Blood and Marrow Transplant Network

NSW Model of Care for

Acute Myeloid Leukaemia
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ACKNOWLEDGEMENTS

A number of people contributed to the development of this document. Special thanks go to the malignant haematology working group members who not only met consistently to review the project’s progress, but also spent large amounts of time reviewing documents and providing feedback.

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## GLOSSARY

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td>Acute promyelocytic leukaemia</td>
<td>Acute promyelocytic leukaemia (APL) is a distinct subtype of acute myeloid leukaemia with common features of serious blood-clotting or bleeding problems</td>
</tr>
<tr>
<td>Bone marrow aspirate</td>
<td>Removal of bone marrow fluid</td>
</tr>
<tr>
<td>Bone marrow trephine biopsy</td>
<td>Removal of bone marrow tissue</td>
</tr>
<tr>
<td>Conditioning treatment</td>
<td>Conditioning treatment desired effect is to kill cancer cells and create space for and prevent rejection of the new bone marrow</td>
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<tr>
<td>Consolidation treatment</td>
<td>Chemotherapy given while patient is in remission, to ensure eradication of any remaining disease</td>
</tr>
<tr>
<td>Cytogenetic</td>
<td>Determination of chromosomal abnormalities that aid in the diagnosis and selection of optimal treatment</td>
</tr>
<tr>
<td>Febrile neutropenia</td>
<td>Febrile neutropenia is classified as a neutrophil count less than 1.0 (x10^9/L) and a temperature greater than or equal to 38°C</td>
</tr>
<tr>
<td>Gated heart pool scan</td>
<td>A nuclear medicine scan to assess cardiac function, measuring blood volume in and out of the left ventricle</td>
</tr>
<tr>
<td>Induction treatment</td>
<td>First line treatment given to induce remission</td>
</tr>
<tr>
<td>Leukopheresis</td>
<td>The selective separation and removal of white blood cells in the peripheral blood</td>
</tr>
<tr>
<td>Morphological</td>
<td>Relating to form and structure, including size and shape</td>
</tr>
<tr>
<td>Myelosuppression</td>
<td>A condition in which bone marrow activity is decreased, resulting in fewer white blood cells, red blood cells, and platelets</td>
</tr>
<tr>
<td>Neutropenia</td>
<td>A low neutrophil count, generally less than 1 X10^9/L. An increased risk of infection is related to neutropenia</td>
</tr>
<tr>
<td>Neutrophil recovery</td>
<td>Neutrophil recovery is defined as an absolute neutrophil count of ≥ 0.5 x 10^9/L for three consecutive laboratory values obtained on different days</td>
</tr>
<tr>
<td>Salvage chemotherapy</td>
<td>Treatment that is given after the AML has not responded to other first-line therapies or following disease recurrence</td>
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EXECUTIVE SUMMARY

Background
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. The onset of AML is usually rapid with presentation and diagnosis occurring within weeks of the onset of symptoms\(^{(1)}\). Diagnosis and management of haematological malignancies require a specialised multidisciplinary approach with systemic treatment in metropolitan centres that have developed clinical expertise within the specialty.

Treatment requires intensive systemic chemotherapy to induce remission and control the disease, and is associated with significant morbidity and mortality\(^{(2)}\). 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. In 2010 / 2011, among all cancers across Australia, acute myeloid leukaemia was responsible for the longest average length of hospital stay at 17.5 days\(^{(3)}\). 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.

AML in NSW
Leukaemia comprises approximately 2.5% of all cancers in NSW, with AML accounting for approximately 33% of all leukaemias\(^{(4)}\). According to the NSW Central Cancer Registry, there were 317 new AML cases in 2008, a 13% increase from 2004 to 2008. This rate of increase is predicted to continue with an increasing and ageing population\(^{(5)}\). Despite an increasing incidence, mortality rates have remained relatively stable.

The demanding nature of treatment, requiring extensive inpatient and outpatient care throughout each treatment cycle, means that despite a low volume of patients annually across the state, treatment is associated with significant hospitalisation and high cost care. Admitted patient activity data shows there has been a steady increase in overnight hospital separations and beddays since 2000, consistent with an increasing incidence. There were 2,338 hospital separations for AML totalling 22,732 beddays in the financial year 2011 / 2012. It is anticipated that ambulatory care utilisation is also increasing however, data for ambulatory care in AML was not readily available. Approximately half of all patients diagnosed with AML are over the age of 65 and 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.

Current Context
Existing models and evidence in the literature support the availability of recognised processes for the provision of care for patients with AML throughout the continuum of their journey. Key factors for a successful model include; defined communication pathways, criteria for referral, identified trigger mechanisms for local emergency health interventions, uniform follow-up guidelines and a coordinated approach to care.
A detailed review of practice models within NSW identified inconsistencies in these key aspects of the patient’s journey. The Agency for Clinical Innovation (ACI) and the Blood and Marrow Transplant (BMT) Network recommend that a standardised model of care, incorporating the entire patient journey from diagnosis to long-term survivorship or end of life care, be established within NSW.

Endorsement
Endorsement of the model has been obtained from groups and individuals that represent the stakeholders involved in or impacted by the model of care.

- Project working group members
- Blood and Marrow Transplant Network Executive
- Agency for Clinical Innovation Executive
- Chief Executives of Local Health Districts (Sydney LHD, South Eastern Sydney LHD, Northern Sydney LHD, South Western Sydney LHD, Western Sydney LHD, Nepean Blue Mountains LHD, Illawarra Shoalhaven LHD, Central Coast LHD, St Vincent’s Hospital Network, Sydney Children’s Hospital Network)
- Ministry of Health
- Chief Executives of Medicare Locals
- Cancer Institute
THE AML MODEL OF CARE

The model of care for AML describes a comprehensive, multidisciplinary approach to providing patient and family-centred care throughout the patient’s journey. The major steps in the patient’s journey are; presentation and referral, diagnosis and work up for treatment, safe treatment models, referral for transplant, follow-up care, identification and management of relapse, long-term survivorship or end of life care. Not all patients will experience every stage of this journey however, the key requirements to support safe and effective care and the underlying principles to guide the way in which care is delivered for each of these stages are outlined within the model.

The model will:

- Provide guidelines for urgent assessment and referral to promote early transfer of patients requiring immediate treatment and medical intervention and reduce emergency department (ED) presentations for semi-urgent patients where a direct ward admission may be arranged.
- Promote a standardised approach to diagnostic testing and work-up enabling rapid progression to treatment.
- Enable a multidisciplinary approach to treatment planning and the provision of care within a safe and appropriate environment that reduces the risk of complications such as infection.
- Promote early identification and referral of suitable patients for transplant with strong communication and collaboration between centres.
- Provide guidelines for early discharge programs for suitable patients and ensure there are appropriate processes for the monitoring, supportive care and readmission as required.
- Promote consistent follow-up for all patients that incorporates ongoing management of treatment-related side effects and psychosocial care.
- Enable an integrated approach from haematology and palliative care teams during care at the end of life.

In order to ensure effective implementation of this model of care across all sites, a step-wise approach is recommended. Sites have vast differences in financial and human resources available and will need to work closely with Agency for Clinical Innovation and the Blood and Marrow Transplant Network to facilitate smooth implementation.
AIMS, OBJECTIVE AND SCOPE OF MODEL OF CARE

This model aims to optimise the quality of care for patients with AML and enable a consistent approach to the provision of care across NSW. It provides a set of principles and outlines the key requirements at each stage of the patient’s journey based on evidence of best practice. It incorporates guidelines related to various components of the model.

Treatment for patients with AML is provided across a range of settings including the acute inpatient, ambulatory care and outreach settings. Important elements for each of these settings are described within the model.

Key points included in this model are:

- Mechanisms to ensure early identification and referral to an AML treatment centre
- A multidisciplinary team (MDT) approach to treatment planning and the provision of care in an appropriate setting
- The use of ambulatory care services to enable early discharge programs in a safe and efficient way
- Effective follow-up and supportive care for all patients with AML

The population group to be targeted within this model is all adult and paediatric patients with AML, including acute promyelocytic leukaemia (APML), through the continuum of their journey from presentation to either long-term survivorship or end of life care.

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. Many of the observations made in this document are relevant and transferable to the management of other haematology cancers.

Bone marrow transplant (BMT), which forms part of the care pathway for many patients with AML, is a complex component of care that is covered with a separate model of care. 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.
BACKGROUND TO THE MODEL

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. Due to the lack of functional white blood cells and resultant vulnerability to infectious organisms, 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\(^2\). 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 using 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\(^6\). 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. The following diagram reflects the location of haematology services within NSW.
Limitations to the provision of intensive chemotherapy treatment for AML in rural centres include:

- Lack of dedicated haematology inpatient beds with nursing staff skilled in the administration of cytotoxic agents and the management and care of patients receiving intensive chemotherapy
- Insufficient haematology cover to enable a 24-hour on call service
- Limited availability of blood products particularly platelets at short notice
- Insufficient supportive services such as infectious diseases physicians
Extent of AML in NSW

Leukaemia accounts for approximately 2.5% of all cancers while AML comprises 33% of all leukaemias, and is the most common acute leukaemia in adults.\(^{(4)}\)

**Graph 1 – Summary of AML Incidence and Mortality in NSW 2004-2008**\(^{(7)}\)

Between 2004 and 2008, the incidence of AML rose by approximately 13%. The NSW Central Cancer Registry prediction figures report an ongoing rise of 14% of new cases expected over the next 5 years\(^{(5)}\). The predicted rise in incidence is attributed to both population growth and ageing, as approximately half of all patients diagnosed with AML are over the age of 65. 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. 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 their quality of life.
**Graph 2 – AML Incidence and Mortality by age**

While the incidence and mortality increases significantly with age, Graph 2 shows a broad distribution across all age ranges.

**Graph 3 – Increasing Trend in Overnight beddays for AML by financial year**

Consistent with an increasing incidence, the admitted patient activity data shows a steady increase in the number of hospital separations and beddays for overnight admissions since 2000. Overall in 2011 / 2012 there were a total of 2338 hospital separations totalling 22,732 beddays for patients with AML. No data is available for ambulatory care utilisation however, anecdotal reports indicate there an increasing number of AML patients accessing ambulatory care services.
International and Interstate Models
Models of care documents were available from a wide variety of organisations across Australia and internationally. The majority of models available focused on facilities, services, workforce requirements and staff training within a broader context of malignant haematology. These models provided high quality evidence for key aspects for the NSW Model of Care for AML.

The models of care reviewed and considered in developing this model included the National Institute for Clinical Excellence (NICE) UK model for haematological malignancy\(^9\), the Victorian Health Framework for AML\(^{10}\), the Queensland Health Clinical Services Capability Framework for haematological malignancy\(^{11-13}\) and the Western Australia model of care for haematological malignancy\(^{14}\).

The following recommendations for a successful model included:
- Locally agreed routine referral patterns for GPs should be available and that these should also enable GPs to identify patients with a suspected haematological malignancy\(^9\).
- Clinical criteria for referral and transfer of patients to and from services\(^{12, 13}\)
- Defined communication pathways\(^{10, 12}\)
- Coordination of care along the patient pathway\(^{10, 12}\)
- Uniform follow-up guidelines for patients considered cured from their malignancy\(^{14}\)
- Trigger mechanisms for local emergency health interventions\(^{15}\)
- Established care protocols and procedures for emergency and unscheduled presentations\(^{15}\)

Support for AML in NSW
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. A list of these organisations has been included at the end of this document. As services and support may change, contact information has been provided in order to confirm the most current information. 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.

The support provided by these organisations assists in easing the burden of illness for patients and their families and play an important role in supporting care for patients with AML.
THE NEED FOR CHANGE

A detailed review of practice models in NSW for patients with AML through consultation with clinicians and patients identified:

- Delays in commencing treatment due to inconsistent referral processes and admission to a treatment centre.
- Variation in the timeliness and availability of diagnostic and work up procedures affecting the time to commencement of treatment.
- Variation in the use, availability and access to appropriate ambulatory care and outpatient services with specialised haematology expertise to optimise early discharge programs.
- Variation in the process for readmission for febrile neutropenia and other treatment related complications. A drop-in service providing assessment and management of unwell patients enabling direct admission through ambulatory care is available in some facilities while assessment and admission through ED is required for the same patients in other centres.
- Difficulties in accessing supportive care following treatment for AML such as central line care, blood product support and palliative care in rural areas.
- Variation in the membership and functions of the haematology multidisciplinary teams treating patients with AML.
- A lack of uniform data to provide a clear picture of outcomes and morbidity associated with the treatment of AML in NSW.
- Variation in the availability of isolation rooms in inpatient and ambulatory care areas for patients who are severely immunocompromised following intensive chemotherapy for AML.

This thorough review is located in the Acute Myeloid Leukaemia Diagnostic Report that preceded this Model of Care.

The following patient stories reflect some of the current challenges in providing care for AML.
Case Study 1: Connor’s Story

Connor is from a medium sized town in rural NSW and was first diagnosed with acute myeloid leukaemia in January 2010. He is a fit and healthy 64-year-old who goes to the gym regularly and has no other significant health issues. He had repeat presentations to his GP over a period of a few weeks with lethargy and a sore throat, having also had recent antibiotic treatment for an infected finger.

The GP performed a blood test and contacted Connor at home as soon as the results became available indicating acute leukaemia. Connor was informed of the results and instructed to present to the emergency department at his local hospital immediately. The following day he was discharged and his wife drove them both to Sydney to see a haematologist where he was again admitted to hospital in order to commence treatment for his AML.

Connor remained in hospital throughout his induction chemotherapy. He developed severe mucositis and had an episode of febrile neutropenia although overall the induction therapy was relatively unremarkable. Following this treatment, he was discharged home for a total of 8 days. During his stay at home, he had a fall, although did not suffer any injuries and did not inform anyone for fear of being brought back to hospital early. He was readmitted to the ward for his first consolidation through which he had another episode of febrile neutropenia and contracted a multi-resistant organism requiring isolation in a single room. Again, he remained in hospital until his blood counts had recovered.

During his second consolidation, Connor was discharged from hospital early to local accommodation with regular follow-up and ambulatory care appointments arranged. Unfortunately, Connor became unwell one evening while out of hospital with a febrile episode, diarrhoea and an altered level of consciousness. His wife called an ambulance and he was readmitted through the emergency department. Connor had several days in hospital that he is unable to remember, but eventually recovered.

Once he felt better, Connor was kept in hospital while waiting for his blood counts to recover. The white cell count recovered somewhat however the platelets and haemoglobin remained persistently low. He was discharged home with the counts still low and follow-up blood tests were arranged through a local pathology centre. Following his discharge home, Connor suffered significant fatigue and at one point there was an attempt to arrange a blood product transfusion at his local hospital, however, this was not possible and Connors blood counts eventually recovered without intervention.

Connor has been in remission for about 2 years now and hopes it will continue. He is eternally grateful to all the staff on the ward for all of their care and attention throughout his illness.
Case Study 2: Lily’s Story

Lily is a 53-year-old lady from the Sydney metropolitan area living within a 15 minute drive of a hospital that provides treatment for AML. In June 2011, she presented to her local hospital emergency department with an abscess on her arm that had worsened since commencing oral antibiotics prescribed by her GP the previous day. She had complained about feeling tired and lethargic for a few weeks preceding this presentation but had blamed it on working a little too hard. She was seen by a haematologist within hours of presentation to the emergency department and was diagnosed with acute leukaemia.

Lily spent the next 6 weeks in hospital receiving treatment for her AML. She found this a very scary period waiting for all the side effects she was told about to start. She tolerated the treatment relatively well although did develop several infections throughout the course of her treatment. This resulted in repeated replacement of her central venous access as a potential infectious source. In total throughout her treatment, Lily describes having 6 different devices inserted.

During the consolidation cycles, Lily was discharged following the chemotherapy and was followed up closely from home and through the ambulatory care department. She required readmission with each cycle of treatment for febrile neutropenia. These admissions were streamlined as direct ward admissions through ambulatory care following a review by the haematology registrar, preventing the need to be processed through the emergency department. At some point through her treatment, Lily developed a multi-resistant organism requiring isolation. She felt confused by the isolation procedures as on the ward she was restricted to her room where everyone had to wear gown and gloves, however whenever she left the ward or she was seen in ambulatory care the same precautions did not apply.

Lily’s biggest stress throughout her treatment was the ward environment when following readmission to hospital as she was placed in a 4-bed bay mixed with general medical patients. She felt this placed her at increased risk of exposure to infections, as the medical patients did not follow the same guidelines regarding limitations to visitors, plants and other precautions that a haematology patient would normally follow.

The caring nursing and medical staff along with living close to the hospital and being near friends and family were the key factors that made a difference for Lily through her treatment for AML. She described all the staff as amazing, very knowledgeable and always willing to help and listen.

Lily remains in remission and has recently started back at work 2 days per week having previously worked full time and feels that this is all she can currently manage. She found returning to work a struggle physically and has difficulty maintaining concentration particularly with the more complex processes required of her at work.
Case Study 3: Prue’s Story

Prue is a 15-year-old girl from Southern NSW. She was diagnosed with AML after presentation to her local hospital for what she thought was tonsillitis. Once the AML was detected, she was immediately sent to Sydney and admitted to hospital that afternoon. For the next few weeks, her parents stayed between the parent’s ward at the hospital and a local hotel until some permanent accommodation became available in Ronald McDonald House. They found this meant she could have both parents stay close by which was a real benefit for her.

Following her first treatment and after several weeks in hospital she was able to go home for 3 days. Prue describes the detail and effort that was required to enable this to happen. A nurse coordinated the trip home, provided the local hospital with information about her in case there was a problem and provided her with a plan of what to do should she develop a problem during the few short days she was away from her treating hospital.

She received 5 treatments in total and spent most of that time alternating between staying in hospital and staying at Ronald McDonald house with her parents. With each stay at Ronald McDonald House, she had to go back into hospital through the emergency department upon developing a fever. She would ring the ward to let them know she had a fever and was going to ED. In turn, the ward would notify ED and she would be fast tracked through triage and into the department so she wasn’t delayed in the waiting room to reduce the risk of contracting an infection from other visitors to ED. Following one of the ED presentations, she was admitted to a different ward due to bed shortages on the haematology ward. This was quite distressing for her family and they felt as though there was a limited understanding from the staff on the ward regarding her illness and the care that she needed.

Prue was in year 10 at school when she was diagnosed with AML and although there were teachers at the hospital that came around to see her every day and her school sent work for her to do, it was easy to turn them away. She completed her School certificate and started year 11 once her treatment was completed, but found she was too far behind in the work and left school to take up an apprenticeship.

While in hospital, Prue kept in touch with her friends and family through Facebook and found this a valuable way to keep everyone updated with her progress. She was very happy to be going home once her treatment was finished and ready to start getting on with having a normal life again.
THE NSW MODEL OF CARE

The model of care for AML describes a comprehensive, multidisciplinary approach to providing patient and family-centred care throughout the patient’s journey. The following diagram provides a framework outlining the major steps in the patient’s journey, the key requirements to support safe and effective care and the underlying principles to guide the way in which care is delivered.
Presentation and Referral

Identification of abnormal blood film (Suspicious of acute leukaemia)

Contact Haematologist

Admit to local facility
(Patients who are haemodynamically unstable, if recommended by haematologist until urgent transfer to an AML treatment centre is arranged)

Monitor as an outpatient
(Patients identified by haematologists as stable may be monitored as an outpatient until admission to an AML treatment centre is arranged)

Transfer to AML treatment centre
(Admit for administration of chemotherapy and immunosuppressed phase of treatment)

As soon as possible (within the same day)

Within 24 hours for urgent patients and up to 72 hours for other patients

The Model

The presentation and referral component of the model promotes early detection and intervention. The initial diagnosis of AML is likely to be made following examination of a peripheral blood film. Early detection and intervention has been shown to improve tolerance to treatment and improved outcomes therefore a low threshold for performing a Full Blood Count is required to ensure early detection.

Patients requiring immediate medical assessment and intervention are identified and admitted to the nearest hospital for resuscitation, intravenous antibiotics and blood product support as required. Transfer to an AML treatment centre within 24 hours is arranged. Patients identified by haematologists as haemodynamically stable who do not require immediate medical management may be appropriately monitored as an outpatient for up to 72 hours until admission to an AML treatment centre is arranged.

It may be appropriate after consultation with a haematologist for the very elderly to be supported locally rather than be transferred to a treatment centre for assessment.
Key Aspects of the Model

Early identification and intervention is achieved through:

- Early identification of potential symptoms and a low threshold for undertaking a full blood count
- Immediate action following identification of suspected AML
- Laboratories with a suspicious sample that was requested by someone other than a haematologist should ensure the sample is reviewed by the pathologist associated with the laboratory.
- Where there is significant suspicion of acute leukaemia, laboratories notify the requesting medical officer immediately.
- GPs notified of a suspicious sample follow-up the patient and act on the results the same day
- All patients with a blood film suspicious of acute leukaemia are regarded as medical emergencies. These cases should be discussed with a clinical haematologist.
- Classification of urgency for transfer to an AML treatment centre is determined by a haematologist.
- Transfer of urgent patients to an AML treatment centre occurs within 24 hours and within 72 hours for all other patients with a suspected diagnosis of acute leukaemia.
- All children ≤ 15 years of age are transferred and treated in a paediatric haematology/oncology centre.

Supporting Evidence

Patients require extensive work-up following diagnosis before commencing treatment. The literature identifies that treatment outcomes may be adversely affected by delays in treatment of greater than five days from diagnosis\(^{(16)}\). Patients waiting in peripheral hospitals for a bed are at risk of developing life-threatening complications. Delays in transfer of up to five days have been reported through consultation with clinicians. This was particularly a problem when the transfer was a hospital-to-hospital transfer and was arranged through bed managers without consultation with the haematologist taking responsibility for the patient.

The NICE guidelines\(^{(9)}\) 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\(^{(10)}\).

What is Needed for this Model

Education and training:

- GPs to ensure low tolerance and recognition of potential symptoms
- ED departments to identify urgency of presentation

Guidelines identifying suspicious signs and symptoms of AML:

- Symptoms are often non-specific and generally related to alteration in normal blood counts. The following symptoms may be suggestive of acute leukaemia and warrant investigation:
  - Fatigue or other symptoms of anaemia
Severe sepsis
- Infection that is either recurring or unresponsive to treatment
- Abnormal bruising or bleeding
- Persistent sore gums or mouth ulcers
- Unexplained bone pain
- Unexplained weight loss

**Classification for urgent referral and intervention**

**Urgent patients within 24 hours:**
Patients falling into this category must be treated as a medical emergency in an acute hospital facility and transferred to an AML treatment facility as soon as possible and no later than 24 hours.

- Patients displaying signs of severe sepsis
- Patients with major laboratory abnormalities
- Patients displaying signs of hyperviscosity
- Patients with uncontrolled bleeding or severe coagulation abnormalities
- All children ≤ 15 years of age

**Semi-urgent patients within 72 hours**
Patients falling into this category may be treated as semi-urgent. Immediate admission to an acute hospital facility may not be required. Presentation or transfer to an AML treatment facility for review and further investigation by a haematologist is required within 72 hours.

- All patients with suspected or confirmed acute leukaemia who do not fall into the category for urgent assessment and treatment
- Identified options for referral (See appendix 1 for potential referral pathways)

*Note:* There will be a small population of patients when transfer to a treatment centre for assessment and management is inappropriate. This will predominantly be the very elderly and a decision not to transfer a patient should be determined in consultation with a haematologist.
Diagnosis and Work-up for Treatment

The Model

The diagnosis and work-up component of this model promotes a rapid standardised work-up for patients preparing to undergo treatment for AML. Diagnosis of AML is confirmed through bone marrow aspirate (BMA) and trephine. Morphological examination enables prompt diagnosis however, molecular and cytogenetic analysis is required to establish disease specific characteristics and prognostic factors. Molecular and cytogenetic results will take longer and treatment is frequently commenced before these are available.

Work-up for treatment is required to determine baseline health status, identify risk factors for potential complications and prepare the patient for treatment. Coordination of work-up is time consuming and requires scheduling of investigations and procedures involving multiple hospital departments. Priority access to services is frequently required to ensure all work-up is completed within acceptable timeframes.

This model enables:

- A standardised approach to diagnostics
- Clear processes for work-up for treatment
- Rapid coordination and completion of work-up for treatment
- Clear and consistent education for patients and families allowing informed decision-making regarding treatment goals and plans

Key Aspects of the Model

Key aspects for diagnostics are:

- Bone marrow biopsies (BMB) are performed in a facility with staff appropriately trained and accredited to perform the procedure and prepare slides to ensure accurate results are available.
- Bone marrow aspirate and trephine’s performed in a facility that is not an AML treatment facility, such as a rural centre with onsite haematologist, provide unstained slides to accompany the patient to the treating facility. It may be appropriate to perform the BMB at the treating centre to avoid the need to repeat the procedure.
- All BMBs on children ≤ 15 are performed in a paediatric centre.
• Molecular and cytogenetic testing is performed for all patients planning to undergo treatment.
• Diagnostic tissue is stored to enable future review and comparison if required.
• Additional testing may be required for enrolment on clinical trials. Potential for enrolment and additional testing should be considered at the time of performing BMB.

Key aspects for work-up for patients planning to undergo treatment are:
• Central venous access devices are inserted within 48 hours of diagnosis.
• Fertility preservation needs are assessed and discussed with every patient planning to undergo intensive chemotherapy for AML.
• Prior to commencing myelosuppressive therapy, initial and confirmatory HLA typing is performed for all patients with the potential to progress to transplant.
• HLA typing for siblings and parents should be completed as soon as practical after diagnosis.
• Early referral to a transplant centre is considered for all suitable patients
• Pre-treatment assessments are performed to determine baseline and ensure suitability for treatment.
• Assessment includes:
  o Physical assessment,
  o Serological screening,
  o Gated Heart Pool Scan (or equivalent),
  o Psychosocial assessment, and
  o Nutritional assessment.

Key aspects for patient and family education are:
• All patients and their families are provided with information relevant to their disease and treatment.
• Information is provided through individual discussion with members of the multidisciplinary team as well as utilising well produced written information or digital media in an appropriate environment.
• Information that is provided is appropriate for their needs considering age, level of education, cultural and linguistic background. When English is not the patient’s first language, the use of an interpreter should be considered.
• A system for providing education is established to ensure that information that is provided is current, clear, honest and consistent.

**Supporting Evidence**

Prognostic indicators and treatment choices for AML rely heavily on morphologic and cytogenetic profiling of leukaemic cells. Recent technological advances have led to an increasing use of molecular markers to further classify risk and assist in minimal residual disease detection\(^{(17)}\). The Victorian Patient Management Framework\(^{(10)}\) recommends that every patient being considered for active treatment should have samples sent for cytogenetics, flow cytometry and molecular diagnostics.

Patient education is an integral and essential component of healthcare 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\(^{(18)}\). 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\(^{(19)}\).

**What is Needed for this Model**

**Training**
- Training program in each facility for registrars performing BMB

**Facilities**
- Nuclear medicine or an ability to assess cardiac function
- Radiological or surgical service for timely insertion of central venous access devices

**Guidelines**
Clear processes or guidelines are available for:
- Molecular and cytogenetic testing
- Central venous access device selection
- Pre-treatment assessments
- Patient education

**Molecular and cytogenetic testing**
Testing should include:
- Genetic biomarkers are used in acute myeloid leukaemia to provide prognostic information, to guide therapeutic decision-making in predicting response to specific therapies, to monitor response to treatment and potentially to identify targets for novel therapies.
- Translocations can be detected by conventional cytogenetics, fluorescence in situ hybridization (FISH) or polymerase chain reaction (PCR) approaches to identifying recurrent breakpoints, while base sequencing is required to identify point mutations and small deletions.
- Some treatment decisions (selection of chemotherapy) need to be made rapidly following diagnosis of AML, and FISH testing and multiplex PCR are particularly useful in screening for specific genetic lesions at that time, while conventional cytogenetics remains useful in screening for less commonly identified genetic biomarkers.
- Karyotype analysis and molecular studies are required on all new diagnoses. This is a rapidly emerging field. Due to how rapidly recommendations may change, the most current recommendations for diagnostic testing will be found on the BMT Network website.
- Minimal residual disease assessment should be performed on all bone marrow assessments on AML patients, when a leukaemia-specific phenotype has been identified at diagnosis. As this is an emerging technique, it is recommended that advice be sought from local experts regarding the optimum panel of antibodies to be included in the initial phenotypic analysis to optimise the likelihood that a leukaemia-specific phenotype will be identified.
Central venous access device
- A minimum of a double lumen central venous access device is required to support induction and consolidation treatment for AML.
- Device selection should be based on local availability and may be a tunneled or non-tunneled device. Tunneled devices may be inserted to cover the entire treatment including induction and consolidation cycles however replacement of non-tunneled devices should considered between each treatment cycle.
- Insertion should be performed within 48 hours of diagnosis to enable prompt commencement of treatment.
- A tunneled catheter is preferred for paediatric patients

Pre-Treatment Assessments

<table>
<thead>
<tr>
<th>Clinical assessment</th>
<th>Intensive chemotherapy</th>
<th>Low dose chemotherapy</th>
<th>APML</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Medical history</td>
<td>Required</td>
<td>Required</td>
<td>Required</td>
</tr>
<tr>
<td>- Performance status</td>
<td>Required</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Assessment of co-morbidities</td>
<td>Required</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Additional investigations / assessments</th>
<th>Intensive chemotherapy</th>
<th>Low dose chemotherapy</th>
<th>APML</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Clinical chemistry, coagulation screen</td>
<td>Required</td>
<td></td>
<td>Required</td>
</tr>
<tr>
<td>- Gated Heart Pool Scan (GHPS) or echocardiogram</td>
<td>Required</td>
<td>Clinical chemistry and coagulation profile is required</td>
<td>Additional cardiac investigations may also be required for protocols including arsenic trioxide</td>
</tr>
<tr>
<td>- Lung function (if clinically indicated)</td>
<td>Required</td>
<td>Additional investigations may not be required. These should be determined based on individual patient factors</td>
<td></td>
</tr>
<tr>
<td>- Dental assessment</td>
<td>Required</td>
<td></td>
<td>Required</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Serology screening</th>
<th>Intensive chemotherapy</th>
<th>Low dose chemotherapy</th>
<th>APML</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Hepatitis B (HBsAg, HBcAb), Hepatitis C (HCV Ab), Cytomegalovirus (CMV), Epstein Barr Virus (EBV), Herpes Simplex Virus (HSV), Varicella Zoster Virus (VZV)</td>
<td>Required</td>
<td>Specific serology screening may be performed based on individual patient history and presentation</td>
<td>Required</td>
</tr>
<tr>
<td>- Consider HIV 1 and 2 if patient at high risk for acquisition</td>
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<table>
<thead>
<tr>
<th>Fertility assessment</th>
<th>Intensive chemotherapy</th>
<th>Low dose chemotherapy</th>
<th>APML</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Serum pregnancy test (for females of reproductive age)</td>
<td>Required</td>
<td>Fertility preservation may not be appropriate in this patient population</td>
<td>Required</td>
</tr>
<tr>
<td>- Assessment and management of fertility preservation options</td>
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</tbody>
</table>
Education for patients and families
Information offered to patients and families should include:

- Sufficient information about basic anatomy and pathology for patients and their carers to understand the disease and how it might affect them
- Realistic information about the disease and the range of individual variation in its impact and rate of progression
- The aims, risks and likely effects of proposed diagnostic procedures. Each procedure should be explained to the patient before it is undertaken
- Balanced information with clear explanations about potential treatment options, including the probability of improved survival or symptom reduction (and uncertainties about benefits), known risks and potential short- and long-term adverse effects
- An outline of their overall treatment plan including potential time scales including the length of time for recovery from treatment
- Information about other potential effects of the illness and treatment on both patients and carers, such as anxiety and depression
- The likelihood of long-term continuing contact with the haematological cancer team

Patients should also be given clear information about the hospital service. This should include:

- A description of the way the clinics and the multidisciplinary team function together
- The way the appointments system operates
- The names of members of the multidisciplinary team (MDT) responsible for managing the patient, and their different responsibilities
- Contact details for people with whom patients or carers can talk if they feel concerned about any aspect of the illness, treatment, or hospital service
The Model

The commencement of treatment frequently occurs rapidly after diagnosis. Determination of treatment requires careful consideration with input from the multidisciplinary team. Treatment may be provided as an inpatient or using a combination of inpatient and outpatient services as depicted in the flow diagrams.

The treatment phase of the model provides a set of principles and guidelines to promote safe and effective care during treatment for AML in the right environment by a skilled workforce. Treatment may be intensive chemotherapy aimed at inducing a remission, low dose chemotherapy for elderly patients or patients with significant co-morbidities who are unsuitable for intensive chemotherapy or supportive care without chemotherapy to control symptoms. This model promotes:

- A multidisciplinary team approach to treatment planning and the provision of care
- Appropriate inpatient facilities and processes to manage and reduce the risk of complications such as infection
- Appropriate patient selection for early discharge and outpatient management
- A suitable ambulatory care setting for all ambulatory care needs with skilled haematology trained nursing staff
- A shared-care approach for adolescents and young adults.

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1 Early discharge following intensive chemotherapy for AML is defined as any discharge after chemotherapy prior to neutrophil recovery[^29]
Key Aspects of the Model

- Comprehensive evidence-based treatment protocols for adult patients are available through the Australasian Leukaemia and Lymphoma Group (ALLG) and the Cancer Institute NSW. These protocols should be used for patients with AML where available and appropriate.
- Paediatric protocols are developed through the Children’s Oncology group (COG) or the Australian New Zealand Children’s Haematology Oncology Group (ANZCHOG).
- Clinical trials should be considered for all patients with AML when open and available.
- A multidisciplinary team approach to care planning and delivery is adopted and incorporated into inpatient and ambulatory care settings.
- Infection control policies and procedures and a clinical environment appropriate for the prevention of infection are provided in inpatient and ambulatory care settings.
- Early discharge and ambulatory care management is offered to suitable patients.
- Patients requiring readmission are admitted to a clinically appropriate ward.
- Inpatient and ambulatory care areas are cleaned according to NSW Health Policy and the Clinical Excellence Commission (CEC) standard operating procedures for extremely high risk areas to minimise risk of hospital-acquired infections from environmental reservoirs.
- Training is provided to maintain staff competencies to enable comprehensive assessment of the immunocompromised patient and identification of early symptoms of infection, acute clinical deterioration and other complications associated with severe immunosuppression and intensive chemotherapy.
- Nursing education competencies and training programs are available based on The National Cancer Nursing Education Project (EdCan) National Professional Development Framework for Cancer Nursing.
- As paediatric and youth cancer treatment centres have resources that may be of use to adolescent and young adult patients, a shared-care approach between the adult, youth and paediatric providers is encouraged.

Supporting Evidence

Intensive treatment using combination chemotherapy is appropriate for patients with AML who do not have significant co-morbidities and are likely to tolerate the treatment. This may include fitter older people, however, careful consideration is required particularly for patients over 60 due to the higher risk of treatment-related mortality (approximately 25%) and poorer response rates due to disease characteristics in this population. Older patients with co-morbidities deemed inappropriate for intensive chemotherapy may benefit from low dose chemotherapy. Low dose chemotherapy will induce a remission in a small proportion of patients and provide an improved survival compared to patients receiving supportive care without chemotherapy.

Patients with AML are highly susceptible to infection and prolonged neutropenia creates the potential for significant morbidity and mortality associated with infection. The increasing prevalence of hospital-acquired pathogens and multi-resistant organisms makes prevention of the transmission of organisms paramount in reducing risk for patients with prolonged neutropenia. Schlesinger et al undertook a meta-analysis study concerning infection control interventions for cancer patients. While it is difficult to establish a single strategy as being effective on its own, these authors described benefits of protective isolation in high-risk...
patients, including patients undergoing treatment for acute leukaemia. An estimated 40% reduced risk of severe adverse outcomes was noted when effective infection control practices that included protective isolation were implemented.

Ambulatory care management where appropriate and isolation rooms to separate immunocompromised patients from other patients form a vital part of reducing the risk of transmission to this high risk patient population\(^{(25, 26)}\). The National Institute for Clinical Excellence (NICE) recommend patients with prolonged neutropenia, such as those undergoing induction treatment for AML, be managed in single rooms during hospitalisation to reduce the transmission of infection to these patients\(^{(9)}\).

Early discharge and outpatient management for patients undergoing intensive chemotherapy for AML has been driven by increasing bed pressures and a need to reduce hospital costs\(^{(27)}\). A study conducted in the United States found that inpatient care was responsible for 84% of the total expense of caring for patients with AML\(^{(28)}\). Regarding early discharge and outpatient management, a potential non-monetary benefit to patients is an improved quality of life during the treatment phase of their illness. The primary concerns limiting the utilisation of early discharge and ambulatory care management through the immunosuppressed phase of treatment have included the reduced surveillance of patients for febrile neutropenia, the risk of bleeding and possible delays in medical intervention compromising the safety of patients\(^{(29, 30)}\). Formal strategies to ensure careful risk stratification for appropriate patient selection, adequate surveillance and management in the ambulatory setting and processes for readmission when needed are required to ensure patient safety.

Many wards have allocated clinical specialties reflecting the interest, training and experience of staff working on these wards. These specialty wards are considered the best option for caring for AML patients. Bed management strategies strive to admit emergency patients to the appropriate specialty ward, however due to limited bed space, patients are admitted to an alternative ward. The resulting effect is that patients of a particular specialty are housed on several different wards with reduced clinical expertise in that specialty, and wards have patients under the care of many different consultants and specialties. These patients are often referred to as outliers and the practice leads to inefficiency and adversely affects the quality of care provided\(^{(31)}\).

There is growing support for adolescents and young adults (AYA) with cancer to be cared for by health care professions who are expert in cancer alongside professionals who are expert in this age group (it is certainly possible for healthcare providers to be experts in both). In areas where specifically designed AYA units are not possible, age-appropriate care can still be given and collaboration from healthcare professionals who routinely deal with these patients can be invaluable\(^{(32)}\).
What is Needed for this Model

Guidelines
- Patient selection criteria for early discharge
- Managing acute deterioration at home and unplanned admissions
- Bed management prioritisation for AML patients
- Coordination of care across multiple settings
- Management of telephone calls from patients and carers after early discharge needing advice for symptoms

Organisational
Assessment and processes are available to ensure:
- An ability to meet demand in ambulatory care areas during operating hours
- Appropriate skill level in inpatient and ambulatory care areas to assess and manage patients
These requirements are defined in more detail in the section outlining facilities and services.

Early Discharge Model

Patient selection criteria for early discharge
The following criteria are recommended for patients selected for early discharge and follow-up through ambulatory care:
- Family or carer is available 24 hours per day (preferably multiple carers are available to support the patient and reduce the burden on individual carers)
- Transport is available 24 hours per day.
- The patient has suitable accommodation within 1 hour travel time from the hospital
- The patient is medically stable requiring treatment no more than once per day. Any coagulopathy or febrile episodes have resolved.
- The patient is compliant with therapy and instructions.
- There is access to a telephone with incoming and outgoing capability.
The patient and/or family have an understanding of their condition and are able to identify possibly toxicities requiring medical intervention and re-presentation to hospital.

**Emergency procedures for early discharge**

Patients are provided with (30):
- Contact information for during-hours and after-hours in the event the patient develops a problem, or has any questions or concerns.
- Documentation or a letter outlining their history, the treatment they received, the treating haematologist or person to contact in case of presentation to ED.

There are processes and guidelines in place for:
- Recognition and isolation of immunocompromised patients in ED
- Management of febrile neutropenia

**Facility**
- ED has capability of isolating immunocompromised patient

**Management for clinical deterioration and unplanned presentations**

There is a process for assessment and management of unwell patients through ambulatory care at short notice that enables direct admission to the ward for appropriate patients. ED bypass or ambulatory drop-in programs reduce ED presentations and improve the patient journey. Patients may be referred via telephone contact, via an outreach or community service or self-presentation.

The following principles are required to ensure and maintain patient safety:
- ED bypass is only available during ambulatory care operating hours and while there is a haematology registrar rostered on duty within the hospital.
- Ambulatory care settings have flexible or quarantined beds for this purpose.
- There is a haematology registrar available within the hospital to provide urgent review and medical treatment if required.
- There are criteria for patients that will be accepted for ambulatory care assessment and direct ward admission. Acutely unwell patients with the potential for rapid deterioration necessitating urgent medical intervention should present to ED.
- There is a process for admission to the ward for patients as needed. Patients may need to be transferred to ED if no bed can be identified by ambulatory care closing time.
- Process or pathways for patient assessment and management of common presenting problems.
- Administration support.

**Management of Telephone Enquiries**

There is a process for managing telephone calls received by patients and carers at home with enquiries regarding their clinical condition.

The following principles are required to ensure appropriate patient management and maintain patient safety (33):
- All enquiries relating to a patient's clinical condition is managed by an experienced haematology registered nurse or medical officer with the ability to undertake a thorough
patient assessment over the phone, identify potential haematological toxicities and recommend the appropriate management strategies.

- There is a standardised evidence-based approach to patient assessment, management and follow-up and standardised pathways for the most common problems e.g., fever, nasogastric tube or catheter displacement.
- There is documentation of the assessment, recommended interventions and follow-up plan.
Transplant

The Model

The transplant component of the model promotes early referral to a transplant centre for all potentially suitable patients. Allogeneic transplantation will be considered for all younger patients with AML in conjunction with the patient’s individual prognostic factors, the potential for long-term remission and the patient’s preferences. Older patients without significant co-morbidities will also be considered for transplantation. Reduced intensity conditioning may be considered appropriate in this patient population. Early referral, regardless of patient age, is necessary to enable planning and scheduling by the transplant centre. Good communication between transplant centre and referring centre is required to ensure all teams are aware of the planned time to transplant and enable a plan for patient management during this period. A collaborative approach between treating centres and transplant centres during consolidation treatments and work up to transplant provides continuity of care for patients across multiple acute care facilities.

This model promotes and enables:
- Early identification of suitable patients
- Strong communication between referring centres and transplant centres

BMT forms part of the care pathway for many patients with AML, however it is a complex component of care that is covered with a separate model of care. This AML model will include the identification of appropriate patients for referral to BMT and initial steps required in the referral process, it will not however, expand on the details specific to transplantation.

Key Aspects of the Model

Key aspects for this model are achieved by:
- All potentially eligible patients have samples sent for HLA typing as early as possible and preferably prior to commencing treatment whenever possible
- Patients are scheduled for transplant according to urgency of need based on prioritisation in accordance with BMT Statewide Specialty Service Plan 2011
- When a transplant centre is unable to schedule a transplant within agreed timeframes according to urgency, the transplant centre will identify an alternative option.
• Communication between treating centre and transplant centre is clearly documented to enable all members of the multidisciplinary team to be kept informed of the patient’s progress to transplant.

Supporting Evidence

Allogeneic stem cell transplantation is a potentially curative treatment option for younger patients with AML, with improved relapse rates and overall survival, however, treatment carries significant toxicity and morbidity\(^{(35)}\). There is a high risk of relapse for patients with AML ranging from between 30% to 80% depending on prognostic factors\(^{(36)}\) and a high proportion of these patients will require an allogeneic transplant.

In NSW an average of 53 allogeneic transplants (related and unrelated) for patients with AML were performed annually between 2004 and 2008\(^{(37)}\). This equates to an average of 17.3% of the annual AML diagnoses\(^{(38)}\). The relatively low percent of AML patients progressing to transplant is in part explained by a high proportion of patients ineligible for transplant due to age, lack of a suitable donor or the presence of significant co-morbidities.

There are several factors that may delay a patient’s progress to transplant including the type of transplant, the availability of a donor, patient condition or the presence of complications following induction chemotherapy. There are no published standards for acceptable waiting times for BMT however criteria-based optimal waiting times provides a measurable way of ensuring all patients progress to transplant in an appropriate time frame\(^{(39)}\).

What is Needed for this Model

Guidelines

• Process for early referral and initiation of donor searches
• Process for communication between transplant and referring centres

Prioritisation

The BMT Statewide Specialty Service Plan 2011 identifies the following criteria for progression to transplant for patients with AML based on specific patient factors\(^{(34)}\).

<table>
<thead>
<tr>
<th>Urgency Category</th>
<th>Timeframe</th>
<th>Patient presentations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Category A</td>
<td>Urgent referral needed for consideration of BMT within 6 weeks of diagnosis</td>
<td><strong>Primary refractory disease or early 1st relapse:</strong> Urgent consideration for myeloablative allogeneic BMT is vital.</td>
</tr>
<tr>
<td>Category B</td>
<td>Rapid referral needed for BMT, proceeding in 6 to 12 weeks</td>
<td><strong>CR1 with intermediate risk cytogenetics:</strong> Consider for allogeneic BMT if a well matched donor is available. <strong>CR1 poor-risk cytogenetics, therapy related AML or an antecedent haematological disorder:</strong> Consider for allogeneic BMT. <strong>Second or subsequent remission:</strong> Consider for allogeneic BMT.</td>
</tr>
</tbody>
</table>
Follow-up Care, Relapse and Long-term Survivorship

The Model

The follow-up care, relapse and long-term survivorship component of this model promotes a comprehensive process for all patients. The model will integrate primary care and community services with acute services to provide a seamless transition from the acute treatment phase of illness to follow-up and long-term survivorship.

Early monitoring following discharge from the acute hospital setting after completion of treatment requires ongoing disease monitoring and follow-up assessment and support for:

- Management of ongoing treatment-related side effects
- Psychosocial needs
- Integration back to work, school and social groups
- Fatigue management

Longer term follow-up and surveillance for disease recurrence is required. Clinical assessment for symptoms of potential late complications of intensive chemotherapy should be performed as part of the routine surveillance. The duration of long-term follow-up in non-transplant patients who have undergone intensive chemotherapy treatment will vary depending on individual patients and their risk of relapse and is required for a minimum of 5 years for all patients but may continue indefinitely for many patients.

Long-term follow-up of patients receiving allogeneic transplant for AML is not covered in this model as this is covered in the Model of Care for Chronic Care following Blood and Marrow Transplant (in development).

Relapse is an opportunity to begin advance care planning conversations. Patients and their carers and families will have many goals regarding their disease, including relief from symptoms, a good quality of life, an ongoing sense of being in control, and maintaining dignity. In the development of the Palliative Care Needs Assessment Guidelines, a review of relevant literature revealed that developing and implementing advance care planning and creating Advance Directives can result in increased patient satisfaction, patients knowing that their doctors have a better understanding of their wishes, greater comfort making end-of-life
decisions, continued discussion of patients’ concerns with their families and increased likelihood of discussing future health plans with their doctors”.

Key Aspects of the Model

Early follow-up and monitoring includes all relevant members of the multidisciplinary team, local GPs and the primary health care team.

- Multidisciplinary needs will vary depending on individual patients but may include medical, nursing and social worker input.
- Referral to relevant local services may be required for patients living long distances from the treating centre.
- Local oncology ambulatory care units may be best placed to provide clinical management, coordination of care and support to rural patients with ongoing health care needs.

Standard surveillance schedule will include\(^9,\,10\):

- Full Blood Count (FBC) every 1 to 3 months with clinical assessment and physical examination at least every 3 months for the first 2 years following completion of treatment.
- FBC and clinical review every 3 to 6 months for up to 5 years following completion of treatment.
- FBC and clinical review annually for 5 years or indefinitely as deemed appropriate for individual patients.
- Bone marrow biopsy may be added to the surveillance schedule for some patients particularly during the first 5 years following completion of treatment. Patients are provided with appropriate discharge education. This will include:
  - Information on the risk of relapse, the symptoms they may experience and recommended actions should symptoms develop.
  - Fatigue management and exercise programs and strategies to assist with rehabilitation.
  - Access to supports for long-term survivorship.
  - Possible long-term effects of treatment including fertility and cardiac effects
  - Assessment for neurocognitive deficits is required for paediatric patients treated with CNS directed treatment.

Relapse

- Following identification of possible relapse, patients are rapidly assessed.
- Treatment intent may aim to be curative, provide disease control or palliative. Treatment intent is determined based on previous treatment history, patient preference and disease prognostic factors.
- Salvage chemotherapy with early progression to allogeneic transplant should be considered for all relapsing patients who do not have significant co-morbidities.

Supporting Evidence

There is a high risk of relapse for patients with AML ranging from between 30% to 80% depending on disease specific prognostic factors\(^36\). A high portion of relapses will occur
within the first 2 years of completing treatment. The relapse rate rapidly declines between 2 and 5 years after completion of treatment however sporadic incidence of relapse can occur beyond 10 years after completing treatment\(^\text{42}\). Disease surveillance throughout the period where there is a high risk of relapse is necessary and assists with ensuring early detection and intervention.

If relapse occurs, this should be seen as a change in clinical condition prompting advance care planning. According to Palliative Care Australia, advanced care planning is not a one-time event but rather an ongoing dialogue and process that supports the patient to consider, and even re-consider, their treatment goals and care preferences in a realistic way.

McGrath has written a series of reports relating to post treatment care and support for patients with a haematological malignancy in regional and rural Queensland. According to these studies, 25% of patients surveyed reported that they had received no local support after returning home following treatment for their haematological malignancies\(^\text{43-45}\). In addition, of the patients who did have contact with local services, 29% felt that their local GPs or hospitals had insufficient knowledge or were poorly informed about their disease\(^\text{45}\). Patients found the lack of local support for ongoing physical symptoms and emotional needs challenging\(^\text{43}\). Access to multidisciplinary support for ongoing physical symptoms and emotional needs is necessary for all patients following completion of treatment for AML.

**What is Needed for this Model**

**Communication**
- Good communication links between treating centres, primary health care teams and rural oncology clinics.
- Identification of suitable rural oncology clinics for referral for supportive care to rural patients.
- In the event of relapse, advanced care planning and a review of the patient’s goals regarding treatment and end of life care should occur.

**Training and education**
- Support and education for isolated primary health care teams and oncology clinics caring for patients in the local community following treatment for AML.

**Supportive care and follow-up in rural areas**
Patients returning to rural areas have the opportunity to access local centres for ongoing supportive care needs if required. Rural oncology and haematology ambulatory care service in rural and regional areas will vary in the supportive care they are able to provide. A guide to rural centres and contact details is available on the BMT Network website (in development). The following points should be considered when referring patients to rural centres for supportive care:
- Local oncology and haematology ambulatory care centres may be able to assist with allied health support, blood transfusion support, central venous access device care and management.
- A treatment summary is sent to local centres for patients in the region being discharged home after treatment for AML particularly if there is a potential for them to present to the local ambulatory care centre.
- Many rural centres will arrange admission for blood transfusion through the GP. A GP with hospital links may need to be identified to enable transfusion support.
End of Life Care

The trajectory of AML makes it difficult to predict which patient will go on to long-term survivorship and which patient will die, making planning for end of life care vital. Some patients may be too unwell for treatment at the time of their diagnosis and others may rapidly progress from intensive treatment with curative intent to end of life care. All health care professionals should be capable of providing care to people who are approaching the end of their life. Specialist palliative care services can support and complement the care provided by primary care services \(^{(40)}\).

The Palliative Care Australia Standards for Providing Quality Palliative Care for All Australians (4th edition) supports quality of care for patients at the end of life, as well as their carers and families. Standard 8 recommends that formal mechanisms are in place to ensure that the patient, their caregiver/s and family have access to bereavement care, information and support services \(^{(46)}\). It is important to remember that end of life care does not stop at the death of the patient. Care for the family and carers, including emotional and bereavement support, continues on \(^{(47)}\).

### The Model

The end of life care component of this model promotes quality of life for the patient and their families through this phase of their journey. An integrated approach from haematology and palliative care teams is required to support care needs and maintain optimal quality of life. This is achieved through:

- Timely referral of patients to specialist palliative care services based on assessed need
- Appropriate management of symptoms
- Support for psychological and emotional concerns, incorporating the cultural and linguistic nuances of each patient
- Bereavement support for families

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\(^2\) Palliative care describes professionals and specialist services whose substantive work is caring for people approaching the end of life.
Key Aspects of the Model

- Palliative care and haematology teams work together to provide integrated care for patients when treatment is no longer curative
- There is a role for palliative chemotherapy and blood product support to optimise quality of life for patients with AML particularly once aggressive treatment is considered inappropriate or ineffective
- There are agreed guidelines for managing the transition from aggressive treatment to palliative care
- If previous advanced care planning conversations have not resulted in advanced care directives, consider for patients when curative care is no longer the goal
- Bereavement counselling is available for all carers and patients’ families

Supporting Evidence

As previously stated, AML is a disease that disproportionally affects the elderly. In Australia, the average age at diagnosis is 62 years old. As elderly patients are often ineligible for intensive chemotherapy due to significant co-morbidities, adverse cytogenetics and poor treatment tolerability, the need for a smooth transition to end of life care and social service support for the patient and family cannot be overstated.

Evidence to the obstacles of introducing palliative care to acute haematology patients is well documented in the literature and 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\(^{(48)}\). The NICE guidelines for Improving Supportive and Palliative Care for Adults with Cancer and McGrath et al. recommend the use of supportive care such as blood product support to improve quality of life throughout the disease trajectory and suggests provision for administration of blood products in the non-acute setting should be explored\(^{(48, 49)}\).

Parker et al reviewed 123 research studies in an effort to provide evidence-based recommendations regarding how to discuss life expectancy and dying with patients and families\(^{(50)}\). The findings of this systematic review included:

- Patient and caregivers needed clear information at all stages of the disease process concerning the disease itself, prognosis and symptom management
- Survival information was important without the need to be too explicit
- Survival information was given in time for the patient to prepare for death, finalise affairs and say good bye
- Caregivers needed more detailed information as the disease progressed to enable them to prepare to care mentally and physically for their loved one
- Patients and caregivers wanted a trusted healthcare provider to give information in small amounts, without medical jargon
- The preferred healthcare provider showed empathy, care, compassion and honesty, and encouraged questions and checked patient and caregiver understanding

The benefits of high quality end of life care extend from the patient, carers and families to the health care system itself. Appropriate palliative care can improve the efficiency and effectiveness of health services and reduce the pressure on acute care services. The
Palliative Care NSW Policy Statement places a conservative estimate of the cost of community based palliative care services at 50% and 300% less expensive than care in an acute or intensive care bed[46].

What is Needed for this Model

Guidelines and processes identifying:

- Guidelines to identify when referrals should occur to ensure they are not occurring too late in the process and the use of transition
- Processes for transition to palliative care and shared care models during end of life care
- Processes for documenting appropriate supportive treatments for individual patients
- Identification of end of life care and palliative care services for all NSW patients.
- Identification of bereavement services for families and carers.
**THE MULTIDISCIPLINARY TEAM**

This section identifies the multidisciplinary team responsible for developing and delivering a treatment plan for patients with AML.

**Core Members of the Multidisciplinary Team**

<table>
<thead>
<tr>
<th>Team Member</th>
<th>Staffing Requirements and Functions</th>
</tr>
</thead>
</table>
| Medical                   | **Clinical Haematologist**  
A designated clinical haematologist will take the lead role for each patient. Provisions must be made for a clinical haematologist to be available at any time of day or night for consultation. There is a process for collaboration with colleagues for haematologists working in isolation.  
**Haematology Registrar**  
Specialist registrars providing after hours cover should be:  
Working in haematology  
Part of the unit  
Familiar with unit protocols  
There is allocated haematology registrar cover for haematology ambulatory care areas. |
| Nursing                   | **Clinical Nurse Consultant / Cancer Care Coordinator**  
Senior experienced nurses are available to oversee and provide clinical advice on the nursing management of complex patients, provide education and training to patients, families and staff and ensure clinical practice and standards are based on up to date evidence of best practice.  
The specific roles and number of senior nurses required to provide these functions will vary depending on the size and level of activity of the clinical unit.  
**Inpatient Ward**  
A nurse-to-patient ratio required for managing neutropenic patients is equivalent to that in a high dependency unit. At least one experienced haematology nurse with the ability and knowledge to recognise early symptoms of infection and respond appropriately to acute clinical deterioration should be rostered on for each shift.  
Given the complexity of care, there is a limited role for enrolled nurses in providing care for patients undergoing intensive chemotherapy for AML.  
**Ambulatory Care**  
The nursing model in ambulatory care needs to ensure continuity of care and consider direct and indirect care needs, patient acuity, complexity of treatments and volume of patients. Staff mix should ensure there is an adequate ratio of experienced haematology nurses with specific knowledge and training compared to less experienced nurses to maintain safe patient care. |
### Allied Health

**Pharmacist**
An experienced pharmacist dedicated to haematology or cancer services with haematology specific knowledge and expertise is required to support treatments for AML.

**Social Worker**
Sufficient social worker support is required to enable assessment of psychosocial needs to all patients at diagnosis and support of complex psychosocial needs throughout the patients journey that includes inpatient and outpatient care.

**Dietician**
Sufficient dietician support is required to enable assessment and education of nutritional needs to all patients at diagnosis and support of nutritional needs throughout the patient’s journey that includes inpatient and outpatient care.

### Extended Team Members
This group includes individuals whose expertise is frequently needed, but may not necessarily be present at multidisciplinary team meetings\(^7,\ 10^\).

<table>
<thead>
<tr>
<th>Team member</th>
<th>Requirements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infectious Diseases</td>
<td>Clinical support from an infectious diseases physician for the management of complex infectious complications including fungal, opportunistic and atypical infections is available.</td>
</tr>
<tr>
<td>Palliative Care</td>
<td>Palliative care team is available to provide advice and guidance on symptom management throughout treatment and during the terminal phase of illness.</td>
</tr>
<tr>
<td>Clinical Psychologist</td>
<td>Clinical psychologist is available to support psychosocial care to patients with complex needs undergoing treatment for AML.</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>All patients with a predicted extended length of stay require assessment from physiotherapy. Patients experiencing significant toxicity from treatment will require physiotherapy support to maintain mobility and function. Some patients will require extensive rehabilitation following treatment.</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>Occupational therapy support including home assessment may be required by a small number of patients completing treatment for AML.</td>
</tr>
<tr>
<td>Pastoral Care</td>
<td>Pastoral care may be appropriate for patients who choose a faith-based support person. In addition, in areas where other allied health team members are unavailable, pastoral care may be an option for persons of all backgrounds (including those who do not identify as having a religious belief system). Accredited chaplains now function under a NSW Health Policy Directive(^6).</td>
</tr>
</tbody>
</table>

### Additional extended team members for paediatric centres

<table>
<thead>
<tr>
<th>Team member</th>
<th>Requirements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Teachers</td>
<td>All children of school age are offered and encouraged to continue their education. Academic exceptions may be required due to the intensity of treatment for key education events.</td>
</tr>
<tr>
<td>Play Therapists and Music Therapists</td>
<td>Play and music therapists are essential to support care provided to patients throughout treatment for AML</td>
</tr>
</tbody>
</table>
Supportive Care Model for Allied Health Needs of Patients with AML

Allied health services provide a range of diagnostic and therapeutic care to support patients throughout their health care journey. Psychosocial and nutritional support is required by a significant portion of patients undergoing treatment for AML while other allied health support such as physiotherapy or occupational therapy may be required by only a small number of patients. The following model for supportive care for patients with AML is adapted from Fitch’s Supportive Care for Cancer Patients and the Victorian Supportive Cancer Care models\(^{(52, 53)}\).

![Image of Supportive Care Model](image)

### Education and Training

Treatment for AML requires a highly skilled workforce with haematology specific training and knowledge. Education and training is important for providing safe and effective quality care to patients and succession planning to ensure a skilled workforce is maintained. Education and training and staff development should consider:

- 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

### Multidisciplinary Team Meetings

A multidisciplinary team meeting is defined by the Cancer Institute NSW\(^{(54)}\) as “a deliberate, regular meeting involving a range of health professionals with expertise in the diagnosis and management of cancer.” The purpose of the meeting is to facilitate best practice management of all patients with cancer.

The urgent need for treatment in many patients with AML means that often patients will commence treatment before a MDT meeting can be held, however, discussion of the treatment plan for these patients should be included in the next MDT meeting. MDT meetings should occur regularly and involve all core members of the team. Systems and processes associated with MDTs should meet the following objectives\(^{(9, 54)}\):
• Establish, record and review diagnoses for all new patients
• Review and discuss individual patient treatment plans.
• Consider patient preferences in developing treatment plans
• Consider eligibility for clinical trials when developing treatment plans
• Have all relevant test results available
• Discuss patients’ responses to treatment
• Consider patients’ other requirements such as suitability for BMT or referral to other services such as palliative care
• Inform patients of recommendations from MDT meetings and consider changes to treatment plans after discussion with patients.
• Communicate outcomes and recommendations to referring hospitals where patients are referred from another centre such as for transplant or from a rural centre where follow-up care will be referred back to that centre.
• Document recommendations from MDT meetings patients’ medical record.

Where haematologists are working in isolation there should be a process for collaboration with colleagues from another site such as through regular videoconferencing or inclusion in team meetings to ensure all patients experience the benefits of collaborative team discussion and decision-making processes.
FACILITIES AND SERVICES

This section outlines the different care locations and facilities required for the provision of treatment for AML. The benefit of single rooms for the protection of immunocompromised patients is acknowledged in the Australian Guidelines for the Prevention and Control of Infection in Healthcare (C6.3).

Further, the importance is acknowledged by international and national bodies who have recommended 80% single-beds rooms in acute care facilities (55, 56). In a systematic review of 600 studies with the research question “How hospital design can impact clinical outcomes” it was demonstrated that single rooms: (57):

- Lowered hospital-induced nosocomial infections,
- Reduced room transfers and associated medical errors,
- Lessened noise level,
- Improved patient privacy and confidentiality,
- Assisted social support by friends and families,
- Improved staff to patient communication,
- Increased patients’ overall satisfaction with health care.

Inpatient Facilities

Inpatient facilities for the treatment of AML requires dedicated haematology beds in a single ward with capacity to treat the planned volume of work and an environment that minimises airborne microbial contamination. In addition, the following should be considered:

- It is preferable to have sufficient single rooms to enable patients undergoing induction treatment for AML to be treated in a single room with ensuite facilities.
- Patients undergoing consolidation treatment, who are not allocated a single room, are co-located with similar patients. For example, co-location with other neutropenic patients during the neutropenic stage of their treatment to reduce the potential for transmission of infection from other patients, family and visitors.
- Guidelines for prioritisation of single rooms with ensuite in sites where there are insufficient single rooms to meet ongoing requirements will ensure resources are allocated to the patient with the highest need.
- Assessment of the demand for single rooms at each facility is performed including the number of admissions with identified requirements for a single room, the duration a single room is required, and the potential for clustering of cases. Predicted trends in estimated need into the future (25) will enable planning for future ward redevelopments. Where demand is not met, this is documented within the organisations capital plan.

Patients most requiring single room facilities with ensuite are; bone marrow transplant patients, patients with transmissible/communicable infections, terminal patients and patients undergoing induction treatment for AML or other high dose chemotherapy regimens.

Ambulatory Care Facilities

Ambulatory care facilities with haematology expertise are required for patients suitable for treatment through an early discharge model and for elderly patients or those with co-morbidities who are not suitable for intensive chemotherapy. Appropriate ambulatory care facilities require:

- Designated area for haematology that enables patient isolation to prevent the transmission of infection
- Ability to provide all haematology ambulatory care by haematology trained nursing staff
- Ability to provide long infusions, multiple units of blood, bone marrow biopsies, central venous access device care, nursing assessment of the immunosuppressed patient
- Extended opening hours to enable long infusions
- A process for undertaking clinical assessment and providing care at short notice during specified ambulatory care operating hours with the ability to enable direct admission to the ward if required
- A haematology registrar is available to provide medical cover to ambulatory care during operating hours
- Provision of the same multidisciplinary model as inpatient services that includes access to allied health, clinical psychologist and palliative care as required

Outreach Services
An outreach service for haematological malignancy enables patients to receive care at home who would otherwise be required to remain in hospital or attend regular ambulatory care clinics. A cancer outreach service is an optional extension of ambulatory care services where some patient care is provided in the comfort of patients’ homes. Ambulatory care and inpatient services will still be required throughout the course of treatment, however, the frequency of visits can be reduced and the provision of care streamlined by the addition of an outreach service. The service can function as an extension of Hospital in the Home (HITH) or Post-Acute Care Services (PACS) or as a standalone service within haematology departments or cancer services. An outreach service can:
- Reduce length of stay and ambulatory care bed utilisation.
- Reduce the frequency of hospital visits to the patient
- Enable early discharge particularly for less mobile patients
- Improve quality of life for patients
- Provide coordination of care between inpatient, ambulatory care and community settings
- Utilise primary health care teams and links with GPs for ongoing health care needs
- Reduce ED presentations through coordination of direct admission to the haematology ward

Possible capability of an outreach service
The following services are an example of what may be provided by an outreach service:
- Clinical assessment and monitoring
- Symptom management assistance, education, health promotion and advice
- Central venous access device troubleshooting, care and maintenance
- Short infusions or treatments (less than 1 hour)
- IV fluids for rehydration
- Septic work-up and first dose antibiotics (for patients found febrile at home prior to transfer to hospital)
- Coordination of direct admission to the ward after assessment at home, in consultation with haematologist when there is a bed available

Requirements for an Outreach Service
Operating hours should be established based on local demand and the availability of hospital, medical and clinical support for the service. It is recommended an outreach service
would operate Monday to Friday 8.30 am – 4.30 pm. There is some added benefit to include a weekend or Saturday service however, haematology medical and clinical support must be available.

Staffing
The minimum staffing requirements for an outreach service are:

- Experienced nurse with haematology knowledge and expertise that meets the criteria for a CNS level in haematology including venepuncture and canulation
- Sufficient staff to cover needed patient care episodes per day. A maximum number of patient care episodes per day will vary depending on patient complexity and the geographical area covered. Each facility requires guidelines for number of patients per staff member that considers these factors
- Access to all members of the multidisciplinary team
- Clinical haematologists or nominated medical officers such as haematology registrars to supervise the clinical care provided to patients through the outreach program and are contactable via telephone for consultation during outreach operating hours
- Access to clerical support

Policy and Guidelines
There are established policies and guidelines encompassing:

- Organisational and clinical governance systems, procedures and clinical practice guidelines that take account of patient acuity, medical accountability, consent and delivery of quality outcomes
- Appropriate referral systems with comprehensive risk assessments prior to accepting patients
- Monitoring of actual and potential risks to patients and staff
- Formalised arrangements for escalation of care at home that includes patient education and self-management and identification of symptoms requiring immediate action including escalation to ‘000’ emergency services
- Medical record documentation and care planning that resembles the hospital record and includes an admission history, physical examination, identified clinical problems, progress notes and current medical orders. A mobile method of electronic record keeping is an ideal tool for the community setting.

Patient Selection for Outreach
The following patient selection criteria are met:

- The patient has a haematological malignancy that would require hospitalisation or frequent ambulatory care visits if an outreach service were not offered
- Patients must be medically stable requiring treatment no more than once per day treatment
- Patients with AML must meet the criteria for the early discharge model
- The patient and carer agree to receive the outreach service and conditions
- The home environment is adequate to provide the treatments required and meet the needs of daily living. This may require assessment on the first visit
- Access to a telephone with incoming and outgoing capability
The patient and environment meet local policy requirements for home visit risk management strategies (such as no history of violence, threatening behaviours, local area vandalism or gang activity)

Support Services
Access to the following supportive services is required to maintain effective safe patient care to patients undergoing treatment for AML.

<table>
<thead>
<tr>
<th>Service type</th>
<th>Requirements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Radiology</td>
<td>Capacity to provide urgent Magnetic Resonance Imaging (MRI) and Computerised Tomography (CT scanning)</td>
</tr>
<tr>
<td>Blood Banking</td>
<td>Rapid availability of blood products including red cells, platelets and plasma derivatives that are CMV negative and irradiated if required.</td>
</tr>
<tr>
<td>Laboratory</td>
<td>Full haematology service able to provide rapid turn-around for blood counts. Microbiology laboratory readily available for the diagnosis of fungal or other opportunistic infections.</td>
</tr>
<tr>
<td>Apheresis</td>
<td>Treatment facilities for AML have the capacity to perform urgent leukopheresis procedures for patients presenting with elevated white cell counts.</td>
</tr>
<tr>
<td></td>
<td>Leukopheresis should be considered for all patients with high white cell count and symptoms associated with hyperviscosity.</td>
</tr>
<tr>
<td>Central Venous Access Device</td>
<td>Access to services for insertion of central venous access devices in emergency situations. Access to services for removal of tunneled and implanted catheters.</td>
</tr>
<tr>
<td>Anaesthetic</td>
<td>Anaesthetic is frequently required for invasive and radiological procedures in paediatric patients. This is based on individual patient assessment prior to arranging each procedure.</td>
</tr>
</tbody>
</table>
NEXT STEPS
Following development of the ideal model and wide consultation, the project will move into the implementation phase. This section describes the steps that need to be considered in order to successfully implement this model of care across all sites within the BMT Network.

Business Proposal
A resourcing analysis will be undertaken in consultation with the Agency for Clinical Innovation Health Economics Team to exam the impacts of the model of care on NSW health services. The business proposal will assist Local Health Districts in developing a business case to meet local implementation needs. This will include:
- The costs to the health care system of not changing
- The impact of costs and service utilisation once the model is implemented
- Identification of impacts on other services

Local Health District Executive Sponsorship
Sponsorship will be sought from each Local Health District. The level of input required from each Local Health District will vary depending on whether patients receive intensive therapy for AML within that LHD, or whether the LHD provides supportive care for patients who have not received aggressive treatment or have received treatment elsewhere and have ongoing supportive care needs. Local Health Districts will be asked to identify primary contacts within their organisations and establish a local implementation group. The primary contacts will include:
- Project lead to assist with implementation locally
- Clinical champion

Communication Plan
A communication strategy will be developed that provides a clear consistent message regarding implementation of the model to relevant stakeholders, sponsors and champions that meets the needs of the target audience. A communication strategy will incorporate project objectives, key messages and action plans. Strategies to ensure effective communication will include:
- Maintenance of up to date information on the BMT Network website
- Regular reporting at BMT Network executive and working group meetings
- Regular updates to stakeholders on key milestones and achievements
- Reporting all new and updated activities in ACI Clinician Connect

Self-Assessment and Gap Analysis
The ACI will assist the local implementation group to undertake a self-assessment and identify gaps in current practice compared to the new model of care. A standardised self-assessment tool will enable evaluation of the care provided at each phase of the patient’s journey and identify areas for local development. The gap analysis will identify:
- What is currently being done
- What can easily be implemented with limited support ,and
- What will require significant assistance and development to implement
**Address the Identified Gaps**

The identified gaps will be prioritised by the local implementation group. The group will action the issues where possible. A business case will be developed using the business proposal to support the case to address issues that cannot be fixed within existing resources.

Implementation will be assisted through the identification of existing tools and guidelines within the network where available.
MONITORING AND EVALUATION

Data Collection:
This Model of Care recognises the importance of uniform data collection across the BMT Network as a component of the monitoring and evaluation process and ultimately to ensure improved patient outcomes.

- The collection of an AML minimum data set (in development) is essential to provide information regarding patient outcome variances. In addition, the BMT Statewide Specialty Plan (point 6.3) identifies the need for system monitoring of outcomes of individual units as a method for benchmark comparisons. Feedback to the LHDs will allow significant variances to be addressed.
- Complete and timely data submission to various cancer registries, including the ABMTRR, will also enhance the monitoring and evaluation of this Model of Care.

It is acknowledged that not all LHDs will have the ability to implement this Model of Care in full at the outset. As stated under the “Next Steps” section, the ACI will provide a self-assessment tool for LHDs to measure their preparedness for implementation and will work with the LHDs to advocate for strategies to address identified gaps.

Further Monitoring and Evaluation to be developed with the ACI Health Economics Team and Implementation Team.
REFERENCES
41. <PallCareNeedsAssessmentGde.pdf>.11-2.
45. McGrath PP. Follow-up of patients with haematological malignancies and their families in regional, rural and remote Queensland: the GPs' perspective. Supportive Care in Cancer. 2001;9(3):199-204.
46. Australia PC. Standards for providing quality palliative care for all Australians: Palliative Care Australia Incorporated; 2005.
# APPENDIX 1 – GUIDELINES AND TOOLS

## Referral Options for AML Management

<table>
<thead>
<tr>
<th>Adult AML Treatment Centers</th>
<th>Existing links</th>
<th>Possible patient origin</th>
</tr>
</thead>
<tbody>
<tr>
<td>Calvary Mater Newcastle</td>
<td>Outreach clinics: Muswellbrook</td>
<td>Hunter New England LHD Mid North Coast LHD Northern NSW LHD</td>
</tr>
<tr>
<td>Concord Repatriation Hospital</td>
<td>Outreach clinics: Bankstown Hospital</td>
<td>Concord and Bankstown local areas</td>
</tr>
<tr>
<td>Gosford Hospital</td>
<td>Outreach clinics: Wyong</td>
<td>Central Coast LHD</td>
</tr>
<tr>
<td>Liverpool Hospital</td>
<td>Outreach clinics: Campbelltown Hospital</td>
<td>South Western Sydney LHD</td>
</tr>
<tr>
<td>Nepean Hospital</td>
<td>Outreach clinics: Lithgow Hospital</td>
<td>Nepean Blue Mountains LHD</td>
</tr>
<tr>
<td>Prince of Wales Hospital</td>
<td>Outreach clinics: Bathurst, Tamworth Video conferencing with: Port Macquarie Hospital</td>
<td>Prince of Wales local area Bathurst (Western NSW LHD) Port Macquarie (Mid North Coast LHD) Tamworth (Hunter New England LHD)</td>
</tr>
<tr>
<td>Royal North Shore Hospital</td>
<td>Outreach clinics: Manly, Armidale Video conferencing with: Lismore, Coffs Harbour</td>
<td>Northern Sydney LHD Mid North Coast LHD Northern NSW LHD</td>
</tr>
<tr>
<td>Royal Prince Alfred Hospital</td>
<td>Outreach clinics: Orange, Dubbo</td>
<td>Sydney LHD Orange and Dubbo (Western NSW LHD)</td>
</tr>
<tr>
<td>St George Hospital</td>
<td>Outreach clinics: Sutherland Hospital</td>
<td>St George and Sutherland local areas</td>
</tr>
<tr>
<td>St Vincent’s Hospital</td>
<td>Outreach clinics: Wagga Wagga, Griffith</td>
<td>St Vincent’s local area Wagga Wagga and Griffith (Murrumbidgee LHD)</td>
</tr>
<tr>
<td>Westmead Hospital</td>
<td>Outreach clinics: Blacktown Hospital</td>
<td>Western Sydney LHD Western NSW LHD Far West NSW LHD</td>
</tr>
<tr>
<td>Wollongong Hospital</td>
<td>Outreach clinics: Nowra / Shoalhaven</td>
<td>Illawarra Shoalhaven LHD Southern NSW LHD</td>
</tr>
<tr>
<td><strong>Paediatric Centers</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Children’s Hospital Westmead</td>
<td></td>
<td>All NSW</td>
</tr>
<tr>
<td>Sydney Children’s Hospital</td>
<td>Outreach clinics: Wagga Wagga, Armidale, Coffs Harbour, Canberra and Campbelltown</td>
<td>All NSW</td>
</tr>
<tr>
<td>John Hunter Hospital</td>
<td></td>
<td>Hunter New England LHD</td>
</tr>
<tr>
<td><strong>Interstate Alternatives</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Canberra Hospital</td>
<td>Outreach clinics: Bega, Goulburn, Moruya Outreach chemotherapy clinic: Cooma</td>
<td>Southern LHD Murrumbidgee LHD</td>
</tr>
<tr>
<td>South Australia</td>
<td></td>
<td>Far West LHD</td>
</tr>
<tr>
<td>Victoria</td>
<td></td>
<td>Albury in-reach area</td>
</tr>
<tr>
<td>Queensland</td>
<td></td>
<td>Tweed Heads / Northern NSW LHD</td>
</tr>
</tbody>
</table>
Flow diagram for determining requirements for fertility preservation interventions adapted from the American Society for Clinical Oncology and Fertile Hope recommendations\(^{(58, 59)}\).

**Fertility Preservation in AML**

1. **Patient to undergo treatment for AML**
2. Assess fertility risk based on treatment regimen and patient factors
   - **Yes**
     - **Patient at risk**
     - Discuss the risk and potential fertility preservation options with the patient
       - (Include family where appropriate)
     - **Yes**
       - Refer to reproductive specialist
     - **No**
   - **No**
     - **Patient not at risk**
     - Proceed with treatment

**Fertility Preservation Options for Men**\(^{(58, 59)}\)

<table>
<thead>
<tr>
<th>Preservation Technique</th>
<th>Time Requirement</th>
<th>Success rates</th>
<th>Other considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sperm cryopreservation</td>
<td>3 collections over a week on alternate days recommended for best sperm quality.</td>
<td>High success.</td>
<td>The patient must be physically able to collect an ejaculate. Some centres will offer sperm cryopreservation after treatment has commenced however this practice is not routinely recommended and there is a risk that no sperm will be present.</td>
</tr>
</tbody>
</table>

**Fertility Preservation Options for Women**\(^{(58, 59)}\)

<table>
<thead>
<tr>
<th>Preservation Technique</th>
<th>Time Requirement</th>
<th>Success rates</th>
<th>Other considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Embryo cryopreservation</td>
<td>10 – 14 days from commencement of menstrual cycle</td>
<td>20 – 33% per embryo transfer. Variation depending on age at collection</td>
<td>Requires a partner for egg fertilization. Impractical in rapidly progressive disease, but maybe a suitable option once remission is established.</td>
</tr>
<tr>
<td>Oocyte cryopreservation</td>
<td>10 – 14 days from commencement of menstrual cycle</td>
<td>Small case series. Approximately 2% per thawed oocyte.</td>
<td>Option for single females. Impractical in rapidly progressive disease, but maybe a suitable option once remission is established.</td>
</tr>
<tr>
<td>Ovarian suppression</td>
<td>In conjunction with chemotherapy</td>
<td>Experimental. Clinical trials in progress</td>
<td>Hormonal therapies protect ovarian tissue during chemotherapy.</td>
</tr>
</tbody>
</table>
New South Wales Support Organisations

**Arrow Bone Marrow Foundation**
Arrow Bone Marrow Foundation supports patients and their families by providing accommodation, patient information guides, help with travel costs and a free Wig Library available to any cancer patient experiencing hair loss through radiotherapy or chemotherapy.

Contact details:
Phone: 02 8382 2698
Address: 16 Leichhardt St
Darlinghurst NSW 2010
Website: http://www.arrow.org.au

**Can Assist**
Can Assist is a community based charity dedicated to supporting country people and their families affected by cancer.
- Financial assistance through local branches to meet medical, pharmaceutical, travel and personal costs
- Supported accommodation
- Home based support service; Can Assist Viva Packs provide short-term support of essential services to meet specific needs. The range of services may include but are not limited to: nursing, transport, child care, domestic help and respite care.

Contact details:
Phone: 02 8217 3400
Address: 1/35-39 Mountain St
Ultimo NSW 2007
Website: http://www.canassist.com.au

**CanTeen**
CanTeen helps young people, aged between 12 and 24 by providing:
- Information for young people with cancer or young people who have a loved-one with cancer or a loved-one who has died of cancer
- Individual support and counselling
- Peer support groups

Contact details:
Phone: 02 9382 1563
Address: Prince Of Wales Hospital/Barker St
Randwick NSW 2031
Website: http://www.canteen.org.au/

**Cancer Council NSW**
The Cancer Council NSW is a community funded cancer charity with membership in Cancer Council Australia. They provide support to patient, families and friends through:
- Information centres
- Telephone support
- Face-to-face support groups
- Cancer Council connect peer support
- Cancer information programs

Cancer Council NSW also provides practical support:
- Legal and financial support
- Accommodation
- Following cancer treatment, Cancer Council NSW offers:
• Face to face programs
• Online support and multimedia resources
• Information regarding healthy lifestyle choice
• Tailored services for young adults 18-45 years
• Cancer Council NSW also provides workplace support with:
  • Information and support for employers and workplaces
  • Workplace information for the employee

Contact details:
Cancer Council NSW Head Office
Phone: 02 9334 1900
Address: 153 Dowling Street, Woolloomooloo NSW 2011
............... PO Box 572, Kings Cross NSW 1340
Website: http://www.cancercouncil.com.au

The Leukaemia Foundation
The Leukaemia Foundation provides free of charge, personalised and practical support for patients and families. Services include:
• Emotional support and counselling
• Information
• Education programs
• Accommodation
• Transport
• Legal advice

Contact details:
Phone 02 9902 2222
Address: Level 4, 44 Hampden Road
          Artarmon NSW 2064
Website: http://www.leukaemia.org.au

NELUNE Foundation
Support to cancer patients include:
• Patient transportation. The NELUNE Foundation provides public hospital transportation services for cancer patients and assistance with medical aids for cancer patients.

Contact details:
Phone: 0412 552 418
       02 8082 8181
Address: PO Box 1033
          Spit Junction NSW 2088
Website: http://www.thenelunefoundation.org/

Redkite Foundation
Redkite’s cancer support services are available for children and young adults (up to the age of 24) and their families.
Hospital-based support includes:
• Professional counselling, care and information provided by Redkite Social Workers
• Music therapy
• Books and resources on cancer and the cancer journey through the Redkite Book Club
• Support packs for the initial diagnosis period
Community based support
• Email counselling and information support
• Telephone counselling and information support
• Telephone cancer support groups called ‘Telegroups’
• Books and resources on cancer and the cancer journey
• Grief counselling and bereavement support
• Family Days
• Digital storytelling pilot

Financial assistance
• Financial grants
• Financial counselling

Education and career assistance
• Redkite’s education and career assistance is provided via financial grants.

Resources and publications

Contact details:
Phone: 02 9219 4000
Address: 1/8 Lawson Square
         Sydney NSW 2016
Website: http://www.redkite.org.au