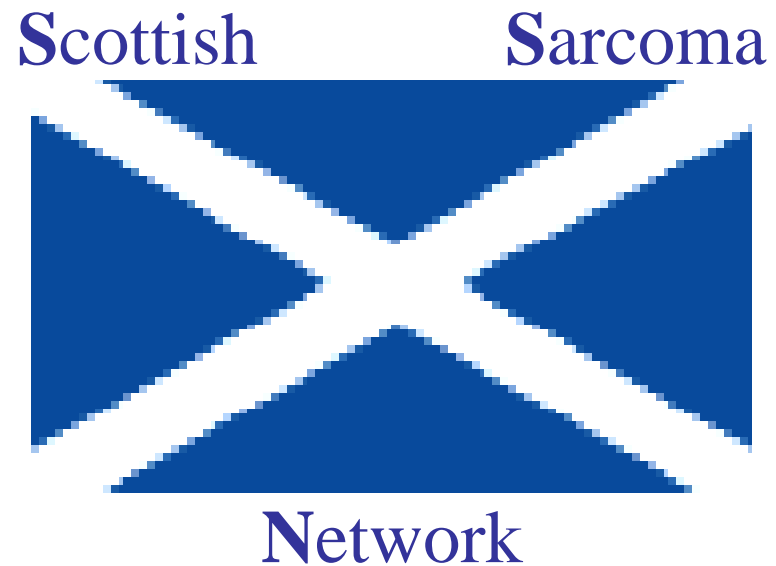


# National Managed Clinical Networks

## Annual Report for 2009-2010



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# Lead Clinician's Report

Sarcoma provision in Scotland has over the past year been the subject of external option appraisal. I appreciate the efforts of all those involved who contributed in this process. The recommendations of the committee are currently awaiting approval by the board chief executives. The key points put to the appraisal committee and accepted by them are outlined below:

1. The provision of care for patients with sarcoma will continue to be provided regionally as before.
2. The Network will act as an umbrella organisation to ensure standards, equality of care, audit and quality assurance across the country. This will require appropriate support.
3. All cases of sarcoma across the country should be presented at a properly constituted MDT with data recorded by the national coordinator.

Chris Burns is our national MDT coordinator who has been working hard to formulate an efficient and helpful national MDM and create an appropriate database of all cases with the help of Jean Campbell at the SBTR. Ashish Mahendra has been developing a lean set of quality outcome measures. Lindsay Campbell has continued to work at streamlining technology in patient referrals. Each centre has undergone restructuring of its services to improve the patient journey, although much work remains. Team working has been encouraged and we have many examples of truly first rate practice in this area.

Attendance at national and European meetings has been excellent. The first sarcoma nursing module in Paisley was well attended and well supported by members of the Network. Dawn Currie and the team at the West of Scotland University are to be congratulated.

As well as working to fine tune work that has already begun, I would like to stress two areas where I believe we must do more. We know that global outcomes especially in soft tissue sarcoma have not shown significant improvement for many years. We must attempt to seize this nettle by reducing the size of tumour at surgery and improving our research effort.

I would like to thank everyone who continues to work hard, work together and work intelligently. I hope that now we have a clearer structure we can focus our efforts on improving the care of our patients.

**Sam Patton, National Lead Clinician**

**31<sup>st</sup> May 2010**

# Introduction

The Scottish Sarcoma Network (SSN) is now in its sixth year and celebrated its fifth birthday at the annual general meeting.

## Description of the Network

The Scottish Sarcoma Network is a National Managed Clinical Network as defined by the NHS MEL (1999) 10 and NHS HDL (2007) 21.

The Network links groups of health professionals and organisations from primary, secondary and tertiary care, and promotes working in a coordinated manner with the aim of delivering high quality, clinically effective and equitable care to patients irrespective of their geographical location.

Mr Sam Patton (Edinburgh) is the National Clinical Lead.

Lindsay Campbell is the Network Manager.

Lynsey Connor provides administrative support and Keith Bryce provides web site support from the West of Scotland Cancer Network (WoSCAN).

Katie Hannah stepped down and George Violaris took over as Patient Participant.

Our web site is [www.ssn.scot.nhs.uk](http://www.ssn.scot.nhs.uk) and will be upgraded to new technology in June 2010 (to match the Scottish HepatoPancreatoBiliary Network ([www.shpbn.scot.nhs.uk](http://www.shpbn.scot.nhs.uk)) and Scottish Adult Neuro-Oncology Network ([www.neurooncology.scot.nhs.uk](http://www.neurooncology.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, Network Manager and WoSCAN support is provided by National Services Division (NSD).

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 pharmaceutical companies.

The Network is integrated with the North of Scotland Cancer Network (NoSCAN) and the South East Scotland Cancer Network (SCAN).

Surgery for adult sarcomas takes place in 3 sites; Aberdeen, Edinburgh and Glasgow.

Surgery for paediatric and adolescent sarcomas takes place in 2 sites; Edinburgh and Glasgow

Oncological treatment is provided in 5 sites; Aberdeen, Dundee, Edinburgh, Glasgow and Inverness.

The Scottish Sarcoma Coordinator started on 18<sup>th</sup> May 2009 and registers new sarcoma cases on the national database (ECASE). Auditors are still required to enter the clinical data into the national database and this is being actioned through the Option Appraisal of the Scottish Musculoskeletal Sarcoma Surgical Service and the Scottish Sarcoma Network.

The Edinburgh Sarcoma Nurse Specialist (0.1 WTE) started on 1<sup>st</sup> July 2009 and cares for patients of all ages.

The national MDT started on 16<sup>th</sup> November 2009 and is a weekly Monday afternoon video conference meeting linking Aberdeen, Dundee, Edinburgh, Glasgow and Inverness. NHS Boards can participate in the national MDT as required, with NHS Dumfries and Galloway participating on 22<sup>nd</sup> February 2010.

The Network steering group meets quarterly and reports back to the Annual General Meeting, which is held in November.

## Purpose of the Network

The purpose of the network is to;

1. register referral, radiological, pathological, surgical, oncological and ongoing treatment details of patients with bone sarcoma, soft tissue sarcoma and Gastro Intestinal Stromal Tumours (GIST's) throughout Scotland
2. provide a Scotland wide forum for service improvement and education
3. provide data for audit and research purposes
4. optimise the treatment of patients with sarcoma in Scotland

Working groups address key priorities;

1. Database and audit
2. Referral guidelines
3. Nursing and allied health professional group
4. Imaging guidelines
5. Pathology guidelines
6. Surgery guidelines
7. Chemotherapy and radiotherapy guidelines
8. Research and education
9. Patient information and involvement

The strong links with the British and Scandinavian Sarcoma Groups have been maintained.

## Objectives of the Network

The objectives of the Network have been agreed with NHS Quality Improvement Scotland (QIS) and are detailed in the Quality Assurance Framework that was finalised in October 2007. The Network Manager can provide this agreement.

## Organisation of the Network

The network is led by a Steering Group who meet quarterly.

Sub-specialty groups report to the Steering Group along with any short working life groups tasked with specific work.

The Steering Group had/has the following members:

Mr Sam Patton	Lead Clinician/Orthopaedic Surgeon, Edinburgh
Dr Michelle Ferguson	NoSCAN Lead/Oncologist, Dundee
Dr Larry Hayward	SCAN Lead/Oncologist, Edinburgh
Dr David Ritchie	WoSCAN Lead /Radiologist, Glasgow
Dr Milind Ronghe	Paediatric Oncologist, Glasgow
Mr Daniel Porter	Orthopaedic Surgeon, Edinburgh
Dr Fiona Cowie	Oncologist, Glasgow
Dawn Currie	Sarcoma Nurse Specialist, Glasgow
Katie Hannah/George Violaris	Patient Participant, Dundee/Glasgow
Professor Paddy O'Dwyer	General Surgeon, Glasgow
Mr Stuart Hamilton	Plastic Surgeon, Edinburgh
Dr Alison Mitchell	Palliative Care Specialist, Glasgow
Professor Donald Salter	Osteoarticular Pathology, Edinburgh
Mr David Boddie	Orthopaedic Surgeon, Aberdeen
Mr Mike Jane	Orthopaedic Oncologist, Glasgow
Susan Groom	General Manager, Glasgow
Dr Jeff White	Oncologist, Glasgow
Cameron Raynor	Prosthetist, Aberdeen



Peter Gent	NoSCAN Manager, Aberdeen
Chris Burns	Scottish Sarcoma Coordinator
Lindsay Campbell	MCN National Manager, Glasgow

## Services covered

A wide range of clinical services are involved and locally funded, apart from the nationally funded Musculoskeletal Sarcoma Surgery Service. NSD are currently conducting an Option Appraisal on this nationally funded service and the Scottish Sarcoma Network.

The medical staff who provide services to patients with sarcomas do not only provide this subspecialty service, but are involved with management of patients with other diseases within their specialty (e.g. other medical or surgical conditions or other cancer types). There are currently two Sarcoma Clinical Nurse Specialists, based in Edinburgh (0.1 WTE) and Glasgow (1.0 WTE).

### **The services covered include the following:**

Radiology

Pathology

Surgery (Orthopaedic, General, Cardiothoracic, Plastic, Vascular)

Oncology

Palliative Care

Clinical Psychology

Sarcoma Specialist Nurse

Nursing and Allied Health Professionals

**Please note the Children and Teenagers Scottish Cancer Network (CATSCAN) started in November 2007 and children and teenage sarcoma patients are managed through the CATSCAN MDT with specialist support from the SSN MDT.**

## **Membership**

All health professionals, patients, carers, charities and pharmaceutical companies with an interest in sarcomas are cordially invited to join and participate in the Network.

Currently the Network has 150 members.

## **Resources**

National Clinical Lead (1 session per week).

National MCN Manager (0.33 WTE).

WoSCAN Administrative support (as required).

WoSCAN website support (as required).

## **Clinical Facilities**

There are full facilities for Radiology at all five centres.

There are full facilities for Pathology at all five centres.

There are full facilities for Surgery in adults at three centres; Aberdeen, Edinburgh and Glasgow.

There are full facilities for Surgery in children at two centres; Edinburgh and Glasgow.

There are full facilities for Oncology at all five centres.

Palliative care provision throughout Scotland is available at all five centres.

Prosthetic and orthotic support is available to basic NHS standards. There are areas of unmet need, eg provision of high quality and sports prosthetics.

Routine PET provision is available on request for sarcoma patients when necessary.

There are sarcoma Specialist Nursing facilities in Edinburgh (0.1 WTE) and Glasgow (1.0 WTE) only, so far.

## **Clinical Quality Indicators**

1. GP's refer suspected sarcoma to a sarcoma centre as early as possible
2. All patients with a suspected sarcoma are seen at a Specialist Clinic
3. Imaging is undertaken by a Radiologist specialising in sarcoma work
4. Biopsy is taken either by a Surgeon or Radiologist with specialist interest in a sarcoma centre
5. All imaging and biopsy findings are discussed at the MDT to establish an accurate diagnosis
6. A definitive plan of clinical management is agreed by the MDT with patients entered into appropriate trials
7. There is multi disciplinary surgical input (e.g. orthopaedics, vascular, plastics, general, thoracic) to allow an appropriate surgical treatment plan to be developed
8. Resection specimen, pathology is fully and triple reported to the MDT to allow the MDT to determine response of bone tumours to chemotherapy and adequacy of margins, and to establish whether radiotherapy may be required post-operatively
9. Specialist nursing advice is provided by the sarcoma Nurse Specialist or Link Nurse with an interest in sarcoma
10. Each patient has a coordinated support package that includes;
  - a. Follow-up imaging
  - b. Follow-up oncology
  - c. Follow-up surgery
  - d. Palliative medicine
  - e. Access to prosthetics
  - f. Physiotherapy

- g. Occupational therapy
- h. Nutrition/dietary advice
- i. Self help group
- j. Psychological support

# Activity Report

## 2009-2010 Work Plan

Objective	Please include reference to specific actions within National Policies e.g. Better Cancer Care (BCC); Living & Dying Well (L&DW)	Key Milestones & Specific Actions	Named Lead	Due date	Status at 1 <sup>st</sup> April 2009
<b>Referral</b>					
Referral guidelines already in place so aiming for 100% electronic referral and vetting	Efficiency Target of 90% by 12/2010	SCI GATEWAY configured, trialled and implemented for SSN	Lindsay Campbell	30/6/2009, 30/9/2009 and 31/12/2009	SCI GATEWAY team reviewing SSN requirements and creating demonstrations for Q1, CY2009
<b>Diagnostics</b>					
Radiology guidelines updated	"good inter-professional communication" P47	Update, finalise and implement	Dr David Ritchie	31/3/2010	Updating existing guidelines
<b>Treatment</b>					
Surgery and Chemotherapy guidelines updated and created	"good inter-professional communication" P47	Update and create, finalise, implement	Mr Mike Jane/Mr Ashish Mahendra/Mr Paddy O'Dwyer and Dr Fiona Cowie	31/3/2010	Updating existing Surgery guidelines
<b>Service Provision &amp; Access</b>					

MDT and Patient Pathway coordination implemented	Efficiency Target of 62 days maximum wait from referral to treatment or 31 days from decision to treat to treatment by 12/2011	Recruit Glasgow-based person, develop national MDT, coordinate with Boards	Lindsay Campbell	1/4/2009, 30/9/2009 and 31/3/2010	Closing date for applications 27/2/2009
<b>Improving Quality of Cancer Care for Patients</b>					
National audit via ECASE operational	“Ensure by 2010, all tumour networks take part in national audit” P90	In collaboration with Boards start collecting audit data via ECASE	Lindsay Campbell	31/3/2010	ECASE defined and tested and Boards already engaged with first Scottish HPB Network national audit
<b>Delivery</b>					
<i>Workforce</i> CNS capacity matches demand	“effective workforce planning is required in order to quantify numbers” P95	Demand and capacity analysis by Board and Region in collaboration with Sandra White and Gillian Knowles	Lindsay Campbell	31/3/2010	Scottish Sarcoma Network has only 1 CNS based at WoSCC and Dawn Currie has Nursing Module available through UWS

## Accomplished service improvements

Electronic referrals from Hospital Consultant to Hospital Consultant through SCI GATEWAY are being trialled by NHS Grampian, NHS Orkney and NHS Shetland.

Radiology, surgery and chemotherapy guidelines have been implemented through the professions rather than the website.

Auditors proposed through the Option Appraisal, which is still in progress.

Chris Burns started as the Scottish Sarcoma Coordinator on 18<sup>th</sup> May 2009 and is also registering new patients in ECASE.

Shona Simon started as the Sarcoma Nurse Specialist (0.1 WTE) in Edinburgh on 1<sup>st</sup> July 2009 and cares for patients of all ages.

Sarcoma Nurse Specialists for Aberdeen, Dundee and Inverness Centres have been highlighted as a priority and possible solutions

are being explored. The Sarcoma Nursing Module at the University of the West of Scotland (UWS) started its first cohort in February 2010.

The national MDT started on 16<sup>th</sup> November 2009 with all 5 Centres participating by video conference. On 22<sup>nd</sup> February 2010 NHS Dumfries and Galloway also participated in the MDT by video conference.

Pathology is tripled reported by Aberdeen, Edinburgh and Glasgow Pathologists.

The generic timed pathway for the first 62 days of care for patients with sarcoma was finalised.

Patient information was standardised on charity booklets and Centre specific information sheet.

## **Number of Meetings held and brief summary of meetings**

The Steering Group met three times; 23<sup>rd</sup> June 2009, 30<sup>th</sup> September 2009 and 16<sup>th</sup> March 2010.

### **23<sup>rd</sup> June 2009 Steering Group Meeting**

Chris Burns participated for the first time. 2009 AGM progressed. No GP identified yet. Next EORTC meeting discussed. Radiology, surgery and chemotherapy guidelines progressed. Auditors progressed. National MDT progressed. Clinical Nurse Specialists for Aberdeen, Dundee, Edinburgh and Inverness progressed. Option Appraisal progressed. Quarterly education meetings progressed. Patient information reviewed. Electronic referrals progressed. Timed pathway was progressed. Sarcoma Nursing Module first cohort planned for February 2010.

### **30<sup>th</sup> September 2009 Steering Group Meeting**

First steering group meeting arranged on the same day as the quarterly education meeting. Option Appraisal progressed. Auditors progressed. National MDT progressed, with GIST patients included for the West of Scotland (North and South East manage through Upper GI MDT). Next EORTC meeting discussed. Radiology and chemotherapy guidelines completed and being

implemented via professions. Surgery guidelines progressed. Timed pathway approved. 2009 AGM progressed. Quality Performance Indicators (QPI's) led by Mr Ashish Mahendra. Patient Information standardised on charity booklets and Centre specific information sheet. No GP identified yet. Shona Simon started as Sarcoma Nurse Specialist in Edinburgh. Scottish patient support group progressed. Electronic referrals progressed.

### **16<sup>th</sup> March 2010 Steering Group Meeting**

Mr Ashish Mahendra participated for the first time. 23/11/2009 AGM was a success. EORTC group meetings attended. National MDT progressed, with video conferencing in ERI and standardising on PowerPoint. CNS's being worked with NHS Grampian, Tayside and Highland. Option Appraisal progressed. TNM7 being implemented. QPI's progressed. Website will be upgraded after SHPBN. UWS Nursing Module first cohort of 20 students has started. Patient support group being progressed with Maggie's. GP representation being pursued.

## **Public and Patient Involvement**

The British Sarcoma Group Conference 2010 took place in London on 4<sup>th</sup> and 5<sup>th</sup> February 2010. Details are available from;  
<http://www.bsgconference.org.uk/abs2010.htm>



## **Audit Activity**

Bone sarcomas are registered by the Scottish Bone Tumour Registry, managed by Jean Campbell ([jean.campbell3@nhs.net](mailto:jean.campbell3@nhs.net)).

To support the Option Appraisal a retrospective audit of 2006 and 2007 was performed. This resulted in the number of new cases of sarcoma per year being increased to 400 (from 250).

## **Quality Assurance Framework (QAF)**

The network has maintained its accreditation with NHS Quality Improvement Scotland (QIS) and it is due for renewal in October 2010.

# Research and Teaching Activity

Full details are available from Mr Daniel Porter ([Daniel.Porter@ed.ac.uk](mailto:Daniel.Porter@ed.ac.uk)).

Scottish Bone Tumour Registry and education meetings are alternating quarterly between Edinburgh and Glasgow.

The Annual General Meeting (AGM) was held on the 23<sup>rd</sup> November 2009 in The Beardmore, Clydebank. There were 37 attendees and the agenda was;

<i>Time</i>	<i>Topic</i>	<i>Presenter</i>
<b>0930-1000</b>	<b><i>Registration, coffee and networking</i></b>	
<b>1000-1020</b>	<b>Introductions and Lead Clinician Report</b>	<b>Mr Sam Patton</b>
<b>1020-1050</b>	<b>Updates on Sarcoma research presented at international meetings in the last year</b>	<b>Dr Jeff White, Dr Larry Hayward and Dr Jairam Sastry</b>
<b>1050-1100</b>	<b>Nursing Module at University of the West of Scotland</b>	<b>Dawn Currie</b>
<b>1100-1110</b>	<b>Research undertaken within the SSN</b>	<b>Mr Daniel Porter</b>
<b>1110-1120</b>	<b>Audit undertaken within the SSN</b>	<b>Dr David Ritchie and Mr Sam Patton</b>
<b>1120-1140</b>	<b><i>Break and networking</i></b>	
<b>1140-1200</b>	<b>Patient's perspective</b>	<b>Mr George Violaris</b>
<b>1200-1230</b>	<b>New developments in pain relief for Sarcoma patients</b>	<b>Dr Alison Mitchell</b>
<b>1230-1330</b>	<b><i>Lunch and networking</i></b>	
<b>1330-1405</b>	<b>GIST developments</b>	<b>Dr Jeff White and Dr Shaun Walsh</b>
<b>Chair: Mr Rod Duncan</b>		
<b>1405-1440</b>	<b>Ewings sarcoma – What is the evidence for the current treatment strategy, with cases.</b>	<b>Dr Fiona Cowie, Dr Dermot Murphy, Dr Maryon Hardie</b>
<b>1440-1455</b>	<b><i>Birthday cake and networking</i></b>	
<b>1455-1530</b>	<b>Osteosarcoma – What is the evidence for</b>	<b>Dr Dermot Murphy, Dr Fiona Cowie, Dr</b>

	<b>the current treatment strategy, with cases.</b>	<b>Derek Grose</b>
<b>1530-1545</b>	<b>Close</b>	<b>Dr Robin Reid</b>

18 questionnaires were returned (60%) and 100% would attend a future AGM. More details are available from the Network Manager.

# Work Plan for 2010-2011

Ref.	Objective (What is the Goal?)	Priority Ranking High (H) Medium (M) Low (L)	Deliverables / Outcomes (Tangible / Measurable benefits)	Planned Timescales		Alignment with National/ Regional Strategies (Reference to Cancer Strategies /LDW etc)
				Start Date	End Date	
1	In collaboration with the Health Boards establish Auditors to enable prospective audit	H	Auditors assigned to sarcoma and clinical data added to ECASE	1/4/2010	31/3/2011	"Ensure by 2010, all tumour networks take part in national audit" P90
2	Undertake preparatory work to identify top 10 QPI's and develop initial list of QPI's to report against <i>(adopt methodology currently being developed by National Cancer Quality Steering group)</i>	H	Top 10 sarcoma QPI's defined and able to be measured	1/4/2010	31/3/2011	"Ensure by 2010, all tumour networks take part in national audit" P90
3	In collaboration with the Health Boards expand Clinical Nurse Specialists to Aberdeen, Dundee and Inverness Centres	H	Clinical Nurse Specialist in each Centre or plans in place for their establishment	1/4/2010	31/3/2011	"Equitable Care" P87
4	In collaboration with the Scottish Cancer Research Network ensure access to trials	H	"to ensure recruitment continues to exceed 13.9%" P67	1/4/2010	31/3/2011	Support SCRN as required
5	Support the service to take forward implementation of the recommendations of the national option appraisal (if accepted for implementation)	H	Implement outcome(s) of the Option Appraisal	1/4/2010	31/3/2011	NSAG decision
6	Undertake an in-depth critical review of MDT practices across the region to optimise efficiency and effectiveness.	H	Clear action plans developed to address issues raised within the specified timescale	1/4/2010	31/3/2011	"Seek ways to improve and speed up communication to patients and between professional disciplines and service" P79

# Finance

The network is operating within budget.