



**NATIONAL MANAGED CLINICAL NETWORK
FOR SARCOMA**

ANNUAL REPORT 2010/11

Scottish

Sarcoma



Network

Hosted by West of Scotland Cancer Network (WoSCAN)

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Executive summary

20 Nurses successfully completed the first sarcoma nursing module at the University of the West of Scotland, and the second cohort is planned for September 2011.

The major milestone of auditing the Scottish Sarcoma MDT from July 2009 to July 2010 was achieved.

The Option Appraisal of the Scottish Musculoskeletal Sarcoma Surgical Service and the Scottish Sarcoma Network was completed.

In collaboration with the Scottish Cancer Research Network it was confirmed that 17% of patients participated in clinical trials during 2009-10, the first time this has been reported through the Network.

Board-level patient pathways have been trialled successfully in NHS Forth Valley and will be rolled out in 2011-12.

NHS Highland have assigned an Audit Facilitator to capture sarcoma patients data into e-CASE, the first Board to do so, and patients diagnosed in 2010 are being captured.

Introduction

Sarcomas (bone cancer and soft tissue sarcomas (including GastroIntestinal Stromal Tumours (GISTs)) have an incidence of approximately 0.8/100,000 and account for less than 1% of all tumours. Most recent *Cancer in Scotland* statistics published in October 2010 report that the lifetime risk of developing sarcoma is 1 in 420 and that sarcomas have increased by 7.8% for males and 30.5% for females between 1998 and 2008. The summary of the Scottish Sarcoma MDT analysis for July 2009 to July 2010 is appendix 3. The MDT is working with the other MDTs across Scotland (that care for patients with sarcoma) so all sarcoma patients are accounted for.

The Scottish Sarcoma Network (SSN) 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 SSN National Managed Clinical Network Manager. Lynsey Connor provides administrative support and Keith Bryce/Douglas Grattan provides web site support from the West of Scotland Cancer Network (WoSCAN). George Violaris/Cindy Glass is our Patient Participant. The website is currently being upgraded (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, 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 2011-12 work plan is being finalised and the objectives are;

1. Optimise effectiveness and efficiency of Multi-Disciplinary Team (MDT) review meetings by implementing agreed actions to address gaps and deficiencies identified during the 2010/11 WoS regional review
2. Support development and implementation of approval process for sarcoma Clinical Management Guideline (CMG)
3. Complete review of evidenced based guidelines for follow up of all cancer patients in Scotland
4. Support delivery of the national clinical audit work programme for 2011/12
5. Use the Forth Valley pathway to guide the other 13 Boards in creating and implementing the corresponding Board specific pathways for sarcoma patients

Network governance

Mr Sam Patton, Consultant Surgeon, Department of Orthopaedics, NHS Lothian is the National Clinical Lead for the Network.

The Network holds quarterly meetings to review progress and educate and one of these meetings is also the annual general meeting. The constitution is being 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, Prof Donald Salter for Pathology, Mr Mike Jane for Surgery, 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, Mr Ashish Mahendra for QPIs, Dawn Currie for Nursing and Allied Health Professionals and Pathways, and Lindsay Campbell for the Website.

The Network works closely with the British Sarcoma Group and our international colleagues.

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. The Regional Cancer Networks are governed by the Regional Planning Groups.

Detailed description of progress over the reporting period

Objective	Planned start/ end dates	Description of progress towards meeting objective	Outcome / evidence	RAG status
EFFECTIVE: Providing services based on scientific knowledge				
Support the service to take forward implementation of the recommendations of the national option appraisal (if accepted for implementation)	Apr 2010 / Mar 2011	The Scottish Musculoskeletal Sarcoma Surgical Service was de-designated on 1 st April 2011. It is proposed that the Scottish MDT Coordinator is transferred to the Scottish Sarcoma Network from NHS Greater Glasgow and Clyde. This has still to be formally agreed and the change implemented. The Regional Planning Groups are agreeing 2011-12 funding of this specialist surgery, using a regional commissioning model.	MSN de-designated and MCN strengthened.	
In collaboration with the Scottish Cancer Research Network ensure access to trials	Apr 2010 / Mar 2011	17% of patients with sarcoma participated in clinical trials during 2009-10.	As reported by the Scottish Cancer Research Network.	
EFFICIENT: Avoiding waste, including waste of equipment, supplies, ideas, and energy				
Undertake an in-depth critical review of MDT practices across the region to optimise efficiency and effectiveness	Apr 2010 / Mar 2011	Scottish MDT operational policy implemented and gaps identified. Gaps will be addressed in 2011-12.	Weekly MDT managing increasing numbers of patients between 2009 and 2010.	
EQUITABLE: Providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location or socio-economic status				
In collaboration with the Health Boards establish Auditors to enable prospective audit	Apr 2010 / Mar 2011	NHS Highland Audit Facilitator started 1 st April 2011 and is capturing 2010 data. The other 13 Boards are being progressed in 2011-12. The Scottish Sarcoma MDT Coordinator provided MDT analysis of July 2009 to July 2010 and is currently analysing 2010.	Patient data being captured into e-CASE, starting from 2010.	

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Objective	Planned start/ end dates	Description of progress towards meeting objective	Outcome / evidence	RAG status
Undertake preparatory work to identify top 10 QPI's and develop initial list of QPI's to report against	Apr 2010 / Mar 2011	Sarcoma QPIs are sequenced for 2012-13. 2010 audit will be analysed using measurability criteria being led by Mr Ashish Mahendra.	QPI sequence developed by National Cancer Quality Sub-Group. Measurability criteria being facilitated by WoSCAN Information Team.	
In collaboration with the Health Boards expand Clinical Nurse Specialists to Aberdeen, Dundee and Inverness Centres	Apr 2010 / Mar 2011	NHS Grampian and Tayside Nurses have successfully completed the sarcoma nursing module at the University of the West of Scotland (UWS). NHS Highland is working towards this but not possible in 2010-11 or 2011-12.	NHS Highland will advise if possible in 2012-13.	

The Option Appraisal of the Scottish Musculoskeletal Sarcoma Surgical Service and the Scottish Sarcoma Network was completed and the National Service de-designated on 1st April 2011, with this specialist surgery being planned through the Regional Planning Groups. The Scottish MDT Coordinator and Scottish Sarcoma Network have been retained and remain centrally funded. NHS Highland started prospective auditing of sarcoma patients diagnosed in 2010 and the Audit Facilitator is working closely with the Scottish MDT Coordinator so 2010 audit can be analysed.

The Quality Performance Indicators (QPIs) national programme has sequenced sarcoma into 2012-13 so for the 2010 audit analysis Mr Ashish Mahendra is leading the creation of sarcoma measurability criteria with support from the WoSCAN Information Team.

20 Nurses successfully completed the first sarcoma Nursing Module at the University of the West of Scotland and the next cohort is being planned for September 2011. NHS Grampian and NHS Tayside are continuing to develop their Nurses but NHS Highland are waiting until 2012-13 before deciding the next step.

The Scottish Cancer Research Network reported that 17% of patients with sarcoma participated in clinical trials in 2009-10. This was an excellent result and the Network is aiming to maintain this. The 2010-11 report is due in June 2011.

The MDT review has yielded an MDT operational policy for the Scottish MDT. The identified gaps in the MDT are being tackled through the WoSCAN MDT improvement initiative.

North, South East and West of Scotland Cancer Networks

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The Network has organised 4 education days per year to enable participation by as many members as possible on each day. The 2010 Annual General Meeting was held in Aberdeen and included the presentation of MDT audit analysis for July 2009 to July 2010. The 2011 AGM will be in Edinburgh.

The waiting times for 30 patients were sampled and 86.7% of patients started their treatment within 31 days of deciding to be treated. The National Cancer Waiting Times Group is deciding how the waiting times for sarcoma patients will be measured going forward.

NHS Forth Valley has developed a sarcoma patient pathway and this is being used as the template for the other 13 Boards to develop their sarcoma patient pathway. This is being focussed through the Lead Cancer Nurses Group along with the HPB and brain/CNS patient pathways.

UK guidelines for bone cancer, soft tissue sarcoma and Gastrointestinal Stromal Tumours (GISTs) were published during 2010 through the British Sarcoma Group.

The first meeting of the Scottish Sarcoma Patient Support Group took place at Maggie's Centre in Glasgow on Wednesday, 16th March 2011 from 2-4PM. The group will continue to meet on the third Wednesday of the month for at least 6 months and then decide the next step.

Edinburgh performed the first computer assisted sarcoma surgery in the UK.

Appendix 1: Network membership



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Directory\MCNs - Disc

Appendix 2: Finance

National Clinical Lead is funded for 1 session 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: 7/2009-7/2010 MDT analysis summary

**Total No. of cases Discussed by
MDT (July 09 – July 10)**

- Glasgow – 335
- Edinburgh - 197
- Aberdeen – 72
- Dundee – 13
- Inverness – 9
- **Total No. of cases discussed = 626**

**No. of New Sarcomas discussed at
MDT (July 09 – July 10)**

- Glasgow – 94 (GIST = 18)
- Edinburgh – 73 (GIST = 1)
- Aberdeen – 20 (GIST = 4)
- Dundee – 7 (GIST = 0)
- Inverness – 3 (GIST = 2)
- **Total No. of new Sarcoma's = 197 (+GIST = 218)**

New Sarcoma's by diagnosis (PAN Scotland)

- Leiomyosarcoma – 36
- GIST - 25
- Chondrosarcoma – 16
- Sarcoma – 15
- Liposarcoma – 14
- Myxofibrosarcoma - 13
- Angiosarcoma - 12
- E-wings – 11
- Osteosarcoma 11
- Myxoid Liposarcoma – 10
- Pleomorphic Sarcoma – 8
- Rhabdomyosarcoma – 4
- Alveolar Rhabdomyosarcoma – 4
- Dermatofibrosarcoma – 4
- Synovial Sarcoma– 4
- Adamantinoma - 3
- Fibrosarcoma – 3
- Spindle Cell Sarcoma – 3
- Pleomorphic Liposarcoma - 3
- Histiocytic Sarcoma – 2
- MPNST – 2
- Chondroblastic Osteosarcoma– 2
- Hemangiopericytoma – 2
- Fibromyxoid Sarcoma – 2
- Kaposi Sarcoma – 1
- Biphasic Synovial Sarcoma – 1
- Carcinosarcoma – 1
- Epithelioid Sarcoma – 1
- MFH – 1
- Myxoinflammatory Fibroblastic Sarcoma – 1
- Myxoid Sarcoma – 1
- Sarcomatous transformation of Teratoma – 1
- Embryonal Rhabdomyosarcoma – 1
- Extraskelatal Myxoid Chondrosarcoma – 1
- Alveolar Soft Part Sarcoma – 1
- Epithelioid hemangioendothelioma - 1

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