Blood and Marrow Transplant Network

Acute Myeloid Leukaemia (AML)
Diagnostic Report
**Acknowledgements**

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1. Executive Summary

Overview
Acute Myeloid Leukaemia (AML) is a rapidly progressive disease of the bone marrow in which too many immature cells from the myeloid lineage are produced. Onset of AML is usually rapid with presentation and diagnosis occurring within weeks of the onset of symptoms[1]. Diagnosis and management of haematological malignancy requires a specialised multidisciplinary approach with systemic treatment in metropolitan centres that have developed clinical expertise within the specialty.

Leukaemia comprises of approximately 2.5% of all cancers in NSW with AML accounting for approximately 33% of all leukaemia’s[2]. The NSW Central Cancer Registry shows there were 317 new cases of AML in 2008. This was an increase in incidence of 13% over 5 years from 2004 to 2008. This rate of increase is predicted to continue with an increasing population[3]. Despite an increasing incidence mortality rates have remained relatively stable.

The intensive nature of treatment requiring extensive inpatient and outpatient care throughout each cycle of treatment means that despite a low volume annually across the state, treatment is associated with significant hospitalisation and a high cost. Admitted patient activity data shows there has been a steady increase in overnight hospital separations and bed days since 2000 consistent with an increasing incidence. There were a total of 2,338 hospital separations for AML totalling 22,732 bed days in the financial year 2011 / 2012. Ambulatory care utilisation rates for AML are not available. Approximately half of all patients diagnosed with AML are over the age of 65. Poorer prognostic factors and increased comorbidities lead to older patients being unsuitable for standard AML treatment. This population will require increased access to ambulatory care services for supportive care to maintain quality of life.

Scope
The primary goal of this project is to develop a model of care for AML. This will include all patients with AML including Acute Promyelocitic Leukaemia (APML) through the continuum of the patients’ journey from presentation through to follow-up care and long term survival. This will incorporate all health care settings where haematology care is provided including acute inpatient care, ambulatory care and outreach settings.

Approach to review
The assessment phase of this project consisted of three key activities in which information was gathered to inform the current state and provide evidence for good practice models. These activities included:

1. Stakeholder consultations
2. Review of current services across NSW
3. Patient Interviews
4. Literature review and national and international comparisons

Visits to 14 metropolitan sites providing acute inpatient care for patients with AML were conducted. Over 90 clinicians including medical, nursing and allied health participated in open discussion forums to identify current practices, challenges and barriers to care and the key components to be included in a model of care for patients with AML.

Patient interviews were conducted with 7 patients providing a mix of metropolitan and rural patients and incorporating diverse background to provide insight into the experiences of patients and families undergoing treatment for AML. Open ended questions to prompt discussion were used during the interview process.
Key Findings
Key findings are themed into six categories: Accessibility, high quality care (safety and appropriateness), integrated and continuous care, responsive patient centred care, efficiency and sustainability and effectiveness. Subthemes and findings within these categories are:

1. Accessibility
Subthemes identified within accessibility are; referral for treatment, referral for transplant, access to inpatient beds, access to ambulatory care spaces, access to support services and access to specific clinical disciplines (specific disciplines include psychosocial support, fertility management & palliative care). Findings associated with these key points are:

**F1.** Referral patterns from rural and regional areas where there is no outreach haematology service are unclear. This leads to delays in the transfer of patients to AML treatment centres due to bed availability particularly when there is no direct communication with a haematologist. Communication and continuity of care is enhanced where formal links between centres exist.

**F 2.** Challenges in the identification and availability of supportive care services for patients in rural areas in between treatments and following completion of treatment for AML inhibits early discharge home for many patients.

**F3.** There is variation in the timing of referral of patients for transplant with no clear referral pathways for transplant across NSW and difficulties for referring centres to identify waiting times at transplant centres.

**F 4.** Admissions for consolidation treatment with chemotherapy are consistently delayed by several days with a high portion of patients treated on outlying wards. Inpatient capacity at some centres has been increased by moving many inpatient treatments to the ambulatory care setting however it is important to recognise the increases in the level of knowledge and expertise required in the ambulatory care setting to support this move.

**F 5.** The opening hours of some ambulatory care units is insufficient to meet the demand and needs of haematology patients requiring frequent medical review and long infusions.

**F 6.** Treatments provided in general ambulatory care units without trained haematology nursing staff increase the resources required to support the haematology patient in these clinical areas and maintain patient safety.

**F 7.** There are barriers to accessing molecular and cytogenetic diagnostic testing and results.

**F 8.** There are delays and barriers to accessing services for insertion of the preferred central venous access devices (CVAD’s) in the time frames required resulting in alternative devices that may be sub optimal for the patient being selected for use.

**F 9.** Psychosocial and clinical psychology support for patients undergoing treatment for AML is an important aspect of providing holistic care to patients. Services for inpatients and outpatients across AML treatment centres are restricted.

**F 10.** Fertility for patients undergoing treatment for AML is a highly sensitive issue with few options available to preserve fertility, particularly for women.

**F 11.** Difficulties in identifying the appropriate time for referral and lack of consensus over supportive care during palliation result in late or inappropriate referrals to palliative care teams particularly when patients are continuing to require supportive care such as blood transfusion.

2. High Quality Care (safety and appropriateness)
Subthemes identified within high quality care are; infrastructure and resources (this specifically identified single rooms for protective isolation & ambulatory care structures and services) and complexity and acuity of patients (particularly identifying management of outlying patients & adolescent and young adult patients as important). Findings associated with these key points are:
F 12. There are insufficient single rooms with ensuite facilities at nearly all treatment centres to cater for the number of patients requiring single rooms. Priority for single rooms goes to transplant patients, patients requiring isolation due to colonisation with multi-resistant organisms and terminal patients meaning many patients undergoing induction therapy for AML are treated in multi bed rooms or bays.

F 13. Ambulatory care structures are varied with segregation of outpatient services for chemotherapy and other ambulatory care needs which creates challenges to clinicians in providing safe and effective care by clinicians skilled in managing patients with AML.

F 14. There is an increasing need for management of patients undergoing treatment for AML to be managed on outlying wards due to capacity problems. There are challenges in ensuring and maintaining a high level of clinical expertise while providing care for these patients.

F 15. Adolescent and Young Adult (AYA) patients are a unique patient group with new specialist teams becoming available in select areas to assist with managing these patients.

3. Integrated and continuous care
Subthemes identified within integrated and continuous care are; Links with external services, health records and communication and patient follow-up. Findings associated with these key points are:

F 16. There are a range of external agencies and organisations supporting care to patients with AML and it is important to ensure that these organisations are recognised in the development of a model of care for AML.

F 17. Electronic recording of health information is increasing however this information is not easily transferrable across Local Health Districts (LHD’s).

F 18. Regular videoconferencing between referral and treatment centres enables good communication between sites however this is limited to a few centres where formal links are established.

F 19. The availability of supportive care following treatment for rural patients is varied and difficult to access.

4. Responsive patient centred care
Subthemes identified within responsive patient centred care are; care coordination, accommodation and transport and patient education. Parking, accommodation and transport were identified as beyond the scope of this project. Other findings associated with these key points are:

F 20. Haematology Clinical Nurse Consultants and Haematology Care Coordinators provide different functions. Both play pivotal roles in the provision of care for haematology patients however care coordinators for haematology are predominantly only available in sites where a Haematology Clinical Nurse Consultant is not available.

F 21. Assistance for parking, transport and accommodation for patients with AML is provided through non-government organisations such as the Leukaemia Foundation however there remains substantial costs in accessing care for many patients.

F 22. Patient education is identified as an important component to providing comprehensive safe and effective care to patients with AML however there are many barriers to providing education and a lack of written material for specific patient populations.

F 23. There is a difficulty accessing interpreter services when required. Rapidly changing patient conditions and treatment plans mean there is a frequent need for repeated sessions with interpreters often at short notice.

5. Efficiency and sustainability
Subthemes identified within efficiency and sustainability are; workforce and education and training. Findings associated with these key points are:
F 24. A multidisciplinary team approach to care for patients with AML is consistent across NSW however there is variation in the membership and functioning of the multidisciplinary team particularly in relation to allied health services.

F 25. The acuity of patients undergoing treatment for AML is high, requiring complex clinical care however there is little documented evidence to identify appropriate staffing and skill levels, particularly medical and nursing staff based on patient numbers, level of activity or acuity.

F 26. Haematology requires a highly skilled workforce. Gaps in education programs for all staff disciplines create challenges for staff development and succession planning into the future.

6. Effectiveness
Subthemes identified within effectiveness are: choice of treatments, clinical trials and data collection. Findings associated with these key points are:

F 27. A selection of comprehensive evidence based treatment protocols are available through the Cancer Institute NSW and Australasian Leukaemia and Lymphoma Group (ALLG) for treating patients with AML providing a consistent approach to treatments across NSW.

F 28. Data relating to AML treatment is collected by various means locally and through NSW health organisations however there is a limited uniform data available to provide a clear picture of outcomes and morbidity associated with treatment in NSW.

Next steps
A series of suggested actions based on each of the findings have been identified. In the next steps the ideal model of care for AML will be developed and documented based on these key findings and suggested actions.
2. **Project Overview**

This section of the report provides an overview of AML and the processes undertaken to commence development of a model of care for AML.

2.1 **Background**

The NSW Blood and Marrow Transplantation (BMT) Network established in 2002 has been highly successful and provides direction and support for coordination of BMT planning and service delivery within a framework that promotes access to, and the safety and efficiency of, services in NSW. BMT is one of several possible pathways in the management of a variety of haematological malignancies such as leukaemia and lymphoma however it is rarely the initial therapy.

Haematology services for Acute Leukaemia are provided in the same centres providing BMT services. The management of patients prior to transplant requires a range of resources and skill from clinicians with a comprehensive multidisciplinary approach from pre-transplant to follow-up care. Development of a model of care for AML in conjunction with the BMT Network would facilitate the group’s ability to make recommendations and consider issues across the continuum of care for this patient population.

2.1.1 **Overview**

The primary goal of this project is to develop a model of care for AML. This will be achieved through the following activities:

- Consultation with clinicians providing haematological services both in the rural and metropolitan setting.
- Investigation of haematological malignancies across NSW by geographic location in order to look at patterns of care and survival and identify inappropriate clinical variation for isolated patients.
- The typical haematology patients’ journey will be mapped for both rural and metropolitan patients.
- A literature review of similar models of care will be undertaken and analysis of the results will be provided to determine recommendations for implementation.
- Consultation with experts and organisations who have undertaken similar work will provide insight into the development of achievable goals, challenges and barriers of the process.
- Critical analysis of any impacts of any proposed model for haematology service providers.
- Development of an implementation plan with short, medium and long term strategies.

The key outcomes of the project are to enable:

- A consistent approach to the provision of care for patients with AML across NSW
- Optimised quality of care for AML based on evidence of best practice
- Identification of key priority areas that impact on clinical practice and development of strategies for system wide clinical improvement and service development
- Strong partnerships and communication between metropolitan, rural centres and GPs
- Expanded opportunities for professional development, collaborative research and teaching for complex issues relating to AML

2.1.2 **Scope**

The focus of the project is management of adult and paediatric patients with AML including APML, through the continuum of the patients’ journey from presentation.
Other types of Leukaemia such as Acute Lymphoblastic Leukaemia, chronic leukaemia, or pre-malignant conditions such as myelodysplasia are not a focus of this work, however may be considered in the broader context of haematology services. Bone Marrow Transplantation (BMT) forms part of the care pathway for many patients with AML, however is a complex component of care that is covered separately with a model of care specifically for BMT. This model will include the identification of appropriate patients for referral to BMT and the initial steps required in the referral process. It will not however expand on the details specific to transplantation.

Models of care for patients with AML were examined across a range of care delivery settings including:

- **Acute inpatient care**
  Hospital-based acute inpatient care is generally delivered by specialist multidisciplinary teams during the acute phase of an illness with the typical goal of discharging patients as soon as they are deemed healthy and stable. Acute inpatient care may be repeated on several occasions during the course of a longer illness.

- **Ambulatory care settings**
  Ambulatory care settings provide an outpatient based service within a health care facility that patients will attend from home for day treatments and care that extends and compliments inpatient services. Ambulatory care services frequently include chemotherapy suites and outpatient clinics.

- **Outreach settings**
  Outreach settings are provided in an alternative location to the primary service site. This will include in the patients home, or at a satellite ambulatory care clinic or treatment centre. Services in the patients home benefit less mobile patients requiring frequent care that does not require hospitalisation and can include clinical assessment, short infusions and symptom management.

### 2.2 Defining of AML

Acute Myeloid Leukaemia (AML) is a rapidly progressive disease of the bone marrow in which too many immature cells from the myeloid lineage are produced. These cells, known as blast cells, fail to mature into normal cells and accumulate in the blood stream. The production and maturation of normal blood cells is suppressed and patients typically present with infection. Onset of AML is usually rapid with presentation and diagnosis occurring within weeks of the onset of symptoms\(^1\).

Diagnosis and management of haematological malignancy requires a specialised multidisciplinary approach. Treatment requires intensive systemic chemotherapy to induce remission and control the disease, and is associated with significant morbidity and mortality\(^4\). Each treatment cycle lasts approximately 28 days with an extended period of neutropenia expected to last for approximately 17 – 22 days from the commencement of treatment. Traditional treatment models have required inpatient stays for the duration of neutropenia. Recent models increasingly utilise ambulatory care settings for monitoring and supportive care, admitting patients only for febrile neutropenia and management of other serious complications that cannot be reasonably supported in the ambulatory setting.

The goal of treatment for AML with intensive chemotherapy is to induce a remission following an initial cycle of treatment followed by a series of treatments to consolidate the remission and prevent recurrence. In order to induce remission intensive doses of chemotherapy are used to suppress the bone marrow and promote regeneration with normal cells. The majority of toxicities associated with treatment occur during this period of myelosuppression. Regular monitoring and assessment
throughout this period is required to ensure early detection and management of symptoms and reduce the morbidity associated with treatment. Inpatient and ambulatory care management requires skilled clinicians and is provided in metropolitan centres that have developed clinical expertise within the specialty. There are limited services available for this highly specialised care in rural NSW.

Leukaemia comprises approximately 2.5% of all cancers with AML accounting for the majority of acute leukaemia in adults and 33% of all leukaemia’s. The NSW Central Cancer Registry has provided incidence and mortality figures for AML from 2004 to 2008. These are summarised in graph 2.2.1.

Graph 2.2.1 – AML Incidence and Mortality

![Graph 2.2.1 – AML Incidence and Mortality](image)

Data Source: NSW Central Cancer Registry, Cancer Institute NSW – Data provided

There is an increasing incidence of approximately 13% over the last 5 years with prediction figures indicating an ongoing rise of 14% of new cases over the next 5 years. The predicted rise in incidence is attributed to both population growth and ageing. Despite the increasing incidence, the mortality associated with AML remains relatively stable. Prevalence data indicates an overall 5 year survival of 35.2% for the 5 years from 2004 to 2008 however survival rates vary depending on age at diagnosis with an increasing associated mortality in the older age groups. Approximately half of all patients diagnosed with AML are over the age of 65. Poorer prognostic factors and increased co morbidities lead to older patients being unsuitable for standard AML treatment. This population will require increased access to ambulatory care services for supportive care to maintain quality of life.

Graph 2.2.2 below depicts the broad distribution and associated mortality of AML across all age groups. While the incidence and mortality increases with age, there is a broad distribution across all age ranges.
Graph 2.2.2 – AML incidence and mortality by age

Consistent with an increasing incidence, the admitted patient activity data shows there has been a steady increase in the number of hospital separations and beddays for overnight admissions since 2000. Graph 2.2.3 shows the increasing trend in overnight beddays associated with AML by financial year. Overall in 2011 / 2012 there were a total of 2338 hospital separations totalling 22,732 beddays for patients with AML. There is no data available for ambulatory care utilisation however anecdotal reports indicate an increasing number of patients with AML accessing ambulatory care services as well.

Graph 2.2.3 – Overnight beddays for AML by financial year

Evaluation of the distribution of AML across the local health districts (LHD’s) identifies relatively even distribution based on population, with the majority of cases occurring in densely populated
areas. It is difficult to draw significance on figures falling above or below the NSW average due to the small numbers. Incidence and mortality figures by LHD are presented in the table below.

<table>
<thead>
<tr>
<th>LHD</th>
<th>Incidence</th>
<th>Mortality</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Cases</td>
<td>per 100,000 population</td>
</tr>
<tr>
<td>Sydney</td>
<td>111</td>
<td>4.27</td>
</tr>
<tr>
<td>South Western Sydney</td>
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<td>4.05</td>
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<tr>
<td>South Eastern Sydney</td>
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<tr>
<td>Illawarra Shoalhaven</td>
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<td>5.52</td>
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<tr>
<td>Western Sydney</td>
<td>153</td>
<td>4.53</td>
</tr>
<tr>
<td>Nepean Blue Mountains</td>
<td>65</td>
<td>4.30</td>
</tr>
<tr>
<td>Northern Sydney</td>
<td>168</td>
<td>3.72</td>
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<tr>
<td>Central Coast</td>
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<td>4.63</td>
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<tr>
<td>Hunter New England</td>
<td>202</td>
<td>4.16</td>
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<tr>
<td>Northern NSW</td>
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<td>Murrumbidgee</td>
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<tr>
<td>Western NSW</td>
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<td>Far West</td>
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<tr>
<td>Albury LHD residents</td>
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<tr>
<td>NSW</td>
<td>1524</td>
<td>4.18</td>
</tr>
</tbody>
</table>

Data Source: NSW Central Cancer Registry, Cancer Institute NSW – Data provided

2.2.1 Models of Care

A model of care has been defined by Queensland Health\[^5\] as ‘A multifaceted concept that provides a structure and framework to broadly define the way a health care service is delivered.’ A successful model is underpinned by principles of safety and quality, equity and patient centred care and is developed through evidence based practice, and the needs and preferences of individuals and organisations throughout the various stages of illness being defined\[^6\].

In the context of this project, a model of care is formulated around the AML patient journey from presentation and referral through to end of life care or long term survivorship. A number of factors support a model of care for patients with AML. These include; communication, education, the multidisciplinary team and external organisations.

2.2.2 Diagnostic report

This report provides a summary of the information collected through the consultations and assessment phase of this project. It includes:

- A review of national and international literature
- A summary site profile for each of the centres treating AML
- A discussion of the site visit findings including good practices and innovations, gaps in service provision, impacts of current care delivery models, opportunities for improvement and enablers and strategies to support new models.
2.2.3 Key Findings

The key findings and discussion are presented in six sections based on the National Health Performance Framework\cite{7,8}. The six dimensions form the broad category of Health system performance developed in 2008 and revised in 2011 to help understand and evaluate health systems.

The six dimensions used within this report are:

- Accessibility
- High Quality Care (Safety and Appropriateness)
- Integrated and Continuous Care
- Responsive Patient Centred Care
- Efficiency and Sustainability
- Effectiveness

2.3 Methodology overview

The assessment phase of this project consisted of three key activities in which information was gathered to inform the current state and provide evidence for good practice models. These activities included:

- Stakeholder consultations
- Review of current services across NSW
- Patient Interviews
- Literature review and national and international comparisons

There are fourteen sites in NSW currently providing acute inpatient care for patients with AML. These are all located within metropolitan local health districts and are listed below:

- Calvary Mater Newcastle
- Concord Repatriation General Hospital
- Gosford Hospital
- Liverpool Hospital
- Nepean Hospital
- Prince of Wales Hospital
- Royal North Shore Hospital
- Royal Prince Alfred Hospital
- St George Hospital
- St Vincent’s Hospital
- Sydney Children’s Hospital
- The Children’s Hospital Westmead
- Westmead Hospital
- Wollongong Hospital

Canberra Hospital in the ACT also provides acute inpatient treatments for patients with AML from rural NSW. This includes areas around Young, Harden, Wagga Wagga, Yass, Cooma, Queanbeyan, Bega, Moruya and other southern coastal regions.

2.3.1 Stakeholder Consultations

Medical and nursing staff from all 14 metropolitan sites was included in the stakeholder consultations. These were conducted as site visits between June 2012 and August 2012.

The aims of the visits were:

1. To introduce the project and provide relevant background to clinicians
2. Identify the challenges and barriers clinicians experience while providing care to patients with haematological malignancies

3. Identify the key components what clinicians see as essential to include in a Model of Care for patients with AML

Stakeholder consultations included medical and nursing staff and were scheduled at a time suitable to clinicians at each site. An open discussion format was used to communicate and engage clinicians in the process and ensure that the model of care developed is owned by the clinicians providing the service to patients. Discussion points were documented for each visit and returned to clinicians for clarification and the opportunity to add any further detail if desired. Clinicians from each site that were not able to be present during the discussions were also invited to add to the discussion points at that stage.

2.3.2 Review of current services

Each of the 14 metropolitan sites provided detailed information relating to their current services. This was captured with a structured approach utilising a data collection tool. The tool captured data in four categories:

1. Bed capacity
2. Supportive services
3. Allied Health support
4. Ambulatory care

In addition to these four categories, information regarding outreach clinics, formal links and referral processes was obtained.

2.3.3 Patient Interviews

Patient interviews were conducted to provide insight into the experiences of patients, families and carers undergoing treatment for AML. The goals of the interview were to map the typical journey for patients, identifying the challenges faced by patients and families and identify differences in the care experience for rural and metropolitan based patients with AML.

Suitable patients who have received and completed treatment for AML were identified by haematology centres. The patient may or may not have progressed to transplant at the time of interview. A mixture of rural and metropolitan patients from a variety of centres will be interviewed and will include patients from culturally and linguistically diverse (CALD) backgrounds.

Patients were provided with an invitation letter, participant information statement and consent form. Interviews were scheduled face to face wherever possible however due to distance rural based patient interviews were conducted by phone. Interviews were scheduled for 1 hour however patients were instructed a follow-up interview may be arranged if 1 hour is insufficient time, or the interviewer would like to follow-up with some clarifying questions.

Interviews were semi structured and took a story telling approach. Interviews were recorded with the patients’ permission to ensure that all the information provided during the interview is collected accurately and a transcript of the interview was developed in a storytelling format and sent back to the patient providing them with the opportunity to review, alter or add anything to the story and approve the content. Stories were themed and incorporated into the findings within this document.

2.3.4 Literature Review and National and International Comparisons

The purpose of the literature review was to provide a body of information that will assist to inform the future development of a model of care for patients with AML in NSW, and provide comparisons from the literature of national and international models of care for patients with AML. An electronic
search was conducted to identify current literature relating to haematology models of care and to review good practice in the specialty of haematology.

The Medline, CINAHL, Pub med and CIAP databases and search engines including Google and Google scholar were searched using keywords including haematology models of care, AML models of care, haematology care framework, AML Framework. The NSW Cancer Institute publications were also explored to identify work already completed within NSW relating to development and review of Haematology services.

3. AML data

Data and performance measures assist to understand productivity, effectiveness and outcomes services and treatments to patients with AML.

3.1 Availability of data

Several data registries exist in NSW from which to collect data relating patients with AML. The most commonly used registries in relation to AML data are described below:

- **NSW Central Cancer Registry (CCR)**
  The NSW Central Cancer Registry is managed by the Cancer Institute NSW for the NSW Department of Health (DOH) and receives notifications of all cancer in NSW based on the WHO ICD coding system. The Registry maintains a record of all cases of cancer diagnosed in NSW in a case based registry in which all notifications are linked to a single person. Data collected by the Central Cancer Registry includes personal identifiers and demographic information and brief clinical details describing the cancer.

  The information provided is of high quality, with accuracy of information validated through multiple systems and cross checked with other cancer registries however availability is delayed by approximately three to four years. This registry does not incorporate information relating to treatment or response to treatment.

- **NSW Clinical Cancer Registry**
  The Cancer Institute NSW have implemented the NSW Clinical Cancer Registry to maintain records of people with cancer in NSW. Data collected by the NSW Clinical Cancer Registry includes personal identifiers, demographic information, the treatment centre information, clinical details about the cancer and initial chemotherapy treatments, although subsequent treatments and information relating to toxicities or response to treatments is not available.

  The information is collected through data collection teams within each Local Health District and is more current than central cancer registry information being available within approximately 18 months of collection. Improvements are under development to enable electronic transfer of information from existing LHD data bases such electronic medical record systems and oncology management systems.

- **Australasian Bone Marrow Transplant Recipient Registry**
  The Australasian Bone Marrow Transplant Recipient Registry (ABMTRR) runs under the auspices of the Bone Marrow Transplant Society of Australia and New Zealand (BMTSANZ) and records details of haemopoietic stem cell transplants from bone marrow, peripheral blood and cord blood for Australia and New Zealand. Information collected include personal identifiers, disease related information, progress of previous transplant patients including relapse and mortality information.
3.2 Outcomes Measures

Outcome measures are an important way to determine that health care practices and services that are provided are achieving the desired effect in a cost effective and efficient way, ensuring that clinical interventions are providing a demonstrable and beneficial result rather than adverse or equivocal outcomes. Outcome measures help us predict which patients will benefit most from a particular intervention and a measure to base individual patient improvements against and better understand the impacts of health care interventions.

Information currently available

Detailed incidence and mortality information linked with demographic data and hospital information is currently available. This information can enable an analysis of:

- Average length of stay
- Average cost of treating AML
- Activity levels in various treatment centres
- Readmission rates for complications such as febrile neutropenia

An analysis of this information is currently in progress however results will not be available for this report.

Ideal outcome measures

Incidence and mortality data within cancer services have long been identified as important outcome measures however additional factors are now also recognised as critically important outcomes. These include factors such as; complications of disease or treatments, responses to treatments, physical and psychosocial functional, quality of life and costs of care.

The following information is not easily identified through existing data registries although are important in successfully capturing comprehensive information relating to outcomes of treatment for patients with AML:

- Patient demographic data
- Diagnosis
- Key prognostic factors
- Details of therapy
- Response to therapy
- Major toxicities
- Relapse information
- Length of follow-up
- Date of death
- Cause of death

The development of a new model of care for patients with AML is contingent on the understanding of the current state along with the challenges and barriers to providing care that exist. This section provides an overview of the current practice and service availability for treatment for AML in NSW in terms of the structural elements of services and process that underpin the patient journey.

4.1 Structural element of service

The service structure and capabilities for each centre are outlined below.

4.1.1 Calvary Mater Newcastle

<table>
<thead>
<tr>
<th>Capacity</th>
<th>Ambulatory Care</th>
<th>Allied Health support</th>
<th>Supportive services</th>
<th>Outreach services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient ward – Haematology (Auto BMT)</td>
<td>There are 2 ambulatory care areas for haematology patients: Oncology &amp; haematology chemotherapy suite Haematology day unit collocated with ward for day treatments and procedures</td>
<td>Dedicated to unit; Pharmacist, Social worker, Clinical psychologist (cancer services), Physiotherapist. Shared with other services; Dietician Available if required; Occupational Therapist, Speech Pathologist.</td>
<td>Fertility; provided off site (Private) Radiology; PET scanner onsite, interventional radiology available Blood products; delivered daily (ordered the day before whenever possible) Apheresis; Haematology patients only</td>
<td>Outreach clinics are provided at Muswellbrook. Referrals are received from multiple centres across Hunter New England and Northern NSW LHD's.</td>
</tr>
<tr>
<td>12 inpatient beds (Flexibility up to 13 beds)</td>
<td>8 single rooms (1 x 4 bedded room)</td>
<td>9 Haematology day unit beds Chemotherapy suite</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
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<td></td>
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<td></td>
</tr>
</tbody>
</table>

4.1.2 Concord Repatriation General Hospital

<table>
<thead>
<tr>
<th>Capacity</th>
<th>Ambulatory Care</th>
<th>Allied Health support</th>
<th>Supportive services</th>
<th>Outreach services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient ward - Combined Haem &amp; Onc. (Auto BMT)</td>
<td>There is a haematology ambulatory care unit collocated with outpatient haematology clinics.</td>
<td>Dedicated to unit; Pharmacist, Clinical Psychologist (cancer services) Shared with other services; Social Worker, Dietician Available if required; Physiotherapist, Occupational Therapist, Speech Therapist</td>
<td>Fertility; On site for males, and off site for females Radiology; PET sent off site, interventional radiology available Blood products; delivered daily Apheresis; service to all patient groups</td>
<td>Outreach clinics are provided to Bankstown Hospital. There is no ambulatory care service for haematology available at this site.</td>
</tr>
<tr>
<td>24 inpatient beds (Flexibility up to 30 beds)</td>
<td>8 single rooms (4 Hepa filtered used for BMT)</td>
<td>16 Haem ambulatory care chairs / beds</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### 4.1.3 Gosford Hospital

<table>
<thead>
<tr>
<th>Capacity</th>
<th>Ambulatory Care</th>
<th>Allied Health support</th>
<th>Supportive services</th>
<th>Outreach services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient ward – Combined Haem &amp; Onc. (Auto BMT)</td>
<td>There are 2 ambulatory care areas for haematology patients: Oncology &amp; haematology ambulatory care provides the majority of treatments General ambulatory care does some Intragram, and other general infusions when needed. There is a haem / Onc outreach ambulatory care unit at Wyong hospital with 10 chairs.</td>
<td>Dedicated to unit (Cancer services); Social Worker, Pharmacist, Dietician, Physiotherapist, Clinical psychologist Shared with other services: Occupational Therapist Available if required; Speech Pathologist</td>
<td>Fertility; Provided off site (Private) Radiology; PET scan is provided off site Blood products; delivered daily late in afternoon. (Ordered the day before whenever possible.) Apheresis; service to all patient groups</td>
<td>Outreach clinics at Wyong Hospital. There is a Haem &amp; Onc ambulatory care unit with 10 chairs at this site.</td>
</tr>
</tbody>
</table>

### 4.1.4 Liverpool Hospital

<table>
<thead>
<tr>
<th>Capacity</th>
<th>Ambulatory Care</th>
<th>Allied Health support</th>
<th>Supportive services</th>
<th>Outreach services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient ward – Haematology (Allo BMT)</td>
<td>There are 3 ambulatory care areas for haematology patients: Oncology &amp; haematology chemotherapy suite BMT &amp; haematology step down unit Apheresis unit</td>
<td>Dedicated to unit; Social Worker, Pharmacist (Cancer services) Shared with other services: Dietician, Physiotherapist, Clinical Psychologist Available if required; Occupational Therapist, Physiotherapist, Speech Pathologist</td>
<td>Fertility; provided off site Radiology; all imaging available on site Blood products; delivered daily Apheresis; service to all patient groups</td>
<td>Referrals are received from centres across South Western Sydney LHD. Outreach clinic is provided at Campbelltown hospital. There is no inpatient or ambulatory care service available at this site.</td>
</tr>
</tbody>
</table>

### 4.1.5 Nepean Hospital

<table>
<thead>
<tr>
<th>Capacity</th>
<th>Ambulatory Care</th>
<th>Allied Health support</th>
<th>Supportive services</th>
<th>Outreach services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient ward – Combined Haem and Onc. and Palliative Care (Auto BMT)</td>
<td>There are 3 ambulatory care areas for haematology patients: Oncology &amp; haematology chemotherapy suite General ambulatory care unit for transfusions &amp; procedures (Mon – Fri). Ambulatory Procedure Clinic (Sat)</td>
<td>Dedicated to unit (Cancer services); Social Worker, Pharmacist, Dietician. Shared with other services; Clinical Psychologist Available if required; Physiotherapist, Occupational Therapist, Speech Pathologist</td>
<td>Fertility; provided off site Radiology; all imaging available on site Blood products; available daily after 4pm Apheresis; haematology patients only Chemotherapy reconstitution; outsourced (not available on site)</td>
<td>Outreach clinics are provided at Lithgow Hospital. Limited haematology ambulatory care services are available within the general ambulatory care unit. Referrals are received from Bathurst Hospital.</td>
</tr>
</tbody>
</table>
### 4.1.6 Prince of Wales Hospital

<table>
<thead>
<tr>
<th>Capacity</th>
<th>Ambulatory Care</th>
<th>Allied Health support</th>
<th>Supportive services</th>
<th>Outreach services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient ward – Haematology (Auto BMT)</td>
<td>There is a haematology short stay unit collocated with the inpatient ward for chemotherapy day treatments and overnight infusions. This is open 6 days per week. Cancer Outreach Team (COT) visits patients at home.</td>
<td>Dedicated to unit; Pharmacist (Cancer services) Shared with other services; Social Worker Available if required; Clinical Psychologist, Dietician, Occupational therapist, Physiotherapist, Speech pathologist.</td>
<td>Fertility; on site at RHW Radiology; All imaging available on site Blood products; delivered daily Apheresis; service to all patient groups</td>
<td>Outreach clinics are provided at Bathurst and Tamworth Hospitals. Referrals for intensive inpatient treatments are received from Port Macquarie Hospital.</td>
</tr>
</tbody>
</table>

### 4.1.7 Royal North Shore Hospital

<table>
<thead>
<tr>
<th>Capacity</th>
<th>Ambulatory Care</th>
<th>Allied Health support</th>
<th>Supportive services</th>
<th>Outreach services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient ward – Haematology (Allo BMT)</td>
<td>There is a haematology ambulatory care unit open 7 days per week.</td>
<td>Dedicated to unit; Social Worker, Pharmacist, Dietician, Clinical Psychologist (cancer services) Shared with other services; Occupational Therapist, Physiotherapist, Speech Pathologist.</td>
<td>Fertility; provided off site (Private) Radiology; all imaging available on site (PET only avail. To inpatients if private patients) Blood products; delivered daily Apheresis; service to all patient groups</td>
<td>Outreach clinics are provided at Manly and Armidale Hospitals. Weekly videoconferencing is conducted with Lismore and Coffs harbour Hospitals and referrals for acute inpatient care are received from these sites as well as from Private facilities within the LHD.</td>
</tr>
</tbody>
</table>

### 4.1.8 Royal Prince Alfred Hospital

<table>
<thead>
<tr>
<th>Capacity</th>
<th>Ambulatory Care</th>
<th>Allied Health support</th>
<th>Supportive services</th>
<th>Outreach services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient ward – Haematology (Allo BMT)</td>
<td>There are 3 ambulatory care areas for haematology patients: Oncology &amp; haematology chemotherapy suite BMT &amp; haematology step down unit Apheresis unit.</td>
<td>Dedicated to unit; Pharmacist, Social Worker, Dietician, Clinical Psychologist Available if required; Occupational Therapist, Physiotherapist, Speech pathologist.</td>
<td>Fertility; Provided onsite Radiology; all imaging available on site Blood products; delivered daily Apheresis; service to all patient groups</td>
<td>Outreach clinics are provided at Orange and Dubbo Hospitals. Referrals for intensive inpatient treatments are received from Broken Hill.</td>
</tr>
</tbody>
</table>
# Acute Myeloid Leukaemia Model of Care

## Diagnostic Report

### 4.1.9 St George Hospital

<table>
<thead>
<tr>
<th>Capacity</th>
<th>Ambulatory Care</th>
<th>Allied Health support</th>
<th>Supportive services</th>
<th>Outreach services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient ward – Mixed specialty (Auto BMT)</td>
<td>There are 2 ambulatory care areas for haematology patients: Oncology &amp; haematology chemotherapy suite General ambulatory care unit for transfusions &amp; procedures. General ambulatory care keeps 1 quarantined bed for 1 hour every afternoon for urgent consultations with the Haematology Registrar. COT visit patients at home.</td>
<td>Dedicated to unit; Social Worker, Pharmacist (Cancer services) Shared with other services; Clinical Psychologist Available if required: Dietician, Physiotherapist, Speech pathologist, Occupational Therapist</td>
<td>Fertility; provided off site (Private) Radiology; PET scanner off site Blood products; delivered daily Apheresis; service to all patient groups</td>
<td>Outreach clinics are provided at Sutherland hospital. There is a Haem &amp; Onc ambulatory care unit at this site.</td>
</tr>
</tbody>
</table>

### 4.1.10 St Vincent’s Hospital

<table>
<thead>
<tr>
<th>Capacity</th>
<th>Ambulatory Care</th>
<th>Allied Health support</th>
<th>Supportive services</th>
<th>Outreach services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient ward – Mixed specialty (Allo BMT)</td>
<td>There are 2 ambulatory care areas for haematology patients: Oncology &amp; haematology ambulatory care Multipurpose ambulatory care for overflow patients and available 8–12 on weekends.</td>
<td>Dedicated to unit; Pharmacist, Social Worker, Dietician, Clinical Psychologist Shared with other services: Occupational therapist, Physiotherapist. Available if required: Speech pathologist</td>
<td>Fertility; provided off site Radiology; all imaging available on site Blood products; delivered daily Apheresis; service to all patient groups</td>
<td>Outreach clinics are provided at Wagga Wagga and Griffith Hospitals.</td>
</tr>
</tbody>
</table>

### 4.1.11 Sydney Children’s Hospital

<table>
<thead>
<tr>
<th>Capacity</th>
<th>Ambulatory Care</th>
<th>Allied Health support</th>
<th>Supportive services</th>
<th>Outreach services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient ward – Paediatric Oncology ward (Allo BMT)</td>
<td>There is an Oncology outpatient unit</td>
<td>Dedicated to unit; Pharmacist, Social Worker, Shared with other services; Dietician, Play Therapist, School Available if required: Occupational therapist, Physiotherapist</td>
<td>Fertility; provided on site at RHW Radiology; All imaging available on site Blood products; delivered daily Apheresis; service to all patient groups</td>
<td>Outreach clinics are provided at Wagga Wagga, Armidale, Coffs harbour, Canberra and Campbelltown.</td>
</tr>
</tbody>
</table>
### 4.1.12 The Children's Hospital at Westmead

<table>
<thead>
<tr>
<th>Capacity</th>
<th>Ambulatory Care</th>
<th>Allied Health support</th>
<th>Supportive services</th>
<th>Outreach services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient ward – Paediatric Oncology ward (Allo BMT)</td>
<td>There is an Oncology ambulatory care unit</td>
<td>Dedicated to unit; Pharmacist, Social Worker, Dietician, Clinical Psychologist. Shared with other services: Occupational Therapist, Physiotherapist. Available if required: Speech Pathologist</td>
<td>Fertility: provided on site at Westmead Radiology; all imaging available on site (PET @ Westmead Hospital) Blood products; delivered daily Apheresis; service to all patient groups</td>
<td></td>
</tr>
<tr>
<td>20 inpatient beds (up to 10 beds on isolation ward)</td>
<td>10 single rooms</td>
<td>3 isolation rooms, 4 beds &amp; 10 chairs ambulatory care</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 4.1.13 Westmead Hospital

<table>
<thead>
<tr>
<th>Capacity</th>
<th>Ambulatory Care</th>
<th>Allied Health support</th>
<th>Supportive services</th>
<th>Outreach services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient ward – Haematology (Allo BMT)</td>
<td>All ambulatory haematology services are provided through general ambulatory unit. This is available 7 days per week for haematology patients.</td>
<td>Dedicated to unit; Pharmacist, Social Worker (1 BMT, 1 shared for cancer services), Clinical psychologist (cancer services) Shared with other services: Dietician. Available if required: Occupational therapist, Physiotherapist, Speech pathologist</td>
<td>Fertility: provided onsite Radiology; all imaging available on site Blood products; delivered daily Apheresis; service for haematology patients and some renal patients. Immunology also provides apheresis services.</td>
<td>Outreach clinics are provided at Blacktown Hospital.</td>
</tr>
<tr>
<td>20 inpatient beds (potential 25 in future)</td>
<td>21 single rooms(2 x 2 bedded rooms)</td>
<td>2 apheresis, 3 beds &amp; 28 chair ambulatory care</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 4.1.14 Wollongong Hospital

<table>
<thead>
<tr>
<th>Capacity</th>
<th>Ambulatory Care</th>
<th>Allied Health support</th>
<th>Supportive services</th>
<th>Outreach services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient ward – Combined Haem &amp; Onc. (Auto BMT)</td>
<td>There are 2 ambulatory care areas for haematology patients: Oncology &amp; haematology chemotherapy suite General ambulatory care unit for transfusions &amp; procedures.</td>
<td>Dedicated to unit (Cancer services); Pharmacist, Social Worker, Clinical Psychologist Shared with other services: Dietician, Physiotherapist. Available if required: Occupational Therapist, Speech pathologist</td>
<td>Fertility: provided off site Radiology; PET scan provided off site Blood products; delivered daily late in afternoon. Ordered on Friday for weekends. Apheresis; service to all patient groups</td>
<td>Outreach clinics are provided at Milton / Ulladulla and Shoalhaven Hospitals. Haem &amp; Onc ambulatory care units are available at both these sites with limited opening hours.</td>
</tr>
<tr>
<td>25 inpatient beds (Flexibility up to 26)</td>
<td>10 single rooms (7 Hepa filtered)</td>
<td>4 beds &amp; 8 chairs ambulatory care</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### The Canberra Hospital

<table>
<thead>
<tr>
<th>Capacity</th>
<th>Ambulatory Care</th>
<th>Allied Health Support</th>
<th>Supportive services</th>
<th>Outreach services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient ward – Combined Haem/onc (Auto BMT)</td>
<td>36 Inpatient beds</td>
<td>Dedicated to unit; Pharmacist, Social Worker, Dietician, Clinical Psychologist.</td>
<td>Fertility: provided off site</td>
<td>Outreach clinics are provided at Goulburn, Bega &amp; Moruya</td>
</tr>
<tr>
<td>12 single rooms (6 Hepa filtered) (3 x 4 and 6 x 2 bed rooms)</td>
<td>8 beds &amp; 23 chairs ambulatory Care</td>
<td>Oncology &amp; haematology chemotherapy suite COT visit pts at home Apheresis unit</td>
<td>Radiology: All imaging available on site Blood products: delivered daily Apheresis: Service to all pt groups</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- **Inpatient ward**
  - Haem/onc (Auto BMT)
  - 36 Inpatient beds
  - 12 single rooms (6 Hepa filtered)
  - (3 x 4 and 6 x 2 bed rooms)
  - 8 beds & 23 chairs ambulatory Care

- **Ambulatory Care**
  - There are 3 ambulatory care areas for haematology patients:
    - Oncology & haematology chemotherapy suite
    - COT visit pts at home
    - Apheresis unit

- **Allied Health Support**
  - Dedicated to unit; Pharmacist, Social Worker, Dietician, Clinical Psychologist.
  - Shared with other services; Occupational Therapist, Physiotherapist.
  - Available if required; Speech Pathologist

- **Supportive services**
  - Fertility: provided off site
  - Radiology: All imaging available on site
  - Blood products: delivered daily
  - Apheresis: Service to all pt groups

- **Outreach services**
  - Outreach clinics are provided at Goulburn, Bega & Moruya
4.2 Map of haematology services in NSW

The following diagram reflects the location of haematology services within NSW. These are categorised into 3 separate categories. These are:

- Sites providing intensive inpatient treatments for patients with AML.
- Rural centres with on-site haematologists. These sites have comprehensive ambulatory care units and are able to provide initial treatment, supportive care and follow-up services for patients with AML, however inpatient services are limited.
- Rural centres with outreach haematology clinics. These centres will have limited ambulatory care units and are able to provide some supportive care for AML patients. Follow-up is provided through haematologist clinics.

![Diagram 4.2.1 – Map of Haematology Services](image)

4.3 Patient journeys across various settings

The journey for patients with AML varies depending on several factors including:

- Type of AML
- Prognostic indicators
- Patient factors such as age and the presence of co morbidities
- Relapse or induction failure

Patients undergoing treatment for AML will receive intensive chemotherapy aimed at inducing a remission. Following remission induction, consolidation therapy to maintain a remission is required.
and young patients will be considered for bone marrow transplantation. Elderly patients with AML, particularly those over 65 will frequently follow a different journey. Elderly patients or those with co-morbidities who would not tolerate intensive chemotherapy may receive low dose regimens with the aim of controlling symptoms and delaying progression of the AML. There will be a small proportion of patients who will only receive supportive care and not have any system treatment for the AML.

Throughout the course of treatment patients will move backwards and forwards between the inpatient and ambulatory care settings. Patients undergoing intensive chemotherapy will spend a large amount of time throughout the treatment in the inpatient setting with short periods where ambulatory care may be appropriate. The aim for patients receiving low dose regimens or supportive care is to maintain quality of life for as long as possible and therefore the provision of care in the ambulatory care setting is important to keep this patient population out of hospital.

Components of the care pathway for AML, depicted below provide an overview of the typical journey for patients and summarises the related processes.

**Diagram 4.3.1 – Schema of care pathway for AML**

- **Presentation and referral**
  - Recognition of potential haematological malignancy
  - Referral patterns
- **Diagnosis and work-up for**
  - Diagnostic requirements
  - Pre-treatment assessments
  - Additional pre-treatment considerations (Venous access, fertility, tissue typing, Allied Health)
- **Treatment**
  - Scope of clinical practice to deliver safe quality care
  - Treatment models (Inpatient, outpatient and outreach services)
- **Transplant**
  - Early identification and referral
  - Early notification of transplant date
- **Follow-up care**
  - Rehabilitation, re-entry to work
  - Frequency, testing, screening
  - GP and community role
  - Back referral processes
- **Relapse or induction failure**
- **End of Life care**
- **Long term survivorship**
  - Determination of intent (Cure, disease control / palliative)
  - Considerations for salvage therapy
  - Role of palliative and supportive treatments
  - Use of palliative chemotherapy & blood product support
  - Bereavement counselling
  - Late effects
  - Survivorship
4.4 Innovative Models of Care

There were a range of good practices and innovative ideas throughout the patient journey to improve the outcome or experience for patients. The table below identifies these models and innovations across the continuum of care.

<table>
<thead>
<tr>
<th>Stage of Journey</th>
<th>Innovative Practices</th>
</tr>
</thead>
</table>
| Presentation and referral        | **Regular videoconferencing**  
Several centres have initiated regular videoconferencing with rural sites. This enables early identification of patients for referral, good communication between centres relating to important patient information, a seamless process for transfer and follow-up of patient’s and collaboration on complex cases.  
**Patient flow initiatives**  
Systems implemented within a LHD to streamline patient flow processes and direct patient transfers from satellite centres once a patient has presented to emergency department for some acute conditions or specialties such as patients requiring ICU care or neonatal beds.  
**AYA services**  
There are services for adolescent and young adult (AYA) patients with haematological and oncological malignancies at some centres. These services provide a specialist in AYA treatments, an AYA CNC, clinical Psychologist and Social Worker who are trained and skilled in managing the unique and complex issues relating this group of patients. |
| Diagnosis and work-up for treatment | **Central Venous Access Device (CVAD) insertion**  
There is a project in place to investigate the use of triple lumen PICC lines inserted at the bedside by nurses using ultrasound guidance. This will reduce waiting times and improve complication rates related to alternative devices.                                                                                                                                                                                                                           |
| Treatment                        | **Extended opening hours for ambulatory care**  
Ambulatory care units open on Saturdays, and Sundays for some centres increase the availability of some treatments as an outpatient rather than requiring hospital admission and inpatient care. Extended opening times into the evening allows for long treatments such as multi-unit blood transfusions to be provided without requiring inpatient admission.  
24 hour short stay beds provides bed flexibility for admissions and caters for overnight treatments such as high dose Methotrexate.  
**ED Bypass processes**  
Direct admission, bypassing ED is available for patients who are unwell following treatment in some units. This is provided through the haematology ambulatory care unit during opening hours in which patients are assessed and initial treatment provided in the ambulatory care unit while awaiting an inpatient bed. This process enables treatment for patients by specialty trained staff, reduces emergency department overcrowding and the risk of infectious exposure to immunocompromised patients.  
**Management of Overflow patients**  
Use of a single ward to house all haematology overflow patients enables up skilling of staff and ensures consistent quality care to all patients.  
**Early discharge with structure follow-up**  
Formalised early discharge program for patients able to reside within the local area with a structures follow-up service provided by the CNC reduces patient length of stay and ensures patient safety. |
One centre has a quarantined bed available daily within the general ambulatory care unit with Haematology Registrar support for urgent medical reviews and treatment, supporting early discharge and a structured follow-up process.

**Outreach programs**
Outreach services have been implemented at a small number of sites. The adult model enables patients within the local hospital catchment area to be seen at home following discharge and have symptoms and side effects of treatment managed from home enabling early discharge for these patients, reducing the need to travel to the hospital as frequently for less mobile patients and decreasing unplanned admissions, keeping patients at home for longer.

The paediatric model provides rural outreach CNC’s to support local hospitals and patients from rural centres enabling some treatments and follow-up to occur in rural areas reducing travel for patients and enabling them to stay at home for longer.

<table>
<thead>
<tr>
<th>Transplant</th>
<th>No innovative practices in this area were identified.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Follow-up care</strong></td>
<td><strong>Exercise tolerance and rehabilitation programs</strong></td>
</tr>
<tr>
<td></td>
<td>Exercise and rehabilitation programs specifically designed for post chemotherapy treatments are available interstate and internationally and as privately operated programs within NSW. These provide a structured approach to combating fatigue and building up strength following intensive treatments enabling patients to integrate back into a balanced life style with work and social interaction.</td>
</tr>
<tr>
<td><strong>End of Life care</strong></td>
<td>No innovative practices in this area were identified.</td>
</tr>
<tr>
<td><strong>Long term survivorship</strong></td>
<td><strong>BMT Long Term Follow-up Program</strong></td>
</tr>
<tr>
<td></td>
<td>A model of care for long term follow-up following allogeneic and MUD transplantation ensures the late effects of treatment are monitored and managed in a multidisciplinary team.</td>
</tr>
</tbody>
</table>

5. **Key Findings**

The key findings and discussion are presented in the following six sections: Accessibility, High Quality Care (Safety and Appropriateness), Integrated and Continuous Care, Responsive patient centred care, Efficiency and Sustainability and Effectiveness.

5.1 **Accessibility**

Accessibility is described by the National Health Performance Framework\(^7\) as ‘People can obtain health care at the right place and right time irrespective of income, physical location and cultural background.’

Access to health care means there is an adequate supply of services within an acceptable timeframe, barriers to accessing health care are identified and addressed, new treatments and technologies are assessed for appropriateness and uniformly available and utilisation is equal across all community sectors including indigenous, low socioeconomic groups and diverse cultures.\(^9,10\)

Treatment for AML is predominantly inpatient based, however more services are moving towards combined inpatient and outpatient treatments particularly during consolidation cycles of treatment.
Access to both inpatient and outpatient beds therefore requires consideration during discussions relating to accessibility.

This section of the report discusses accessibility in terms of patient referral, capacity, access to support services and access to specific clinical disciplines.

5.1.1 Referral for Treatment

The initial diagnosis of AML is frequently made via a peripheral blood film and may be identified by the patients’ general practitioner or local hospital. Referral to a metropolitan centre that treats AML is then required. Diagnosis is then confirmed by the treating centre following further investigations.

Referrals to AML treatment centres are influenced by two key factors. The first is in areas where a visiting haematologist is available and referral is most frequently made to the main treating centre of that haematologist. This enables continuity of follow-up locally following completion of treatment in a metropolitan centre. The second factor is the establishment of links between centres with on-site haematologists and AML treatment centres in which regular communication via videoconferencing occurs. In these instances communication is usually directly with the haematologist and admission to an acute treating facility is arranged promptly. Consultations revealed that formal systems and referral patterns aide with the patient flow process. Established links and referral pathways are provided in appendix 1.

There are 6 centres in rural NSW with on-site haematologists, and 9 centres with visiting haematologists with the east coast of NSW well represented, however there are large areas of rural NSW that do not have the benefit of these existing links particularly in Western NSW and Far West Local Health Districts. Referral patterns from these areas are less clear and rely on the knowledge of the general practitioners and emergency physicians. This creates the potential for gaps in the provision of prompt access to appropriate haematological care and creates large geographical areas for some centres to cover.

Patients from some regions of NSW are treated interstate due to individual preference and proximity of interstate facilities. This includes patients from southern NSW receiving treatment in Canberra or Melbourne, patients from Northern NSW receiving treatment in Brisbane and patients from far west NSW receiving treatment in Adelaide. This creates cross border challenges that include; communication with health care teams, care coordination, transfer of information and funding issues particularly with high cost outpatient pharmaceuticals.

Consultation with clinicians revealed that in instances where access to referral centres is arranged through means other than directly with the haematologist, there are reports of delays in transfer of up to 5 days from peripheral hospitals to the treatment centre while waiting for an available bed. Dohner et al. have identified that treatment outcomes may be adversely affected by delays in treatment of greater than 5 days from diagnosis [11].

The NICE guidelines [12] state that a blood film suggestive of acute or chronic leukaemia requires urgent referral, and that routine referral should follow a locally agreed referral guide. The Victorian Framework similarly identifies signs and symptoms of a low white cell count or abnormal coagulation as requiring immediate assessment as a medical emergency and a new or suspected diagnosis of AML requiring immediate discussion directly with a haematologist or haematology registrar with adequate experience [6].

Referral back to rural centres for supportive care following completion of treatment was also identified as difficult however this was quite variable and primarily dependent on the patient
location. The Cancer Institute NSW identified 35 units in rural areas providing chemotherapy and haematology services[13], however information relating to the location and services available in these clinics is not readily available for clinicians in metropolitan treating centres. Furthermore, consultation revealed that when rural centres are approached to provide supportive care, there is often a reluctance to take on haematology patients for blood transfusion support or Central Venous Access Device (CVAD) care. It is hypothesised that this is due to a lack of knowledge and confidence in managing this group of patients.

### Findings:

**F1.** Referral patterns from rural and regional areas where there is no outreach haematology service are unclear. This leads to delays in the transfer of patients to AML treatment centres due to bed availability particularly when there is no direct communication with a haematologist. Communication and continuity of care is enhanced where formal links between centres exist.

**F2.** Challenges in the identification and availability of supportive care services for patients in rural areas in between treatments and following completion of treatment for AML inhibits early discharge home for many patients.

### Suggested Actions:

1. Guidelines and processes for referral with time frames for review by a haematologist based on urgency for suspected haematological malignancy are included in a model of care for AML.
2. The easy identification of facilities with the capacity to provide supportive care for patients undergoing treatment for AML and the process for accessing care is supported in a model of care for AML.

### 5.1.2 Referral for Transplant

There is a high risk of relapse for patients with AML ranging from between 30% to 80% depending on prognostic factors[14] and a high proportion of these patients will require an allogeneic transplant. In NSW 5 of the 12 adult centres and 2 paediatric centres undertake allogeneic transplant. Referral for transplant from an AML treatment centre to an allogeneic transplant centre is frequently required.

Feedback during consultations suggested that there are inconsistencies in the timing for referral across all the centres and no clear referral pathways for transplant. Early referral enables planning and scheduling by the transplant centre and a collaborative approach between treating centre and transplant centre in consolidation treatments and work up to transplant. The choice of referral centre was reported to frequently be dictated by waiting time for transplant however there was limited information regarding waiting times available to clinicians wishing to refer patients. At the same time, transplant centres are reporting a large increase in the number of patients referred for transplant and difficulties in managing this. Mechanisms to identify waiting times for transplantation has been discussed within the BMT network, however suitable parameters for measurement have been difficult to determine and a system for identifying waiting times has not been implemented.
5.1.3 Access to inpatient beds

Access to inpatient beds for patients with AML is required for 3 reasons. These are: New diagnosis requiring diagnostic work-up and treatment, readmission for subsequent cycles of treatment and supportive care for febrile neutropenia following outpatient management of consolidation cycles. The consultation process revealed that access to beds for chemotherapy admissions relies heavily on discharges occurring and patients admitted for supportive care and febrile neutropenia will be placed in outlying wards if no bed is available in the haematology unit. Some centres reported a consistently high number of outlying patients leading to an increased amount of resources to provide support to staff, patients and carers on outlying wards.

The evidence suggests that patients managed on wards that are not clinically appropriate experience an increased risk of adverse events\[15\]. Adverse events lead to an increased length of stay and cost of treatment and poorer patient outcomes. Analysis from the patient stories provides insight into the concerns from patients when managed in an environment that is not specifically designed for haematology patients. These concerns included an increased risk of infection when cohorted with non-haematology patients and a decrease in the knowledge and skill of clinicians providing day to day care on outlying wards.

Chemotherapy admissions are frequently delayed in many centres often by several days. This poses challenges to patients travelling long distances to access care including accommodation issues and expenses or late arrival further delaying treatment. The use of a short stay unit collocated with the inpatient ward in one centre provides some flexibility for patients waiting admission for chemotherapy. Other centres have moved a significant number of treatments to the ambulatory care setting through the use of early discharge programs for appropriate patients to increase the availability of inpatient beds however this is hampered in many centres by the ability to readmit the patient into an appropriate bed when required.

Findings:
F 4. Admissions for consolidation treatment with chemotherapy are consistently delayed by several days with a high portion of patients treated on outlying wards. Inpatient capacity at some centres has been increased by moving many inpatient treatments to the ambulatory care setting however it is important to recognise the increases in the level of knowledge and expertise required in the ambulatory care setting to support this move.
5.1.4 Access to ambulatory care spaces
There has been a dramatic increase in the number of patients receiving care and treatments in oncology and haematology ambulatory care settings in recent years. Several centres have chemotherapy suites with trained oncology staff where outpatient chemotherapy may be administered, but have limited space for other supportive care needs of the haematology patient such as blood product support, assessment of chemotherapy related side effects or central venous access device care. This is explored further in section 5.2.1.

In some centres these services are provided in a range of various settings including general ambulatory care. Haematology specific knowledge and skills in general ambulatory care settings varies depending on the centre. An increased level of support from experienced clinicians such as CNC’s and educators is required to support the provision of care for patients in most general ambulatory care settings. Operating hours of ambulatory care settings range from 8am till 5pm Monday to Friday up to 6 and 7 day services with extended opening hours into the evening in some centres to cater for long infusions. Extended operating hours allows increased patient throughput, multiple units of blood products to be administered where admission to the ward would otherwise be required and the ability to provide 7 day per week treatments such as Azacitidine, as an outpatient.

The NICE guidelines recommend a designated area for outpatient care with the provision for isolation and long infusions\(^ \text{12} \). Specialised haematology step down units are available in only a few centres and bookings into ambulatory care units at short notice are difficult to arrange. Patients are admitted to the ward overnight to receive care when outpatient beds are unavailable. A shortage in the availability of appropriate ambulatory care beds at some centres impacts on the ability to provide early discharge for appropriate patients.

**Findings:**

F 5. The opening hours of some ambulatory care units is insufficient to meet demand and the needs of haematology patients requiring frequent medical review and long infusions.

F 6. Treatments provided in a general ambulatory care unit without trained haematology nursing staff increases the resources required to support the haematology patient in these clinical areas and maintain patient safety.

**Suggested Actions:**

R 5. The requirements for outpatient care of patients receiving treatment for AML including staff training and recommendations for operating hours are included in a model of care.
5.1.5 Access to support services

Three areas relating to access to support services were identified as problematic. These are: availability and access to new or high cost pharmaceutical agents, molecular and cytogenetic testing at diagnosis and timely access to central venous access device insertion.

Pharmaceutical
The consultation process identified 2 key aspects relating to availability and access to pharmaceutical agents for patients with AML. These are:

- Limited availability of many high cost or non PBS medications in rural areas. If patients are commenced on a treatment in a metropolitan centre, they are required to provide the drug on an ongoing basis. This results in hospitals needing to ship medications to patients in rural areas via mail or courier particularly after transplant. Commonly used examples for AML patients include Posaconazole and Valacyclovir.
- An inability to provide treatment with Azacitidine in rural centres due to administration and reconstitution requirements. The drug is used for treatment of some forms of AML and is administered as a subcutaneous injection daily for 7 days on a 4 weekly cycle. While patients would otherwise manage at home, they are required to come to Sydney for 1 week every month to receive the treatment. In metropolitan centres, those with a 7 day ambulatory care service have the ability to provide this treatment as an outpatient, whereas centres without a 7 day service are required to admit patients for the treatment. Patients are frequently admitted for the entire week to ensure bed availability for the weekend component of the treatment.

Diagnostic
There were reports from some centres regarding fragmentation of diagnostic services in relation to molecular and cytogenetic testing. The extent to which this was problematic varied between sites, with some centres having all testing available on site while others are required to send multiple samples to various laboratories for different molecular and cytogenetic tests. The requirement to use multiple laboratories and the use of paper based reporting systems has led to some reported difficulties in accessing results.

Slow turnaround times and underfunding for diagnostic testing was almost universally reported. Funding for these tests is currently absorbed by the requesting centres leading to rationalisation of the tests ordered and an inconsistency between centres in the diagnostic markers requested for each new diagnosis of AML. It was identified that not all the testing that is performed is necessary, and not all testing require urgent results, however in some instances slow turnaround was reported to impact the ability to enrol patients on clinical trials, and delay decisions regarding treatment. It was identified that these challenges may become more problematic as new markers are developed and become available.

The Victorian Patient Management Framework\(^6\) identifies that every patient being considered for active treatment should have samples sent for cytogenetics, flow cytometry and molecular diagnostics, but doesn’t go as far as to describe the specific testing required. Suggestions made during the consultation process to improve practice in NSW included; standardisation of testing and requirements for diagnosis and work-up to treatment, a system for identifying urgency of testing to enable faster turnaround times, and identification of centres with facilities to undertake the various tests required.

Central Venous Access Devices (CVAD’s)
Many centres reported barriers to timely access to services for central venous access device (CVAD) insertion. The preference for many centres is a Hickman catheter however delays in access to insertion mean that alternative devices such as central venous catheter or PICC lines are often
arranged. A Hickman catheter is a tunnelled device with long term dwell capability to meet the needs throughout the patients’ course of treatment while the alternative devices are suitable for short term use and will require replacement between treatment cycles.

Device insertion is required within 1-2 days of diagnosis to allow immediate commencement of treatment. Insertion is generally performed by either a surgeon in theatre, or by an Interventional Radiologist in the Medical Imaging department. Access to theatre time within this time frame is frequently difficult and a lack of adequate sedation during radiological insertion can be traumatic for many patients. Trauma experienced by patients during radiological placement of CVADs was demonstrated through the patient stories and careful screening of patients for suitability of radiological placement should be considered.

Existing frameworks and guidelines did not specifically address the timeliness for insertion of devices, however the NICE guidelines\textsuperscript{[12]} stated that the insertion of CVAD’s should be carried out in dedicated areas and real time imaging should be available.

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<thead>
<tr>
<th>Findings:</th>
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<tbody>
<tr>
<td>F 7. There are barriers to accessing molecular and cytogenetic diagnostic testing and results.</td>
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<tr>
<td>F 8. There are delays and barriers to accessing services for insertion of the preferred central venous access devices (CVAD’s) in the time frames required resulting in alternative devices that may be sub optimal for the patient being selected for use.</td>
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<th>Suggested Actions:</th>
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<tr>
<td>6. Molecular and cytogenetic testing for all patients planning to undergo treatment is standardised and documented within a model of care for AML.</td>
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<tr>
<td>7. Appropriate timeframes for the insertion of central venous access devices are identified within a model of care for AML.</td>
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### 5.1.6 Access to specific clinical disciplines

Psychosocial support and access to Clinical Psychology services was the most frequently reported problem across centres with regard to accessing specific clinical disciplines. The other 2 areas identified are access to Palliative Care beds in some areas and consistency in addressing the fertility needs of patients undergoing intensive treatments.

**Psychosocial support**

The availability of psychosocial support including clinical psychology and mental health services was inconsistent across centres, with varying levels of support depending on whether the patient is an inpatient or outpatient and little or no service for family members or carers also requiring psychosocial support. Some centres reported having full time clinical psychologist for haematology and BMT services while other centres had very limited access to clinical psychologist and relied on services primarily dedicated to other departments. Despite this, all centres reported insufficient support to meet the needs of their patients.

The Victorian Patient Management Framework\textsuperscript{[6]} acknowledges the emotional stress for patients with AML recommending regular screening and ongoing monitoring for psychological distress and
that referral to psychologist or psychiatrist may be required. Paul et al. discusses the devastating effects of haematological malignancy on the lives of patients and families to include sexuality, fertility altered family roles and an inability to generate income and reports the rate of psychological distress to be between 32% and 48%.[16]

Fertility
Feedback from the consultation process suggested that the fertility needs of patients with AML are not uniformly addressed. The risk of infertility following intensive chemotherapy is high and can be a sensitive issue. The urgency of treatment in AML limits the options for fertility management and preservation particularly in female patients although there are some emerging strategies that may provide some benefit. Strategies and agreed procedures for addressing fertility for patients undergoing treatment for AML are required[6, 12].

Information on risks to fertility and options to preserve fertility are included in limited detail in the leukaemia foundation booklet for AML and there is a range of different websites available with information for patients undergoing cancer treatments. Identification of appropriate sources of information for patients will assist in ensuring patients are informed about fertility concerns related to treatment.

Palliative Care
The consultation process identified that the patterns for referral to palliative care is varied and it is difficult for clinicians to identify the appropriate time for referral in many instances. Contributing to this, in part is the intensive nature of treatments and reluctance on the part of some palliative care teams to become involved while patients are receiving active treatment. The use of supportive care such as blood transfusions during palliation adds to the complexity of managing this group of patients in the palliative setting and there is little agreement as to the appropriateness of various supportive treatments during the terminal phase of illness.

Access to palliative care beds in the non-acute setting was a concern for some centres with the only option for longer term palliative beds being provided in nursing home facilities which is felt inappropriate for younger patients with haematological malignancies. Not all centres experienced this problem and one centre expressed a desire for access to palliative care beds within the acute care facility to be made available to enable the continued input of haematology once transfer to palliative care is made.

Suggested recommendations provided during the consultation process include the integration of palliative care into care pathways for patients with haematological malignancy, development of guidelines to identify when referrals should occur to ensure they are not occurring too late in the process and the use of transition processes or shared care models during end of life care. The NICE guidelines for haematology state that Palliative care services and haematology teams should work together to provide integrated care for patients, and advocate the presence of agreed guidelines for managing the transition from aggressive treatment to palliative care[12].

The integration of palliative care with haematology and oncology teams is outlined in more detail in the NICE guidelines for supportive and palliative care for adults with cancer[17]. Evidence of the obstacles to introducing palliative care to acute haematology patients is well documented in the literature to include; The high intensity and invasive nature of treatments for haematological malignancy, the significant sequelae from treatment, the speed of change to a terminal event, the frequency of need for supportive care such as blood tests and transfusions and the possibility of catastrophic haemorrhage.[18]. The literature further recommends the use of supportive care such as blood product support to improve quality of life throughout the disease trajectory and suggests that provision for administration of blood products in the non acute setting should be explored[17, 18].
5.2 High Quality Care (Safety and Appropriateness)

High quality care is defined as care that is appropriate and safe.\cite{8} The National Health Performance Framework\cite{7} describes safety as ‘The avoidance or reduction to acceptable limits of actual or potential harm from health-care management or the environment in which health care is delivered’. Appropriateness ensures that treatments and interventions are selected based on the likelihood that the treatment will produce the best outcome. It is also considered in the context of the right setting. This may be influenced by a number of factors including government policy, organisational structure and strategic aims and patient eligibility. Appropriateness can be reflected through outcome measures for services and is provided according to accepted standards.\cite{8}

Safe and appropriate care for patients with AML can be measured in the overall treatment outcomes however parameters such as complications rates, early death rates and ICU admissions may provide further insight into this dimension of care.

This section of the report discusses findings relating to appropriateness and safety in terms of infrastructure and resources and complexity and acuity of patients.

5.2.1 Infrastructure and resources

There were 2 key aspects relating to infrastructure and resources that were identified. These are; the number of single rooms available with ensuite facilities and the differences in setup of ambulatory care services across centres in NSW.

Single Rooms with ensuite

The varying size and patient mix of ward units makes it difficult to draw comparisons on the number single rooms with ensuite facilities available for patients with AML however many centres report insufficient single rooms to cater for the number of patients requiring single rooms. Preference is given to patients requiring isolation due to the presence of infections such as MRSA or VRE, patients in the terminal phase of illness and patients undergoing bone marrow transplantation.
The growing number of multi-resistant organisms is becoming a significant problem on haematology units increasing the morbidity associated with intensive treatments. The prolonged period of neutropenia associated with treatment for AML places this patient population at high risk of developing a hospital acquired infection. Limiting contact with potentially pathogenic organisms is an essential method of reducing the risk of hospital acquired infection \[^{19}\]. Patients undergoing treatment for AML would benefit from isolation in a single room and ensuite facilities to reduce exposure to microorganisms that lead to infectious complications.

In addition to insufficient single rooms, not all available single rooms had ensuite facilities and one centre reported an overall shortage of bathroom and hand washing facilities across the unit. Queensland Health\[^{20}\] recommend a minimum of 1 isolation room with ensuite facilities for every 5 inpatient beds while the NICE guidelines recommend all patients undergoing induction therapy for AML should be treated in a single room with ensuite facilities\[^{12}\]. The Victorian Framework requires appropriate inpatient and outpatient facilities for managing these patients' but does not elaborate on what the requirements for an appropriate facility with respect to single rooms and bathrooms would be\[^{6}\].

**Ambulatory Care Services**

There are a variety of methods for providing ambulatory care services to patients with a haematological malignancy. Six of the twelve adult centres and both paediatric centres provide a comprehensive ambulatory care service in a single setting for haematology patients, while the other 6 centres have multiple locations for providing haematology care. Treatment in these centres is mostly shared between a chemotherapy suite and either a haematology step down unit, or general ambulatory care. Capacity for isolation in the ambulatory care setting is not available at all centres.

Feedback from clinicians suggests that the segregation of outpatient services for chemotherapy and other ambulatory care needs creates the following challenges for clinicians and patients:

- Disjointed care creating a lack of continuity with reports of patients needing to go to multiple different places to receive care in the same day
- Difficulty maintaining skills and knowledge in general ambulatory care setting
- Decreased haematology specific knowledge in chemotherapy suite as many staff have an oncology background rather than haematology specific knowledge
- Increased support required from senior nursing clinicians such as CNC’s and CNE’s to maintain safe and effective care in general ambulatory care and chemotherapy suites

**Findings:**

**F 12.** There are insufficient single rooms with ensuite facilities at nearly all treatment centres to cater for the number of patients requiring single rooms. Priority for single rooms goes to transplant patients, patients requiring isolation due to colonisation with multi-resistant organisms and terminal patients meaning many patients undergoing induction therapy for AML are treated in multi bed rooms or bays.

**F 13.** Ambulatory care structures are varied with segregation of outpatient services for chemotherapy and other ambulatory care needs which creates challenges to clinicians in providing safe and effective care by clinicians skilled in managing patients with AML.
5.2.2 Complexity and acuity of patients

There were 2 key aspects relating to complexity and acuity of patients identified. These are the management of patients on outlying wards and the unique needs of the adolescent and young adult group of patients.

Management of patients on outlying wards

The nursing management of a patient undergoing treatment for AML is complex. Patients can become unstable and critically unwell in a short period of time. Nursing care requires specialised knowledge and skill to monitor and detect changes in clinical condition quickly. Feedback from clinicians indicated there are a high number of outlying patients in some centres creating concern relating to patient safety, nursing skill levels on outlying wards and the appropriate management of complications relating to treatment.

One centre has attempted to develop strategies to manage the high frequency of outlying patients. Following a failed attempt to manage outlying patients’ through the development of roving teams with medical, nursing and allied health support, a single unit was identified to house all outlying patients. The repeated need for outlying beds meant that training a small number of staff on a single ward was manageable and sustainable and the high frequency of patients on this ward meant the knowledge gained was retained by the staff. The patient stories highlighted the negative impact and stress to patients and families when being treated on an outlying ward.

Existing patient management frameworks\[^6, 12, 20\] do not specifically discuss the management of patients on outlying wards, however do advocate that patients should be cared for by registered nurses with knowledge and skills to support patients. Goulding, et al. has described several factors relating to patient safety when patients are managed on outlying wards, citing a lack of specialist knowledge or expertise on outlying wards as a problem and refers to Reason’s Swiss cheese model of accident causation exposing outlying patients to a higher degree of risk for adverse events\[^21\]. The predicted rate of increase for new cancer cases is approximately 5000 cases every 5 years, 10% of which will be haematological malignancy\[^3\]. This equates to an increasing demand for haematology services at a rate of approximately 14% over the next 5 years. Suggestions through the consultation process identified the development of guidelines for managing outlying patients as a possible strategy to assist with improving patient safety however the ongoing increasing demand dictates that longer term solutions are identified to ensure patients are managed in an appropriate environment for their complexity and needs. This includes discussion and consideration of current and future needs in local facility strategic planning meetings.

Adolescent and Young Adults

Adolescent and Young Adults (AYA) are emerging as a unique patient group within cancer care. The age range for this patient population is not clear although predominantly relates to patients between the ages of 15 and 24 but can include patients up to the age of 30\[^22\]. AYA specific treatment programs have now been developed in the United Kingdom, United States, New Zealand and Australia\[^23\]. There are three AYA teams in NSW. Two are based in Paediatric centres and one across paediatric and adult services providing a Local Health District approach to care for these patients. AYA teams consist of a paediatric and adolescent oncologist, and a CNC, Social Worker and Clinical

**Suggested Actions:**

9. Guidelines for ambulatory care and ward facilities are documented in a model of care for AML. Future ward development or renovations consider the recommendations for isolation facilities and haematology related ambulatory care treatments.
Psychologist specially trained in the needs of AYA patients. Due to the age range for this patient population, AYA services that cross paediatric and adult services would appear to provide the most comprehensive service.

During the consultation phase, one centre identified the challenges of providing care to AYA patients without the benefit of a specialised team. Teams providing AYA services identified challenges relating to the availability of a dedicated space for AYA patients with age appropriate facilities, the transition of care between centres, particularly for patients transitioning between paediatric and adult centres, and the differences in practice between centres including isolation procedure and the use of sedation and anaesthetic for invasive procedures.

**Findings:**

F 14. There is an increasing need for management of patients undergoing treatment for AML to be managed on outlying wards due to capacity problems. There are challenges in ensuring and maintaining a high level of clinical expertise while providing care for these patients.

F 15. AYA patients are a unique patient group with new specialist teams becoming available in select areas to assist with managing these patients.

**Suggested Actions:**

10. Skill levels and the requirements to maintain safe patient care of complex patients undergoing treatment for AML are included in a model of care.

### 5.3 Integrated and Continuous Care

Continuity of care is described by the National Health Performance Framework\(^\text{[7]}\) as the ‘Ability to provide uninterrupted, coordinated care or service across programs, practitioners, organisations and levels over time. Integration requires a smooth transition between acute inpatient setting, outpatient and ambulatory care and the community and primary care sectors.’

Patients undergoing treatment for AML require treatment as an inpatient, although some centres provide early discharge programs with follow-up care through ambulatory care and outpatient settings. Rural patients are treated in metropolitan hospitals and following completion of treatment, day to day care and support for these patients is provided in local hospitals or by community and primary care teams in collaboration with the treating haematologist. Communication between organisations and teams is essential in ensuring an integrated approach to care with seamless transition between services.

This section of the report discusses findings in relation to Integrated and continuous care in terms of Transition and transfer of care, links with external services, health records and communication and patient follow-up.

### 5.3.1 Links with external services

There are a number of support organisations assisting patients and families living with leukaemia and other haematological malignancies. These include; Leukaemia Foundation, NSW Cancer Council, Arrow bone marrow transplant foundation, Nelune Foundation, CanTeen, Redkite and CanAssist. These organisations provide a variety of services and support for patients with AML including the
development and provision of age appropriate patient education material, financial assistance, transport, accommodation, support groups and a helpline. It was identified that these services need to be acknowledged and included in the development of a model of care for patients with AML. Through the patient stories, patients described the support for transport and accommodation provided by external organisations as a great benefit indicating that it would have been difficult to manage without this support.

Findings:
F 16. There are a range of external agencies and organisations supporting care to patients with AML and it is important to ensure that these organisations are recognised in the development of a model of care for AML.

Suggested Actions:
11. The services available are recognised in a model of care for AML. There is documentation of the available services that is accessible by health care professionals and patients and families.

5.3.2 Health records and communication
Electronic recording of health information is rapidly increasing with pathology services within NSW Health logged electronically and many centres now using oncology management systems for prescribing treatments and recording complications, toxicities and response to treatment however these systems are not uniform across all centres, and the linking of information between centres particularly when travelling across different local health districts is not available. This means that manual transfer of information is required resulting in either reliable information not being made available for clinicians, or a delay in the availability of information required for patient treatments.

Communication between health professionals and clinicians at referring and treating sites is essential for safe patient care in an integrated way. Regular videoconferencing with referring centres has been shown to induce successful communication with the multidisciplinary team however this system for communication was only identified at 2 sites. Participation from the multidisciplinary team where videoconferencing was available is varied. Suggestions for improving communication included developing an information template for AML that captures all the relevant disease and treatment related aspects of care.

Findings:
F 17. Electronic recording of health information is increasing however this information is not easily transferrable across LHD.
F 18. Regular videoconferencing between referral and treatment centres enables good communication between sites however this is limited to a few centres where formal links are established.

Suggested Actions:
12. There are clear processes for communication between centres documented within a model of care, particularly where care is provided across more than one LHD.
5.3.3 Patient follow-up

Follow-up at the completion of treatment including intermediate and long term follow-up is primarily performed by the patients’ haematologist with a focus on disease monitoring. This is undertaken either in a rural outreach clinic if available or in the metropolitan treating centre. The consultation process identified a paediatric model in which follow-up care is shared between local paediatricians and paediatric oncologists for rural patients to reduce travel needs of patients to attend follow-up clinics and providing some local support if required in between clinic visits.

One LHD reported many rural patients with ongoing supportive care needs are referred back to GP’s at completion of treatment and the local oncology / haematology unit is rarely included in follow-up care. This has led to poor coordination of ongoing care needs. An example was provided in which a patient with relapsed disease required supportive care with weekly platelets. This patient was sent home with GP follow up and was receiving platelet transfusions in the day surgery area even though there was an oncology ambulatory care unit on the same site. Support for other disease related symptoms and coordination of care could have been provided had the oncology clinic been aware of the patient.

The patient stories highlighted the importance of follow-up care for rural patients with one patient reporting an inability to receive blood product support locally while another patient reported a lack of confidence in nursing staff managing her Hickman catheter following admission to a rural hospital with febrile neutropenia. It is recognised that there are difficulties in obtaining blood products in rural areas particularly at short notice and when there are additional requirements of the products such as a requirement for CMV negative or irradiated products. Identifying patient needs in advance and careful planning can assist with managing these challenges in stable patients. Patients indicated a preference to maintain contact with the treating centre for all follow-up care. This was related to their confidence in the treating team in managing their unique health needs.

The literature identifies a disparity in the support needs required compared to the support actually available for many rural patients returning home following extended periods in metropolitan centres for treatment of haematological malignancy\cite{24}. An Australian study found patients reported their follow-up care needs to include psychosocial support and medical intervention relating to ongoing side effects and symptoms from treatment\cite{25}, while GP’s reported a discouragement of GP involvement, distance to specialist backup and a lack of knowledge on management to be the difficulties they experienced in relation to providing care following treatment for a haematological malignancy\cite{26}.

**Findings:**

F 19. The availability of supportive care following treatment for rural patients is varied and difficult to access.

**Suggested Actions:**

13. A model of care promotes clear documentation of follow-up plans for all patients undergoing treatment of AML that is communicated with primary health and rural services.

14. There is documentation of services available for patients following treatment for AML in rural areas that includes clear processes for accessing these services.

15. Processes for improving and maintaining skills for providing supportive care to patients following treatment for AML in rural settings are implemented.
5.4 Responsive Patient Centred Care

Responsiveness is described by the National Health Performance Framework[7] as a ‘service that is client-oriented. Clients are treated with dignity and confidentiality, and encouraged to participate in choices relating to their care.’ In a patient-centred model, patients become active participants in their own care and receive services designed to focus on their individual needs and preferences in addition to advice and counsel from health professionals. The Picker principles for patient centred care are widely accepted values for the development of a patient centred model. These eight principles reflect patient and family or carer values and needs with a coordinated and integrated approach to care that is easily accessible, has good communication and emotional support[27].

This section of the report discusses aspects relating to patient centered care in terms of care coordination, meeting patient needs and patient education.

5.4.1 Care coordination

Cancer care Coordinators were introduced to NSW cancer services through the Cancer Institute NSW in 2005. Since then, there has been a growing number of these positions most of which are employed within a tumour stream. The consultation process identified a limited number of haematology cancer care coordinators across sites treating patients with AML and an expressed desire for a haematology care coordinator in many of those sites without this service.

The chasing of results, coordinating complex protocols, ensuring all diagnostic investigations are booked, completed and results available is a time consuming process that is performed by a variety of clinicians with no one person taking overall responsibility. Care coordination streamlines this process and eases the burden of ensuring safe and effective care by ensuring responsibility is allocated to a single person. It was noted that centres tended to have either a Cancer Care Coordinator or a Clinical Nurse Consultant for Haematology however there are significant differences in the role and function of the two positions.

Care coordinator roles have been identified in the literature to enable a patient centred approach to care, provide improved navigation of the patient journey and a single point of contact for patients. Patients with access to care coordinators felt their care was well coordinated and they were well informed about their illness and treatment[28]. An evaluation of cancer care coordinator roles in NSW identified that the addition of these roles provided an improvement in patient satisfaction and the quality and capacity of cancer services. There was however, a limited capacity for these roles to undertake functions similar to those traditionally performed by Clinical Nurse Consultants such as development of service delivery infrastructure, protocols and data collection and quality improvement initiatives[28].

Findings:

F 20. Haematology Clinical Nurse Consultants and Haematology Care Coordinators provide different functions. Both play pivotal roles in the provision of care for haematology patients however care coordinators for haematology are predominantly only available in sites where a Haematology Clinical Nurse Consultant is not available.

Suggested Actions:

16. Staffing roles, structures and skill levels for managing patients with AML is documented within a model of care for AML.
5.4.2 Accommodation and Transport

Clinicians identified accommodation, parking and transport as the main challenges for patients during their treatment for AML. Treatment is provided over an extended period of time through which many patients and families suffer a loss of income. The high cost of accessing treatment for some patients is a significant burden.

Parking or transport is required on a daily basis for patients following discharge during consolidation therapy or post transplant where regular visits to ambulatory care settings are still required, or by family members supporting admitted patients through their treatment. There is very limited free or cheap parking around most hospitals and costs can escalate to upwards of $20 per day at some sites. Public transport to many sites is limited and not suitable for immunocompromised patients. Support for transport can be provided through the Nelune Foundation and Leukaemia foundation for some patients on a priority basis however this is not available for weekends.

Many patients undergoing treatment for AML will be eligible for disability parking. Suggestions to improve parking options for patients included the consideration of disability parking permits for all patients undergoing treatment for AML, and a website with information available to patients that includes transport and parking options.

Subsidised hospital based accommodation is available at some sites for rural patients requiring frequent outpatient treatments or the family members of rural patients staying locally to support the patient through treatment, however this is not uniformly available. The Leukaemia Foundation provides accommodation at 2 sites in Sydney with daily transport to hospital sites. This requires booking in advance and has limited availability. There is considerable cost for patients and families associated with accommodation when these facilities are not available.

Findings:
F 21. Assistance for parking, transport and accommodation for patients with AML is provided through non-government organisations such as Leukaemia Foundation however there remains substantial costs in accessing care for many patients.

Suggested Actions:
This is beyond the scope of a model of care for AML.

5.4.3 Patient education

During the consultation process, a range of issues relating to the provision of patient education were raised as outlined below:

- Detailed chemotherapy education is ideally provided by experienced nurses and includes practical information relating to chemotherapy safety as well as treatment schedules, hospital specific information and treatment side effects. One centre reported insufficient experienced nursing staff to provide chemotherapy education to inpatients, leaving education to medical officers who are not able to provide the level of detailed information required.
- A large portion of patient education is specifically focused on chemotherapy and chemotherapy related side effects and lacks important disease specific information.
- There is no information available specifically for adolescent patients.
- Written patient information material is available from many different sources including the Leukaemia Foundation, the Cancer Council, the BMT Network and the Cancer Institute NSW and they all contain varying information. Identification of appropriate available information for patients would assist in ensuring every patient receives the appropriate information for their needs.
- The Cancer Institute NSW provides treatment specific information for treatment protocols available on the evisit however there is no individual drug information that can be used for patients receiving single agent treatments, modified protocols or protocols from clinical trials.
- The written information available in different languages is not comprehensive and does not cover the range of languages necessary to meet the diverse culture in NSW.

The literature identifies that patient education is an integral and essential component of nursing practice and patients with haematological malignancies benefit from appropriate information when making treatment decisions, in managing and preventing unwanted side effects from treatment and improving compliance with treatment[29]. Many factors influence the effectiveness of patient education and exploration of alternative methods of education delivery that enables patient interaction and delivery at a time suitable to the patient such as electronic media and video format is warranted. Alternative strategies to deliver information have been demonstrated to be an effective method of providing education in a variety of clinical settings[30].

The information provided to patients was discussed extensively in the patient interviews. Many patients indicated that they really only wanted small amounts of information relating to what was happening at that particularly point in their journey however many family members sought additional information through the internet and other sources. This highlights the differing needs of individuals in relation to information and education relating to their disease and the importance of tailoring information to individual patients using a variety of methods to deliver relevant education.

Interpreter services were identified as a particular problem for patient education as well as during general communication with patients and undertaking clinical assessment. There is poor availability of interpreter services for many languages, particularly at short notice. The nature of AML requires urgent treatments and frequent changes to management at short notice. Delayed access to interpreters can create delays in progressing treatment and provide challenges in assessing and managing complications of treatment. The use of interpreters in the outpatient setting creates scheduling and timing issues, especially if the clinic is running late and interpreters are only available for specific time period.

It is well documented in the literature that language barriers prevent clinicians from obtaining accurate patient histories, impair the ability to engage patients in participating in decision-making regarding treatment, and limit the patients' ability to obtain sufficient information for preventing, managing and reporting side effects of treatment[31].

**Findings:**

F 22. Patient education is identified as an important component to providing comprehensive safe and effective care to patients with AML however there are many barriers to providing education and a lack of written material for specific patient populations.

F 23. There is a difficulty accessing interpreter services. Rapidly changing patient conditions and treatment plans mean there is a frequent need for repeated sessions with interpreters often at short notice.
5.5 Efficiency and Sustainability

Efficiency and sustainability is described by the National Health Performance Framework\(^7\) as ‘Achieving desired results with the most cost-effective use of resources. Capacity of the system to sustain workforce and infrastructure, to innovate and respond to emerging needs.’

Capacity refers to the ability of a service to provide care in a particular setting with adequate workforce and resource support. This requires an adequate infrastructure and multidisciplinary team with the relevant skills and knowledge to meet patient care needs now and into the future.

Efficiency refers to the extent to which outcomes are achieved in relation to the resources consumed. Outcomes may be thought of in 2 broad categories; health outcomes or patient satisfaction.\(^3\)

This section of the report discusses aspects relating to Efficiency and Sustainability in terms of workforce and education and training.

5.5.1 Workforce

All centres reported a good multidisciplinary team environment and approach to care for patients with AML however the consultation process identified variation in the availability, structure and input from the multidisciplinary team, particularly in relation to allied health services. The multidisciplinary team plays an integral role in the support and management of patients undergoing treatment for AML. The particular concerns raised during the consultation process identified:

- A lack of continuity for patients readmitted to outlying wards in some centres. Social worker and other allied health staff are attached to a ward rather than a specialty service so they will change if a patient is admitted to another ward. In some instances the staff member will follow the patients regardless of ward allocation, however it was reported that this does not occur consistently.
- There is limited or no clinical psychology support at some centres while other centres have support for either inpatients or outpatients but not both depending on the set up of services, and some centres reported a lack of support available for carers and family members struggling to cope with the illness of a family member.
- Physiotherapy support is available in all units, however the frequency and type of service available is varied. Physiotherapy is recommended for all long stay patients to maintain mobility however many services are provided after mobility is diminished rather than a preventative measure.
- All centres reported having access to a pharmacist either dedicated specifically to haematology or for cancer services. Clinicians expressed a need for pharmacy support to be provided by a dedicated experienced haematology pharmacist with haematology specific knowledge and expertise, and felt a lack of appropriate pharmacy support with haematology specific knowledge in some areas was a safety concern.

The NICE guidelines\(^12\) and the Victorian patient management framework\(^6\) clearly outline the appropriate members of a multidisciplinary team for patients with a haematological malignancy, the roles and functions of a multidisciplinary team and the frequency and to include a clinical
haematologist, a Registered Nurse with haematology knowledge and expertise, Pharmacist and social worker with further access to microbiologist and other health professionals such as palliative care teams. The multidisciplinary team approach is described to; incorporate treatment planning and ongoing care, meet regularly, have clear goals and communication processes and involve the patient.

There were several questions raised during the consultation process with regard to staff levels particularly in relation to medical and nursing staff. The expansion of some units with increasing medical staff without increasing other resources such as nursing and allied health raised the question as to whether there is an appropriate number of haematologists based on the number of patient presentations, what other staffing ratio’s per patient presentation should be, the appropriate skill level of those staff members and whether there is an appropriate ratio of nurses and allied health staff per clinical haematologist.

The consultation process also raised concerns that the acuity of haematology patients and the differing characteristics of the haematology patient from oncology patients when considering staffing requirements were not always recognised by hospital administration. Daily nursing responsibilities in the haematology setting will include the support and education to patients undergoing complex treatments, administration of complex chemotherapy regimens, recognition of an impending or actual problem in a timely manner and an ability to provide appropriate interventions as necessary to prevent acute clinical deterioration across inpatient, ambulatory care and community based settings. The Cancer Institute NSW has made some progress in identifying the complexity of chemotherapy treatments in the ambulatory care setting through the use of a time weighted algorithm, however this does not include the provision of non-chemotherapy related care such as blood transfusion, apheresis, assistance for bone marrow biopsy or CVAD care. The Western Australian model of care for haematological malignancy recognises the importance of allied health and nursing within the framework for care and recommends that an appropriate model for service provision with agreed guidelines for optimal staff configurations is developed.

Suggested Actions:
18. The minimum requirements for staffing levels are documented within a model of care for AML.

Findings:
F 24. A multidisciplinary team approach to care for patients with AML is consistent across NSW however there is variation in the membership and functioning of the multidisciplinary team particularly in relation to allied health services.
F 25. The acuity of patients undergoing treatment for AML is high, requiring complex clinical care however there is little documented evidence to identify appropriate staffing and skill levels, particularly medical and nursing staff based on patient numbers, level of activity or acuity.
5.5.2 Education and Training

The diminishing nursing workforce is well documented and high burnout rates within cancer nursing creates challenges for developing and sustaining an experienced nursing workforce\(^{(33)}\). Similarly other departments including pharmacy and social work are experiencing difficulties in recruiting and training staff.

Education and training is regarded with significant importance for all members of the haematology multidisciplinary team. The consultation process identified concerns relating to gaps in the availability of education for haematology clinicians. In particular the gaps identified include the:

- Provision of education programs regarding disease processes for haematology nurses
- Provision of haematology specific education programs for pharmacists and dieticians
- Programs to aid transition from haematology registrar to specialist

In addition to these identifiable gaps, it was reported that most nursing education programs are oncology derived with only a small component dedicated to haematology or focus predominantly on chemotherapy administration. Reports through the consultation process of slow or delayed escalation of care for acutely unwell patients particularly afterhours when the clinical expertise is diluted highlights the need for high level knowledge and experience within the specialty.

Succession planning and development programs to entice staff to the specialty and encourage development are required to create a sustainable workforce with knowledge and expertise within the specialty. In addition, sufficient staffing levels are required to enable sufficient time for education, training and succession planning to occur.

**Findings:**

F 26. Haematology requires a highly skilled workforce. Gaps in education programs for all staff disciplines create challenges for staff development and succession planning into the future.

**Suggested Actions:**

19. Succession planning and development programs are considered in conjunction with a model of care to ensure they entice staff to the specialty and promote staff development to ensure a sustainable workforce with the required knowledge and expertise within the specialty to manage patients with AML in a safe and effective manner.

5.6 Effectiveness

Effectiveness is described by the National Health Performance Framework\(^{(7)}\) as the ‘Care, Intervention or action provided is relevant to the client’s needs and based on established standards. Care, intervention or action achieves desired outcome.’ There is an expectation that treatments and interventions will produce a measurable benefit. The extent to which this is achieved is a measure of efficiency. Indicators of effectiveness include hospital admissions that could potentially have been prevented through the provision of appropriate non-hospital health services and five year survival of patients following treatment for malignant disease.\(^{(7)}\)

This section of the report discusses aspects of effectiveness in terms of Choice of treatment, clinical trials and data collection.
5.6.1 Choice of treatments

Peer reviewed treatment protocols for patients with haematological malignancies are available through the Cancer Institute NSW that are evidence based and well established. The Australasian Leukaemia and Lymphoma Group (ALLG) have well developed clinical trial protocols that are investigator led based on scientific merit and research. ALLG and Cancer Institute NSW protocols combined provide a wide selection of protocols for APML, AML induction, consolidation and salvage treatments and treatments for elderly patients. This allows clinicians a choice of protocols enabling clinical decision making based on patient characteristics and other contributing factors impacting on treatment selection.

Protocols provide recommendations for patient selection criteria, dose modifications, administration details, supportive management and prophylaxis. Despite utilising treatment options based on best available evidence, clinicians reported that patients with poor prognostic markers, particularly the elderly continue to have poor outcomes with a relatively low long term survival rate.

There remain few treatment options to offer elderly patients with AML and this patient population spend significantly longer in hospital than younger patients with AML. Treatment options that enable ambulatory care administration and management to maintain quality of life and keep patients at home longer are required.

One centre is developing an algorithm for selecting which protocol to use based on patient characteristics and prognostic markers to aid in the decision making process. There is value in treatment algorithms however treatment decisions are based on many factors which may not necessarily be transferrable across centres. A multidisciplinary team approach to determining appropriate treatments for individuals is required.

Findings:

F 27. A selection of comprehensive evidence based treatment protocols are available through the Cancer Institute NSW and Australasian Leukaemia and Lymphoma Group (ALLG) for treating patients with AML providing a consistent approach to treatments across NSW.

Suggested Actions:

20. A model of care for AML supports the use of evidence based treatment protocols developed through Cancer Institute NSW.

5.6.2 Clinical trials

There were several suggestions during the consultation process suggesting that all patients with AML should be enrolled on a clinical trial. Access to clinical trials however is limited by a number of factors. Opening clinical trials is time consuming and for many smaller centres where there will only be a small number of patients to enter on a single trial and the benefit for the effort required to be a trial centre needs to be considered. Other centres identified a difficulty in knowing what trials were open and where. Rural patients who would normally be eligible for a trial will often miss out as they would need to travel to Sydney to receive all their treatment rather than receiving it in a local treating centre. It is recognised that patients on clinical trials do better, however there is no funding to patients for travel relating research and clinical trials, making this costly and increasing the length of time patients need to be away from home.
A streamlined process that enables multi centre trials to be approved through a single application process was identified as an ideal approach. There is a single application process for multicentre trials however the workload to initiate trials for individual centres with small patient numbers remains a challenge.

### 5.6.3 Data collection

Data is collected by many centres. The detail, type and method of collecting information are different for various centres and largely dependent on individuals to collect the data. Data that is collected includes information such as activity data through ambulatory care units, number of transplants performed, information relating to time to engraftment or recovery, stem cell collection information, central venous access device complication rates, treatment related toxicities, ambulatory care waiting times for treatment, unexpected readmissions, chemotherapy extravasations, death in first 100 days post transplant. Data is collected in a variety of manners using local excel spreadsheets or downloaded from electronic record or oncology management systems that are in place.

Data collected is utilised locally to monitor and improve practice, but is not consistent or comparable between centres to enable benchmarking. Clinicians reported a desire for outcome data that describes toxicity and complication rates that is comparable between centres. Measuring the utilisation and performance of health services through tracking throughputs such as bed occupancy rates and length of stay has some ongoing utility however they yield no information as to the clinical effectiveness of the services provided.

The Australian Bone Marrow Transplant Recipient Registry (ABMTRR) is a good example for successful national data collection that is well established and provides up to date relevant clinical data to clinicians annually. The cancer Institute NSW is establishing a minimum data set for haematology to enable collection of comparable outcome data collection in the future.

### Findings:

**F 28.** Data relating to AML treatment is collected by various means locally and through NSW health organisations however there is a limited uniform data available to provide a clear picture of outcomes and morbidity associated with treatment in NSW.

### Suggested Actions:

**21.** A model of care for AML supports the collection of appropriate standardised data to enable measurement of outcomes that are relevant and meaningful to clinical practice.

### 6. Summary of Findings

The findings from the review are summarised below:

**F1.** Referral patterns from rural and regional areas where there is no outreach haematology service are unclear. This leads to delays in the transfer of patients to AML treatment centres due to bed availability particularly when there is no direct communication with a
haematologist. Communication and continuity of care is enhanced where formal links between centres exist.

**F 2.** Challenges in the identification and availability of supportive care services for patients in rural areas in between treatments and following completion of treatment for AML inhibits early discharge home for many patients.

**F 3.** There is variation in the timing of referral of patients for transplant with no clear referral pathways for transplant across NSW and difficulties for referring centres to identify waiting times at transplant centres.

**F 4.** Admissions for consolidation treatment with chemotherapy are consistently delayed by several days with a high portion of patients treated on outlying wards. Inpatient capacity at some centres has been increased by moving many inpatient treatments to the ambulatory care setting however it is important to recognise the increases in the level of knowledge and expertise required in the ambulatory care setting to support this move.

**F 5.** The opening hours of some ambulatory care units is insufficient to meet the demand and needs of haematology patients requiring frequent medical review and long infusions.

**F 6.** Treatments provided in a general ambulatory care units without trained haematology nursing staff increases the resources required to support the haematology patient in these clinical areas and maintain patient safety.

**F 7.** There are barriers to accessing molecular and cytogenetic diagnostic testing and results.

**F 8.** There are delays and barriers to accessing services for insertion of the preferred central venous access devices (CVAD’s) in the time frames required resulting in alternative devices that may be sub optimal for the patient being selected for use.

**F 9.** Psychosocial and clinical psychology support for patients undergoing treatment for AML is an important aspect of providing holistic care to patients. Services for inpatients and outpatients across AML treatment centres are restricted.

**F 10.** Fertility for patients undergoing treatment for AML is a highly sensitive issue with few options available to preserve fertility, particularly for women.

**F 11.** Difficulties in identifying the appropriate time for referral and lack of consensus over supportive care during palliation result in late or inappropriate referrals to palliative care teams particularly when patients are continuing to require supportive care such as blood transfusion.

**F 12.** There are insufficient single rooms with ensuite facilities at nearly all treatment centres to cater for the number of patients requiring single rooms. Priority for single rooms goes to transplant patients, patients requiring isolation due to colonisation with multi-resistant organisms and terminal patients meaning many patients undergoing induction therapy for AML are treated in multi bed rooms or bays.

**F 13.** Ambulatory care structures are varied with segregation of outpatient services for chemotherapy and other ambulatory care needs which creates challenges to clinicians in providing safe and effective care by clinicians skilled in managing patients with AML.

**F 14.** There is an increasing need for management of patients undergoing treatment for AML to be managed on outlying wards due to capacity problems. There are challenges in ensuring and maintaining a high level of clinical expertise while providing care for these patients.

**F 15.** Adolescent and Young Adult (AYA) patients are a unique patient group with new specialist teams becoming available in select areas to assist with managing these patients.

**F 16.** There are a range of external agencies and organisations supporting care to patients with AML and it is important to ensure that these organisations are recognised in the development of a model of care for AML.

**F 17.** Electronic recording of health information is increasing however this information is not easily transferrable across Local Health Districts (LHD’s).
F 18. Regular videoconferencing between referral and treatment centres enables good communication between sites however this is limited to a few centres where formal links are established.

F 19. The availability of supportive care following treatment for rural patients is varied and difficult to access.

F 20. Haematology Clinical Nurse Consultants and Haematology Care Coordinators provide different functions. Both play pivotal roles in the provision of care for haematology patients however care coordinators for haematology are predominantly only available in sites where a Haematology Clinical Nurse Consultant is not available.

F 21. Assistance for parking, transport and accommodation for patients with AML is provided through non-government organisations such as the Leukaemia Foundation however there remains substantial costs in accessing care for many patients.

F 22. Patient education is identified as an important component to providing comprehensive safe and effective care to patients with AML however there are many barriers to providing education and a lack of written material for specific patient populations.

F 23. There is a difficulty accessing interpreter services when required. Rapidly changing patient conditions and treatment plans mean there is a frequent need for repeated sessions with interpreters often at short notice.

F 24. A multidisciplinary team approach to care for patients with AML is consistent across NSW however there is variation in the membership and functioning of the multidisciplinary team particularly in relation to allied health services.

F 25. The acuity of patients undergoing treatment for AML is high, requiring complex clinical care however there is little documented evidence to identify appropriate staffing and skill levels, particularly medical and nursing staff based on patient numbers, level of activity or acuity.

F 26. Haematology requires a highly skilled workforce. Gaps in education programs for all staff disciplines create challenges for staff development and succession planning into the future.

F 27. A selection of comprehensive evidence based treatment protocols are available through the Cancer Institute NSW and Australasian Leukaemia and Lymphoma Group (ALLG) for treating patients with AML providing a consistent approach to treatments across NSW.

F 28. Data relating to AML treatment is collected by various means locally and through NSW health organisations however there is a limited uniform data available to provide a clear picture of outcomes and morbidity associated with treatment in NSW.

7. Next steps

The next stage is to determine what the ideal model of care will look like. The findings above will be considered when identifying the ideal model and the following suggested action will be explored in order to identify solutions.

Suggested Actions;
1. Guidelines and processes for referral with time frames for review by a haematologist based on urgency for suspected haematological malignancy are included in a model of care for AML.
2. The easy identification of facilities with the capacity to provide supportive care for patients undergoing treatment for AML and the process for accessing care is supported in a model of care for AML.
3. Established referral pathways promoting better communication between centres allowing clearer planning and scheduling for transplant are included in a model of care.
4. Skill levels and the requirements to maintain safe patient care of complex patients undergoing treatment for AML in inpatient and ambulatory care settings are included in a model of care.
5. The requirements for outpatient care of patients receiving treatment for AML, including staff training and recommendations for operating hours, are included in a model of care.
6. Molecular and cytogenetic testing for all patients planning to undergo treatment is standardised and documented within a model of care for AML.
7. Appropriate timeframes for the insertion of central venous access devices are identified within a model of care for AML.
8. The support services required for patients with AML are documented within a model of care incorporating guidelines to assist with early assessment and referral to appropriate services that include allied health, fertility specialist, and palliative care teams.
9. Guidelines for ambulatory care and ward facilities are documented in a model of care for AML. Future ward development or renovations consider the recommendations for isolation facilities and haematology-related ambulatory care treatments.
10. Skill levels and the requirements to maintain safe patient care of complex patients undergoing treatment for AML are included in a model of care.
11. The services available from external organisations are recognised in a model of care for AML. There is documentation of the available services that is accessible by health care professionals and patients and families.
12. There are clear processes for communication between centres documented within a model of care, particularly where care is provided across LHD.
13. A model of care promotes clear documentation of follow-up plans for all patients undergoing treatment of AML that is communicated with primary health and rural services.
14. There is documentation of services available for patients following treatment for AML in rural areas that includes clear processes for accessing these services.
15. Processes for improving and maintaining skills for providing supportive care to patients following treatment for AML in rural settings are implemented.
16. Staffing roles, structures, and skill levels for managing patients with AML are documented within a model of care for AML.
17. There are documented requirements for patient education included in a model of care to ensure the education provided is consistent and meeting patient needs.
18. The minimum requirements for staffing levels are documented within a model of care for AML.
19. Succession planning and development programs are considered in conjunction with a model of care to ensure they entice staff to the specialty and promote staff development to ensure a sustainable workforce with the required knowledge and expertise within the specialty to manage patients with AML in a safe and effective manner.
20. A model of care for AML supports the use of evidence-based treatment protocols developed through Cancer Institute NSW.
21. A model of care for AML supports the collection of appropriate standardised data to enable measurement of outcomes that are relevant and meaningful to clinical practice.

Parking, transport, and accommodation for patients are beyond the scope of a model of care but remain important factors that limit access to care for patients with AML.
8. References


34. Department of Health Western Australia, *Haematological Malignancy Model of Care*. 2009, Cancer and Palliative Care Network, Department of Health: Perth.