

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



**Sarcoma
National Managed Clinical Network**

Annual Report

April 2016 – March 2017

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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 NMCN between April 2016 and March 2017. It also reports on service developments and improvements based on the analysis of 2014 Cancer Registry data, the second year of the quality performance indicators (first year reported and second in progress) and looking forward from April 2017 to March 2018.

NMCN Objectives

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

- **Guideline Development and Review**
The first regional clinical management guideline on cutaneous sarcoma was developed in partnership with the West of Scotland skin cancer managed clinical network. Positron emission tomography–computed tomography guideline was reviewed. The gastrointestinal stromal tumour clinical management guideline was updated to version four. The bone and soft tissue clinical management guidelines reviews along with the development of the fibromatosis clinical management guideline are nearing completion (estimated June 2017). NHS Forth Valley, NHS Greater Glasgow & Clyde and NHS Western Isles patient pathways are in review.
- **Education**
The three Scottish education days were in Aberdeen in May, Glasgow in September and Edinburgh in December 2016, with the British Sarcoma Group conference in Bristol in March 2017. GIST Support UK held the second meeting of GIST patients and carers in parallel with the education day in Edinburgh. In partnership with NHS Education Scotland a less common cancers (soft tissue sarcoma, pancreatic cancer and brain tumour) module for practice based small group learning was developed in September 2016 and is available to be studied by their two thousand seven hundred and twenty three members across Scotland.
- **National Clinical Audit**
The second audit of performance against quality performance indicators (for patients diagnosed between 1st April 2015 and 31st March 2016) is in progress (North and West of Scotland analysed and awaiting South East). The actions from the first audit were completed and quality performance indicator 6 is reported for both years. The first reporting of the clinical trials quality performance indicator is awaited (expected in 2016/17 clinical audit analysis). The Scottish Cancer Registry data for 2014 has been analysed enabling the five year average for 2010 to 2014 to be calculated.
- **Service Map**
The high-level West of Scotland service map was reviewed during 2016. During 2017 the service map is being improved and then the North and South East will be included.
- **Transforming Care After Treatment (TCAT)**
The NMCN is supporting the TCAT work through the national project for reintegration after cancer treatment (ReACT) for teenagers and young adults being led by Drs Angela Edgar

(Edinburgh) and Jeff White (Glasgow). The TCAT programme updates are also communicated to the NMCN members.

- **Survey of Scottish Patients**

The survey of Scottish sarcoma patients was successfully completed in partnership with Sarcoma UK and Quality Health England and the results presented at the May education day in Aberdeen. Patient information provided by the three Charities was reviewed and is available through the specialist centres (Clinical Nurse Specialists) and the Maggie's centres (starting with Highlands).

- **Multi-disciplinary Team Working**

The Scottish sarcoma MDT Coordinator analysed the first thirteen months of operation utilising the NHS Greater Glasgow and Clyde MDT coordination application and it was presented to the December 2016 education day in Edinburgh. Dr Walter Mmekka is the Locum Oncologist in the Inverness centre and Diane Stuchbury is the Clinical Nurse Specialist in the Aberdeen centre. The Aberdeen centre is piloting an MDT to improve patient management with the Scottish sarcoma MDT.

- **Research and Development**

In collaboration with Sarcoma UK, Bone Cancer Research Trust and GIST Support UK a map of sarcoma research performed across the UK is being created. The Scottish centres continue to be successful in their bids for research funding. The Scottish Bone Tumour Registry is reviewing the digital storage of radiology, pathology and case notes to enable linkage with the bio-repositories and analysis within the Safe Havens using Community Health Index (CHI).

- **Website**

Debi Kirk (sarcoma patient and website entrepreneur) reviewed the NMCN website and gave her analysis and recommendations to the December education day in Edinburgh. Debi (and her team) are designing an improved website that will be demonstrated at the May 2017 education day in Perth (and will go live as soon as possible thereafter).

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 guideline development and review, education, quality performance indicators, service map and TCAT continue as priorities in the work plan.

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 5.405 million¹.

The sarcoma NMCN continues to support and develop the clinical service for sarcoma patients (bone, soft tissue and gastrointestinal stromal tumour). The 2014 analysis of Cancer Registry indicates the number of sarcomas in that year was 376 (giving an average of 338 cases for 2010 to 2014 inclusive). The effective management of these patients throughout Scotland relies on co-ordinated delivery of treatment and care that requires close collaboration of professions from a range of specialties. Most sarcoma patients are discussed initially in the five centres across Scotland (Aberdeen, Dundee and Inverness in the North; Edinburgh in the South East; Glasgow in the West) and referred to the Scottish sarcoma multi-disciplinary team (MDT). Gastrointestinal stromal tumour patients are managed by the upper gastrointestinal MDTs in the North and South East of Scotland, and by the Scottish sarcoma MDT in the West. Small numbers of sarcoma patients are managed by local or regional MDTs (e.g. head and neck, gynaecological oncology, skin) with the support of the Scottish sarcoma MDT.

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 Audit Report.

NMCN Governance

The NMCN formally meets three times per annum with representation from patients, carers, charities, external companies, local authorities, universities and NHS Boards and all relevant specialties involved in the management of sarcoma. The NMCN is consulted between meetings as required by the Clinical Lead and Manager through the virtual steering group.

Dr Ioanna Nixon, Consultant Clinical Oncologist, NHS Lothian is in her second year as national Clinical Lead. The membership and terms of reference of the NMCN are detailed on the [NMCN website](#).

2. NMCN Workplan and Activities (reporting period 04/2016 to 03/2017)

2.1 Core Objectives

Guideline Development and Review

Clinical management guidelines (CMGs) and clinical guidance documents (CGDs) ensure the safe and equitable management of patients across Scotland whilst optimising the effectiveness of treatment and care.

- The cutaneous sarcoma CMG was developed in partnership with the West of Scotland skin cancer MCN and Scottish melanoma group and published as a regional guideline by May 2016. The South East of Scotland have analysed their clinical audit data and are considering the development of their regional guideline in partnership with their skin cancer

¹ <https://www.nrscotland.gov.uk/statistics-and-data/statistics/stats-at-a-glance/infographics-and-visualisations>
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group. The North of Scotland skin cancer MCN are considering the development of their regional guideline in partnership with the Aberdeen, Dundee and Inverness centres.

- The NMCN reviewed the guideline for the use of positron emission tomography–computed tomography (PET-CT) in the management of sarcoma patients and submitted it to the Scottish Clinical Imaging Network’s review of PET-CT by September 2016.
- The NMCN reviewed the gastrointestinal stromal tumour (GIST) CMG, to include the Medicines and Healthcare products Regulatory Agency advice to test for hepatitis B virus before starting treatment with imatinib, by January 2017.
- The reviews of the bone and soft tissue CMGs and the development of the fibromatosis CMG are nearing completion (estimated June 2017) and reflect the treatments currently available in Scotland.
- NHS Forth Valley patient pathway is in review and NHS Forth Valley are separating bone and soft tissue from GIST as bone and soft tissue patients are managed by the West of Scotland musculoskeletal oncology MDT and Scottish sarcoma MDT, while GIST patients are managed by their local upper gastrointestinal cancer MDT and South East of Scotland upper gastrointestinal cancer MDT. NHS Greater Glasgow & Clyde and NHS Western Isles pathway are in review.

CMGs and CGDs can be accessed from the [West of Scotland Cancer Network intranet site](#) (when connected to the NHS network).

Education

The NMCN continues to support three education days per year with an average attendance of forty two members;

- Summer education day included an update from the Aberdeen centre including ongoing care of a patient, results of the survey of Scottish sarcoma patients, updates on the NHS Tayside sarcoma patient pathway after 4 years of operation, research update on clinical trials and the Aberdeen centre gave an update on their research project, presentation of the quality performance indicators for the first year and their review for capturing the data for the second year, and the review of the bone and soft tissue clinical management guidelines.
- Autumn education day included analysis of pazopanib and other individual patient treatment requests across Scotland, emerging treatments for soft tissue sarcoma, 30 day mortality and morbidity for the Glasgow centre during 2016, overview of Finding Your Feet charity by its founder, research update and the Glasgow centre gave an update on their research project, review of recent care of three patients in the Glasgow centre with emphasis on pathology, radiology and surgery, review of the Scottish Bone Tumour Registry and how it can be further improved through digital data and Community Health Index (CHI) linkage, and update on the Forth Valley sarcoma patient pathway after 4 years of operation.
- Winter education day included a closed session for oncologists to discuss Ewing’s sarcoma clinical trials, testimony from a patient and her spouse on their recent proton beam therapy in Florida USA, head and neck sarcoma practice in London, update on research in the Edinburgh centre, quality performance indicators for 2015/16 for the North and West of Scotland (South East awaited), South East of Scotland audit of cutaneous sarcoma in preparation for their regional clinical management guideline, analysis of Scottish sarcoma MDT after one year of operation with the NHS Greater Glasgow and Clyde application, review of the NMCN website by Debi Kirk (patient and website entrepreneur) and Debi’s recommendation on how to redesign it, and an update on the national TCAT project. The presentations are temporarily available on the [NMCN website](#).
- The 2017 British Sarcoma Group conference was held on 1st and 2nd March and presentations can be requested from [their website](#). Scotland was well represented and an update will be given to the education day in Perth in May.
- In partnership with NHS Education Scotland a less common cancers (soft tissue sarcoma, pancreatic cancer and brain tumour) module for practice based small group learning was developed in September 2016 and is available to be studied by their two thousand seven hundred and twenty three members across Scotland.

National Clinical Audit Programme

A key area of the sarcoma NMCN was to effectively utilise audit findings to inform and drive service improvement.

- Prospective clinical audit data was captured by the fourteen NHS Boards for patients diagnosed between 1st April 2015 and 31st March 2016 (the second year) and the eleven quality performance indicators analysed for the North and West of Scotland while the South East analysis is awaited.
- The actions from the first year were completed and quality performance indicator 6 was calculated for both years.
- The NMCN was able to analyse Cancer Registry for patients diagnosed during 2014 and an average for 5 years (2010 to 2014 inclusive) for the first time.
- Audit of cutaneous sarcoma in the South East of Scotland has been conducted and is being utilised to develop the regional CMG.
- The first reporting of the clinical trials quality performance indicator for sarcoma is awaited and is expected to be included in the 2016/17 clinical audit report.

Service Map

Work was undertaken to review the high-level map of sarcoma services in the West of Scotland. The updated baseline position describes the points of delivery, the service components available at each point and the interconnections between these in regard to access to tertiary services. The mapped information was included in a consolidated regional report in December 2016 and during 2017 the service map is being improved and then the North and South East will be included.

Transforming Care After Treatment (TCAT)

In support of the national programme, the NMCN is supporting the national project for reintegration after cancer treatment (ReACT) for teenagers and young people, being led by Drs Angela Edgar (Edinburgh) and Jeff White (Glasgow). An update was given to the December education day in Edinburgh.

2.2 Other NMCN Activities

Multi-disciplinary Team Working

The Scottish sarcoma MDT Coordinator analysed the first year of the MDT coordinated using the NHS Greater Glasgow and Clyde and this was presented to the December education day in Edinburgh. Dr Walter Mmekka is the Locum Oncologist in the Inverness centre and Diane Stuchbury is the Clinical Nurse Specialist in the Aberdeen centre. The Aberdeen centre are piloting an MDT (similar to Glasgow) to improve patient management with the Scottish sarcoma MDT.

Research and Development

We are collaborating with Sarcoma UK, Bone Cancer Research Trust and GIST Support UK to map the sarcoma research performed across the UK and identify research projects the Scottish Researchers can bid for. The Scottish Bone Tumour Registry is reviewing the digital capture of radiology, pathology and case notes along with CHI as the patient identifier to enable linking inside the Scottish Safe Havens.

Charities

Sarcoma UK funded a survey of sarcoma patients in England and Scotland and Public Health England analysed the returned surveys and compared the two countries. The results were presented at the May 2016 education day in Aberdeen and a review of patient information provided by Sarcoma UK, Bone Cancer Research Trust and GIST Support UK was led by Catriona Graham (Glasgow centre Clinical Nurse Specialist). The updated information is available from all five specialist centres (typically through the Clinical Nurse Specialists) and Maggie's centres across Scotland (starting with Maggie's Highlands).

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 Scotland. The NMCN prospective clinical audit programme underpins much of the service improvement work of the NMCN. It supports quality assurance (QA) by providing the means for regular assessment, and reporting, against recognised and agreed measures of service performance and quality.

The National Cancer Quality Programme requires comparative assessment of performance to be published annually by Regional Cancer Networks and every three years a national comparative report will be produced by Information Services Division (ISD) containing trend and survival analysis.

Audit and Governance Process

The clinical audit process captured new cases of sarcoma between 1st April 2015 and 31st March 2016. These data have been used to measure quality of clinical care provided, utilising national cancer Quality Performance Indicators (QPIs), with the North and West of Scotland analysed and the South East awaited.

Following analyses of the local, regional and national data by the WoSCAN Information Team and reporting of provisional results, local multi-disciplinary teams are required to critically review and verify their own results before these are collated to provide local, regional and national comparative report of performance.

As the report of the 2015/16 clinical audit data is delayed (planned for 11th January 2017) its publication may be delayed until the third year of analysis (new sarcoma cases between 1st April 2016 to 31st March 2017 inclusive) can be included too (planned for 29th November 2017).

Following publication of the report and in accordance with agreed governance procedure, the five specialist centres will be asked to produce an Action/Improvement Plan in response to the key findings and actions identified in the report. Initial responses are required to be submitted to the WoSCAN Information Manager within two months of publication of the audit report. All actions should be progressed and monitored via local Board governance structures.

Progress against these actions is monitored throughout the year by the NMCN.

Action/Improvement Plan Progression on 2014 Audit Report

All three Regions returned their action/improvement plans in response to the 2014/15 audit report and successfully completed their actions.

Escalation Process

Any service or clinical issue which the NMCN considers not to have been adequately addressed will be escalated to the Regional Lead Cancer Clinician and relevant Territorial NHS Board Cancer Clinical Lead by the NMCN Clinical Lead. There were no issues needing to be escalated this year.

Service Development and Improvement

Scottish Cancer Registry data for 2014 indicates 376 sarcoma patients were diagnosed across all fourteen NHS Boards, 77% received surgery, 17% systemic anti-cancer therapy and 22%

radiotherapy with leiomyosarcoma the most common morphology. With five years (2010 to 2014 inclusive) of analyses completed on average 338 sarcoma patients were diagnosed, 75% received surgery, 18% systemic anti-cancer therapy and 22% radiotherapy with leiomyosarcomas the most common morphology.

Analysis of the Scottish sarcoma MDT activity from October 2015 to October 2016 inclusive was presented to the December 2016 education day in Edinburgh. On average twenty five patients were discussed per week. The [home page of the Scottish Sarcoma Network website](#) continues to provide the patient referral template and [Scottish sarcoma MDT NHSmail box](#) to email the referral to. The outcomes of the weekly MDT are emailed to the fourteen NHS Boards to enable the capture of waiting times and prospective clinical audit data.

4. Key Priority Areas for the NMCN in the next twelve 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

- Manage the development/review of clinical management guidelines/clinical guideline documents;
- Participation in the rolling programme of national education events; utilising the opportunity for learning and sharing of current best practice and innovation;
- Support delivery of the national cancer quality programme for 2017/18, ensuring the regional/national governance process is adhered to;
- Annual update of the national service map, detailing the points of service delivery and the connections between them; and
- Continue to support the Transforming Care After Treatment programme of work.

Individual MCN Objectives

- Continue to support the national project to reintegrate after cancer treatment (ReACT) for teenagers and young people.

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

5. Conclusion

This has been a productive year and the NMCN has continued to work closely with local, regional and national clinical and management teams across Scotland to progress the work plan objectives.

Ongoing development and update of CMGs and other clinical guidance continue to drive consistency of practice and provide improved care for patients with sarcoma in Scotland.

Recognising the pressures on clinical time, the NMCN is looking at the most time efficient and effective way to engage and involve members in NMCN activities to ensure essential clinical input to the ongoing improvement and development of sarcoma services in Scotland.

Looking ahead the membership welcomes the opportunity to ensure the MDTs continue to improve their functioning and to continue to support and improve the treatment pathway and effective patient journey around local, regional and national services.

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 Scottish Children and Young people with Cancer Managed Service Network, the Scottish Cancer Research Network, the Scottish Primary Care Cancer Group, the Scottish Clinical Imaging Network, the Scottish Pathology Network, the Scottish Imaging Network and NHS Education for Scotland for their support and collaboration.