

**NATIONAL MANAGED CLINICAL NETWORK**  
**FOR SARCOMA**

**ANNUAL REPORT 2011-12**

Scottish

Sarcoma



Network

**Hosted by West of Scotland Cancer Network (WoSCAN)**

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## **Executive summary**

Mr Sam Patton stepped down as National Clinical Lead in September 2011, replaced by Dr Jeff White.

The Scottish Sarcoma MDT 2010 data has been analysed, the first full year this has been possible, and has continued to improve its operation. A small number of patients with Ewing's sarcoma have been discussed in a Ewing's MDT hosted by NHS England to prove the technology and improve the management of this group of patients.

Follow up guidelines for bone and soft tissue have been updated and the clinical management guidelines are being updated in 2012-13. GastroIntestinal Stromal Tumours (GISTs) clinical management guidelines are being updated in 2012-13 to reflect the Scottish Medicines Consortium extension of adjuvant imatinib from 1 year to 3 years for patients with high risk of recurrence following complete resection.

NHS Highland and Tayside have assigned Audit Facilitators and sarcoma Quality Performance Indicators are planned to be available for the start of 2014, when the other 12 Boards will be required to allocate resource to collect clinical audit data.

NHS Forth Valley sarcoma patient pathway is being audited after 1 year of operation, NHS Tayside pathway is finalised, NHS Fife and NHS Greater Glasgow and Clyde pathways are being initiated.

The second cohort for the sarcoma nursing module at the University of the West of Scotland was postponed from 2011 until 2012 due to lack of demand.

Musculoskeletal sarcoma surgery continues in Aberdeen, Edinburgh and Glasgow through regional funding and 2011-12 activity has been analysed to plan 2012-13.

In collaboration with the Scottish Cancer Research Network it was confirmed that 16% of patients participated in clinical trials during 2010-11, compared to 17% in 2009-10.

Dawn Currie, Clinical Nurse Specialist, was unanimously supported to act as the Scottish representative on the British Sarcoma Group.

## Introduction

Sarcomas (bone cancer and soft tissue sarcomas (including GastroIntestinal Stromal Tumours (GISTs)) have an incidence of approximately 3/100,000 and account for less than 1% of all tumours<sup>1</sup>.

The lifetime risk of developing sarcoma is 1 in 412 and sarcomas have increased by 3.2% for males and 2.9% for females between 2000 and 2010<sup>1</sup>.

Deaths from sarcoma have decreased by 5.2% for males and increased by 17.8% for females between 2000 and 2010<sup>1</sup>. This difference is due to natural variation over time.

EUROCARE-4 analysis of patients diagnosed between 1995 and 1999<sup>2</sup> gives the relative survival for bone tumour patients after 1 year of 78.7% and after 5 years of 57.0%; for soft tissue sarcoma patients after 1 year of 77.5% and after 5 years of 59.5%.

During 2010, 229 new sarcoma patients were diagnosed and managed by the national Multi-Disciplinary Team (MDT).

Mr Sam Patton (Edinburgh) was the National Clinical Lead until October 2011 when he handed over to Dr Jeff White (Glasgow).

Christopher Burns is the Scottish Sarcoma MDT Coordinator and Lindsay Campbell is the Network Manager.

Lynsey Connor provides administrative support and Douglas Grattan/Kris McAlpine provides web site support from the West of Scotland Cancer Network (WoSCAN).

Cindy Glass is our Patient Participant and Lindsey Bennister and Michael Hannah participate from Sarcoma UK, the largest sarcoma charity in the UK.

The Network's website is [www.ssn.scot.nhs.uk](http://www.ssn.scot.nhs.uk).

The Network is hosted by the West of Scotland Cancer Network (WoSCAN) which in turn is hosted by NHS Greater Glasgow and Clyde. Funding for the National Clinical Lead, Scottish Sarcoma MDT Coordinator, Network Manager and WoSCAN support is provided by National Services Division. The Network comprises of persons with an interest in the management and support of patients with sarcoma across Scotland and a desire to work together to improve existing services. The Network also includes links and support from patients, carers, charities and external companies. The Network is integrated with the North of Scotland Cancer Network (NOSCAN) and the South East of Scotland Cancer Network (SCAN).

## Aim and purpose of network

The Network's aim is the delivery of high quality, clinically effective and equitable care to patients irrespective of where they reside in Scotland.

The purpose of the Network is to continually improve the quality of care to patients through partnership working with patients, their families or carers, charities, external Companies and the NHS Scotland staff who care for patients with sarcoma.

## Plans for the year ahead

The 2012-13 work plan is being finalised and the objectives are;

1. Optimise effectiveness and efficiency of Multi-Disciplinary Team (MDT) review meetings.

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<sup>1</sup> <http://www.isdscotland.org/Health-Topics/Cancer/Cancer-Statistics/Bone-and-Connective-Tissue/>

<sup>2</sup> <http://www.eurocare.it/Results/tabid/79/Default.aspx#surv9599>

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2. Update the bone and soft tissue clinical management guidelines to reflect last year's updates to the follow up of these patients and other evidence based changes in management of these conditions. Update the GIST clinical management guidelines to reflect the extension of adjuvant imatinib from 1 to 3 years for high risk patients following complete resection.
3. Continue the improvements in the follow up of sarcoma patients in Scotland.
4. Analyse the MDT for patients diagnosed during 2011 and agree continual improvements with the centres.
5. Continue working with each Board to realise or improve their sarcoma patient pathway.
6. Assess potential enhanced recovery techniques and practices for sarcoma patients across Scotland.
7. Create the service map for sarcoma care in Scotland, detailing the services delivered and their interconnections.
8. Develop Quality Performance Indicators (QPIs) for sarcoma care across Scotland.

### **Network governance**

Mr Sam Patton, Consultant Surgeon, Department of Orthopaedics, NHS Lothian was the National Clinical Lead for the Network until October 2011 when Dr Jeff White, Consultant Medical Oncologist, Beatson West of Scotland Cancer Centre, NHS Greater Glasgow and Clyde took over.

The Network holds quarterly meetings to review progress and educate and one of these meetings is also the annual general meeting. As of 2012 the spring education day is also the annual conference of the British Sarcoma Group.

The constitution was updated.

Mr David Boddie is the lead for the Aberdeen Centre, Dr Michelle Ferguson for Dundee, Dr Larry Hayward for Edinburgh, Dr David Ritchie for Glasgow and Dr David Whillis for Inverness.

Dr Douglas Colville leads for Primary Care, Dr David Ritchie for Radiology, Professor Donald Salter for Pathology, Mr Ashish Mahendra for Surgery and Quality Performance Indicators (QPIs), Dr Donald Bissett for the Scottish Medicines Consortium (SMC), Dr Fiona Cowie for Oncology, Dr Alison Mitchell for Palliative Care, Dr Jeff White for Audit, Dr Sinclair Dundas for Research and Education, Dawn Currie for pathways, and Lindsay Campbell for the Website. Dawn Currie stepped down as lead for Nursing and Allied Health Professionals and has not been replaced.

The Network works closely with the British Sarcoma Group and our international colleagues, with Dawn Currie taking over as the Scottish representative on the British Sarcoma Group in 2012.

The Network is governed by the West of Scotland Cancer Network, in partnership with the North and South East of Scotland Cancer Networks; with an annual report presented to their Regional Cancer Advisory Group (WoS in April 2012, SEoS in May 2012 and NoS in June 2012). The Regional Cancer Networks are governed by the Regional Planning Groups.

**Detailed description of progress over the reporting period**

RAG status	Description			
<b>RED (R)</b>	Little/no progress been made to date to achieving network objective/standard			
<b>AMBER (A)</b>	Significant progress been made to date to achieving network objective/standard, however further work is required to fully achieve the network objective			
<b>GREEN (G)</b>	The network has been successful in achieving the network objective/standard			
Objective	Planned start/ end dates	Description of progress towards meeting objective	Outcome / evidence	RAG status
<b>EFFECTIVE: Providing services based on scientific knowledge</b>				
Support development and implementation of approval process for sarcoma CMG	Apr 2011 / Mar 2012	The bone and soft tissue CMGs are being updated to reflect the updating of the follow up of these patients. The WoS CMG approval process has been reviewed by the NoS and SEoS and their equivalent process will be used to approve this CMG.	9/2008 CMG replaced with updated CMG, circulated to members and on the website.	A
Complete review of evidenced based guidelines for follow up of all cancer patients in Scotland	Apr 2011 / Mar 2012	The 9/2008 guidelines for the follow up of bone and soft tissue sarcoma patients have been updated and approved in April 2012 by the WoS RCAG. The guidelines are now being approved by the NoS and SEoS RCAGs as well as the 14 Boards. Implementation is expected during summer 2012.	Follow up guidelines circulated to members and added to the website.	A
<b>EFFICIENT: Avoiding waste, including waste of equipment, supplies, ideas, and energy</b>				
Optimise effectiveness and efficiency of MDT review meetings by implementing agreed actions to address gaps and deficiencies identified during the 2010/11 national review	Apr 2011 / Mar 2012	Scottish sarcoma MDT created generic NHSmail box to improve communications and standard templates for MDT referral, presentation and outcome. Scotland-wide IT application researched and proposed to eHealth Leads. Coordinator's laptop	Accounting for sarcoma patients managed through other MDTs (e.g. Upper GI, Gynae, and Neuro).	G

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		upgraded to full wireless capability to enable operation in all 5 centres.		
<b>EQUITABLE: Providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location or socio-economic status</b>				
Use the Forth Valley pathway to guide the other 13 Boards in creating and implementing the corresponding Board specific pathways for sarcoma patients	Apr 2011 / Mar 2012	NHS Forth Valley auditing the first year of operation. NHS Tayside have finalised their pathway and are agreeing a start date for its operation. NHS Fife and Greater Glasgow and Clyde are initiating their pathway.	Awaiting results of audit in Forth Valley and start of pathway in Tayside.	A
<b>SAFE: Avoiding injuries to patients from care that is intended to help them</b>				
Support delivery of the national clinical audit work programme for 2011/12	Apr 2011 / Mar 2012	Scottish Sarcoma MDT Coordinator analysed the MDT for patients diagnosed during 2010, the first full year to be analysed. Patients managed through the MDT in the last 6 months of 2009 are being compared with Cancer Registry to ensure all sarcoma patients are accounted for. QPIs are scheduled for creation during 2013 and patients are expected to be captured into eCase from the start of 2014 by each Board.	2010 MDT analysis presented at the 2011 AGM by the National Clinical Lead and summary attached as appendix 3.	G

Musculoskeletal sarcoma surgery continues to be performed in Aberdeen, Edinburgh and Glasgow and 2011-12 has been analysed to plan for 2012-13.

NHS Highland Audit facilitator captured sarcoma patients diagnosed in 2010 into eCase to verify the eCase sarcoma module and the Scottish Sarcoma MDT Coordinator continues to register patients in eCase. NHS Tayside assigned Audit Facilitators. It is anticipated that other NHS Boards will assign Audit Facilitators when the Quality Performance Indicators (QPIs) are implemented at the start of 2014.

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The second cohort for the sarcoma Nursing Module at the University of the West of Scotland had to be postponed due to a lack of demand. Dundee Clinical Nurse Specialist started in August 2011 and Edinburgh Clinical Nurse Specialist role is now job shared.

The Scottish Cancer Research Network reported that 16% of patients with sarcoma participated in clinical trials in 2010-11, compared to 17% in 2009-10. This maintained the excellent performance for this rare cancer. The 2011-12 report is due in September 2012.

The Network organised 4 education days per year to enable participation by as many members as possible on each day. The 2011 Annual General Meeting was held in Edinburgh and included the presentation of MDT audit analysis for 2010, the first full year to be analysed. The 2012 AGM will be in Glasgow and will celebrate the 50<sup>th</sup> anniversary of the Scottish Bone Tumour Registry.

The waiting times for sarcoma patients will be measured as part of a rolling programme of short term surveys/audits and reported for performance management purposes (to ensure the 31 and 62 days targets are being met) only, and will not be published. The date for the first survey/audit is to be confirmed.

The Sarcoma Patient Support Group continues to meet monthly at Maggie's Centre in Glasgow on every third Wednesday of the month from 2.30-4PM. Sarcoma UK is working with the other Maggie's Centres in Scotland to get patient support groups started. Sarcoma UK has also developed online support for patients.

Mr Sam Patton is a member of the Sarcoma UK Research Advisory Committee and the next call for research proposals is September 2012.

Dr Jeff White visited Aberdeen, Dundee, Edinburgh and Inverness centres as part of his induction and identified improvements for all 5 centres that will be discussed, developed and implemented through the quarterly education days.

The Scottish Clinicians have successfully participated in the Ewing's sarcoma MDT that is hosted by NHS England, enabling Scottish patients with Ewing's sarcoma to be discussed in both the Scottish and UK MDTs.



## Appendix 1: Network membership



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Directory\MCNs - Disc

## Appendix 2: Finance

National Clinical Lead is funded for 2 sessions per week.

West of Scotland Cancer Network funds 1 WTE Manager (Band 6) and 30 hours Administration / Information Management support (Band 4/5), to support 3 National Networks.

## Appendix 3: 2010 MDT analysis summary

### Totals

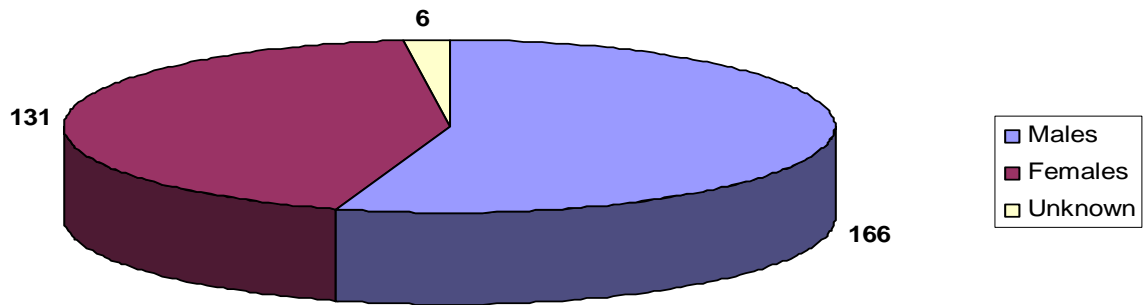
- **Total number of cases** discussed by Scottish Sarcoma Network at MDT in 2010 – **598**
- **Total number of sarcoma** cases discussed by Scottish Sarcoma Network in 2010 – **274** (excluding GIST's)
- **Total number of NEW sarcoma** cases discussed by Scottish Sarcoma Network in 2010 – **204** (excluding GIST's)
- **Total number of RETURN** sarcoma cases discussed by Scottish Sarcoma Network in 2010 – **65** (excluding GIST's)

### GIST Totals

- **Total number GIST cases** discussed at Sarcoma MDT by Scottish Sarcoma Network 2010 – **31**
- Total number of **NEW GIST** cases discussed by Scottish Sarcoma Network 2010 – **25**
- Total number of **RETURN GIST** cases discussed by Scottish Sarcoma Network 2010 – **5**
- *Health Board GIST analysis –*
- GGC – 12
- Ayrshire & Arran – 5
- Lanarkshire – 4
- Highland – 3
- Grampian - 4
- Unknown - 2

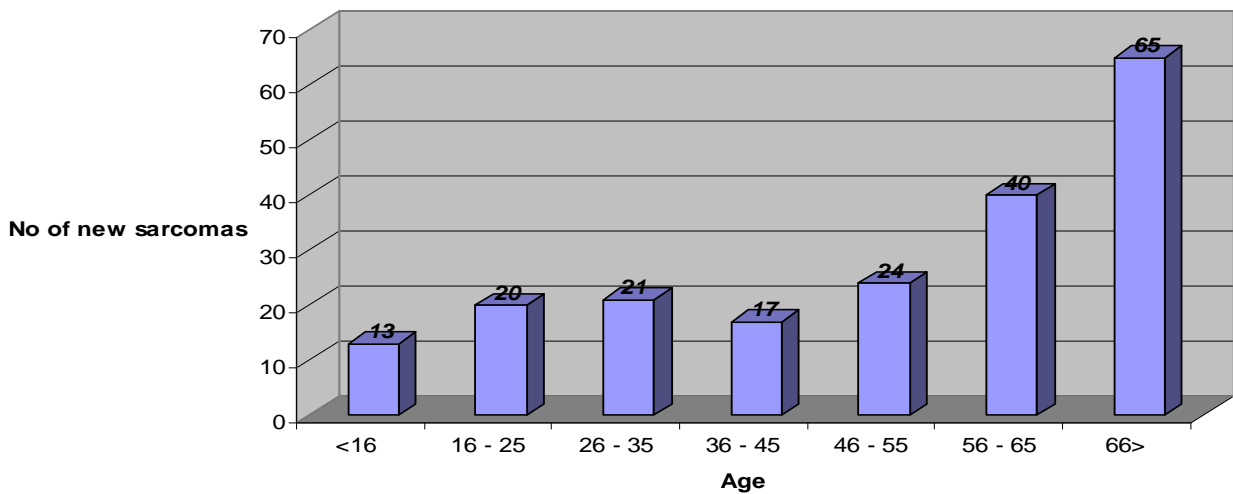
# TOTAL

Total No. Male-Female analysis PAN Scotland



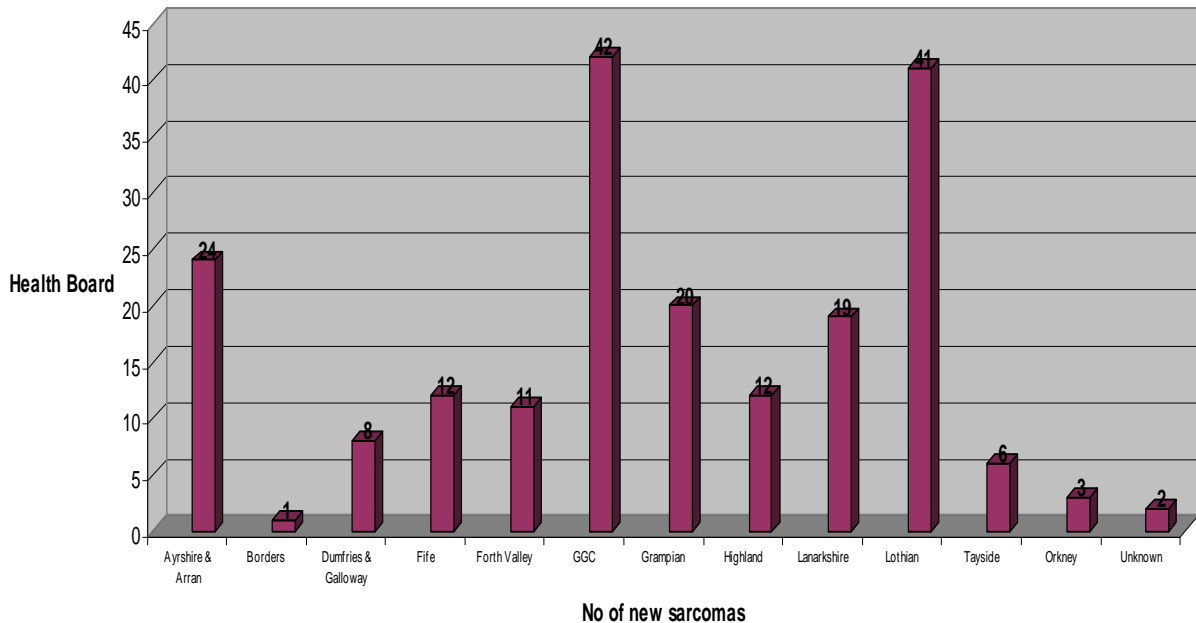
# TOTAL

Total No. age analysis new sarcomas PAN Scotland



# TOTAL

Total No. Health Board analysis PAN Scotland 2010



## Total number Sarcoma Types PAN Scotland 2010

- Leiomyosarcoma – 30
- Liposarcoma – 27
- Chondrosarcoma – 21
- Sarcoma (unclassified) – 21
- Pleomorphic Sarcoma – 15
- Osteosarcoma – 14
- Ewing – 11
- Angiosarcoma – 9
- Myxofibrosarcoma – 6
- Rhabdomyosarcoma – 4
- Alveolar Rhabdomyosarcoma – 4
- Dermatofibrosarcoma protuberans – 4
- Fibromyxoid sarcoma – 3
- Synovial Sarcoma - 3
- MPNST – 3
- Hemangiopericytoma – 3
- Atypical lipomatous tumour – 3
- Epithelioid hemangioendothelioma – 2
- Spindle cell sarcoma – 2
- Histiocytic sarcoma – 2
- PNET – 2
- Malignant Solitary fibrous Tumour – 1
- Myxoinflammatory fibroblastic sarcoma – 1
- Sclerosing Epithelioid Fibrosarcoma – 1
- Smooth Muscle tumour – 1
- Embryonal Rhabdomyosarcoma – 1
- Epithelioid Sarcoma – 1
- Adamantinoma – 1
- Biphasic Synovial Sarcoma – 1
- Myxoid Sarcoma – 1
- Fibrosarcoma – 1
- Metastatic alveolar soft part sarcoma – 1
- Proximal variant epithelioid sarcoma – 1
- Soft tissue sarcoma – 1
- Chordoma – 1