

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

**Sarcoma
National Managed Clinical Network**



Activity Report

April 2013 – March 2014

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Executive Summary

Introduction

The purpose of this document is to report the Sarcoma National Managed Clinical Network (NMCN) activities in respect of:

- Performance against agreed work plan objectives;
- Outcomes achieved; and
- Challenges encountered and actions taken to remedy defined issues.

This report covers the activity of the network between April 2013 and March 2014. It also reports on service developments and improvements based on the analysis of 2012 activity data captured by the multi-disciplinary team, as well as looking forward from April 2014 to March 2015.

NMCN Objectives

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

- **National Cancer Quality Performance Indicators (QPI)**
The sarcoma QPIs have been implemented for all patients diagnosed with sarcoma on, or after, 1st April 2014. The sarcoma dataset and measurability specification, developed as part of the QPI development process, facilitates consistent measurement and comparative reporting of QPIs across Scotland.
- **Enhanced Recover After Surgery**
Enhanced recovery after surgery development in the Glasgow centre is concentrating on rehabilitation for patients with bone tumour.
- **Multi-disciplinary Team (MDT) Working**
The national priority is to ensure all cancer patients are efficiently managed by a MDT. The Scottish sarcoma MDT is well established with good representation from multiple disciplines and administrative groups, and clinical audit starting in April 2014.
- **Service Mapping**
Completion of a West of Scotland service map for sarcoma service provision, detailing the points of service provision and the connections between them.
- **Guideline and Protocol Development and Review**
The updating of clinical management guidelines (CMGs) is a core component of NMCN activity and following approval the revised gastrointestinal stromal tumour CMG has been published.

The sarcoma protocol for Positron Emission Tomography (PET) has been drafted and is being reviewed by the Scottish PET group.

- **NHS Board-level Sarcoma Patient Pathways**
NHS Forth Valley pathway has operated for 3 years and is being reviewed, and the NHS Greater Glasgow and Clyde pathway is being finalised (including the West of Scotland musculoskeletal oncology referral pathway).
- **Patient Information**
The generic information is available on [NHS inform](#) and the tailored information is being developed in partnership with the UK sarcoma Charities.

- **National Clinical Audit**

The 2012 analysis of the Scottish Sarcoma MDT activity data was presented at the December 2013 education event and detailed 255 new diagnoses and 38 ongoing cases.

An audit of performance against waiting times for patients with primary sarcomas is being undertaken by the 14 NHS Boards during 2014.

- **Clinical Trials**

22% of patients participated in clinical trials during 2012-13 (14% during 2011-12, 16% during 2010-11 and 17% during 2009-10).

- **The Scottish Bone Tumour Registry**

The Scottish Bone Tumour Registry is now available in Aberdeen (and Inverness), Dundee and Edinburgh as well as Glasgow.

- **Education**

During Autumn/Winter of 2013/14, the Network hosted three (all from West of Scotland Deanery) of the top 5 performing students from Sarcoma UK's junior doctor and medical students UK wide education initiative.

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. A number of objectives will be carried over from this year as enhanced recovery after surgery, MDT working, guideline and protocol development/review, patient pathways and patient information continue as priorities in the work plan. A new NMCN objective to be progressed in the coming year is supporting the Children and Young People with Cancer managed service network with a national bid to the Transforming Care After Treatment programme for patient end of treatment summaries.

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, covering a population of 5.295 million.

The sarcoma 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. Neurology or Dermatology), 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. Neuro-Oncology and Skin). All MDTs work together and specialist surgery is performed in Aberdeen, Edinburgh and Glasgow.

There were 255 new diagnoses of sarcoma recorded by the Scottish sarcoma MDT during 2012 and 38 referrals for patients living with their sarcoma. Of the new diagnoses 232 were bone or soft tissue and 23 were GIST, and of the existing diagnoses 33 were bone or soft tissue and 5 were GIST.

Prospective clinical audit is operational from April 2014 with the implementation of the Quality Performance Indicators (QPIs). The waiting times of sarcoma patients are being audited during the first and last 3 months of 2014.

The NMCN website is 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, universities and NHS Boards and all relevant specialities involved in the management of sarcoma. The Network is consulted between meetings as required by the Clinical Lead and Network Manager. Dr Jeff White has now led the NMCN for over 2 years. The membership of the Network is refreshed regularly.

2. NMCN Workplan and Activities (reporting period 04/2013 to 03/2014)

2.1 Core Objectives

National Clinical Audit Programme

Prospective clinical audit is operational as of April 2014 and the NMCN was able to analyse the Scottish sarcoma MDT activity data for patients referred during 2012. 255 new (232 bone/soft tissue and 23 GIST) and 38 existing (33 bone/soft tissue and 5 GIST) patients were referred during 2012, with 492 cases discussed in total. Leiomyosarcoma was the most common morphology (29) of the 36 different morphologies diagnosed. All 14 NHS Boards had patients discussed at the MDT.

An audit of performance against waiting times for patients with primary sarcomas is being undertaken by the 14 NHS Boards during 2014.

Enhanced Recovery After Surgery

Mr Ashish Mahendra in the Glasgow centre is developing a pathway for patients with bone tumour that includes their rehabilitation via a local hospital to home.

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 and the reliability of the national video conferencing service. The MDT Coordinator was replaced and now has cover for leave. The MDT referral and outcome proforma is being updated to include waiting time and prospective clinical audit data. Sarcoma patients managed by other MDTs are given specialised advice when requested. Ewing's sarcoma patients are also discussed in the UK Ewing's sarcoma MDT.

Vacancies due to extended leave and retirement of Clinical Oncologists in Aberdeen and Inverness respectively are being covered by their colleagues in Dundee, Edinburgh and Glasgow.

Service Mapping

A high level map of sarcoma service provision was collated for the 4 WoS NHS Boards. This detailed the aspects of the service provided by each hospital, identifying connections between them and highlighting areas of shared service. The mapped information was included in a consolidated regional report which was presented to the Regional Cancer Clinical Leads Group in October 2013 and shared with WoS Board Cancer Managers in December 2013. The service map will be updated annually to maintain a baseline position, and this high level summary information has been utilised as an internal planning resource. The map will be expanded to the NoS and SEoS during 2014/15.

2.2 Individual NMCN Objectives

National Quality Performance Indicator (QPI) Development Programme

The implementation of sarcoma QPIs through the national programme is April 2014, with the 14 NHS Boards receiving the weekly outcomes of the Scottish sarcoma MDT to enable the patient data to be captured.

Guideline and Protocol Development and Review

Development and review of clinical management guidelines (CMGs) is a core component of NMCN activity. During 2013 the gastrointestinal stromal tumour CMG was revised and approved by the Regional Prescribing Advisory Group and local Area Drug and Therapeutics Committees. All CMGs can be accessed directly from the intranet site (www.intranet.woscan.scot.nhs.uk) or via the chemotherapy electronic prescribing and administration system (CEPAS).

The Scottish Positron Emission Tomography (PET) group requested a sarcoma protocol and that was drafted and submitted for their approval.

NHS Board-level Sarcoma Patient Pathways

NHS Forth Valley is currently reviewing their patient pathway which has been operational for 3 years. The NHS Greater Glasgow and Clyde pathway is being finalised (including the West of Scotland musculoskeletal oncology referral pathway); thereafter the pathway will be adapted for use by NHS Ayrshire & Arran and NHS Lanarkshire, with NHS Dumfries & Galloway drafting their own pathway.

Patient Information

The generic information is available in [NHS inform](#), split into bone, soft tissue and GIST. The tailored information is being created with the 3 charities (Bone Cancer Research Trust, Sarcoma UK and GIST Support UK).

2.3 Other NMCN Activities

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.

- Summer education day included the review of the impact of the revised bone and soft tissue GP referral posters that had been electronically circulated to all GPs in Scotland. Through the Detect Cancer Early programme the sarcoma referral guidelines are being reviewed during 2014/15.
- Autumn education day included a presentation from the 5th year Medical Student who conducted his elective in the Glasgow centre, and the third survey of cancer patients in England was also reviewed with support from Sarcoma UK.
- Winter education day included a presentation on the national specialist prosthetics service delivered from Glasgow and Edinburgh, and the first analysis of survival in the UK.
- The 2014 British Sarcoma Group conference included the posters and presentations from the 3 Scottish winners of the junior doctor and medical students UK wide education initiative. The 3 students will present their experience of 1 week placements at the Beatson West of Scotland Cancer Centre during the autumn 2014 education day.
- Scottish Bone Tumour Registry (SBTR) continues to be utilised for Radiologist awareness in the 14 NHS Boards.
- The SBTR has been expanded to Aberdeen (which will support Inverness), Dundee and Edinburgh from Glasgow. This was achieved through a capital grant from National Services Division.

Clinical Trials

In collaboration with the Scottish Cancer Research Network 22% of patients participated in clinical trials during 2012/13. This compares with 14% in 2011/12, 16% in 2010/11 and 17% in 2009/10.

Charities

Sarcoma UK awarded research grants to Aberdeen (for rhabdomyosarcoma) and Edinburgh (for drug targeting) which are in progress and updates will be provided at the 2014/15 education days.

3. Quality Assurance / Service Development and Improvement

The primary function of the NMCN is to facilitate continuous 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 in April 2014 with the implementation of the sarcoma QPIs. 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 research, with “Next Generation Sequencing of transcriptome of High Grade Soft Tissue Sarcomas” being presented at the winter 2013 education day.

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 2012, 492 patients were discussed. 255 new (232 bone/soft tissue and 23 GIST) and 38 existing (33 bone/soft tissue and 5 GIST) patients were referred. Leiomyosarcoma was the most common morphology (29) of the 36 different morphologies diagnosed. All 14 NHS Boards had patients discussed at the MDT.

The 4 Cancer Registries in the UK analysed survival for sarcoma patients for the first time and reported “There were significant improvements in soft tissue sarcoma 5-year relative survival rates over the 10-year period studied, with rates increasing from 51% in 1996-2000 to 55% in 2006-2010. From the year 2000 onwards, 5-year relative survival was significantly higher in males than females, by a difference of up to four percentage points. This could be due to the increased incidence of well-differentiated liposarcomas in males. Bone sarcoma 5-year relative survival rates did not change significantly in the 10-year period studied and increased by only two percentage points from 54% in 1996-2000 to 56% in 2001-2005. There were no significant differences between the 5-year relative survival rates for bone sarcomas diagnosed in males and females.”

Scottish Cancer Registry data for 2009-2011 indicates 73% of patients received surgery, 20% systemic anti-cancer therapy and 23% radiotherapy. This data has also been utilised to arrange radiotherapy support for Aberdeen and Inverness by Dundee, Edinburgh and Glasgow.

Service Development and Improvements

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

- Starting with NHS Greater Glasgow and Clyde include the West of Scotland musculoskeletal oncology referral process (an online referral form emailed to an NHSmail box).
- The Scottish Sarcoma Network website provides the [patient referral template](#) and [Scottish sarcoma MDT NHSmail box](#) to email the referral to.
- Via the Scottish sarcoma MDT NHSmail box the outcomes of the weekly MDT are emailed to the 14 NHS Boards to enable the capture of waiting times and prospective clinical audit data.
- The Scottish Bone Tumour Registry is providing awareness training to Radiologists on a 6-monthly basis.

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:

Core Objectives

- Review clinical guidance documents that have been in use for 3 years.
- Support the Children and Young People with Cancer Managed Service Network with the national bid on end of treatment summaries being made to the Transforming Care After Treatment programme.
- Through the enhanced recovery after surgery initiative develop a pathway for bone tumour surgery in the Glasgow centre.

Individual MCN Objectives

- Continue the improvements in the Scottish sarcoma MDT, including the data required for QPIs and waiting times being captured by the 14 NHS Boards.
- Continue working with the 14 NHS Boards to develop or review sarcoma patient pathways.
- Through partnership working with NHS24 and sarcoma charities develop the tailored information for bone tumours, soft tissue sarcomas and GISTs.
- Support the Scottish PET Group to approve and implement the sarcoma protocol.

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

5. Conclusion

This has been a productive and eventful year and the continued support of the members has been essential in the NMCN achieving, and continuing to progress and achieve their work plan objectives.

Looking ahead the membership welcomes the opportunity to work with the Detecting Cancer Early programme on the review of referral guidelines which aims to detect sarcomas as early as possible; work with the Enhanced Recovery After Surgery initiative to enhance recovery after sarcoma surgery; work with the regional Systemic Anti-Cancer Therapy groups and Scottish Radiotherapy programme board on developments in sarcoma systemic anti-cancer therapy and radiotherapy; work with the Transforming Care After Treatment programme for sarcoma patients and carers; support the 14 NHS Boards to audit the sarcoma waiting times experienced by patients during 2014; and support the 14 NHS Boards to prospectively audit 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.