

**North, South East and West of Scotland  
Cancer Networks**

**Sarcoma  
National Managed Clinical Network**



# **Activity Report**

**April 2012 – March 2013**

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## Executive Summary

### Introduction

The Sarcoma National Managed Clinical Network (NMCN) continues to support and develop the clinical service for approximately 300 new sarcoma patients each year. Management of this patient group relies heavily on close collaboration between General Practitioners (GPs), Radiologists, Pathologists, Surgeons, Oncologists, Clinical Nurse Specialists, District Nurses and Allied Health Professionals. The NMCN continues to benefit from enthusiastic engagement from a range of healthcare professionals, administrators and managers across Scotland.

There were 286 new diagnoses of sarcoma recorded by the Scottish sarcoma MDT during 2011 and 52 referrals for patients living with their sarcoma. Sarcoma is predominantly an older person's cancer with approximately 130 over 65's diagnosed. Approximately 20 children and young people (under 25) were diagnosed and the NMCN collaborates closely with the Scottish Children and Young People with Cancer Managed Service Network.

Prospective clinical audit is not operational yet but Quality Performance Indicators (QPIs) are in development and it is expected that prospective clinical audit will start in 2014. NHS Boards will be required to align clinical audit resource to support data capture from that time.

### NMCN Objectives

The sarcoma NMCN has made progress and delivered a number of key objectives which include:

- Multi-disciplinary Team Working: The national priority is to ensure all cancer patients are efficiently managed by a multi-disciplinary team (MDT). The Scottish sarcoma MDT is well established with good representation from multiple disciplines and administrative groups, apart from Clinical Audit (which is expected to start in 2014).
- Clinical Management Guideline (CMG) Review: The review process for the bone and soft tissue sarcoma CMGs was completed in line with the agreed governance framework. The review process for the Gastrointestinal Stromal Tumour (GIST) CMG is in progress and should be completed by summer 2013.
- Implementation of National Follow Up Consensus Guidelines: Following NMCN wide engagement, the future model for follow up was presented to and ratified by the Regional Cancer Clinical Leads Groups and the Regional Cancer Advisory Groups in April 2012 for bone and soft tissue and October 2012 for GIST. Implementation is currently being assessed across the partner Boards.
- National Clinical Audit: The 2011 analysis of the Scottish Sarcoma MDT activity data was presented at the December 2012 education event and detailed 286 new diagnoses and 56 ongoing cases. Continual improvements were agreed and implemented on the [website](#).
- NHS Board-level Sarcoma Patient Pathway: NHS Forth Valley audited their pathway and implemented an improvement. NHS Tayside started operating their pathway in July 2012 and has piloted awareness training for General Practitioners (GPs) and Physiotherapists.
- Enhanced Recovery: The Surgical Lead has reviewed the enhanced recovery developments made in other cancers and is planning sarcoma developments during 2013/14.
- Quality Performance Indicator (QPI) Development: NMCN members are well represented in this national programme and sarcoma QPIs are being developed, with expected implementation in 2014.
- 14% of patients participated in clinical trials in 2011/12, compared to 16% in 2010/11 and 17% in 2009/10.
- The Scottish Bone Tumour Registry celebrated its 50th anniversary with a special event on 7th September 2012 attended by 57 delegates from Charities, external companies, NHS England and Scotland. On average 100 patients per year have been registered.

### **Key Priority Areas for the NMCN in the next 12 months**

The NMCN work plan has been developed with an emphasis on identifying outcomes that improve the quality of patient care and overall efficiency. Below are the objectives to be progressed in the coming year:

- Complete the development of sarcoma QPIs and prepare for data capture by the 14 NHS Boards from 2014;
- Develop enhanced recovery techniques for sarcoma patients across Scotland;
- Analyse the Scottish Sarcoma MDT activity data for 2012 and continually improve the quality of sarcoma care in Scotland and the operation of the Scottish sarcoma MDT;
- Develop the service map for sarcoma care across Scotland;
- Complete the review of the GIST CMG;
- Complete the development of NHS Board-level sarcoma patient pathways;
- Support NHS inform with the development of bone, soft tissue and GIST information for the people of Scotland; and
- Develop the Positron Emitting Tomography-Computer Tomography (PET-CT) protocols for sarcoma.

## 1. Introduction

The sarcoma national managed clinical network (NMCN) was established in 2004 as a means of delivering equitable high quality clinical care to all sarcoma patients across Scotland.

The Sarcoma National Managed Clinical Network (NMCN) continues to support and develop the clinical service for approximately 300 new sarcoma patients each year. Management of this patient group relies heavily on close collaboration between General Practitioners (GPs), Radiologists, Pathologists, Surgeons, Oncologists, Clinical Nurse Specialists, District Nurses and Allied Health Professionals. The NMCN continues to benefit from enthusiastic engagement from a range of healthcare professionals, administrators and managers across Scotland.

Research by the Network has indicated a GP will care for 1 sarcoma patient in 30 years but care for 3000 patients who present with symptoms indicative of sarcoma. Bone and soft tissue sarcoma patients present to a GP who will refer them to a local Orthopaedic Surgeon for investigation, Gastrointestinal Stromal Tumours (GISTs) to Upper Gastrointestinal services, some to Professionals as indicated by where the sarcoma is developing (e.g. Gynaecology or Ear, Nose and Throat (ENT)), and a few patients will present to the Emergency Department. If the local Radiologist is suspicious of sarcoma they will contact their colleague in the specialist centre to confirm the diagnosis and refer the patient to the multi-disciplinary team (MDT). If the local Pathologist diagnoses sarcoma they will contact their colleague in the specialist centre to confirm and refer the patient to the MDT. There are 5 sarcoma specialist centres in Scotland (Aberdeen, Dundee, Edinburgh, Glasgow and Inverness) with 1 Scottish sarcoma MDT for bone and soft tissue. GIST patients are managed through the Scottish sarcoma MDT in the West of Scotland (WoS) and through the Upper Gastrointestinal MDTs in the North (NoS) and South East of Scotland (SEoS). Small numbers of sarcoma patients are managed through other MDTs (e.g. Gynaecology and Head and Neck). All MDTs work together and specialist surgery is performed in Aberdeen, Edinburgh and Glasgow.

There were 286 new diagnoses of sarcoma recorded by the Scottish sarcoma MDT during 2011 and 52 referrals for patients living with their sarcoma. Sarcoma is predominantly an older person's cancer with approximately 130 over 65's diagnosed. Approximately 20 children and young people (under 25) were diagnosed and the NMCN collaborates closely with the Scottish Children and Young People with Cancer Managed Service Network.

Prospective clinical audit is not operational yet but Quality Performance Indicators (QPIs) are in development and it is expected that prospective clinical audit will start in 2014. NHS Boards will be required to align clinical audit resource to support data capture from that time.

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

The purpose of this document is to report the sarcoma NMCN activities in respect of:

- Performance against agreed objectives;
- Outcomes achieved;
- Challenges encountered and actions taken to remedy defined issues; and
- Update on progress of actions identified from the analysis of the Scottish sarcoma MDT.

### **NMCN Governance**

The Network meets three times per annum with representation from charities, external companies and NHS Boards and all relevant specialities involved in the management of sarcoma.

The Network is consulted between meetings as required by the lead and manager. Dr Jeff White has now led the NMCN for over a year. The membership of the Network is refreshed regularly.

## **2. NMCN Workplan and Activities (reporting period 04/2012 to 03/2013)**

### **2.1 Core Objectives**

#### **Multi-disciplinary Team (MDT) Working**

The Scottish sarcoma MDT continues to operate as effectively and efficiently as possible, given the lack of Scotland-wide eHealth solutions to enable real time communications and the single-handed MDT Coordinator. Sarcoma patients managed by other MDTs are given specialised advice when requested. Ewing's sarcoma patients are also discussed in the Ewing's sarcoma MDT in England (along with Northern Irish and Welsh patients) and ongoing participation in this MDT is being progressed from an informal to a formal basis through National Services Division (NSD). Regional or national eHealth solutions would enable further improvement in real time communications while the other members of the MDT cover for the MDT Coordinator as best they can.

Vacancies due to retirements of Oncologists in Aberdeen and Edinburgh have been covered by their colleagues. NHS Lothian has appointed an Oncologist and NHS Grampian are recruiting as soon as possible.

The Glasgow Pathology team is back to its full complement and Paediatric Pathologists are also being included in the pathology guideline to maximise the number of Pathologists reporting sarcomas in Scotland. Paediatric Surgeons and Oncologists already participate in the Scottish sarcoma MDT.

#### **Implementation of National Follow Up Consensus Guidelines**

The follow up guidelines for bone, soft tissue and GIST were updated and are available on the [WoSCAN intranet website](#). The updated follow up guidelines are included in the updated Clinical Management Guidelines (CMGs). Sarcoma patients at higher risk are being followed up more frequently while all patients are being discharged from follow up after 10 years, if possible, giving an overall reduction in the follow up care.

#### **National Clinical Audit Programme**

Prospective clinical audit is not operational yet but the NMCN was able to analyse the Scottish sarcoma MDT activity data for patients referred during 2011. 286 new (256 bone/soft tissue and 30 GIST) and 52 existing (47 and 5) patients were referred during 2011, with 535 cases discussed in total. Leiomyosarcoma was the most common morphology (33) of the 30 different morphologies diagnosed. All 14 NHS Boards had patients discussed at the MDT and the age profile is predominantly over 65. Approximately 20 children and young people (under 25) were diagnosed and the NMCN collaborates closely with Children and Young people with Cancer Managed Service Network.

#### **Application of Enhanced Recovery Techniques**

Mr Ashish Mahendra, the lead for surgery, has reviewed the enhanced recovery progress in other cancers and confirmed sarcoma will benefit from sharing this good practice. Sarcoma enhanced recovery will be developed in 2013/14, starting with the Glasgow centre and then sharing with the Aberdeen and Edinburgh centres.

#### **Service Mapping**

A pilot exercise was completed in the development of a West of Scotland Upper Gastrointestinal cancer service map which details the points of service delivery and the connections between them. The sarcoma service map for Scotland will be developed in 2013/14.

## 2.2 Individual NMCN Objectives

### National Quality Performance Indicator (QPI) Development Programme

The development of sarcoma QPIs is in progress through the national programme and is expected to be completed by the middle of 2014. This will enable the NHS Boards to start capturing clinical audit data from the middle of 2014.

### Review of Bone, Soft Tissue and Gastrointestinal Stromal Tumour Clinical Management Guidelines (CMGs)

CMGs ensure the safe and equitable management of patients across Scotland whilst optimising the effectiveness of treatment and care. The review of bone and soft tissue CMGs was led by oncologist Dr Fiona Cowie while the review of the GIST CMG was led by oncologist Dr Lucy Wall. The review process progressed well with input from allied health professionals, nursing, oncology, pharmacy, radiology, pathology and surgical colleagues. The bone and soft tissue CMGs received Prescribing Advisory Sub Group (PASG) chair's approval in October 2012 and are published on the West of Scotland Cancer Network (WoSCAN) [intranet site](#). The GIST CMG has been approved by the Prescribing Advisory Sub Group and is being submitted to the Area Drug and Therapeutic Committees for approval, and is expected to be published on the site in summer 2013.

### NHS Board-level Sarcoma Patient Pathways

NHS Forth Valley audited its pathway and to improve real time communications the MDT Coordinator will email MDT outcomes for Forth Valley patients to the Forth Valley Lead Cancer Team NHSmail box.

NHS Tayside started operating its pathway in July 2012 and has successfully piloted awareness/education of GPs and Physiotherapists. Bone and soft tissue posters have been updated with the Surgeon or Oncologist to contact along with the Scottish sarcoma MDT NHSmail box to email the referral to. The [referral proforma](#) is available on the NMCN website.

NHS Fife and NHS Greater Glasgow and Clyde are drafting their pathways. The other NHS Board patient pathways will be completed by March 2014.

## 2.3 Other NMCN Activities

### Patient Information

Patient information is being transitioned to NHS inform, starting with bone and soft tissue, and is being led by the National Clinical Lead with the support of the Clinical Nurse Specialists and Sarcoma UK.

### Education

The NMCN continues to support three education days per year, which are well attended by members, and include the work of the Steering Group, subgroups, research, audit and education.

- The autumn education day was devoted to the 50<sup>th</sup> anniversary celebration of the Scottish Bone Tumour Registry (SBTR), with 57 delegates from Charities, external companies and staff from NHS England and Scotland.
- The 2013 British Sarcoma Group (BSG) conference was attended by 3 Scottish members; with Dr Jeff White participating in the “for” team in the debate “This house believes all non surgical oncology treatment for soft tissues sarcoma (STS) should be delivered in a centre that hosts a sarcoma MDT”, Dawn Currie chairing the session for Nurses on GIST management, Dawn Currie representing Scotland on the BSG Executive, 2 posters displayed and 1 oral presentation given.
- The University of the West of Scotland offered the sarcoma nursing module but it was unable to be run due to insufficient numbers, and is the second time this has happened.

**Retirements**

Two Oncologists, one in the Aberdeen and one in the Edinburgh centre, retired and their colleagues are covering for them while their replacements are recruited. This is challenging, with Edinburgh failing to recruit in the first round and recruiting in the second round.

The Aberdeen Oncologist was also the sarcoma advisor to the Scottish Medicines Consortium and an Edinburgh Oncologist is their replacement.

**Clinical Trials**

In collaboration with the Scottish Cancer Research Network 14% of patients participated in clinical trials during 2011/12. This compares with 16% in 2010/11 and 17% in 2009/10.

The lead for the Edinburgh centre has secured National Research Ethics Service funding and is working with the Chief Scientist Office to streamline approval of clinical trials for all 5 centres.

**Charities**

Sarcoma UK are the major charity in Scotland and are working with the 5 centres and Maggie's Cancer Caring Centres to realise support groups for sarcoma patients and their carers, including a trial of phone conferencing between the Scottish Maggie's centres. Sarcoma UK has also developed phone and online support for patients and carers. Sarcoma UK awarded 4 research grants, with 2 going to Scotland (Aberdeen for rhabdomyosarcoma and Edinburgh for drug targeting).



### 3. Quality Assurance / Service Development and Improvement

The primary function of the NMCN is to facilitate continuous clinical service improvement, supporting delivery of high-quality, equitable treatment and care to patients with sarcoma in the Scotland. The NMCN prospective clinical audit programme will start when the sarcoma quality performance indicators are implemented (expected in the middle of 2014). Until then the Scottish sarcoma MDT activity data is being utilised.

The Scottish sarcoma MDT Coordinator is providing Clinicians with MDT activity data to support further clinical audit analysis and the latest is the [July 2009 to June 2010 analysis comparing deprivation with the size of soft tissue tumour](#) and will be presented at one of the 2013 education days.

In addition the Boards are provided with MDT analysis to utilise for their sarcoma patient pathway, and to plan their capacity for sarcoma care.

During 2011, 570 patients were discussed, comprised of 535 bone/soft tissue sarcomas and 35 GISTs. 286 new (256 bone/soft tissue and 30 GIST) and 52 existing (47 and 5) patients were referred. Leiomyosarcoma was the most common morphology (33) of the 30 different morphologies diagnosed. All 14 NHS Boards had patients discussed at the MDT and the age profile is predominantly over 65, with approximately 20 children and young people (under 25 years old) diagnosed.

#### Service Development and Improvements

The 14 NHS Board-level sarcoma patient pathways are being utilised to integrate the following service developments or improvements.

- Referral posters (bone and soft tissue) have been updated and circulated to General Practitioners (GPs), Community Pharmacies and Physiotherapists (piloted in NHS Tayside).
- The Scottish Bone Tumour Registry is providing awareness training to Radiologists (piloted in January 2013).
- The Scottish Sarcoma Network website provides the [patient referral template](#) and [Scottish sarcoma MDT NHSmail box](#) to email the referral to.
- The Scottish sarcoma MDT NHSmail box emails the outcomes of the weekly MDT to Referring Clinicians and NHS Board NHSmail boxes within 2 days, including the planned follow up.

#### **4. Key Priority Areas for the NMCN in the next 12 months**

The NMCN work plan has been developed with an emphasis on identifying outcomes that improve the quality of patient care and overall efficiency. Below are the objectives to be progressed in the coming year:

- Support the development of the sarcoma quality performance indicators during 2013 and the start of data capture in 2014;
- Continue the development of enhanced recovery for sarcoma surgery;
- Analyse the 2012 Scottish sarcoma MDT activity data to inform and drive service improvement and improve the operation of the Scottish sarcoma MDT;
- Develop a sarcoma service map of Scotland;
- Complete the review of the GIST clinical management guideline
- Complete the development of NHS Board-level sarcoma patient pathways
- Support the development of bone, soft tissue and GIST patient information in NHS inform; and
- Develop positron emitting tomography – computerised tomography (PET-CT) protocols for GIST and Ewing's sarcoma.

The work plan is published on the [website](#).

#### **5. Conclusion**

This has been a productive year and the continued support of patients, carers, charities, external companies, universities, local government and the NHS is essential in order for the NMCN to achieve their work plan objectives. Over the last 12 months, the NMCN has continued to work closely with local, regional and national colleagues across Scotland to support the MDT. The NMCN has updated the bone and soft tissue referral guidelines and is raising awareness among GPs, Community Pharmacists and Physiotherapists. The NMCN has completed the review of the bone and soft tissue CMGs and is completing the review of the GIST CMG. The NMCN has regularly reviewed the implementation of the national consensus guidelines for follow up of sarcoma, which indicates that the guidelines have been accepted and utilised. These developments are being integrated through the NHS Board-level sarcoma patient pathways and will continue to drive consistency of practice and provide improved care for patients with sarcoma in Scotland.

Looking ahead the membership welcomes the opportunity to work with the Detecting Cancer Early programme to detect sarcomas as early as possible; work with the Enhanced Recovery After Surgery programme to enhance recovery after sarcoma surgery; work with the Systemic Anti-Cancer Therapy and Radiotherapy programme boards on developments in sarcoma systemic anti-cancer therapy and radiotherapy; work with the Transforming Care After Treatment programme for sarcoma patients and carers; and the start of prospective clinical audit of sarcoma across Scotland through the quality performance indicators.

## **Acknowledgement**

This report represents the achievements and challenges progressed across the fourteen partner NHS Boards of the North, South East and West of Scotland Cancer Networks:

NHS Ayrshire & Arran  
NHS Borders  
NHS Dumfries & Galloway  
NHS Forth Valley  
NHS Fife  
NHS Grampian  
NHS Greater Glasgow and Clyde  
NHS Highland  
NHS Lanarkshire  
NHS Lothian  
NHS Orkney  
NHS Tayside  
NHS Shetland  
NHS Western Isles

We would like to thank all members and active participants in the cancer network for their continued support of the National Managed Clinical Network, without their efforts this level of progress would not be possible.

We would also like to thank the Golden Jubilee National Hospital, the Scottish Children and Young people with Cancer Managed Service Network, the Scottish Cancer Research Network, the Scottish Primary Care Cancer Group, the Scottish Managed Diagnostic Imaging Clinical Network, the Scottish Pathology Network and the Scottish Imaging Network for their support and collaboration.