HAEMATOLOGICAL CANCER
This working paper has been compiled by Professor A K Burnett, Professor of Haematology, University of Wales College of Medicine and Clinical Director of Haematology at the University Hospital of Wales. The material results from available epidemiological data, national and international guidelines and the extensive clinical experience of Consultant Haematologists in Wales. The recommendations in this report have been agreed by the Cancer Services Expert Group. Further information, regarding recommendation priorities and mechanisms for monitoring their implementation, is available from the Project Office.
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1. EXECUTIVE SUMMARY

1. The incidence of haematological cancers in Wales and the geographic location is precisely known as a result of an ongoing Epidemiology Study.

2. The facilities to manage such cases have been defined by the Clinical Task Force of the British Society for Haematology.

3. All patients in Wales already have access to appropriate levels of care either locally or by central referral, although this might not be geographically optimal.

4. The provider unit should provide a treatment plan for each patient.

5. The optimal care team requires medical, nursing, pharmacy, social and counselling support with good communication with primary health care. All team members should be acquainted with the treatment plan and their role in it.

6. Comprehensive care requires a wide range of specialist support services, e.g. Histopathology (routine and specialist expertise in Lymphoma), blood transfusion, tissue typing, microbiological guidelines and infection control, social work and counselling, specialist medical services.

7. There should be provision of on-going education and training of all members of the care team. The service should provide specialist training for medical and nursing staff.

8. Participation in clinical research should be facilitated.

9. Shared care, education and training between provider units should be developed.

10. Measurements of treatment outcome and effectiveness should be developed and implemented.

11. On-going supervision of care and its development in line with Calman/Hine should be the remit of involved professional groups, who should produce status reports for interested parties i.e Directors of Public Health Medicine, Purchasers, Chief Executive and General Practitioners.
2. THE DIAGNOSTIC GROUPS WITHIN HAEMATOLOGICAL ONCOLOGY

2.1 The recommendations apply to the following haematological cancers:

- Non Hodgkin's Lymphoma
- Hodgkin's Disease
- Acute Lymphoblastic Leukaemia
- Chronic Lymphocytic Leukaemia
- Acute Myeloid Leukaemia
- Chronic Myeloid Leukaemia
- Myeloma
- Primary Polycythaemia
- Primary Thrombocythaemia
- Myelodysplastic Syndromes
- Other Myeloproliferative Disorders

3. THE EPIDEMIOLOGY AND INCIDENCE IN WALES

3.1 Welsh data for haematological cancers, as a group, are included in Volume 1 and are summarised as follows:

- Average yearly (1984-88) registrations: 912
- Registrations in 1990: 979
- Projected new registrations in the year 2000: 1,429
- 5 Year survival: Hodgkin’s 72%; Non Hodgkin’s Lymphoma 36%; Leukaemia 28%
- Deaths from 1985-94: 5,484
- Years of Life Lost for death under 70 years (1985-94): 35,435

Survival data are from the West Midlands Cancer Registry. For other data sources and ICD9 codes see CSEG Report, Volume 1

Because it was recognised by Haematologists in Wales that there were serious inaccuracies in the Welsh Cancer Registry and the Leukaemia Research Fund UK National Survey, a Registry was established in Wales of all Haematological Cancers (excluding Lymphoma and Hodgkin's Disease) from January 1991. This Registry is run by the Haematologists in Wales under the leadership of Dr J A Whittaker and is supported by recurrent grants from the Leukaemia Research Appeal for Wales (LRAW). For the disease categories defined above with the exception of Non-Hodgkin’s Lymphoma and Hodgkin’s Disease the following numbers are recorded and presented in the First Interim Report.

3.2 Incidence of Haematological Malignancy in Wales excluding Lymphoma and Hodgkin's Disease, the Welsh Epidemiology Study observed 26.78 new cases of Haematological cancer per 100,000 per annum. The major subdivisions are shown in Table 1. The most accurate prospective study involving Wales was formerly the Leukaemia Research Funds' Leeds Data Collection Study but this under recorded by about 30% on age standardised rates comparison.

**TABLE 1 - Haematological Malignancy in Wales: Observed Incidence Rates**

<table>
<thead>
<tr>
<th></th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute Myeloid</td>
<td>3.13</td>
<td>2.16</td>
<td>2.63</td>
</tr>
<tr>
<td>Chronic Myeloid</td>
<td>1.27</td>
<td>1.15</td>
<td>1.21</td>
</tr>
<tr>
<td>Acute Lymphoblastic</td>
<td>1.55</td>
<td>1.08</td>
<td>1.31</td>
</tr>
<tr>
<td>Chronic Lymphocytic</td>
<td>7.46</td>
<td>5.18</td>
<td>6.29</td>
</tr>
<tr>
<td>Myelodysplasia</td>
<td>5.57</td>
<td>5.23</td>
<td>5.39</td>
</tr>
<tr>
<td>Other Myeloproliferative</td>
<td>4.14</td>
<td>3.78</td>
<td>3.96</td>
</tr>
<tr>
<td>Aplastic Anaemia</td>
<td>0.36</td>
<td>0.42</td>
<td>0.39</td>
</tr>
<tr>
<td>Myeloma</td>
<td>6.09</td>
<td>5.15</td>
<td>5.61</td>
</tr>
<tr>
<td>All Diagnosis</td>
<td>29.57</td>
<td>24.14</td>
<td>26.78</td>
</tr>
</tbody>
</table>
3.3 The age distribution of all these cases is primarily in the older age range, with the exception of Acute Lymphoblastic Leukaemia which primarily presents in the Paediatric age range.

FIGURE 1 (Data available from the Project Office)

3.4 Diagnostic registration of Lymphoma and Hodgkin's Disease was not part of the Epidemiology study. The Welsh Cancer Registry recorded 429 cases in 1990 coded under ICD200-202. This coding is insensitive to modern diagnostic classifications and in addition certainly represents a substantial under-recording error.

Geographic Presentation of Cases

3.5 The distribution of case load for Haematological Malignancy excluding Lymphoma and Hodgkin's Disease is shown as hospital of presentation:

<table>
<thead>
<tr>
<th>Hospital</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bronglais General Hospital</td>
<td>3.6%</td>
</tr>
<tr>
<td>East Glamorgan General Hospital</td>
<td>5.4%</td>
</tr>
<tr>
<td>Llandough Hospital</td>
<td>5.8%</td>
</tr>
<tr>
<td>Prince Philip Hospital</td>
<td>4.2%</td>
</tr>
<tr>
<td>Wrexham Maelor Hospital</td>
<td>3.4%</td>
</tr>
<tr>
<td>Morriston Hospital</td>
<td>5.4%</td>
</tr>
<tr>
<td>Neath General Hospital</td>
<td>4.3%</td>
</tr>
<tr>
<td>Nevill Hall Hospital</td>
<td>6.3%</td>
</tr>
<tr>
<td>Prince Charles Hospital</td>
<td>4.3%</td>
</tr>
<tr>
<td>Bridgend General Hospital</td>
<td>3.3%</td>
</tr>
<tr>
<td>Royal Gwent Hospital</td>
<td>9.0%</td>
</tr>
<tr>
<td>Singleton Hospital</td>
<td>4.2%</td>
</tr>
<tr>
<td>University Hospital of Wales</td>
<td>16.3%</td>
</tr>
<tr>
<td>West Wales General Hospital</td>
<td>4.0%</td>
</tr>
<tr>
<td>Withybush General Hospital</td>
<td>4.0%</td>
</tr>
<tr>
<td>Ysbyty Glan Clwyd</td>
<td>6.6%</td>
</tr>
<tr>
<td>Ysbyty Gwynedd</td>
<td>8.1%</td>
</tr>
</tbody>
</table>
4. ASPIRATIONS OF TREATMENT

4.1 For some diseases potentially curative treatment is available and it is therefore imperative that this is available to all patients irrespective of where the patient lives. Intensive chemotherapy for acute lymphoblastic and acute myeloid leukaemia with some cases utilising stem cell transplantation, stem cells transplantation for chronic myeloid leukaemia and high dose therapy as salvage for Hodgkin's Disease and Non Hodgkin's Lymphoma, are all accepted practice which require specialist facilities delivered by an experienced Centre. High dose therapy for myeloma is accepted practice for relapsed disease but is still under trial evaluation as first line. Such intensive treatment is usually only applicable to patients under 60 years.

4.2 For Non Hodgkin's Lymphoma, Hodgkin's Disease conventional treatment, substantially on an outpatient or day-case basis can provide cure.

4.3 For some diseases, e.g. thrombocythaemia, polycythaemia, myelodysplasia, chronic lymphoid and myeloid leukaemia and myeloma, currently available treatment is not curative either because the disease occurs in the elderly, it has a long natural history, or treatments devised so far are inadequate. It is nevertheless important to ensure that appropriate treatment is delivered to ensure the maximum high quality time is available to the patient. A recognition of the opportunities for cure and optimisation of care, where cure is not the ultimate aim, must be implicit in the care delivered to the patient.

5. FACILITIES REQUIRED FOR TREATMENT PROVISION

5.01 The levels of staffing and physical resources for the treatment of haematological cancers have been defined by two groups in recent years with broadly similar results:

- The Advisory Group on Cancer Services in London.

5.02 The BSH Document is accepted as a valid model by Clinical Haematologists in Wales. This defines in broad terms the levels of staffing, experience, physical resource and support services required to deal with the different complexities of care needed, given the aspirations for treatment discussed above.

5.03 It is therefore possible to define four categories of care provision at each institution.

5.04 A substantial proportion of haematological cancers can be dealt with in a so called level 1 or 2 environment (defined below). Patients with potentially curable disease requiring high dose therapy will require a level 3 or 4 facility. All patients in Wales already have access to such care, with South and West Wales using Cardiff and North Wales associated with Liverpool or Manchester.

Relationship between Numbers of Patients Treated and Outcome

5.05 Allogeneic bone marrow transplantation is carried out only at the University Hospital of Wales for adult disease. This requires considerable infrastructure which must be centralised on grounds of (a) cost (b) cumulative expertise. North American and European guidelines suggest that a minimum number of cases should be treated. This should be not less than 10-12 per annum. This figure is based on an analysis of international registries as a level below which there is a negative impact on outcome. (European Bone Marrow Transplant Group, American Association of Clinical Oncology). Recent recommendations on autologous procedures recommend a similar figure.

5.06 Intensive chemotherapy for acute leukaemia and other haematological malignancies requires appropriate infrastructure. In contrast to paediatric experience there is limited evidence available to suggest a case load which should be achieved to produce optimal outcome.

Levels of Care Provision

5.07 The Haematological malignancies therefore represent a therapeutic spectrum, ranging from the obligation to ensure the delivery of curative treatment which usually involves sophisticated intensive treatment requiring a large team, to the almost exclusive outpatient management over a decade or more. This pattern is reflected in the facilities required to deliver care to which a patient requires access. This has been defined in a recent report of the Clinical Task Force of the British Committee for Standards in Haematology, where four care levels were defined:
Level 1

5.08 General Haematology Patients such as those with Chronic Lymphocytic Leukaemia, low grade non Hodgkin's Lymphoma, Chronic Myeloid Leukaemia, and other Myelo-proliferative disorders; Multiple Myeloma (older patients receiving non-intensive treatment), and Myelodysplasia, being diagnosed and managed using conventional doses of chemotherapy which would not normally be planned to produce prolonged neutropenia. The numbers of patients in these categories significantly exceed those with acute leukaemia and high grade lymphoma. The workload for haematologists is steadily rising because of an increased incidence of myelodysplasia in an ageing population, increasing incidence of lymphoma and expanding use of chemotherapy both in haematology and by other specialties.

5.09 Hospitals providing general Haematology care at this level should be capable of the safe management of a patient with transient severe neutropenia prior to transfer to a centre providing care at a higher level, including that of patients with severe aplastic anaemia. Some hospitals at this level will wish to use combined chemotherapy regimes for lymphomas, such as CHOP and CHIVPP.

Level 2

5.10 This will cover facilities required for remission induction in acute myeloid or acute lymphoblastic leukaemia using current standard intensive chemotherapy regimes such as those used in Medical Research Council Trials AML 10 and UKALL 12. Such facilities will also be required for managing patients with Hodgkin's or non Hodgkin's lymphoma using pulses of chemotherapy such as CHOP, MOPP, EVAP, DHAP and VAPEC-B. Early after-care of patients receiving autologous transplants elsewhere is also appropriate at this level.

Level 3

5.11 Level three facilities will be capable of carrying out autologous transplants using either bone marrow or peripheral blood stem cells and conditioning regimes such as high dose Melphalan or BEAM.

Level 4

5.12 At this level, related allogeneic bone marrow transplants and autologous transplants using total body irradiation (TBI) or busulphan/cyclophosphamide (Bu/Cy) would be included. The reason for including autologous transplants using these regimes at level 4 rather than level 3 is that evidence is emerging from MRC trials of continuing morbidity and mortality over one year post-transplant in patients receiving TBI + Bu/Cy conditioning.

5.13 Centres of Level 4 standard will already have a proven record in autologous transplantation and be registered with the MRC and EBMT. In order to maintain expertise, there should be agreement between the centre and the prime purchaser(s) for at least ten sibling donor allografts in addition to ten autografts annually. In some geographical locations a centre functioning at this level may be viable despite being unable to meet the target of ten allografts, while performing more than ten autografts annually. The programme should not commence with patients rejected by other more established allograft centres. New centres should achieve the target number of cases within two years.

5.14 A small number of centres at level 4 will be capable of carrying out transplants using techniques for patients without a sibling donor. This may involve autologous bone marrow transplantation from a matched unrelated donor (MUD transplantation) or a number of other techniques including autologous transplantation after long term bone marrow culture, etc. The Unit should normally be transplanting at least ten allogeneic (related) cases per year, estimated from the average for the previous three years (WMDA 1992). There must be agreement between physicians, senior nurses and managers for a programme of unrelated volunteer transplants, with the aim being at least three per year in addition to the minimum of ten related transplants. The programme should not commence with patient rejected by more established centres.

5.15 As most districts are too small to provide sufficient patients to maintain local expertise, centres of Level 3 and 4 standard will be dealing with a significant proportion of tertiary referrals. Contracts should secure access to comprehensive care on a planned basis. In view of the unpredictability of need and the potentially large cost involved, simple block contracts and ECRs may not be appropriate. Purchasers may wish to move towards more sophisticated block or threshold contracts and to increase their use of cost and volume and cost per case contracts (similar to those required in haemophilia care) (Health Service Guidelines, 1993).
5.16 Recommendations on staffing requirements and facilities to be available at these levels of care are given in the BSH Guidelines which because of general professional acceptance should be fully acceptable to purchasers in Wales.

The Team Approach

5.17 In common with other approaches to comprehensive care the approach to haematological malignancy should be characterised by evidence of an interdisciplinary team supporting the patients, all of whom require to focus their particular professional skills on a cohesive care package. Each will require to develop knowledge of the particular needs of patients with (haematological) malignancy and have a good understanding of the overall treatment plan and expected outcomes.

The General Practitioner

5.18 Increasing use of laboratory diagnosis to the primary care team has resulted in the majority of diagnosis of haematological malignancies emerging in General Practice. This will usually result in referral for a Specialist Haematologist (or Oncologist) opinion. Ready access to the Specialist is required which may be via a clinic, to a Day Unit service or by hospital admission. For each disease the primary care team need contact names and locations in their area to initiate access of their patient to the care package.

5.19 It is desirable for the General Practitioner to become acquainted with the overall treatment plan and the components which may involve the primary care team. He/she should also be aware of the implications of the diagnosis and its treatment for the patient and the patient's family and who to contact in the event of an emergency arising.

Medical Staff

5.20 Patient care should be supervised by a trained specialist. Professional training in Haematology specifically provides for all haematological malignancies. Medical or Radiation Oncology training will cover some but not all of these diseases. Special experience and training is required for the provision of transplantation and high dose therapy. Access to specialist medical staff should be available at all times.

5.21 Hospital providers will offer a spectrum of components of care ranging over the diagnostic, differing levels of complexity of care and follow-up referred to else-where in this report. These will broadly be via Pathology Services Specialist (Haematologist/Oncologist) Outpatient Clinics, Day Units or direct admission. These facilities should be under the direct supervision of the Specialist and supporting staff.

Nursing

5.22 A second major component of improved outcome in recent years is the pivotal role of the nurse, specifically training in Haematological Oncology, whose expertise is required for Inpatient and Day Unit care. Particular experience at Outpatient clinics is desirable.

5.23 Nurses should aspire to take on major components of the delivery of care, e.g. blood sampling, administration of drugs and ultimately invasive procedures, e.g. bone marrow aspiration. It is essential that such tasks are undertaken following adequate training.

5.24 The nurse has a major role to play in the exchange of information with the patient and the patient's family as well as communication and specialist education of district and practice nurses.

5.25 There are a number of training courses available for haematology nurses. Further education in Haematological Oncology is provided by the Royal College of Nursing at national or regional meetings. Secondment to experienced units on a regular basis is desirable.

Pharmacists

5.26 Administration of anything beyond simple chemotherapy should involve a named pharmacist. The pharmacist will play a role in eliminating prescription errors, and giving advice on drug interactions as well as supervising the central reconstitution of chemotherapeutic agents and other drugs (e.g. antibiotics).

5.27 It is desirable for chemotherapy reconstitution to be provided in pharmacy at all times. It is not necessary for the named pharmacist to be exclusively devoted to Haematological Oncology.
Central Venous Access
5.28 For more intensive chemotherapy an indwelling central catheter is usually needed. It is to be recommended that insertion of catheters is carried out by a limited number of individuals (preferably one) within an institution to foster expertise.

Microbiological Support
5.29 The prevention and treatment of infection in immunosuppressed patients is a major theme of treatment. It is desirable for guidelines to staff to exist concerning prevention of infection and response to infective episodes, to exist. Such episodes may occur in the inpatient setting or at home. The guidelines should be known to the patient and those in the primary care and hospital based teams.
5.30 The derivation of these guidelines should have input from a Consultant Microbiologist and take into account the microbiological environment of the hospital. Diagnostic microbiological services should have in place guidelines on the processing of samples from immuno compromised patients.

Social Support and Counselling
5.31 There is evidence to suggest that informed counselling can alleviate patient anxiety and circumvent non-disclosure of significant psychological morbidity.
5.32 At any point in the care plan, patients should have access to Social Services. Formal counselling by the staff involved in the treatment team or dedicated counsellors is desirable.
5.33 In any location consideration should be given to how best to make counselling services available. Some patients will require the services of a Clinical Psychologist.
5.34 Many cancer patients have special socio-economic needs which are exacerbated by the illness and its treatment, and require full support from Social Services. Preferably each providing service should have access to allocated staff who can become acquainted with the particular needs of these patients.
5.35 The particular needs of young adults should be defined and met where possible by care providers. The long term consequences of treatment on fertility require in vitro storage services.

Specialist Medical Services
5.36 For the minority of patients who require intensive chemotherapy the spectrum of medical services to support intensive care are required - preferably on site.
5.37 These include renal dialysis, bronchoscopy services and respiratory intensive care, radiology and imaging.
5.38 In a few radiation treatment alone is curative. Services should be available within easy reach of all patients. Palliative care services should be accessible, although much is already undertaken by the provider team.

Laboratory Support
5.39 All provider units require 24 hour services in Haematology, Biochemistry, Microbiology and Blood Banking. The diagnosis of Hodgkin's Disease and Non-Hodgkin's Lymphoma is dependent on expert Histopathology augmented by techniques of immunocytochemistry and occasionally molecular diagnosis. The diagnostic classifications of these diseases continue to evolve internationally and the facility to adopt this locally is required, this is very likely to mean the availability of a Histopathologist with special expertise in Haematology-Oncology.

Specialist Diagnostic Services

Cytogenetics
5.40 An increasing proportion of cases of haematological cancer are associated with an abnormal karyotype. Such information can be a necessary aid to diagnosis (e.g. myelodysplasia) and is now being adopted in acute leukaemias to direct appropriate therapy, since it clearly identifies different biological subtypes of disease with differing responses to treatment.
Molecular Diagnosis and Monitoring of Treatment
5.41 The techniques of Fluorescent In Situ Hybridisation and Polymerase Chain Reaction (PCR) are rapidly becoming applicable to a progressively higher proportion of cases and in some circumstances add to the diagnostic precision achievable by cytogenetics. They also have a greater level of sensitivity for detection of disease tissue than cytogenetics and are currently being evaluated for monitoring treatment. Recent evidence suggests that diagnostic precision may be increased by more than 20% using molecular techniques. These methods should be provided only in centralised laboratories within a research environment.

Immunophenotyping
5.42 A wide range of monoclonal antibodies are now available for diagnostic purposes. Immunophenotyping by flow cytometry or immunocytochemistry is an essential diagnostic tool in acute leukaemias and chronic lymphoid malignancies, Hodgkin's Disease and Non Hodgkin's Lymphoma. Interpretation of test data requires considerable expertise derived from extensive experience and may require associated morphological and molecular - genetic information.
5.43 Aberrant antigen expression is a recently recognised feature of disease and may facilitate a novel method of treatment monitoring in the future.

Cell Biology
5.44 The role of marrow culture in diagnosis has a limited application (Myelodysplasia and Myeloproliferative disorders). In treatment involving stem cell reinfusion and/or manipulation in vitro culture represents the only functional assessment of graft viability.

Stem Cell Collection
5.45 Haemopoietic stem cells to support high dose therapy can be obtained from bone marrow or peripheral blood of the patient (autologous) or a suitable donor (allogeneic), either following mobilisation and leucaphoresis (for blood stem cells) on a cell separator or multiple aspiration under anaesthetic (for bone marrow). Other sources such as cord blood are in development.

Haemopoietic Cell Cryopreservation
5.46 High dose therapy requiring stem cell reinfusion will almost always require cryopreservation. As well as employing established techniques of controlled rate freezing, other processes of harvesting and manipulation and graft evaluation (immuno-phenotyping, in vitro culture and molecular genetic techniques) both of viability and freedom from contaminating disease should be available. A number of techniques designed to remove contaminating tumour cells from the stem cell collection are available.

General Comments on Laboratory Support for the Care of Haematological Malignancies
4.47 The full range of routine laboratory services including blood banking should be available at all treatment sites, in which evidence of quality standards should be available (e.g. CPA accreditation and participation in NEQAS schemes). Guidelines to purchases on laboratory services are available.
4.48 Specialist support services (enumerated 5.40-5.46 above) require highly specialist personnel and equipment but do not require to be on site. To maintain expertise, optimise fixed costs, and keep abreast of the rapid pace of development such support should be limited to specialist laboratories only. These services should also be evaluated with respect to CPA and NEQAS scheme results where schemes are available.

Blood Transfusion Services
5.49 A major reason for the evolution of (usually more intensive) treatment including Stem Cell Transplantation, has been improved in supportive care measures. Pre-eminent among these has been the ready availability of blood products particularly platelet and coagulation support. Ready access to this support must be available within hours to patient with haematological malignancy. This availability is a major pre-requisite for dealing where patients can safely receive treatment and follow-up. Institutional guidelines for the use of platelets are desirable.
Appropriate arrangements with the National Blood Transfusion Service should be in place. Where more intensive treatment is given a facility to hold platelets in stock is desirable. Close liaison with the Blood Transfusion Service to optimise transfusion support should be developed.

**Tissue Typing Services**

Tissue typing services are required for the identification of potential individuals to act as donors to support allogeneic stem cell transplantation. In addition some patients become refractory to blood products (ie platelets). The facility to provide HLA matched platelets to such patients must be available as part of the Blood Transfusion provision.

6. **CLINICAL RESEARCH**

6.1 No treatment of haematological cancer is optimal. The substantial improvements in the last 10-15 years has in no small way been the result of extensive clinical research. The outcomes obtained in studies conducted under the auspices of the Medical Research Council are among the best in the world. There has been an increasing number of patients entering such trials and an increasing number of institutions taking part.

6.2 There is evidence to suggest that outcomes for patients treated within the context of clinical trials is superior to those outside formal trials.

6.3 It is advantageous both in the short and long term for patients to participate in clinical trials of appropriate statistical validity and suitability endorsed by Local Ethics Committees. Providers of care should be in a position to offer patients opportunities to access trials. This is frequently complicated by the increasing burden of work, the lack of a central ethics review mechanism and lack of assistance with data recording.

The **College of Medicine**

6.4 The Academic Department of Haematology has a recognised major interest in haematological malignancy ranging from programme funded basic research to clinical trials. Four of the current MRC trials are coordinated from Cardiff. This Department can be expected to play a leading role in clinical innovation, to the benefit of patients in Wales.

7. **EDUCATION AND TRAINING**

7.1 A comprehensive care programme, however geographically configured should foster education and training. In order to execute an effective care plan, all participants from the hospital staff, team members, the primary care team relatives and the patients must be suitably informed. The burden of this education process should fall on the provider units, who in turn should derive support from the large Level 3/Level 4 provider, and or The College of Medicine.

7.2 The programme will provide medical and nursing staff with educational needs for specialist training. All providers should demonstrate appropriate participation in continuous educational opportunities.

7.3 Within the context of Wales consideration should be given to multi-institutional, multi-disciplinary continuous education provision, aimed to ensure that new developments become universally available.

8. **THE POSITION IN WALES**

8.1 The majority of patients in Wales receive all of their care at the hospital to which they present. Those requiring radiation therapy are to travel to Velindre or Swansea in South Wales or Clatterbridge or the Christie from North Wales. The geographic location of radiotherapy is not problematic in South Wales, but although of high quality in North Wales, is geographically inconvenient.

8.2 A small number of patients are referred for all or part of the chemotherapy care in South Wales to UHW, and North Wales to Liverpool or Manchester. As a result of this, care is well coordinated and often satisfactorily shared between the centre and the original hospital. Care could be further improved by strengthening these existing links and developing more extensive shared patterns of care to minimise inconvenience and expense to patients.

8.3 There is already participation in UK national trials, but participation is geographically patchy, and generally suboptimal.
High quality services are available virtually everywhere in Wales to patients. This is achieved despite increasing other pressures, and further support of single-handed Consultants in particular will be needed to maintain or enhance care.

Because of the chronicity of many haematological malignancies the accumulated and accumulating case load per Haematologist is disproportionate and not well reflected in disease incidence data.

Survival Data on all diagnosis except Hodgkin’s Disease and Non-Hodgkin’s Lymphoma - which are not part of the LRAW Haematology Registry - are now available. Common treatment plans have not yet been devised.

9. **HAEMATOLOGICAL ONCOLOGY IN WALES - THE FUTURE**

9.1 The existing pattern of management of cases in Wales already achieves much of what is envisaged in the Calman/Hine Report. Specialist services can be accessed in all hospitals in Wales, appropriate diagnostic facilities are available on site, augmented by specialist laboratories at other hospitals.

- Most patients receive care locally, but where more extensive facilities are required they are referred on to UHW (for South Wales patients) or Liverpool/Manchester (for North Wales patients).
- All providers have Outpatient and Day Unit access. The level of care available on a Day Unit and Inpatient basis varies between different hospitals as anticipated by the different levels of facilities described.
- Shared care between the centres and partner hospitals is only partially developed and should be further developed in the interest of patient convenience.
- More formal outcome measurements need to be developed, throughout the service in Wales.

9.2 In Wales there is already a functional group involving all the Haematologists providing clinical care of patients with haematological malignancy. This group already conducts joint studies on the epidemiology of disease (excluding Lymphoma and Hodgkin's Disease) and conducts Audit.

9.3 It is proposed that this grouping, with its established track record, be given the remit of developing and monitoring the delivery of care for haematological malignancies in the Principality. The group should be augmented in a number of ways to be fully effective. It will be necessary for non-Haematologists who provide care of the lymphomas to be included, as well as representation of Directors of Public Health Medicine.

9.4 The Academic Department of Haematology should provide the lead in care plan development and assessment for Haematological Oncology in Wales.

- The group is augmented by Oncologists who provide care of Lymphoma.
- There should be a Secretariat.
- IT and statistical support should be available.
- A mutually acceptable way should be devised of harmonising the interests of the Welsh Haematologist’s Group in the epidemiology of haematological malignancy in Wales and the statutory requirements of the Cancer Registry.
- The interests of the Directors of Public Health Medicine should be represented in the group.

  The remit of the Group, apart from any of its own professional or scientific interests should be:

- To promote the accurate registration of haematological malignancy in Wales, including Lymphoma.
- To develop portfolios of treatment strategies which, where possible, should be evidence based.
- To incorporate outcome measures of treatment.
- To foster or conduct appropriate clinical research.
- To optimise the necessary diagnostic and ancillary services required by patients.
- To conduct all Wales Audit.
- To foster the training and expertise of professional groups involved in the care of Haematological cases.
- To provide information on all these areas to interested professional groups, e.g. General Practitioners, Trust Medical Directors, Directors of Public Health Medicine and Purchasers.
10. RECOMMENDATIONS

1. The registration of disease which is already undertaken by haematologists in Wales should continue and extended to non-Hodgkin’s Lymphoma and Hodgkin’s Disease.

2. Established patterns of care should broadly continue with further development of shared care.

3. Appropriate support should be provided to haematologists, as suits local needs, to facilitate the adoption of guidelines of care, clinical trial participation and outcome measurements. This will require extra medical sessions, provision of nurse practitioners and clerical resources.

4. All individuals involved in the provision of care should be aware of their role within the multidisciplinary team. They should have access to continuous training.

5. The continuing delivery of optimum care should be the responsibility of a supervisory group who are at present primarily involved in the supervision of patients with haematological malignancies. This group would be responsible for developing and implementing guidelines/protocols, brokering clinical research and devising appropriate training for staff involved in treatment delivery. This group will also develop outcome measurements and make such information available to Health Authorities, NHS Trusts Directors of Public Health Medicine and General Practitioners on an annual basis. This group will require appropriate administrative and statistical support.

6. Means of communicating treatment intentions to colleagues in primary care should be improved.

**Evidence base:**

a. All Wales Register of Haematological Malignancy: First Interim Report 1991 - 1993
b. Comprehensive Care in Leukaemia. Leukaemia and Lymphoma Forum 1994
c. BSH guidelines on the provision of facilities for adults with haematological malignancies
d. Published papers

11. REFERENCES

2. BSH Guidelines on the Provision of Facilities for the Care of Adults with Haematological Malignancies (including Leukaemia and Lymphoma and Severe Bone Marrow Failure). Clinical Laboratory Haematology 1995; 17: 3-10.
4. Standards for Specialist Units Undertaking Blood and Marrow Stem Cell Transplants - Recommendations from the EBMT Bone Marrow Transplantation 1995; 16: 733-736.

12. ACKNOWLEDGEMENTS

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