

# The West of Scotland Adult Blood Cancer Managed Clinical Network 2002-08



Dr Edward J Fitzsimons Lead Clinician

Dr Shirley-Anne Savage Network Manager

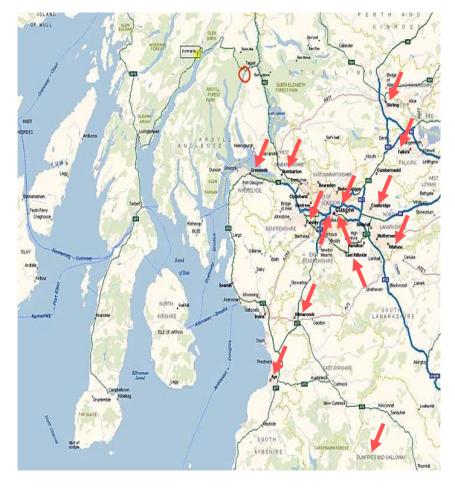
# Content

• History	3
The West of Scotland Blood Cancer Managed Clinical	Network
• Introduction	4
<ul> <li>MCN Advisory Board</li> </ul>	5
Aim	
West of Scotland Cancer Network (WoSCAN) Team	
Scottish Blood Cancer Group (SBCG)	
<ul> <li>Laboratory Diagnosis of Blood Cancer</li> </ul>	7
<ul> <li>Registration and Data Collection</li> </ul>	8
<ul> <li>Multi-disciplinary Teams (MDTs)</li> </ul>	11
Regional MDTs	
Lymphoma MDT	
Leukaemia MDT	10
Clinical Audit of Lymphoma	12
Analysis of Lymphoma Patients 2004-06	
Demographics	
Audit of Lymphoma Treatment Hodgkin Lymphoma	
Non-Hodgkin Lymphoma: DLBC	
Non-Hodgkin Lymphoma: Follicular	
Audit of Survival of Lymphoma Patients	
<ul> <li>Lymphoma Waiting Times</li> </ul>	19
<ul> <li>Collaboration with Other Cancer Networks</li> </ul>	20
Lymphoma Neck Lump Audit	
Cancer Waiting Times: the Clinical Perspective	
<ul> <li>Teenagers and Young Adults</li> </ul>	22
<ul> <li>MCN Guidelines</li> </ul>	23
• Educational Programme	24
• The Future	25
<ul> <li>Funding acquired by MCN</li> </ul>	26
• References	27

# **HISTORY**

## The West of Scotland Blood Cancer Managed Clinical Network

The West of Scotland Blood Cancer Managed Clinical Network (MCN) was formed in August 2002 with support from all those across the Region with an interest in Haematological Cancer. The MCN includes the 5 Health Board areas, Greater Glasgow & Clyde, Ayrshire & Arran, Lanarkshire, Forth Valley and Dumfries & Galloway. It includes multiple clinical sites, 45 consultant haemato-oncologists and extensive membership from the many professional groups involved in multi-disciplinary care of patients with Blood Cancer.



The West of Scotland Blood Cancer MCN

- 5 Health Boards
- 2.7M Population
- Arrows indicate clinical sites

It is predicted that between 2001-2020 the blood cancers (lymphoma and leukaemia) will increase by 71% and 44% respectively.

Cancer in Scotland: Sustaining Change, 2004

# INTRODUCTION

The role of the Managed Clinical Network (MCN) is to promote consistency and quality of service throughout the care pathway, across the region and where appropriate across the country.

NHS HDL (2007) Strengthening the Role of Managed Clinical Networks

**Blood Cancer** (Haematological Cancer) is the fifth major cancer and accounts for 7% of UK cancers. Blood Cancer presents in a number of different forms. These include:

## • Lymphoma

Lymphoma is the most common and accounts for approximately 50% of all blood cancers. The term lymphoma covers a wide range of related Blood Cancers which share a common origin in malignant lymphocytes and malignant lymphatic tissues. Lymphoma can be subdivided as follows:

- o Hodgkin Lymphoma (HL)
- o Non-Hodgkin Lymphoma (NHL).

Thereafter there are two main forms of NHL High grade Diffuse Large B Cell (DLBC) NHL and Low grade Follicular NHL

#### Acute Leukaemia

Acute Leukaemia is a high grade cancer of the bone marrow. It is subdivided as follows:

- o Acute Lymphoblastic Leukaemia (ALL)
- o Acute Myeloid Leukaemia (AML)

#### • Chronic Leukaemia

Chronic leukaemia is a more chronic low grade cancer of the bone marrow. It can be subdivided as follows:

- o Chronic Lymphatic Leukaemia (CLL)
- o Chronic Myeloid Leukaemia (CML)

## • Myeloma and Plasma Cell Dyscrasias

Myeloma is a blood cancer of bone and the bone marrow.

#### Other Blood Cancers include

- o Myeloproliferative Disorders (MPD)
- Myelodysplastic Syndromes (MDS)

# MCN ADVISORY BOARD

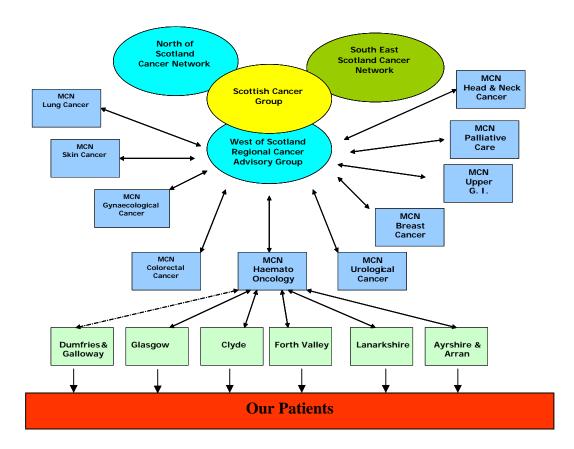
The MCN appointed Dr Edward Fitzsimons as Lead Clinician for the MCN and formed an Advisory Board with representation from each of the Health Board areas. The Advisory Board consists of approx 20 members and meets every 3 months. All members of the network are invited to attend the Advisory Board meetings. Sub Groups have been formed for each particular blood cancer (e.g. acute leukaemia, chronic leukaemia, lymphoma, myeloma etc). Sub Group Leads are chosen on the basis of specialist interests.

#### Aim

The aim of the West of Scotland Blood Cancer MCN is to improve the quality of care and ultimately the outcomes for all blood cancer patients.

#### West of Scotland Cancer Network (WoSCAN) Team

The West of Scotland Blood Cancer MCN is part of the WoSCAN Team. The team is managed by the Regional Cancer Co-ordinator (Evelyn Thomson). Dr Shirley-Anne Savage was appointed MCN manager for Blood Cancer from April 2003 and works within WoSCAN which provides administration, audit, IT and statistical support to the Network.



## **Scottish Blood Cancer Group**

The Scottish Blood Cancer Group was formed in 2003 to unite the 3 Regional Blood Cancer MCNs (West, North and East of Scotland). The purpose of this group was to secure and expand data collection (previously carried out by the Scotland and Newcastle Lymphoma Group (SNLG) and the Scottish Leukaemia Registry (SLR)) to include all Blood Cancers and patient follow up. A further aim was to ensure common treatment protocols and equity of access for all Scottish patients.

This group secured long term funding from Scottish Executive (2004). See page 26.

## Data Collection and Clinical Audit of Blood Cancers in Scotland from 2004 onwards.

#### **Grant Holders:**

- West: Edward Fitzsimons, Shirley-Anne Savage, Pam McKay

- North: David Bowen, Dominic Culligan

- East: Mike Mackie, Peter Johnson

The WoS Blood Cancer MCN has used this funding (£68k p.a to Scotland with £34k p.a. to West of Scotland) to ensure high quality data collection and prospective audit.



The Blood Cancer MCN Team

# **Laboratory Diagnosis of Blood Cancer**

It has previously been shown that up to 5% of people treated for lymphoma, outwith Scotland, actually had benign disease. A further 10% may receive suboptimal treatment because their lymphoma is classified incorrectly.

Improving Outcomes in Haematological Cancer. NICE 2003

This MCN recognises the importance of accurate laboratory analysis to:

- Provide precise diagnosis
- Guide treatment and
- Monitor the response to treatment.

Various methods are employed to ensure accurate diagnoses and treatment. These include:

## 1. Morphology/Microscopy

- 2. **Immunocytochemistry**; the regional Haematopathologists meet every 4 weeks to review morphology and immunocytochemistry. North Glasgow Haematologists meet weekly with the lead regional Haematopathologist to discuss cases across the West of Scotland
- 3. **Flow cytometry;** centralised regional service available at the West of Scotland Haemato-oncology laboratory at Gartnavel. The MCN collects all data from the 3 Flow Cytometer sites in the WoS.
- 4. **Cytogenetics;** chromosome analysis of blood and bone marrow is performed by the Regional Cytogenetics laboratory at the Royal Hospital for Sick Children (RHSC), Glasgow
- 5. **Molecular Pathology;** molecular testing is highly sensitive and is now recognised as an indispensable '*standard of care*' for many forms of Blood Cancer. This service is provided jointly by the Cytogenetics laboratory RHSC and the regional molecular pathology laboratory at Glasgow Royal Infirmary. This MCN has secured long term funding for the development on Molecular Pathology in Blood Cancer. See page 26.

# REGISTRATION AND DATA COLLECTION

High quality data collection and its analysis is the energy source for clinical audit. Clinical audit underpins the activity of every MCN and is the key to service improvement and better cancer care.

Scottish Medical Journal 2008, 53, 2-4

This MCN employs two talented and committed audit staff, Heather Wotherspoon (HW) and Denise Pentland (DP), to ensure high quality data collection and clinical audit of blood cancers across the West of Scotland.

Our Audit Facilitator (HW) is directly supported by the Scottish Executive through their grant to the Scottish Blood Cancer Group. Our Audit Officer (DP) is funded by ongoing unrestricted educational grants from the pharmaceutical industry with some short term funding (2004) from the Regional Cancer Advisory Group.

This MCN, in collaboration with The Information and Statistics Division (ISD), has developed the National datasets, data definitions and an Access database for all Scottish cases of lymphoma and acute leukaemia. In 2004 the West of Scotland MCN registered 1164 blood cancers. Registration by the MCN appears to be highly effective. In 2004 470 cases of lymphoma (35% more than Scotland and Newcastle Lymphoma Group (SNLG) (347) recorded in 2002) and 106 cases of acute leukaemia were captured (91 AML, 15 ALL, 23% more than Scottish Leukaemia Registry in 2002). Tables 1-4

Table 1. Blood Cancer Registration in WoS 2004-06

Disease type	2004	2005	2006
Acute leukaemia	106	100	109
Lymphoma	470	478	465
Myelodysplastic syndrome	71	77	104
Myeloproliferative disorders	103	101	112
Other lympho-proliferative disorders	248	249	208
Plasma cell dyscrasias	166	189	216
N=	1164	1194	1214

# REGISTRATION AND DATA COLLECTION (CONTINUED)

Table 2. Blood Cancer Registration by Health Board Area 2004

Disease Type	Ayrshire & Arran	Argyll & Clyde	Forth Valley	Lanark shire	Greater Glasgow	Dumfries & Galloway	Total
Acute leukaemia	24	8	2	22	48	2	106
Lymphoma	75	54	59	90	170	22	470
Myelodysplastic syndrome	14	8	0	34	15	0	71
Myeloproliferative disorders	13	14	3	39	34	0	103
Other lympho- proliferative disorders	36	42	3	52	89	26	248
Plasma cell dyscrasias	33	18	3	48	64	0	166
N=	195	144	70	285	420	50	1164

**Table 3. Blood Cancer Registration by Health Board Area 2005** 

Disease type	Ayrshire & Arran	Argyll & Clyde	Forth Valley	Lanark shire	Greater Glasgow	Dumfries& Galloway	Total
Acute leukaemia	15	13	2	21	39	10	100
Lymphoma	69	65	39	87	180	38	478
Myelodysplastic syndrome	12	9	1	27	24	4	77
Myeloproliferative disorders	12	14	1	30	42	2	101
Other lympho- proliferative disorders	42	34	3	56	92	21	249
Plasma cell dyscrasias	22	28	11	42	77	9	189
N=	172	163	57	263	454	84	1194

# REGISTRATION AND DATA COLLECTION (CONTINUED)

Table 4. Blood Cancer by Health Board Area 2006

Disease type	Ayrshire & Arran	Argyll & Clyde	Forth Valley	Lanark shire	Greater Glasgow	Dumfries& Galloway	Total
Acute leukaemia	15	12	8	19	40	15	109
Lymphoma	53	58	47	91	180	35	465
Myelodysplastic syndrome	17	9	2	29	40	7	104
Myeloproliferative disorders	20	14	0	17	51	10	112
Other lympho- proliferative disorders	39	23	6	60	69	11	208
Plasma cell dyscrasias	22	17	9	44	103	21	216
N=	166	133	72	260	483	99	1214

## Conclusion

The MCN now achieves almost 100% case registration for

- Lymphoma
- Acute leukaemia
- CML
- CLL

Registration of other blood cancers continues to improve but is probably not yet complete.

# **MULTI DISCIPLINARY TEAMS (MDTs)**

MDTs are central to services for cancer. They represent a way of working that offers advantages to both clinicians and patients. They lead to improved clinical policies, more effective delivery of care and more participation in Clinical Audit and Research.

Calman Hine Report, 1995

All patients with Haematological cancer should be managed by MDTs that serve populations of 500,000 or more.

Improving Outcomes in Haematological Cancer. NICE 2003

The ideal MDT should consist of haematologists, medical and clinical oncologists, pathologists, radiologists, pharmacy and nursing. It should meet regularly to discuss the diagnosis and treatment of all new cases and problematic cases of haematological cancer.

## **Regional MDTs**

### 1. Lymphoma MDT

A regional lymphoma MDT was established in 2002. The initial purpose of this meeting was to provide expert pathology review of lymphomas with input from haematologists and pathologists from Greater Glasgow, Clyde and Lanarkshire. State of the art video-conferencing facilities at the Beatson Oncology Centre and across other sites in the region are now utilised by the lymphoma MDT.

The success of the meeting was such that by 2007 >50% of all new cases in West of Scotland were presented at the meeting.

- Now links to 10 video-conferencing sites at any one time
- Treatment options and review of pathology are discussed
- Wide multi-disciplinary involvement
- Educational benefit for junior medical staff
- Patients suitable for clinical trials are identified
- Audit data is captured
- A report of the discussion is issued to the referring consultant

#### 2. Leukaemia MDT

A monthly acute leukaemia MDT was introduced in May 2005. This meeting discusses new cases, review/problem cases, patients with chronic myeloid leukaemia (CML) and problem patients with chronic lymphatic leukaemia (CLL).

# CLINICAL AUDIT OF LYMPHOMA

Clinical audit underpins the activity of every MCN and is the key to service improvement and better cancer care.

Scottish Medical Journal 2008, 53, 2-4

### **Analysis of Lymphoma Patients 2004-06**

M:F ratio, 50:50>60 years: 62%

Hodgkin lymphoma: 16%

• NHL: 84%

• DLBC NHL 50% (of all NHL), Follicular NHL 25% (of all NHL)

## **Demographics**

Hodgkin lymphoma (HL) is slightly more common in females and its distribution is bimodal. The incidence peaks in patients aged 15-35 years and again in patients over 60 years. Non-Hodgkin lymphoma (NHL) occurs in equal frequency in males and females and is primarily a disease of the elderly.

Figure 1. Age and sex distribution for cases of HL diagnosed 2004-2006

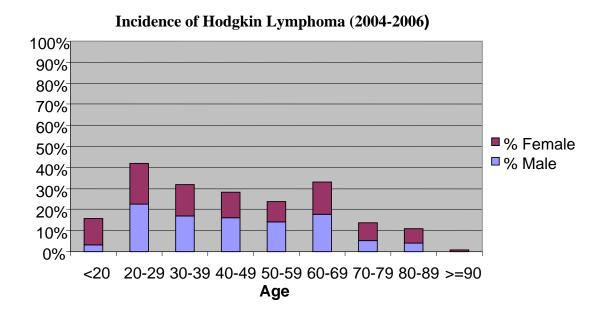
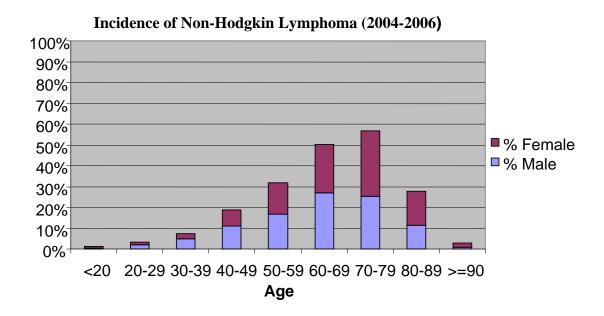


Figure 2. Age and sex distribution for cases of NHL diagnosed 2004-2006



# **Audit of Lymphoma Treatment**

# **1.** Hodgkin Lymphoma (HL) (2004-06)

84% of HL patients received treatment with chemotherapy; 6% with radiotherapy alone. Of those who had chemotherapy, 84% had ABVD/AVD.

Table 5. Chemotherapy treatment for Hodgkin Lymphoma (2004-2006)

Chemotherapy	2004		2005		2006	
	N	%	N	%	N	%
ABVD/AVD	49	80.3	51	89.5	58	80.6
PVACE-BOP	2	3.3	2	3.5	5	6.9
'Other' chemotherapy	10	16.4	4	7.0	9	12.5
Not recorded	0	0.0	0	0.0	0.0	0.0
N =	61		57		72	

## Conclusion

Treatment of HL across the WoS is extremely consistent. The drug combination ABVD ( $\pm$  bleomycin) is used in >80% of patients.

## **Audit of Lymphoma Treatment (Continued)**

## 2. Non Hodgkin Lymphoma (NHL): DLBC NHL

83% of patients with DLBC NHL received chemotherapy.

Table 6. Chemotherapy treatment for DLBCL (2004-2006)

Chemotherapy	2004		200	05	2006	
	N	%	N	%	N	%
СНОР	35	23.0	5	3.2	6	4.5
R-CHOP	85	55.9	123	78.4	100	74.7
'Other' chemotherapy + Rituximab	2	1.4	9	5.7	11	8.1
'Other' chemotherapy - Rituximab	30	19.7	20	12.7	17	12.7
Not recorded	0	0.0	0	0.0	0	0.0
N =	152		15	7	134	4

In 2004, 56% of chemotherapy was R-CHOP rising to 78% in 2005 and 75% in 2006. There was a corresponding decrease in the use of CHOP (23% in 2004 falling to 3% and 5% in 2005 and 2006 respectively) Table 6. The increase in R-CHOP chemotherapy and diminishing use of CHOP alone indicates consistency of chemotherapy across the region and reflects the benefits of rituximab to all cases of DLBC NHL.

## **Conclusion**

R-CHOP chemotherapy is now used in almost 80% of cases in the WoS.

## **Audit of Lymphoma Treatment (Continued)**

## 3. Non Hodgkin Lymphoma (NHL): Follicular NHL

Not all patients with follicular lymphoma require immediate treatment. They may enter a period of watchful waiting and start treatment if and when symptoms develop. In 2004, 05 and 06, 28%, 37% and 33% of patients entered a period of watchful waiting and 62%, 56% and 51% had chemotherapy (Table 7). Chemotherapy choice in 2004 was most likely to be CVP. By 2005 and 2006, however R-CVP was the most common treatment choice (Table 8).

Table 7. Treatment choice for follicular lymphoma (2004-2006)

	2004	2005	2006
Watchful waiting	28%	37%	33%
Chemotherapy	62%	56%	51%
Radiotherapy alone	8%	8%	11%
Other	2%	0%	1%
NR	0%	0%	3%
Number of patients	96	79	90

<sup>\*\*</sup>Other treatment includes died before treatment, surgery, supportive care, patient refused treatment.

Table 8. Chemotherapy treatment for follicular lymphoma (2004-2006)

Chemotherapy	2004		2005		2006	
	N	%	N	%	N	%
Rituximab alone	1	1.7	1	2.3	2	4.3
CVP	22	37.3	4	9.1	1	2.2
R-CVP	2	3.4	24	54.5	31	67.4
СНОР	6	10.2	4	9.1	0	0.0
R-CHOP	12	20.3	9	20.4	7	15.2
'Other' chemotherapy + Rituximab	0	0.0	0	0.0	1	2.2
'Other' chemotherapy - Rituximab	16	27.1	2	4.6	4	8.7
N =		59	4	4	46	)

#### Conclusion

By 2006 chemotherapy prescribing for follicular lymphoma across the region shows remarkable consistency. More than 80% of cases receive R-CVP (± adriamycin). The use of 'Other' chemotherapy regimens diminishes from ~ 30% in 2004 to ~ 10% in 2006. **Rituximab use has increased from 25% to 89% in patients receiving chemotherapy.** 

# **Audit of Survival of Lymphoma Patients**

Two year outcome data is now available for patients with lymphoma who were diagnosed in 2004. Overall survival for HL, DLBC and follicular lymphoma was 83%, 58% and 82% respectively. Age was found to significantly affect survival (Table 9).

## Overall 2 year Survival:

Hodgkin Lymphoma: 95% for those <45 yrs; 71% for those >45 yrs
 Follicular NHL: 97% for those <60 yrs; 75% for those >60 yrs
 DLBCL NHL: 72% for those < 60 yrs; 53% for those >60 yrs

Table 9. Overall 2 year survival for lymphoma patients 2004

	Overall Survival							
	Lymphoma	HL	NHL	DLBC	Follicular			
Number of cases	434	72	362	178	89			
Overall survival %	68.4	83.2	65.5	57.8	82.2			
% Survival by sex								
Male	69.3	80.6	67.1	61.4	78.5			
Female	67.5	85.9	63.8	54.7	85.9			
% Survival by deprivation index								
Affluent	59.9	76.9	55.2	37.5	91.7			
Intermediate	72.9	91.8	69.7	61.0	84.7			
Deprived	62.8	75.0	60.5	60.6	72.0			
Not Known	80.0	50.0						
% Survival by Stage								
I	82.4	92.3	80.7	77.4	89.7			
II	77.4	93.3	70.1	66.2	75.0			
III	73.7	87.5	69.9	57.7	90.9			
IV	56.0	41.7	57.2	45.0	74.8			
Not Known	25.0		25.0	0				
% Survival by Age								
<45		94.6						
>=45		70.8						
<60			77.1	72.3	96.8			
>=60			60.7	53.1	74.7			

Table 10. Disease free 2 year survival for lymphoma patients 2004

	Disease Free Survival							
	Lymphoma	HL	NHL	DLBC	Follicular			
Number of cases	434	72	362	178	89			
Overall Survival %	82.4	91.5	80.5	76.8	92.7			
% Survival by sex								
Male	83.0	94.4	80.7	79.6	89.5			
Female	81.9	88.7	80.3	73.9	95.3			
% Survival by deprivation index								
Affluent	78.9	92.3	75.1	60.1				
Intermediate	84.2	94.6	82.2	76.7	93.8			
Deprived	80.4	88.8	78.6	85.0	85.8			
Not Known	80.0	50.0						
% Survival by Stage								
I	92.2		90.9	88.6				
II	89.6		84.1	83.7	88.2			
III	86.6	93.8	84.3	75.0				
IV	70.2	55.6	71.6	64.0	84.3			
Not Known	80.2		80.2	83.3				
% Survival by Age								
<45		97.3						
>=45		84.9						
<60			85.7	82.1				
>=60			78.2	75.2	88.3			

# Survival by Age

Survival in HL was analysed in relation to 45 years. This is the age cut-off that is applied in the Hasenclever prognostic index.

In NHL, survival was analysed in relation to age 60 years. This is the age cut-off that applies in the NHL prognostic index.

It is hoped that further audit of outcome for patients with Blood Cancer will be available late autumn 2009 for the 2005 cohort of lymphoma patients.

## **Lymphoma Waiting Times**

Lymphoma subtype is a major factor determining the rate of progress from presentation to the start of treatment and hence the waiting time.

Scottish Medical Journal 2008, 53, 5-7

Waiting times for patients with lymphoma have been reported across the UK since 2005. Lymphoma however is not a single disease but a wide spectrum of lymphoid tumours that range from the most malignant to the most indolent, from highly curable to incurable. We now question the value of the current system that reports lymphoma waiting time on a quarterly basis and makes no allowance for the different types of lymphoma.

469 cases of lymphoma were registered in the West of Scotland in 2004. Complete datasets were available on 428. Patient demographic data, subtypes of lymphoma, biopsy site and referral urgency data were linked to the waiting times analysis for 2004 for the 3 major lymphoma subtypes, Hodgkin lymphoma (HL), diffuse large B cell (DLBC) and follicular non Hodgkin lymphoma (NHL).

Patients with HL were younger, more likely to receive urgent referral and have a diagnosis made from neck node biopsy than the other two groups. Patients with DLBC NHL however had the shortest interval between presentation and the start of treatment and were subsequently more likely to receive treatment within 63 days than patients with either follicular NHL (p<0.001) or HL (p<0.005).

## **Collaboration with Other Cancer Networks**

## Lymphoma Neck Lump Audit

It is recommended that there should be access for all patients with cervical lymphadenopathy to a weekly neck lump clinic with standardised protocols for lymphoma diagnosis. This should ensure that patients are diagnosed accurately and treated in a timely manner.

Scottish Medical Journal 2008, 53, 15-17

A joint audit project with the West of Scotland Head & Neck Cancer MCN was undertaken to assess methods used in the diagnosis of lymphoma presenting in the neck.

Currently there is no protocol in the West of Scotland for the investigation of a patient with a lymph node in the neck which might contain lymphoma. The aim of this audit was to examine the current management of these patients.

Data was collected on 112 patients diagnosed with lymphoma from neck node biopsy between 1<sup>st</sup> November 2004 to 31<sup>st</sup> October 2005. Biopsy data were collected in combination with the first point of consultation, investigations used to arrive at diagnosis and any associated complications.

87% of patients underwent excision biopsy with complications noted in 7%. Fine needle aspiration cytology (FNAC) was carried out in 60% of which 34% were ultrasound guided. Core biopsy was carried out in 17% of which 63% were ultrasound guided. Forty-five percent of patients were first referred to ear, nose and throat (ENT) surgery, 17% to general surgery, 14% to haematology, 13% to general medicine and 11% to other specialties.

This audit showed a wide range of first point consultations and diagnostic procedures. It is recommended that there should be access for all patients with cervical lymphadenopathy to a weekly neck lump clinic with standardised protocols for lymphoma diagnosis. This should ensure that patients are diagnosed accurately and treated in a timely manner.

## **Cancer Waiting Times: the Clinical Perspective**

The Lead Clinicians of the West of Scotland Managed Clinical Networks for Adult Cancer submitted an editorial to the Scottish Medical Journal which was published in August 2008.

## **Summary**

There is much to celebrate in the form of the service developments that have resulted from the waiting times initiative. The improvements in staffing, imaging facilities, diagnostic services and equipment provide a solid backbone on which to develop 'Better Cancer Care'. The initiative however does not provide the most appropriate measure of cancer care and has serious flaws particularly in the damage it has done to clinical audit of treatment and outcome. The pressures now on audit staff are excessive and there is urgent need to develop systems to electronically capture data in 'real time'. Pressures also result from demands to report waiting times from each previous quarter. These demands are clinically unnecessary and current timelines could be relaxed. An interval of six to nine months would still allow timely monitoring and simultaneous collection of data for both clinical audit and Waiting times, without unnecessary duplication of effort.

Now it is time to refocus attention to quality of care and clinical audit rather than waiting times. Clinical audit underpins the activity of each MCN and is key to service improvement and better cancer care. This must now be the focus of Better Cancer Care and thereafter waiting times must be a product of clinical audit, not vice versa.

Scottish Medical Journal 2008, 53, 2-4

#### Where are we now?

Our new Action Plan for Cancer, 'Better Cancer Care' recognises the importance of clinical audit of outcome and treatment.

'There is need to focus on the quality of care we are providing to the people of Scotland – this encompasses clinical outcomes, improving the way people experience care and ensuring that we spend resources in the best way possible'.

Dr Harry Burns. Chief Medical Officer. Better Cancer Care 2008

Despite this assurance audit staff throughout the region remain consumed by Waiting Times reporting and this Report is only able to include survival figures for the cohort of Lymphoma patients treated in 2004.

# TEENAGERS AND YOUNG ADULTS

Planning, commissioning and funding for all aspects of care for children and young people with cancer, across the whole healthcare system, should be co-ordinated to ensure that there is an appropriate balance of service provision and allocation of resources. The principle that underpins the guidance is that of age-appropriate, safe and effective services as locally as possible, not local services as safely as possible.

All patients <19 years (and possibly up to 24 yrs) with cancer must be treated in age appropriate facilities.

NICE Improving Outcomes in Children and Young People with Cancer, 2005

## Teenagers and Young Adults with Cancer (TYAC): Regional Service

The Teenage Cancer Trust invested £400K in providing a TYAC Unit in the new Regional Cancer Centre. This MCN led the proposal for a Lead Nurse/TYAC Service Co-ordinator through the Regional Cancer Advisory Group (RCAG) and Regional Planning Group (RPG). Funding was secured in 2006 and a Clinical Nurse Specialist appointed in 2008.

The MCN jointly led a proposal with the Royal Hospital for Sick Children for a dedicated consultant for teenagers and young adults with Blood Cancer through the same process (RCAG and RPG) in 2007/08. The case won approval and has been awarded national funding to create the first such consultant post of its kind in Scotland. This post has gone to advert and will interview for appointment in July 2009. See page 26.

# MCN GUIDELINES

## **Clinical Management Guidelines (CMGs)**

As part of the HDL(2005)29 on Guidance for the Safe Use of Chemotherapy it is recommended that CMGs are in place for all common tumour types. These should be prepared by a multi-disciplinary professional group with representation from each of the professions likely to contribute to care under the protocol. All CMGs have been approved by the MCN and local clinical governance structures.

Clinical Management Guidelines have been completed by the MCN for:

- Hodgkin Lymphoma
- DLBC NHL
- Follicular NHL
- Essential Thrombocythaemia (ET)
- Polycythaemia Rubra Vera (PRV)
- CLL
- CML

Other CMGs nearing completion are:

- Myeloma
- Waldenstroms

# EDUCATIONAL PROGRAMME

Educational sessions organised by the MCN are documented below.

## **MCN Study Days**

- 15<sup>th</sup> March 2006: Research Highlights in Lymphoid Malignancy
- 20<sup>th</sup> March 2006: NHL Study Day
- 7<sup>th</sup> June 2006: Research and Trials Educational Day
- 26<sup>th</sup> October 2006: Research Highlights in Myeloid Malignancy
- November 2006: NHL Study Day

## **WoS Lymphoma Group Meetings**

The WoS Lymphoma group meeting contains an educational component. These meetings are held every 3 months. The following educational sessions have taken place:

#### 2005

- 24th February 2005: Consensus opinion on the treatment and prophylaxis of lymphomatous meningitis
- 26th May 2005: Dr Grant McQuaker: Transplantation in Lymphoma
- 15th September 2005: Feedback from International Lymphoma Meeting
- 24th November 2005: Professor John Gribben: Low Grade Lymphomas

#### 2006

- 11th May 2006: Dr David Bilsland: Cutaneous Lymphomas.
- 30<sup>th</sup> Nov 2006: Prof J Radford. The present and future in Hodgkin Lymphoma.

#### 2007

- 22<sup>nd</sup> Feb 2007: Late effects monitoring in patients with DLBCL, CNS prophylaxis, Reactivation of hepatitis B by rituximab.
- 31<sup>st</sup> May 2007: NCRI trials update, Potential use of liposomal doxorubicin (Myocet) in DLBCL
- 13<sup>th</sup> Sept 2007: Audit of the management of patients with early stage Hodgkin's lymphoma. Audit of the prognostic value of the end of treatment PET Scan in Hodgkin's disease.
- 29<sup>th</sup> Nov 2007: Dr Tom Lynch: Current use of PET Scanning in Hodgkin Lymphoma.

#### 2008

- 28<sup>th</sup> Feb 2008: Update from the American Society of Haematology
- 15<sup>th</sup> May 2008:
  - MRI in Enteropathy Associate T Cell Lymphoma, Dr Mike Leach
  - Mantle cell lymphoma, NCRI Lymphoma Clinical Studies Group, Dr Pam McKay
  - Lymphoma follow-up and late effects of cancer treatment, Dr Noelle O'Rourke

# THE FUTURE

It is with great regret that this Report on MCN activity 2002-08 can only present outcome data for the cohort of Lymphoma patients who presented during 2004. The 2 year survival data for Lymphoma and Acute Leukaemia 2005 and 2006 has been collected but not yet analysed. Without this information we fail to answer the single most important question asked by all our West of Scotland patients, 'what are my chances? will I survive?' We would urge the Scottish Government to take heed of the views of the Lead Clinicians for Adult Cancer in the West of Scotland 'now is the time to refocus attention on quality of care and clinical audit'.

Dr Fitzsimons and Dr Savage have now demitted office. It has been our great privilege to represent our colleagues from the many professional groups that care for patients with Blood Cancer. At all times we have been greatly encouraged by their support for the MCN and their confidence in us both. Our thanks to all.

And lastly the patients. We very much hope that the unity this MCN provides across the region translates to Better Patient Care. They are most deserving of the best care. Unlike many cancers our Blood Cancers do not lend themselves to prevention or screening. Improvements in patient treatment and outcome must remain the emphasis of this MCN......and we do not get there without clinical audit.

The work of the Blood Cancer MCN of course continues and transfers to very safe hands. Dr Pamela McKay has now taken up the role of Lead Clinician and Heather Wotherspoon the role of Network Manager. We wish them well.

# **FUNDING ACQUIRED BY MCN**

# **Support for Blood Cancer Clinical Audit**

- £20K: Regional Cancer Advisory Group: (2005)
- £34K per annum: Scottish Executive: (ongoing from 2004)
- **£40K per annum**: Pharmaceutical Support: unrestricted educational grants (from 2004)
- £12K: Regional Cancer Advisory Group: (2004)

## **Support for Teenagers and Young Adults with Cancer (TYAC)**

- £37K per annum: Clinical Nurse Specialist; Regional Planning Group 2007
- £150K per annum: Consultant Haematologist for TYAC Units; National funding 2008

## **Support for Molecular Haematology**

- £12K per annum: Molecular studies of Chronic Lymphatic Leukaemia; Regional Planning Group 2006
- **£39.4K per annum**: Development of Adult Molecular Diagnostic Service for Haematological Cancer

# **REFERENCES**

- 1. Cancer in Scotland: Sustaining Change, 2004. Edinburgh, Scottish Executive.
- 2. NHS HDL (2007) Strengthening the Role of Managed Clinical Networks.
- 3. A Policy Framework for Commissioning Cancer services: A Report by the Expert Advisory Committee to the Chief Medical Officer of England and Wales. Calman and Hine, 1995.
- 4. Improving Outcomes in Haematological Cancer, National Institute of Clinical Excellence, 2003.
- 5. Cancer waiting Times: the Clinical Perspective. The Lead Clinicians, The West of Scotland Managed Clinical Networks for Adult Cancers. Scottish Medical Journal 2008, 53, 2-4
- 6. What is the value of lymphoma waiting times? Savage, S.A., Wotherspoon, H., Pentland, D. & Fitzsimons E.J. Scottish Medical Journal, 2008, 53, 5-7.
- 7. Cervical lymphadenopathy resulting in a diagnosis of lymphoma. Savage, S.A.H, Wotherspoon, H.A., Fitzsimons E.J. & MacKenzie K. Scottish Medical Journal, 2008, 53, 15-17.
- 8. Improving Outcomes in Children and Young People with Cancer, National Institute of Clinical Excellence, 2005