogeneic transplant within this Model of Care, the requirements form the basis of all TCT services provision in Aotearoa and ensure New Zealanders have optimal access to unrelated donors for TCT.

Alongside clinically safe services, cultural safety is an essential attribute of optimal TCT services in Aotearoa. Cultural safety focuses on the experience of the person receiving treatment to define and improve the quality of care provided (Medical Council of New Zealand 2019).

# Attributes

7.1 All providers will align with nationally agreed written protocols and standard operating procedures that describe the treatment pathway from informed consent and donor selection, through to administration of haematopoietic stem cells and other cellular therapies and includes workforce health and safety, and data management.

7.2 All apheresis providers will have documented protocols and policies that guide all aspects of the apheresis procedure, in accordance with FACT accreditation standards and Medsafe regulations.

7.3 All providers will refer to Te Ao Māori Framework | Health Quality & Safety Commission to improve the quality of care afforded to Māori.

7.4 All providers will contribute to the Australasian Transplant and Cellular Therapies Recipient Registry, based in Sydney Australia.

7.5 All providers will have access to clinical informatics capability that enables the submission of data to registries and facilitates quality improvement.

7.6 All allogeneic providers will collect and maintain data necessary to fulfil FACT accreditation requirements. This includes reporting all allogeneic transplant activity to the Centre for International Blood & Bone Marrow Transplant Research.

7.7 All allogeneic HSCT providers will be FACT accredited.

7.8 All autologous HSCT providers will assess local practice against FACT accreditation standards. Formal accreditation status is not required.

7.9 All allogeneic providers will undertake Centre for International Blood & Bone Marrow Transplant Research audits to support FACT accreditation.

7.10 All stem cell processing providers will work collaboratively with TCT providers to maintain services in accordance with FACT accreditation standards, as appropriate, across the TCT pathway.

7.11 All stem cell processing providers will maintain Medsafe licenses as required for the agreed TCT processes and products.

7.12 The New Zealand Bone Marrow Donor Registry will ensure that the processing of incoming requests, facilitation of outgoing requests and the coordination of the donation, collection and transportation of stem cells meets the standards of the World Marrow Donor Association.

7.13 All providers will manage risk to people and whānau accessing TCT services, staff, and the public in accordance with the relevant health and safety legislation, WorkSafe Mahi Haumaru Aotearoa guidance and Te Whatu Ora processes.

7.14 All providers will have a Quality Manager responsible for establishing and maintaining systems to review, modify and approve policies and standard operating procedures (See Section 4. Workforce Profile).

7.15 All providers will retain records related to quality control, personnel training and competency, facility maintenance, facility management, complaints, or other general facility issues for a minimum period of ten years, or longer in accordance with applicable law.

7.16 All staff who administer and manage systemic anti-cancer therapies and/or stem cell transplantation will hold current certification of competency by completing an evidence-based training programme.

7.17 All providers will have mechanisms for regular reassessment of staff competency.

7.18 All providers will implement and maintain regular audit and service evaluation to ensure all key performance attributes are operating as intended.

7.19 All providers will have mechanisms for training staff in modern technologies and updated policies or procedures.

7.20 All providers will have established mechanisms for developing and strengthening staff cultural safety including the ability to examine unconscious bias and implementing reflective practice (See also Section 4 – Workforce).

7.21 All providers will have a quality assurance program to assess the ongoing performance of all equipment used in treatment delivery.

7.22 All providers will have mechanisms to formally document and undertake validation testing of any change of equipment, utilities or processes specifically used in the delivery of HSCT.

# 8. RESEARCH AND CLINICAL TRIALS

Transplant and Cellular Therapy providers will participate in research and clinical trials, recognising the potential of trials to improve outcomes, enhance care and provide access to novel treatments.

Health research is a crucial tool in improving the health system and the adoption of innovative practices into the standard of care (Ministry of Health 2017). For people and whānau with blood cancer enrolment in pharmaceutical trials is also a highly impactful mechanism in reducing blood cancer deaths, ensuring more equitable health outcomes, and improving quality of life (The Leukaemia Foundation 2020).

In 2019 less than 8% of registered clinical trials in Australia and Aotearoa were related to cancer (Yeong et al 2019). This number is less than 2% of people in Aotearoa alone. In general, people and whānau welcome the opportunity to participate in clinical trials, but face barriers to participation which include randomisation of treatment, treatment toxicities, accessibility of suitable trials, time and cost of visits, individual choice (Yeong et al 2019).

Contributory to this poor participation in international clinical trials is insufficient access to 'standard of care' pharmaceuticals which are specified for use within the trial. One example is the lack of access to using Treosulfan (rather than Busulfan) for the conditioning treatment prior to allogeneic transplant.

Despite the barriers there are a range of clinical haematology trials open for enrolment in Aotearoa which benefit people and whānau. Most significant to the future of this work is the ENABLE trial sponsored by the Malaghan Institute. This is a trial to evaluate the safety, feasibility, efficacy and kinetics of a new third-generation autologous CAR T-cell product for the treatment of people with relapsed B-cell Non-Hodgkin Lymphoma. It has also been an exemplar for using research to develop the clinical protocols and equity-led processes required for future standard of care delivery.

Research and clinical trials provide multiple benefits particularly including provision of access to novel medication, and the development of future care protocols. However, this cannot be a substitute for standard of care longer term and needs to be part of a robust continuous cycle of research activity evolving into routing care.

Access to high quality research information is also a vital component of a comprehensive model of care for transplant and cellular therapy, and a core requirement of FACT accreditation. Key to this research development is the ability to participate in registries. In Aotearoa comprehensive donor and recipient data is collected and submitted to local and international research registries. The research community then uses this data to undertake observational studies and provide the evidence base for peer reviewed publications.

However, the logistics of collecting, maintaining and submitting accurate data are complex and time consuming. Having the right enablers to ensure TCT services, and people and whānau accessing these services, benefit from the outcomes of this health research is essential, and has been detailed throughout the workforce, performance and quality attributes of this model.

# Attributes

8.1 All providers will consider all people undergoing treatment for clinically relevant and available trials, including both local and international trials.

8.2 To increase trial eligibility, all providers will have access to better mechanisms to access standard of care regimens.

8.3 All providers will demonstrate participant diversity within clinical trials and research including but not limited to Māori and Pacific people, those living in remote to trial centres and older persons.

8.4 All providers will have mechanisms to ensure people electing to participate in clinical research or trials are not disadvantaged by incurring costs related to the study.

8.5 All providers must balance fully funded high-cost systemic anti-cancer therapy trials with unfunded cooperative trials which focus on quality of life and whānau-centric clinical trials.

8.6 All providers will ensure collaboration between stakeholders establishes, maintains, and reviews clinical trial eligibility, ensuring there is enough scope to be more inclusive, thereby increasing trial enrolments.

8.7 All providers will have knowledge of, or access to information on, currently active clinical trials supporting people and whānau and providing immediate and appropriate care regardless of the region of domicile.

8.8 All providers will have the infrastructure sufficient to support clinical trials. This must include the ability to scale up the clinical trial when required and if supported by results, the ability to plan and support implementation of trial protocols into standard of care.

8.9 All providers will further develop and formalise international and national partnerships, create networks to embed research and clinical trials into blood cancer treatments and foster champions to promote awareness.

8.10 All providers will prioritise clinical trials, including qualitative trials, which focus on holistic improvements to the current standard of care.

8.11 All providers will support ongoing TCT research through contributing transplant activity data to research registries, such as the Centre for International Blood & Bone Marrow Transplant Research.

# REFERENCES


Aljurf, M, Snowden, J, Hayden, P, Orchard, K and McGrath, E. (Ed). 2021. *Quality Management and Accreditation in Hematopoietic Stem Cell Transplantation and Cellular Therapy: The JACIE Guide.* Springer. DOI: 10.1007/978-3-030-64492-5. Health and Disability Sector Standards

Central Cancer Network. 2016. He Anga Whakaahuru – Supportive Care Framework. URL:
https://thinkhauorawebsite.blob.core.windows.net/websitepublished/CCP/Resources/General%20Cancer%20docs/MC/He%20Anga%20Whakaahuru%20Interactive%20PDF%20Final.pdf (accessed 2 February 2023)

Ellison-Loschmann, L., & Pearce, N. (2006). Improving Access to Health Care Among New Zealand's Māori Population. *American Journal of Public Health*, *96*(4), 612-617. DOI: 10.2105/AJPH.2005.070680

European Society for Blood and Marrow Transplantation. 2019. *The EBMT Handbook.* Springer Open

Health and Disability System Review. 2020. *Health and Disability System Review – Final Report – Pūrongo Whakamutunga.* Wellington: HDSR (Health and Disability System Review)

Gulliver, J. 2016. Social Work Pre-Assessment for Bone Marrow Transplant – Guidelines and Templates for working with people preparing for Bone Marrow Transplant.

Kenyon, M., & Babic, A. 2018. *The European Blood and Marrow Transplantation Textbook for Nurses: Under the Auspices of EBMT*. Springer Nature.

Macmillan Cancer Support. 2020. *Principles and guidance for prehabilitation within the management and support of people with cancer. URL:*
https://cdn.macmillan.org.uk/dfsmedia/1a6f23537f7f4519bb0cf14c45b2a629/1532-10061/prehabilitation-for-people-with-cancer-tcm9-353994

Majhail NS, Mau LW, Chitphakdithai P, et al. 2015. National Survey of Hematopoietic Cell Transplantation Center Personnel, Infrastructure, and Models of Care Delivery. *Biol Blood Marrow Transplant*. 21(7):1308-14. DOI: 10.1016/j.bbmt.2015.03.020.

Medical Council of New Zealand. 2019. *Statement on Cultural Safety. URL:*
https://www.mcnz.org.nz/assets/standards/b71d139dca/Statement-on-cultural-safety.pdf (accessed 12 April 2023).

Ministry of Health, Ministry of Business, Innovation and Employment. 2017. *New Zealand Health Research Strategy 2017-2027.* June 2017. Wellington: Ministry of Health.

Ministry of Health. 2011. *Bone Marrow Transplant Services in New Zealand for Adults – Service Improvement Plan*. Wellington: Ministry of Health.

Ministry of Health. 2012. Mātātuhi Tuawhenua: Health of Rural Māori 2012. Wellington: Ministry of Health.

Ministry of Health. 2017. New Zealand Health Research Strategy 2017 – 2027. URL: https://www.health.govt.nz/system/files/documents/publications/nz-health-research-strategy-jun17.pdf (accessed 1 February 2023).

Ministry of Health. 2018. Haematopoietic Stem Cell Transplant (Bone Marrow Transplant) Services in New Zealand: Update document 2018. Wellington: Ministry of Health

Ministry of Health. 2019. New Zealand Cancer Action Plan 2019-2029 – Te Mahere mō te Mate Pukupuku o Aotearoa 2019-2029. Revised January 2020. Wellington: Ministry of Health. Ministry of Health. 2021a. *Ngā Parewa Health and Disability Services Standard*. Standards New Zealand.

Ministry of Health. 2021b. Allied Health. URL: https://www.health.govt.nz/about-ministry/leadership-ministry/allied-health (accessed 30 January 2023).

Ministry of Health and Toitū te Wairoa. 2021. Kaiāwhina Workforce Plan 2020 – 2025. URL: https://kaiawhinaplan.org.nz/wp-content/uploads/2021/10/Kaia%CC%84whina-Workforce-Plan-2020-2025.pdf (accessed 17 January 2023).

Ministry of Social Development. 2006. The Social Report 2006: indicators of social wellbeing in New Zealand. Wellington: Ministry of Social Development. URL: https://www.socialreport.msd.govt.nz/2006/index.html

New Zealand Hospital Pharmacists' Association. 2019. *Standards of Practice for New Zealand Hospital Clinical Pharmacy Services*. URL: https://nzhpa.org.nz/media/28398/new%20zealand%20hospital%20pharamcists%20association%20standards%20of%20practice%20june%202019.pdf (accessed 12 December 2022)

New Zealand Institute of Economic Research. 2021. *A critical missing ingredient – the case for increased dietetic input in tier 1 health services.* URL: https://dietitians.org.nz/wp-content/uploads/2021/05/Dietitians-NZ-Final-report.pdf ort.pdf (accessed 12 December 2022)

Nivison-Smith I, Milliken S, Dodds A J, et al. 2017. Activity and Capacity Profile of Transplant Physicians and Centres in Australia and New Zealand. *Biology of Blood and Marrow Transplant, 24*(1), 169-174. DOI: 10.1016/j.bbmt.2017.09.011

NSW Ministry of Health. 2021. Role Delineation of Clinical Services. URL: https://www.health.nsw.gov.au/services/Pages/role-delineation-of-clinical-services.aspx

Pitama S, Cave T, Huria T, et al. 2012. Exploring Māori health worker perspectives on colorectal screening. New Zealand Medical Journal 125(1356): 75-84. URL: https://journal.nzma.org.nz/journal-articles/exploring-maori-health-worker-perspectives-on-colorectal-cancer-and-screening (Accessed 24 August 2023)

Rafferty AM, Clarke SP, Coles J, et al. Outcomes of variation in hospital nurse staffing in English hospitals: cross-sectional analysis of survey data and discharge records. *Int J Nurs Stud*. 2007;44(2):175-182. doi:10.1016/j.ijnurstu.2006.08.003

Safe Staffing and Care Capacity Demand Management: Effective Implementation Accord. 2018. URL: https://www.nzno.org.nz/Portals/0/Files/Documents/Campaigns/Care%20Point/2018-

07-30%20Safe%20Staffing%20and%20Care%20Capacity%20Demand%20Management%20Accord.pdf

Safe Staffing Healthy Workplaces Aotearoa. 2023. Care Capacity and Demand Management (CCDM) programme. URL: https://sshw.health.nz/ccdm-programme/ (Accessed 16 January 2023)

Stevens W, Graham S, Kolbe J, et al. 2008. Ethnic differences in the management of lung cancer in New Zealand. Journal of Thoracic Oncology 3(3): 237-244. URL: https://www.jto.org/article/S1556-0864(15)31366-6/fulltext (Accessed 24 August 2023)

Te Aho o Te Kahu. 2022. He Mahere Ratonga Mate Pukupuku Cancer Services Planning – A vision for cancer treatment in the reformed health system. URL: https://hcmsitesstorage.blob.core.windows.net/cca/assets/Final_Draft_Cancer_Services_Planning_full_updated_a2a614da35.pdf

Te Aho o Te Kahu. 2023. *Rongohia Te Reo, Whatua He Oranga – The voices of whānau Māori affected by cancer.* URL: https://teaho.govt.nz/publications/hui-reports

Te Aka Whai Ora, Te Whatu Ora. 2022. *Te Pae Tata l Interim New Zealand Health Plan.* URL: https://www.tewhatuora.govt.nz/about-us/publications/te-pae-tata-interim-new-zealand-health-plan-2022/

Te Whatu Ora. 2022a. Planed Care Taskforce Reset and Restore Plan. URL: https://www.tewhatuora.govt.nz/assets/Taskforces/Reset-and-restore-plan-confirmed-final-20220902.pdf

Te Whatu Ora. 2022b. *New Zealand Health Facility Design Guidance Note*. Wellington: Te Whatu Ora.

The Leukaemia Foundation. 2020. *National Strategic Action Plan for Blood Cancer*. URL: https://www.leukaemia.org.au/national-action-plan/

Yeojeong JS, Jameson M, Newton V, et al. 2019. Investigating strategies to improve clinical trial opportunities for patients with cancer in New Zealand – INSIGHT. *The New Zealand Medical Journal 132(*1498). URL: https://journal.nzma.org.nz/journal-articles/investigating-strategies-to-improve-clinical-trial-opportunities-for-patients-with-cancer-in-new-zealand-insight

# BIBLIOGRAPHY

AYA (Adolescent and Young Adult) Cancer Network Aotearoa. 2016. Service Provision for Adolescent and Young Adult Cancer Patients in New Zealand including Standards of Care. URL: https://ayacancernetwork.org.nz/wp-content/uploads/2021/07/AYA_Standards_low_res.pdf

Carmen E, Guerra, CE, Fleury, ME, Byatt, LP. 2022. Strategies to Advance Equity in Cancer Clinical Trials. DOI: 10.1200/EDBK_350565. American Society of Clinical Oncology Educational Book 42 (accessed June 10, 2022) 127-137.

Clinical Trials New Zealand. 2021. Strategic Plan 2021-2026. www.cancertrialsnz.ac.nz. (Accessed 15th November 2022).

Crowe J, Francis JJ, Edbrooke L, Loeliger J, Joyce T, Prickett C, Martin A, Khot, A and Denehy L. 2021. Impacts of an allied health prehabilitation service for haematologic patients receiving high-dose chemotherapy in a large cancer centre. Supportive Care in Cancer, 30:1841 – 1852. DOI: 10.1007/s00520-021-06607-w

Gagelmann N, Sureda A, Montoto S, et al. 2022. Access to and affordability of CAR-T cell therapy in multiple myeloma: an EBMT position paper. Lancet Haematology, 9. e786 – 795. www.thelancet.com/haematology.

Health Quality & Safety Commission New Zealand. 2017. Clinical Governance – Guidance for Health and Disability Providers. URL: https://www.hqsc.govt.nz/assets/Our-work/Leadership-and-capability/Building-leadership-and-capability/Publications-resources/HQS-ClinicalGovernance.pdf

Lloyd, J, Lee, CJ. 2022. Use of Telemedicine in Care of Hematologic Malignancy Patients: Challenges and Opportunities Hematologic Malignancy Reports. 17:25–30.

Ministry of Health, Health Research Council of New Zealand. 2022. Enhancing Aotearoa New Zealand Clinical Trials. URL: https://cdn.auckland.ac.nz/assets/liggins/docs/HP8537%20-%20LIG_Clinical%20Trials_FINAL_v6.pdf

Ministry of Health. 2020a. 'Ola Manuia: Pacific Health and Wellbeing Action Plan 2020-2025. Wellington: Ministry of Health.

Ministry of Health. 2020b. Whakamaua: Māori Health Action Plan 2020–2025. Wellington: Ministry of Health.

New Zealand Bone Marrow Donor Registry. (n.d). Frequently Asked Questions. URL: https://www.bonemarrow.org.nz/information/faqs/(accessed 16th January 2023).

Parker C, Berkovic D, Ayton, et al. 2022. Patient Perceived Financial Burden in Haematological Malignancies: A Systematic Review. Current. Oncology 29, 3807–3824.

Pitama S, Robertson P, Cram F, et al. 2007. Meihana Model: A Clinical Assessment Framework. New Zealand Journal of Psychology;36(3):118-35.

Unger, JM, Vaidya R, Hershman D. 2019. Systematic Review and Meta-Analysis of the Magnitude of Structural, Clinical, and Physician and Patient Barriers to Cancer Clinical Trial Participation. JNCI J Natl Cancer Inst 111(3). 245-255.

# APPENDIX 1:
# THE ROLE AND FUNCTION OF THE NEW ZEALAND BLOOD SERVICE

New Zealand Blood Service (NZBS) is a Crown Entity and was established in 1998 under the New Zealand Public Health and Disability Act 2000 and is an appointed entity pursuant to section 63 of the Human Tissue Act 2008.

NZBS plays several vital roles in the delivery of Stem Cell Transplant & Cellular Therapy Services in Aotearoa New Zealand. These functions include:

Histocompatibility testing (also known as 'tissue typing') is needed to help match a person who needs a transplant to a suitable donor. This testing is carried out in the New Zealand Transplantation and Immunogenetics Laboratory (NZTIL) at NZBS in Auckland.

The New Zealand Bone Marrow Donor Registry (NZBMDR) is also based at NZBS Auckland and provides a service that enables matched donors to be found for people who require allogeneic transplantation. NZBMDR can identify donors through its own registry or source stem cells from other registries around the world.

Stem cell collection is carried out by the NZBS Therapeutic Apheresis clinical teams, who work with providers around the country. The stem cells collected are transferred to specialist Cellular Therapy and Tissue Banking services (CTTB) at NZBS in Auckland, Wellington, and Christchurch, where they are processed and prepared for transplantation. When required, CTTB also prepares stem cells for cryopreservation and storage. When a patient is ready for transplantation, the stem cells are transferred to the provider.

Most patients undergoing stem cell transplant will need blood or blood products to support them during their treatment. NZBS is responsible for collecting, testing, processing, and storing blood and blood products in Aotearoa New Zealand. NZBS delivers or supports blood banks and other specialist services, including apheresis services, across Aotearoa New Zealand.

The expert doctors, nurses, scientists, and support teams of NZBS work in partnership with providers throughout the stem cell transplant patient journey.

Safety is the cornerstone of everything NZBS does, and this is reflected in the quality of Stem Cell Transplant & Cellular Therapy Services available to patients in Aotearoa New Zealand.

# APPENDIX 2:
# POSITION STATEMENT ON COLLECTION OF CANCER DATA

Te Aho o Te Kahu position statement on the collection of cancer data in Aotearoa in relation to hapū and iwi affiliation, Māori descent and ethnicity.

*Te Aho o Te Kahu, Cancer Control Agency is committed to improving cancer care and making a meaningful difference to all New Zealanders affected by cancer. We are equity led, whānau centred, knowledge-driven and outcomes focused.*

*We are mindful of the privilege we have in accessing people's cancer data. We understand our obligations to ensure cancer information is timely, sharable, relevant, and accessible, and used appropriately for the purpose for which it was intended.*

*To give effect to Te Tiriti o Waitangi, we treat data as a taonga (treasure) and apply appropriate safeguards to secure and protect Māori data from misuse. In particular, Te Aho o Te Kahu recognises the rights and interests of Māori in the collection, ownership, and application of data. To that end we are actively working with our partners to better understand and put into practice our obligations and responsibilities with respect to Māori data sovereignty and governance.*

*In that context, we believe that hapū and iwi affiliation is an important component of cancer data and information. It could be used to drive equity focused decisions, better inform the measurement of outcomes, and ensure Māori have the information needed to exercise their tino rangatiratanga. We support the findings of WAI2575 that collecting ethnicity data is essential to ensure that data is complete and adequately reflects Māori measures of identity. This also aligns with the intentions and aspirations of the Pae Ora Act with the refocused Manatū Hauora and the establishment of Te Whatu Ora and Te Aka Whai Ora.*

*To that end, we support a comprehensive and coordinated approach across the sector to ensure health information systems capture and continuously improve ethnicity data while enabling people to access and control their own health information.*

*Te Aho o Te Kahu will ensure our efforts align with this commitment and will work in partnership with the cancer sector to achieve it.*