

# WA Cancer and Palliative Care Network

## Haematologic Malignancy Model of Care



Government of **Western Australia**  
Department of **Health**



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## 1. Introduction

In developing a model of care for Haematologic malignancies there are a number of steps that need to be considered other to develop a sustainable plan

1. Define the General Principles of the Model of Care
2. Develop a plan for ideal service delivery
3. Develop a resource plan appropriate to the service delivery model
4. Review the feasibility
5. Develop a transition plan

The discussion below mostly addresses the first 2 issues. Progress towards implementation i.e. 3-6 will depend on resource constraints, both staff and infrastructure and the transition plan will need to take resource issues into consideration. Currently there is a strong focus on developing distributed models of care. Health planners have already modelled treatment into Cancer Centres and Units and planning (and in some cases construction) of these treatment sites has commenced. To date the additional resources to support a more distributed model of care have not been determined.

Any attempt to develop a model of care for haematologic malignancy must recognise that this group encompasses a diverse range of illnesses with a wide variety of treatment needs. There has been substantial evolution in treatment paradigms for a number of these illnesses and this is likely to continue. Newer treatments are not always simpler, often more resources are required if the therapy is more intensive, conversely less intensive therapies can also increase resource utilisation by allowing treatment to be extended to patient groups previously not able to receive therapy i.e. unless curative, newer treatments often increase resource utilisation.

Ultimately the approach to development of the MOC for each malignancy must be tailored to the specific needs for that disease. The following document attempts to identify the critical issues to be considered in the development of a MOC for Haematologic Malignancy; rather than a diagnosis specific model, a functional model which matches resource requirements (i.e. patient needs) to resource availability is proposed; hopefully this will be a more flexible approach accommodating changing treatment paradigms. When considering Haematologic malignancy, a model based on specific diagnosis alone will not provide enough detail of resource requirements nor be flexible enough to allow planning of appropriate facilities.

The following recommendations relate to patients > 16 yo, younger patients should continue to be managed in the Paediatric Total Care Unit.”

### **Recommendation 1**

Diagnosis alone should not be used as the major/sole determinant for planning the MOC for Haematologic Malignancy



## 1.1 Disease Incidence

The table below details the incidence of new haematologic malignancies reported to the WA Cancer Registry in 2005.

**Table 1. Incidences of new haematologic malignancies reported to the WA Cancer Registry in 2005**

	Adult	Child	Total	Metro/Rural
<b>Lymphoma</b>			364	304/60
<b>Mature B</b>	233	1		
<b>Mature T/NK</b>	32	0		
<b>Unclassified</b>	50	2		
<b>NOS</b>	8	0		
<b>Hodgkin's disease</b>	34	4		
<b>Leukaemia</b>			209	173/36
<b>ALL</b>	14	17		
<b>AML</b>	58	5		
<b>NOS</b>	28	4		
<b>CLL</b>	64	0		
<b>CML</b>	19	0		
<b>Myeloma</b>	112	0	112	99/13
<b>Myelodysplasia</b>	112	1	113	89/23
<b>Myeloproliferative</b>			61	54/7
<b>PRV</b>	29	0		
<b>Myelofibrosis</b>	8	0		
<b>Other</b>	16	0		
<b>NOS</b>	8	0		
<b>Total</b>	825	34	859	719/139

Most haematologic malignancy occurs in adults, 16% of cases are outside the metropolitan area and 4% are in children. Reporting is probably incomplete for some subgroups e.g. myeloproliferative syndromes, chronic lymphocytic leukemia. An independent audit of CLL (Michael Watson – personal communication) over a 2 year period 2004/5 showed very significant under-reporting. There is no prevalence data available for haematologic malignancies in WA and this is of considerable importance as many of these illnesses are chronic and require active management over many years.

### Recommendation 2

Service planning needs to take into account both the incidence and prevalence as both impact on resource requirements



## 2. Area/State Model

The WA Cancer Taskforce model for the delivery of cancer services recommended the establishment of Cancer Centres at tertiary hospital sites and the establishment of Cancer Units at some other sites. At the time these recommendations were formulated there was insufficient detailed information to underpin any specific recommendation regarding the number or location of Cancer Units. It was recognized that, due to limited resources and expertise, Cancer Units would have a more limited scope of practice and recommended that the Cancer Network should be responsible for determining the scope of practice at Cancer Units. It was also recommended that the Cancer Network develop processes for credentialing Cancer facilities and staff.

### 2.1 Modelling Haematology Services and Planning Redistribution

Planning for Cancer Services often focuses on the delivery of chemotherapy and the development of appropriate facilities for this facet of treatment. In part this is a reflection of the type of data available. Although an outpatient episode of care may be recorded as chemotherapy, in fact a number of services may have been provided including medical review and other interventions. These other components of treatment e.g. diagnostic, supportive care needs, palliative care needs must also be recognized and considered in the planning process. This is particularly for haematology patients where management of bone marrow failure in the ambulatory setting can be very resource intensive; for many hematologic malignancies administration of chemotherapy is the simplest part of the treatment plan. Data from the haematology service at RPH reveal that two thirds of day patient services delivered to haematology patients are “non-chemotherapy”. **Comprehensive planning for all of these care needs, particularly for patients in ambulatory and outpatient programs, must be considered now as there are specific infrastructure requirements.** Planning at both Cancer Centres and Cancer Units must involve members of the multidisciplinary team currently providing care for this group of patients to ensure facilities are appropriate and facilitate delivery of a multidisciplinary model of care i.e. more than just chemotherapy beds.

#### Recommendation 3

Better information, particularly with regard to ambulatory care is required to progress planning of ambulatory services

Planning for non malignant hematologic illness and laboratory services must be integrated with cancer services planning as clinical staff and facilities will be shared. Planning of tertiary laboratory services is well advanced, but secondary level pathology models of service delivery and facility design have received little input from haematologists. To date there has been little planning for non malignant disease e.g. general haematology and disorders of thrombosis and haemostasis. A greater proportion of non malignant haematology will be managed in the secondary sector. Aligning service delivery for both malignant and non-malignant hematologic illness will improve the sustainability of haematology services in the secondary sector.

#### Recommendation 4

Planning for haematologic malignancies should be integrated with planning for non malignant haematologic illness and laboratory services



Ongoing interaction between the NMAHS and SMAHS Haematology services should be planned for all multidisciplinary teams. This will serve the strategic needs of the network and develop an agenda to review the state-wide provision of “services” such as clinical care, education, research and workforce planning. This more strategic interaction should be facilitated by the Cancer Network.

Attempts to model redistribution of patients with cancer to Cancer Units have been limited by available data; crude modelling based on diagnosis and postcode is of very limited value and is likely to lead to erroneous allocation of resources. **Modelling based on diagnosis alone is not likely to accurately reflect the treatment requirements for many haematologic cancers**, there will probably be a significant number of patients who will require tertiary and secondary care at different phases of treatment. It seems unlikely that adequate data will ever be available to allow accurate modelling. Probably the best strategy is develop a flexible/adaptive transition plan which allows evolution of the model of care as new facilities are commissioned; such a strategy will require ongoing dialogue between clinicians, planners and area health services to match available resources with the acuity of care required.

## 2.2 Cancer centres

Comprehensive Cancer Centres will be established at FSH and SCGH, to date there has been no discussion of the development of a Cancer Centre at Joondalup once this hospital attains tertiary status. The impact on cancer services of the recent decision to retain RPH as a tertiary institution will not be known until there has been a review of the metropolitan clinical services plan. The Cancer Centres will provide area based inpatient, ambulatory and outpatient services for tertiary level indications as well secondary level care for patients within the “local area”. Tertiary level services cannot necessarily be designated by the disease or treatment e.g. a frail elderly patient may require tertiary level care to deliver modest therapy. Ultimately it will be the combination of disease and other factors e.g. co-morbidities which will determine where a patient is best cared for. In general, Cancer Centres will care for the most complex haematology patients including patients with acute leukemia, those requiring intensive chemotherapy and bone marrow transplantation. FSH will be the designated state allogeneic bone marrow transplant centre.

Outpatient and ambulatory chemotherapy treatment which is significantly myelosuppressive should be managed from Cancer Centres where extended supportive care services are available.

Most current public sector inpatient (malignant) haematology care is delivered at tertiary hospitals and most inpatients require tertiary level care. Smaller numbers of non tertiary inpatients could potentially be cared for at secondary hospitals if a viable model for inpatient services at these centres can be developed.

## 2.3 Cancer Units

Cancer Units will provide a more limited scope of care to the local population. For haematology patients this will include outpatient review, outpatient treatment and day patient treatment with less intensive chemotherapy protocols. It is likely that as demand grows and resources improve in these centres, that more intensive treatment will be offered in cancer units.



It is planned that Cancer Units would be affiliated with a designated Cancer Centre and that medical staff would work across both sites functioning as a single service at multiple sites. Options for staffing model for other members of the team have not yet been determined, but should be developed.

#### **Recommendation 5**

The development of Cancer Centres and Units within an area based model is supported for haematologic malignancy

### **2.4 Ambulatory Care Models**

Currently RPH provides 2 services for non admitted care, a nurse lead Home Bone Marrow Transplant service (provided for RPH patients) and a nurse lead (pharmacist managed) Home Cancer Chemotherapy Service which provides services across institutions within the metropolitan area. Both of these services provide chemotherapy and supportive care to patients. At SCGH there is a nurse practitioner lead outpatient BMT service.

While management of patients in ambulatory models of care reduces inpatient demand, there is an increased need for appropriate day facilities and staff resources to review these patients at short notice. Management of pancytopenic patients in the community can only be safely undertaken if

- There is a dedicated ambulatory care service which reports to the haematology service
- Governance is unambiguous
- Care is administered by appropriately trained and credentialed nursing staff,
- There are clear treatment algorithms,
- There are adequate facilities for acute assessment and treatment in the Cancer Centre – including beds and medical staff.

At RPH there is a dedicated ambulatory care team (Nursing Staff, Pharmacist, RMO and Registrar) within the haematology department. Urgent review of these patients via the Emergency Centre is not appropriate, adequate isolation facilities are usually not available and ED staff are usually unfamiliar with specific treatment algorithms.

It is important that there is an adequate range of facilities for new models of care within the Cancer Centres; the phase II plans for the SCGH Cancer Centre should be reviewed to ensure there is adequate provision for future management of ambulatory patients

#### **Recommendation 6**

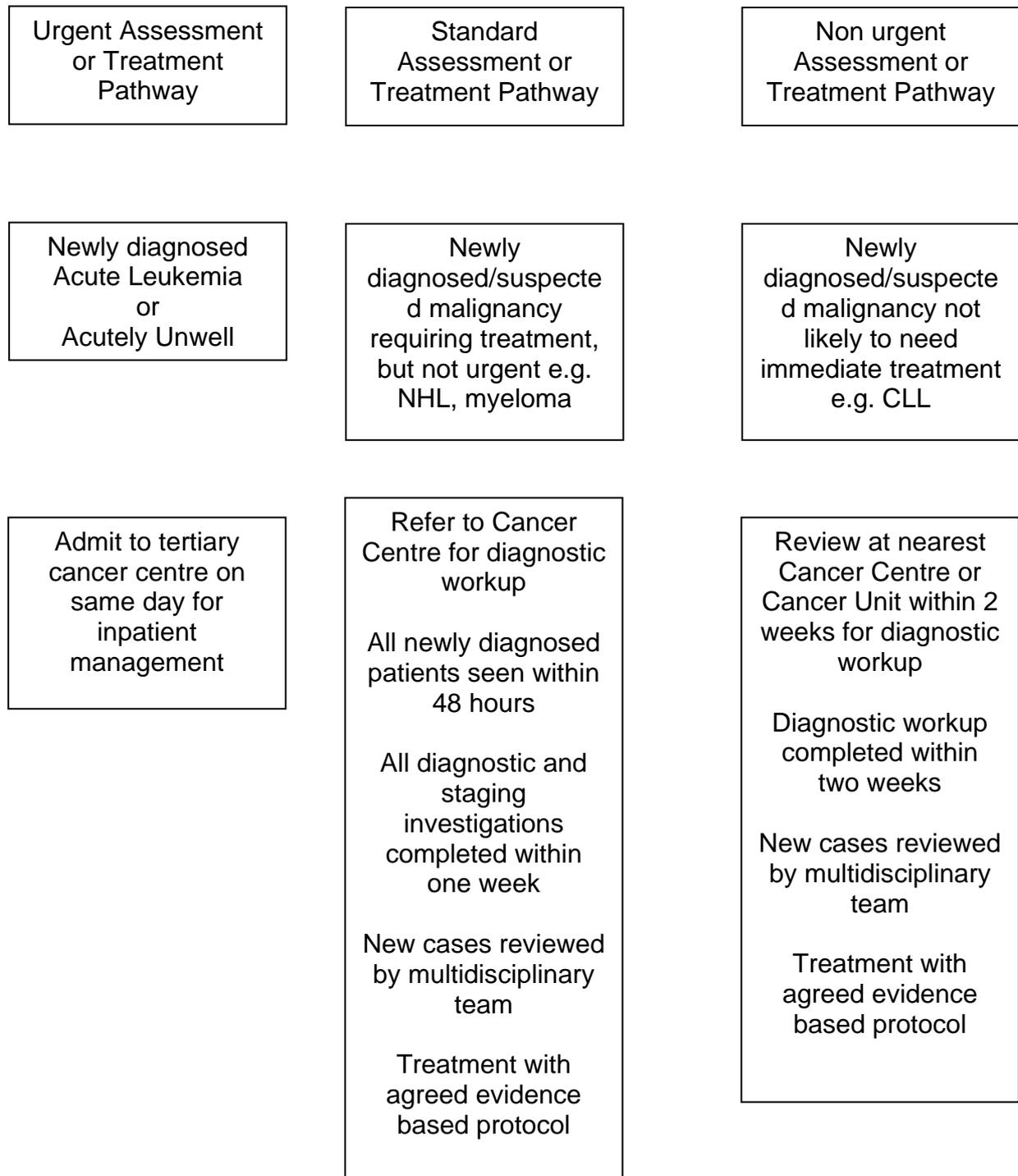
With the relocation of RPH, the 2 RPH ambulatory programmes should be combined to form the SMAHS ambulatory cancer service and a dedicated NMAHS ambulatory service should be developed. Governance arrangements should be formalised and uniform for the 2 area based services.

#### **Recommendation 7**

Planning of Cancer Centres and Units must consider the infrastructure needs in day therapy units for patients cared for in ambulatory programmes as much of the need for haematology patients is for supportive care and urgent assessment rather than chemotherapy.



**Figure 1. Referral Pathway Algorithm**





## 2.5 Credentialing of Cancer Treatment Facilities

It was proposed in the “State Cancer Plan” that a credentialing process be developed for cancer treatment facilities to ensure that the care undertaken at a particular site was appropriate to the resources available at that site. The Haematology Tumour Collaborative should advise the Cancer Network on the credentialing of Cancer Units and Centres for haematologic malignancy.

### **Recommendation 8**

Policy and appropriate governance must be developed to ensure compliance of staff and facilities with credentialing recommendations.

## 2.6 Multidisciplinary Care

Inpatient tertiary care is delivered by a multi disciplinary team, with day to day care being provided by

- Chaplaincy
- Counselling staff
- Dieticians
- Haematologists/trainees
- Infectious disease physicians
- Junior Medical Staff
- Nursing Staff
- Pharmacists

Most of these acute care services must be available “24/7”

A number of other services are available on a consultation basis:

- Immunology (at allogeneic transplant centre)
- Interpreter Services
- Infectious disease physicians
- Pain Service
- Palliative Care.
- Psychiatry Services
- Radiotherapists
- Radiology Services
- Renal Physicians
- Respiratory Physicians
- Surgical Services
- Vascular access services

Tertiary outpatient services require many of the same services, and Cancer Centre ambulatory facilities must be designed to accommodate a multidisciplinary model of service provision

The scope of multidisciplinary services provided at Cancer Units located in secondary hospitals will be more limited initially but will probably increase with time. A specific proposal for minimum infrastructure and staffing requirements for Cancer Units should be developed by the Cancer Network in collaboration with stakeholders.



Unless there is an adequate scope of services, patients treated in Cancer Units may be disadvantaged. For haematology services a suggested minimum requirement is:

- Chaplaincy service
- Counselling staff
- Dieticians
- Haematologists/trainees
- Infectious disease physicians
- Junior Medical Staff
- Nursing Staff
- Pharmacy

#### **Recommendation 9**

Minimum criteria for infrastructure and clinical services should be developed for Cancer Centres and Cancer Units to enable the delivery of multi-disciplinary care.

### **2.7 Cancer Network services**

Current cancer service delivery has evolved over several decades from site based services; the Cancer Network facilitates improved communication between site based stakeholders and is well positioned to assist with the planning and development of a distributed service model. There are a number of projects which are of high priority at the current stage of service development

- The Network will have an important role in helping service delivery to extend more effectively into regional areas by assisting with identification of resource requirements and development of business plans for these services.
- The network has developed a data management group in recognition of the need for more clinically relevant information about patients and treatments.
- A high priority for most staff is the implementation of computer based prescribing and treatment records, available remotely, wirelessly and at multiple locations simultaneously.
- The psycho-oncology group has focussed on non inpatient support and therefore for haematology patients there is still a major unmet need, providing support to the newly diagnosed and their carers. Like most acute care services this function is probably better managed at the area based delivery level, but it is often difficult to gain support for what are perceived as soft services when competing for scarce funding. The Cancer Network should further investigate service models for acute counselling services and funding mechanisms.

Most of the budget for cancer services remains integrated with area based budgets and in the city, most clinical service delivery is probably more effectively managed when closely integrated with area based service delivery. There is probably a very limited role for clinical service delivery by the Cancer Network.

#### **Recommendation 10**

The Cancer Network should continue to support the strategic development of cancer services. Direct involvement in clinical service delivery should be carefully considered due to the potential to fragment current service delivery models



## 2.8 Services for rural patients

### Tertiary based

There are a range of conditions which can only be managed in tertiary centres and this group of patients will have to travel to the city for treatment. Ensuring timely and equitable access for rural patients should be considered a high priority in planning of new infrastructure. Currently the Leukaemia Foundation provides accommodation assistance for patients requiring tertiary care in city hospitals, and substantial inpatient bed days are saved by accommodating patients and carers in these facilities. A needs analysis for rural patients requiring tertiary care should be performed so that adequate facilities can be planned.

### Non tertiary services

Currently a number of practitioners provide haematology services in a rural setting including

- visiting oncologists
- local physician (Albany, Geraldton)
- local haematologist (Bunbury)
- local GP's - often in collaboration with tertiary specialists

Notably there are no visiting haematology services. It is likely that visiting Haematology services would be viable in a number of larger regional centres in partnership with local physicians. Currently many patients with chronic malignancies travel to the city for treatment. A scoping project for rural services should be developed to assess the viability of visiting haematology services and a business case developed for the provision of rural services in centres where this is likely to be viable. Where a service already exists, discussion with current providers should focus on supporting current services i.e. identifying the specific needs at that site. The level of care delivered to rural patients is likely to be similar to that delivered in metropolitan Cancer Units

#### **Recommendation 11**

Plans for providing rural services should be developed based on an area based model by area based health services.

## 2.9 Integration with primary care

### Referral

The development of area based Cancer Centres with centrally managed referral triage should simplify the referral process. A web based referral system, part of a Cancer Services website, has the potential to further reduce delays in the referral process.

### Communication

Probably the key to improved integration with primary care is improved communication between providers across the spectrum of care. An integrated electronic record available to designated care providers across the spectrum of care is a potential solution, but there are enormous challenges to overcome for a bidirectional record to be implemented. In the intermediate term primary care access



to relevant sections of the hospital electronic patient record would hopefully improve the reliability of communication with primary care providers.

Electronic patient record systems projects have been plagued by cost overruns, overpromising, under-delivering and usually taking years longer than planned. The current NHS clinical record system under development will cost an estimated 12 billion pounds is 4 years late. The planned date for implementation is 2014. Consideration may need to be given to development a specific electronic record for patients undergoing cancer treatment which contains relevant diagnostic, treatment, prognostic and follow-up information.

Strategies for improved communication at a professional level should be developed. This could take the form of Haematology collaborative or “area based service” sponsored educational activities around care of patients with haematologic malignancy. The Cancer Network could develop a more generic education program for primary care clinicians. Initial discussion with GP divisions should be a first step to identifying needs and improving the bilateral flow of information.

### **Treatment guidelines**

Web based treatment guidelines for haematologic illness managed by primary care clinicians should be developed. These should include a map to Cancer Services in WA, diagnostic algorithms for common malignancies, prognostic information to help clinicians better inform patients about outcomes of common cancers and guidelines for referral to support services.

#### **Recommendation 12**

Improved integration with primary care services should be developed. The approach should probably be uniform across tumour collaboratives and may best be facilitated by the Cancer Network. Improved information sharing (electronic records) would greatly facilitate such integration.

### **2.10 Integration with Private Sector – clinical and other**

Many patients choose to be cared for in the private sector, but at times require care in the public sector. Current information systems are a significant barrier to ready exchange of clinical and diagnostic information: improvements would facilitate easier and safer transition between these treatment settings. Resources requirements to support participation in clinical trials for patients cared for in the private sector should be determined and options for funding developed.

Public and private sector clinicians should work collaboratively to develop common policies and guidelines where possible. At an organisational level the Cancer Network should facilitate this interaction, and at a professional level the HSAZ, Transplant Nurses Group and Haematology Collaborative and others should assist.

### **2.11 Non Government Organisations**

A number of external organisations provide support for patients and their families including the Leukemia Foundation and Cancer Council. The close professional relationship between clinicians and these organisations helps to ensure a well focussed development of these resources. The provision of accommodation and transport facilities for rural patients has enabled rural patients needing tertiary services to be treated out of hospital with the assistance of their usual carers.



Possibly one of the most pressing needs is to identify how this model can be implemented at the new FSH.

As care becomes more distributed a plan for access to the services provided by NGO's across treatment networks should be developed.



### **3. Care Delivery Targets**

#### **3.1 Prevention**

For most de novo haematologic malignancies no preventative strategy is appropriate; although haematologic malignancy may occur as a secondary cancer in a number of circumstances e.g. following prior chemo/radiotherapy, immunosuppression associated with organ transplantation and HIV infection. Specific strategies to reduce the risk of secondary malignancy include avoidance of highly leukemogenic schedules where possible, restoration of immune function etc but are largely outside of the control of haematologist.

#### **3.2 Screening**

There is no current recommendation for primary screening for any haematologic malignancy; many of these illnesses are diagnosed co-incidentally during routine health screening. Familial clustering is seen for some haematologic malignancies and may warrant further screening within those families by the treating haematologist

#### **3.3 Initial Assessment**

All patients with haematologic malignancy including

- Hodgkin's' Lymphoma
- Non Hodgkin's' Lymphoma
- Myeloma
- Chronic Lymphocytic Leukemia
- Chronic Myeloid Leukemia
- Acute Myeloid Leukemia
- Acute Lymphoblastic Leukemia
- Myelodysplastic Syndromes
- Myeloproliferative Syndromes – Polycythemia and Essential Thrombocythemia
- Mastocytosis

Other rare haematologic malignancies should have access to specialist haematologist assessment to confirm diagnosis and develop a treatment plan. Usually this will entail direct review of the patient by the haematologist in a centre with diagnostic facilities appropriate to the illness and patient under consideration.

#### **3.4 Treatment**

Evidence based treatment guidelines should be developed for all haematologic malignancies for treatment at diagnosis and relapse. Where possible these guidelines should be uniform across all institutions. Participation in clinical trials should be offered when available and support for non pharmaceutical sponsored studies should available across all institutions managing this group of patients to ensure equitable access for all patients. Arrangements for pharmacy and data management support should be reviewed and proposals for funding models should be developed. Support of clinical trial activity should be seen as a core component of the cancer treatment service.



Treatment should be delivered by a multidisciplinary team at a site considered appropriate to the intensity of the treatment to be administered and patient specific variables e.g. acuity. It is difficult to specify the site of treatment i.e. Cancer Centre or Cancer Unit, based on diagnosis alone as patients may move between facilities at different phases of treatment.

#### **Recommendation 13**

All patients with newly diagnosed Haematologic malignancy should have access to a Haematology Service to develop a management plan.

### **3.5 Follow-up**

Follow-up guidelines should be available for all haematologic malignancies. The specific haematologic diagnosis cannot alone be used to predict the follow-up needs, and for some patients will change during the course of the illness. A follow-up algorithm based on functional status is more likely to predict the follow-up needs rather than a model based on initial histologic diagnosis. Broadly patients will fall into a number of groups

- 1)** Those cured and asymptomatic where surveillance is targeted to detect relapse and late effects. This group will be the easiest group in which to develop follow-up guidelines, although unfortunately this is probably the smallest subset. Examples include Hodgkin Lymphoma, Diffuse Large Cell Lymphoma and Acute Promyelocytic Leukemia. The frequency of clinical review and investigations as well as surveillance for late effects should be readily standardised. When available already published evidence based guidelines can be used.
- 2)** Cured but symptomatic e.g. post allogeneic bone marrow transplant where ongoing management of symptoms in addition to surveillance to detect relapse is required.
- 3)** Chronic malignancy where ongoing review will be need to actively manage the malignancy and symptoms.

Follow-up algorithms will need to be more flexible for groups 2) and 3), but should include minimum follow-up recommendations e.g. frequency of bcr abl molecular quantitation in chronic myeloid leukemia, QEP in MGUS etc

#### **Recommendation 14**

Uniform follow-up guidelines should be available for patients considered cured from their malignancy. Guidelines for follow-up of other groups will be more complex to formulate but should focus on critical issue relevant to the specific malignancy.

### **3.6 Palliative Care**

The palliative care needs of haematologic patients can challenge traditional paradigms for palliative care. Patients with advanced disease may still benefit from active treatment with chemotherapy and blood product support. Many patients, particularly younger patients, will continue with active therapies despite having advanced or incurable illness. Not uncommonly there is a transition phase when patients need the assistance of the palliative care service to assist with symptom control but still wish to continue with other active therapies. Patients would probably



benefit from a more formal agreed approach for shared care between palliative care services and haematology services.



## **4. Workforce**

### **4.1 Allied Health - Dietician, Physiotherapy, Pharmacy, Counselling Services**

Allied Health support is critical for the delivery of multidisciplinary care and an appropriate model for service provision for distributed services must be developed. Agreed guidelines for optimal staff configurations for Cancer Units and Cancer Centres should be developed and an appropriate Governance framework which engenders area based interaction should be developed. There are inequities between sites with regard to access to these services; the Cancer Network together with the Tumour Collaboratives should develop guidelines for staffing requirements for new facilities.

### **4.2 Nursing – Area based, Network Services**

Nursing staff play a central and increasingly diverse role in management of patient with haematologic malignancy in a variety of settings

- Inpatient
- Outpatient
- Day patient
- Home Services

There is a critical requirement that area based services deliver treatment in a coordinated and seamless fashion and an appropriate governance frame work must be developed. New models of care for delivery of nursing services will continue to develop in response to the challenges of a more distributed service model.

The role of the Cancer Network Nursing Services in future service delivery needs to be clarified, direct patient care services should probably be devolved to area health services.

### **4.3 Medical Staff Anticipated workforce – tertiary, secondary, ambulatory**

A range of consultant haematology services will be required at various locations

- Tertiary
  - Laboratory, Transfusion Medicine, Coagulation, General Haematology, Malignant Haematology, Autologous Transplantation, Allogeneic Transplantation (FSH)
- Secondary
  - Laboratory, Transfusion Medicine, Coagulation, General Haematology, Malignant Haematology
- Rural
  - Laboratory, Transfusion Medicine, Coagulation, General Haematology, Malignant Haematology

The model for service delivery is likely to evolve with time, particularly in the non tertiary sector, as the secondary hospital increase in size, the service capability matures and the availability of skilled staff improves.



### Initially

- Tertiary sites - Full range of services and inpatient, outpatient and ambulatory management
- Secondary sites - visiting outpatient consultative, day treatment services to secondary and rural sites. Integration of home based services with area based program.

### Later

- Tertiary sites - Full range of services and inpatient, outpatient and ambulatory management
- Secondary sites - some inpatient services, visiting outpatient consultative, day treatment services to secondary and rural sites. Integration of home based services with area based program.
- Resident Haematology Services in large regional centres.

The development of inpatient services at secondary hospitals may well be driven by demand for non malignant haematology services. **The proposal in the clinical services framework that general physicians manage the care of patients with haematologic malignancy at secondary sites is not supported by the haematology community.** Limited exposure during physician training and supervision of small numbers of patients is not a sound basis for management of patients with life threatening illness.

The development of a distributed model of care as well as the anticipated growth in cancer presentations will require growth in the medical workforce to manage haematologic illness. At present no planning information is available for projected requirements for specialist physician services. Given the lead times for training physicians, availability of consultant staff may well limit the rate at which this plan can be implemented.

#### 4.4 Distribution - Full Time vs. Visiting Medical Officer

Currently there is a mix of full time and VMO positions and some consideration should be given to the optimal mix and responsibilities in a more distributed model of service delivery. It may be that most inpatient management should be allocated to full time staff and VMO positions used to mostly to assist in outpatient and ambulatory care. Due consideration of the rights to private practice must be given, VMO staff must be able to admit patients requiring tertiary care under their care if they elect to do so, but given the relocation of facilities it may no longer be possible for VMO staff with < 5 sessions to provide daily review of inpatients or participate in “consultation” review of inpatients given the much greater distances and travelling times which are likely.

This issue will probably be considered by a number of groups e.g. clinical redesign, workforce. Clear credentialing and scope of practice guidelines for new models of care should be developed by area health services.

#### **Recommendation 15**

Development of the workforce plan for a distributed model of service delivery should commence once clinical service profiles for tertiary and secondary hospitals have been finalised.



## 5. Special needs

### 5.1 Apheresis

Includes peripheral blood stem cell collection, plasmapheresis, platelet collection and other less commonly performed procedures - will be available at tertiary centres. Patients requiring these services will be transferred to a tertiary facility for treatment. On call services to cover after hours needs will be required at each site.

#### **Recommendation 16**

Apheresis services should be available at tertiary sites

### 5.2 Allografting

A single state adult inpatient centre is planned at FSH, current workload data and analysis of national trends in transplant activity suggests little growth in activity. Outpatient follow-up should continue under the supervision of an experienced allograft physician. Given the re-location of the inpatient centre to FSH an outpatient clinic should be established at SCGH under the supervision of the FSH transplant service. All inpatient management, including re-admissions after initial discharge will be to the FSH unit which has been designed to reduce the risk of (fungal) infection in this group of highly immunosuppressed patients.

#### **Recommendation 17**

A single state allogeneic BMT service should be established at FSH

### 5.3 Adolescents

Patients older than 18 years will continue to be offered treatment in adult centres. The potential relocation of PMH to the SCGH site may create opportunities for re-organisation of services at the combined site. Irrespective of the physical re-organisation there is a need for closer collaboration between adult and paediatric services to develop a model of care at all sites in which adolescents and young adults are seen. Specific teams at each adult tertiary site should be established. Collaboration between adult sites and with the paediatric site should be formalised to ensure that adolescent and young adult services can be provided at adult tertiary sites when appropriate.

#### **Recommendation 18**

Dedicated services for adolescent and young adult patients cared for in adult institutions should be developed where appropriate.

### 5.4 Integration with non malignant haematology services

Like most cancer practitioners, haematologists care for patients with non malignant disease as well as providing laboratory services. The planning process to date has focussed on malignant disease; planning decisions, particularly workforce considerations, will need to take into account other clinical and laboratory services provided by haematologists.



## 5.5 Data/Research

Currently the Haematology Collaborative, in partnership with the Cancer Network, is establishing a patient database which is intended to provide a more complete picture of disease incidence and more meaningful treatment outcome information. Information obtained will be useful to patients, clinicians and will be used for service planning. The Network will play a long term role in providing resources for this service, developing benchmarks for the service and ensuring dissemination of data across the network.

## 5.6 Clinical Trials

The Reid review was critical of the low participation rates in clinical research for Cancer patients in Western Australia. There are some specific barriers to the conduct of clinical trials in haematologic malignancy

- Many of these illnesses are uncommon – large number of small studies
- The states population is small
- Poor data re incidence of specific malignancies making it difficult to plan studies
- Access to hospital funding support is a significant barrier to the conduct of physician sponsored studies.

The network should consider how it can best assist in the provision of resources for investigator driven studies. This is an area where policy development is needed to ensure equitable arrangements across the state. Cancer Centres have a responsibility to “lead” in this area and will need to be resourced.

There have been a number major advances in the treatment of haematologic malignancies over the last two decades and not surprisingly there is a lot of ongoing clinical trial activity sponsored by the Pharmaceutical industry. Haematology services manage a broad range of relatively uncommon malignancies which presents the challenge of managing a large number of small studies. Unfortunately this is relatively inefficient but should be improved by the formation of a tertiary based clinical trial hub at FSH and SCGH, with central management of an area based clinical trial network.

It is important that adequate clinical trial infrastructure is developed at both tertiary and secondary sites, so that there is equitable access for patients to clinical trials and to ensure that lack of resources does not undermine the model of care.

### **Recommendation 19**

Increased participation in clinical trials is supported. Support for non industry sponsored trials should be reviewed as a matter of urgency. Mechanisms for funding non industry studies from with the Area Health Service budget should be developed.

## 5.7 Disease specific clinics

The re-organisation of services proposed in the clinical services plan will see the creation of Cancer Units at secondary hospitals. Unlike many of the surgical disciplines, both Haematologists and Medical Oncologists deal with many different malignancies. Consequently there is no single model of care for hematologic disease, but an amalgam of models. For example, some haematologic malignancies are cured with relatively little treatment toxicity and long term review focuses on late effects and disease recurrence. Patients undergoing Allografting may well be cured



but may suffer serious long term morbidity which requires expert management. In contrast some haematologic malignancies are "chronic illnesses" and require long term supervision by the haematology service with the ongoing need for treatment.

The likely impact of the proposed infrastructure model is that outpatient care of chronic hematologic malignancies will be managed in both Cancer Centres and Cancer Units, with care for high grade malignancies and transplant services being provided at Cancer Centres only. This physical re-distribution of patients will facilitate the development of disease specific clinics.

#### Potential Cancer Centre Model Disease Streams

- Acute Leukemia
- Allogeneic Bone marrow transplantation
- General Haematology
- Lymphoma and Hodgkin's' Disease
- Myeloma
- MDS/CLL/Myeloproliferative Disease

#### Potential Cancer Unit Model Disease Streams

Initially

- General Haematology
- Malignant Haematology (NHL/HD/CLL/MDS/Myeloproliferative disease)

Later – depending on growth

- General Haematology
- Lymphoma and Hodgkin's' Disease
- Myeloma
- MDS/CLL/Myeloproliferative Disease

Treatments for haematologic malignancies are continuously evolving and there is likely to be redistribution (both ways) between Cancer Centres and Units.

#### **Recommendation 20**

Re-organisation of current services to allow the development of disease specific clinics should be considered where patient numbers are sufficient.

### **5.8 Patient information systems**

A critical issue in delivering care across a number of settings is the development of an electronic record containing up to date

- clinical
- diagnostic and
- treatment information

All too often the medical record is incomplete and difficult to access. A well designed and complete electronic record will greatly facilitate the proposed models of care and improve patient safety.



A complete electronic patient medical record will take some years to develop and some components will need to be implemented earlier. Currently electronic prescribing and treatment records are considered an urgent priority.

### **5.9 Drug Formulary and high cost drugs**

A number of pharmaceuticals used to treat haematologic malignancy or for supportive care are high cost items, with the potential for a substantial impact on the pharmacy budget. Items such as mabthera and Velcade could potentially be administered in Cancer Units. While some high cost drugs may be restricted by site, it will be important to ensure that formulary listing and pharmacy budgets are appropriate to ensure that the provision of high cost drugs does not undermine the model of care. Currently hospital formulary listings vary between sites and that access to some treatments is not equitable between institutions.

### **5.10 Teaching and Education**

Teaching and education are essential functions for any clinical service and a specific model should be developed to address the needs of a distributed network. Ideally all staff should be able to move between different facilities within their network to ensure adequate training. Appropriate ratios of senior to junior staff need to be implemented to ensure adequate supervision and training of junior (medical) staff and safe patient care. The ratios suggested by the state workforce group are

- 30% Consultants
- 30% Registrars
- 25% Resident Medical Officers
- 15% Interns



## 6. Transition

### 6.1 Evolving workforce roles

Reform in health care delivery is a continuous process, many senior clinicians have seen substantial evolution in care delivery during their careers, many would not consider this reform but a more logical and incremental process of evidence based change. The current process of reform seems to be conceived of as a more active process of evolving at the fastest pace possible. Reform requires cultural change and the haematology community has embraced cultural change in workforce roles over the last decade, and is likely to adapt well to the reform process. This evolution is likely to be more successful if it is collaborative rather than adversarial. Issue relating to direct delivery of clinical services are probably better managed at the area level by those most directly involved in treating patients than at the Network level.

### 6.2 Evolving infrastructure

There has been substantial evolution of the infrastructure plan since the Reid Review was first detailed. This continuous revision of both the infrastructure and the clinical services plan provides an ongoing challenge in developing models of care. Despite the ongoing revision, there are a number of principles which are assumed to be constant

- That care should be delivered closer to where patients live
- That there is Network/Area based rather than institution based management of Cancer Services
- That Cancer centres will provide comprehensive services
- That low incidence malignancies will be treated at designated sites and will be appropriately resourced
- That Cancer Units will be developed but will provide a more limited scope of care

At present there is no transition plan for Cancer Services, but it appears that the various Cancer Units and Centres will be completed at different times. Phase I of the Cancer Centre at SCGH is already complete and funding for Phase II has been approved. The transition process will be less complex across the NMAHS where there will be the addition of a single new Cancer Unit at the Midland hospital. The main challenge for the NMAHS will be establishing an adequate workforce and determining its distribution.

In the SMAHS the FSH Cancer Centre will not be completed until 2014, but the Rockingham development will be completed in 2009. There are already (unused) chemotherapy beds at Armadale Hospital.

In the South, it seems likely that a plan to provide services at Cancer Units before completion of the FSH will need to be developed. Additional staff will need to be allocated to RPH and FH to participate in the area based services, with a reconfiguration at the time FSH is completed.

Resource constraints may well limit the provision of haematology services at Cancer Units. Provision of adequate regional services is probably a greater priority than outer metropolitan services if resources are limiting.



### **6.3 Evolving treatments**

Advances in patient management have been significant in Hematologic malignancy over the last 2 decades and will likely continue. Bone marrow transplantation appears to have reached a plateau and there is little need for further expansion of services at present. New pharmaceuticals have improved treatment outcomes but paradoxically increased the prevalence of many hematologic illnesses. As survivors are treated repeatedly with effective salvage regimens their illness is perceived more as a chronic disease than a malignancy. This longer treatment phase requires longer medical supervision; this is not an area for role substitution. Models of care, Service delivery and infrastructure requirements will continue to evolve in parallel with treatment options

### **6.4 Ensuring Sustainability**

The transition strategy should give particular attention to the issue of sustainability.

Attempting to substantially increase the number of sites offering Cancer services carries risks. One theme of the Reid Report on Cancer Services was to consolidate care for uncommon malignancies to a limited number of sites. It is important that there is an adequate case-load at treatment centres to allow expertise to develop. The Cancer Network together with the Tumour Collaboratives need to develop a framework for defining sustainability i.e. how many patients should be seen, what is the minimum number of staff needed etc. It is critical that the establishment of Cancer Units does not undermine the viability of Cancer Centres, the latter must be viable before services at Cancer Units are established.



## 7. Summary of Major Recommendations

### **Recommendation 1**

Diagnosis alone should not be used as the major/sole determinant for planning the MOC for Haematologic Malignancy

### **Recommendation 2**

Service planning needs to take into account both the incidence and prevalence as both impact of resource requirements

### **Recommendation 3**

Better information, particularly with regard to ambulatory care is required to progress planning of ambulatory services

### **Recommendation 4**

Planning for haematologic malignancies should be integrated with planning for non malignant haematologic illness and laboratory services

### **Recommendation 5**

The development of Cancer Centres and Units within an area based model is supported for haematologic malignancy

### **Recommendation 6**

With the relocation of RPH, the 2 RPH ambulatory programmes should be combined to form the SMAHS ambulatory cancer service and a dedicated NMAHS ambulatory service should be developed. Governance arrangements should be formalised and uniform for the 2 area based services.

### **Recommendation 7**

Planning of Cancer Centres and Units must consider the infrastructure needs in day therapy units for patients cared for in ambulatory programmes as much of the need for haematology patients is for supportive care and urgent assessment rather than chemotherapy

### **Recommendation 8**

Policy and appropriate governance must be developed to ensure compliance of staff and facilities with credentialing recommendations.

### **Recommendation 9**

Minimum criteria for infrastructure and clinical services should be developed for Cancer Centres and Cancer Units to enable the delivery of multi-disciplinary care.

**Recommendation 10**

The Cancer Network should continue to support the strategic development of cancer services. Direct involvement in clinical service delivery should be carefully considered due to the potential to fragment current service delivery models

**Recommendation 11**

Plans for providing rural services should be developed based on an area based model by area based health services

**Recommendation 12**

Improved integration with primary care services should be developed. The approach should probably be uniform across tumour collaboratives and may best be facilitated by the Cancer Network. Improved information sharing (electronic records) would greatly facilitate such integration.

**Recommendation 13**

All patients with newly diagnosed Haematologic malignancy should have access to a Haematology Service to develop a management plan.

**Recommendation 14**

Uniform follow-up guidelines should be available for patients considered cured from their malignancy. Guidelines for follow-up of other groups will be more complex to formulate but should focus on critical issue relevant to the specific malignancy.

**Recommendation 15**

Development of the workforce plan for a distributed model of service delivery should commence once clinical service profiles for tertiary and secondary hospitals have been finalised.

**Recommendation 16**

Apheresis services should be available at tertiary sites

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Delivering a **Healthy WA**

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