

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

**Sarcoma
National Managed Clinical Network**



Annual Report

April 2021 – March 2022

Dr Ioanna Nixon / Miss Louise McCullough
Consultant Clinical Oncologist / Consultant Orthopaedic and Trauma
Surgeon
NMCN Clinical Lead

Lindsay Campbell
NMCN Manager

CONTENTS

EXECUTIVE SUMMARY	3
1. INTRODUCTION	6
SARCOMA OVERVIEW	6
CANCER WAITING TIMES	7
CURRENT SERVICE CONFIGURATION AND SERVICE DELIVERY	7
NMCN GOVERNANCE	8
2. NMCN WORK PLAN AND ACTIVITIES (04/2021 TO 03/2022)	8
MULTI-DISCIPLINARY TEAM WORKING	8
RESEARCH AND INNOVATION	9
WEBSITE	9
GUIDELINE DEVELOPMENT AND REVIEW	9
SERVICE MAP	10
EDUCATION	10
NATIONAL CLINICAL AUDIT PROGRAMME	10
NEWSLETTER	12
CLINICAL LEAD	12
EXTERNAL SCRUTINY	12
CHARITIES	12
3. QUALITY ASSURANCE / SERVICE DEVELOPMENT / IMPROVEMENT	12
AUDIT AND GOVERNANCE PROCESS	12
ACTION/IMPROVEMENT PLAN PROGRESSION	13
ESCALATION PROCESS	13
SERVICE DEVELOPMENT AND IMPROVEMENT	13
4. KEY PRIORITY AREAS FOR THE NMCN IN 2022/23	14
5. CONCLUSION	14
ACKNOWLEDGEMENT	14

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 2021 and March 2022. It also reports on the findings and resultant actions required from the 2020/21 clinical audit report, as well as looking forward from April 2022 to March 2023.

The COVID-19 pandemic

The Sarcoma NMCN continued to support Scottish sarcoma patients and carers throughout the pandemic by reviewing sarcoma pandemic guidelines and delivering care from another location when the normal location was unavailable (e.g. surgery delivered from Golden Jubilee National Hospital rather than Glasgow Royal Infirmary). This resulted in the impact of the pandemic to sarcoma patients and carers being minimised.

NMCN Objectives

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

- **Multi-disciplinary Team (MDT) Working**
The Scottish MDT, Edinburgh centre MDT and Glasgow centre musculoskeletal (MSK) virtual clinic continue to operate weekly. The Aberdeen centre MSK virtual clinic started in October 2021 and operates bi-weekly. The Scottish MDT implemented a Chair's rota in March 2022 and is participating in the West of Scotland (WoS) MDT improvement programme.
- **Research and Innovation**
The Scottish sarcoma research strategy continues to be implemented in partnership with the Charities and Universities.

The Scottish bone tumour registry was parked in September 2018 and the migration to a wholly digital solution is awaiting the completion of NHS Scotland's transition to Microsoft 365.

The NMCN website has a [Clinical Trials page](#) that links to the sarcoma trials available in Scotland and news on the sarcoma trials Scottish patients participates in.

- **Website**
The [Scottish Sarcoma Network website](#) continues to be improved through a clinically-led sub-group, with NMCN members being surveyed annually along with website activity.
- **Guideline Development and Review**
Guideline development or review has been delayed by the pandemic and the NMCN is progressing them as fast as possible.
- **Service Map**
The WoS sarcoma service map is being split into 4 components, to match the MDT teams; MSK, gastrointestinal, skin/breast and head & neck.
- **Education**
The Charities held patient and carer events and Scottish Clinicians participated in them. The NMCN education event was devoted to molecular pathology in March 2022. The British Sarcoma Group 2022 conference was in Liverpool in March 2022.

- **National Clinical Audit**

Assessment of quality performance indicators (QPIs) using the [2020/21 audit data](#) shows continued improvements in the quality of care across Scotland and identifies areas where further improvement is required.

- **Newsletter**

The NMCN published its second [newsletter](#) in August 2021.

- **Clinical Lead**

Dr Ioanna Nixon stepped down in October and Miss Lousie McCullough started in November 2021. The NMCN's rapid response group continues through WhatsApp.

- **Quality Assurance / Service Development and Improvement**

The target of 95% of patients with extremity sarcoma who are discussed at a MDT meeting before definitive treatment is challenging (QPI 2 and improved in 2020/21) given some patients are diagnosed after surgery and some patients need surgery urgently.

The target of 95% of patients with extremity soft tissue who undergo staging CT where the results are available prior to definitive treatment is challenging (QPI 3i and improved in 2020/21) given some patients need surgery urgently. The target of 95% of patients with extremity soft tissue sarcoma who are clinically staged using the TNM staging system is challenging (QPI 3ii and declined in 2020/21) given some patients need surgery urgently and all centres are improving the recording on TNM by the MDTs.

The target of 90% of patients with GISTs who have a mutational analysis within 3 months of diagnosis (QPI 5 and improved in 2020/21) is challenging given some patients did not have it performed as they were unfit for surgery. The second formal review of the QPIs is considering which patients require mutational analysis and will update the definition accordingly.

The target of 90% of patients aged 16 and over, with extremity sarcoma who commenced post-operative radiotherapy within 3 months of surgery is challenging (QPI 8 and improved in 2020/21) given some patients take longer to recover from their surgery.

The target of 90% of patients with osteosarcoma who receive multi-agent chemotherapy (QPI 9i and declined in 2020/21) is challenging given the very small number of patients per year.

The target of 90% of patients with high risk GIST who commence post-operative imatinib is challenging (QPI 10i and declined in 2020/21) and the NMCN is further investigating why with improvements aiming to be made for 2022/23.

The target of 15% of patients diagnosed with sarcoma who are consented for a clinical trial / research study is challenging (QPI 12 and declined in 2020/21) and the NMCN's research strategy aims to improve this, with the NMCN expecting this target to be achieved in 2022/23.

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:

- In conjunction with the Regional MDT Improvement Programme, complete FIT activity and implement Microsoft Teams application
- Migrate the Scottish Bone Tumour Registry to a digital and networked solution ensuring robust governance is in place to manage the registry in line with NHS Greater Glasgow and Clyde requirements (SBTR "parked" in September 2018)

- Sustain SSN website to ensure it meets requirements for patients and healthcare professionals and raises network profile through sharing information and education events
- Develop and maintain regional / national clinical guidelines
- Maintain regional service map to support planning functions
- Deliver national sarcoma education events to promote shared learning of current best practice and innovation
- Use clinical data to drive improvement in quality of care and outcomes.

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 5.466 million¹.

The sarcoma NMCN continues to support and develop the clinical service for sarcoma patients (bone, soft tissue and gastrointestinal stromal tumour (GIST)). The 2020/21 national audit data indicates the number of sarcomas in that year was 299. The effective management of these patients throughout Scotland relies on coordinated delivery of treatment and care that requires close collaboration of professions from a range of specialties

Bone and soft tissue sarcoma patients are managed by the Scottish or South East of Scotland (SEoS or Edinburgh centre) sarcoma MDTs with the Clinicians based in the five centres across Scotland (Aberdeen, Dundee and Inverness in the North; Edinburgh in the South East; Glasgow in the West). West of Scotland (WoS) patients are initially managed by the WoS musculoskeletal (MSK) virtual clinic before being referred to the Scottish sarcoma MDT.

As of October 2021, North of Scotland (NoS) patients are initially managed by the NoS MSK virtual clinic before being referred to the Scottish sarcoma MDT.

GIST patients are managed by the colorectal, hepatopancreatobiliary or upper gastrointestinal MDTs in the NoS and SEoS, and by the Scottish sarcoma MDT in the WoS.

Small numbers of sarcoma patients are managed by the other MDTs (breast, gynaecological oncology, head and neck, lung, neuro-oncology, skin and urological) with the support of the Scottish or SEoS sarcoma MDTs.

Scottish Ewing's sarcoma patients are re-discussed at the UK Ewing's sarcoma MDT as appropriate.

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.

Sarcoma Overview

Approximately 350 patients are diagnosed with sarcoma annually across Scotland. Sarcomas are a rare group of cancers that arise from connective tissue, including: bone, cartilage, muscle, blood vessels, nerves and fat which are broadly divided into bone, soft tissue sarcomas and GISTs. In 2020/21 the audit identified 299 patients diagnosed with a new primary invasive sarcoma in Scotland.

Sarcomas account for around 1% of all new cancer diagnoses in the UK². In Scotland bone and connective tissue cancers are ranked 25th most common cancer, accounting for only 0.5% of all cancers diagnosed in 2018³. The most common site of sarcoma is the extremities which provides the focus for the majority of the quality performance indicators (QPI) data analysis.

Incidence of bone sarcomas has been stable in the UK since the late 1970s whilst incidence of soft tissue sarcoma has increased overall since the late 1990s. This likely reflects improved diagnosis and data recording rather than a true increase in incidence. There has been improvement in survival

¹ <https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-estimates/mid-year-population-estimates/mid-2020>

² http://www.ncin.org.uk/cancer_type_and_topic_specific_work/cancer_type_specific_work/sarcomas/

³ <https://www.isdscotland.org/Health-Topics/Cancer/Cancer-Statistics/Bone-and-Connective-Tissue/>

over the past few decades, with 5 year survival rising from 51% in 1996-2000 to 55% in 2006-2010 for soft tissue sarcoma. The picture is very similar for bone sarcoma.

Unlike many other cancers, bone and soft tissue sarcomas can affect people of any age. From 2012 to 2014 in the UK 47% of all bone sarcomas occurred in people under the age of 45, whilst 57% of soft tissue sarcomas occurred in the under 65s in 2010.

GISTs are rare with an estimated occurrence of 1/100,000. These tumours are extremely rare in children and young people, with the median age reported as 60-65.

Cancer Waiting Times

Sarcoma patients are not reported against the 31 and 62 day standards (95%).

An audit in 2014 indicated 94% of patients met the 31 day standard and 82% the 62 day standard. The NMCN investigated the ten patients who did not meet the standards and their complex care was delivered between multiple specialties and locations.

NHS Boards do track sarcoma patients and the NMCN reviews the activity of the MDTs and virtual clinics annually.

Current Service Configuration and Service Delivery

Whilst the logistics of delivering a safe sarcoma service for both patients and clinical staff during the pandemic remains challenging, clinical teams throughout Scotland have worked flexibly and collaboratively to maintain sarcoma services.

The NMCN continues to use a WhatsApp group to agree guidelines and coordinate changes.

Referrals

The NMCN continues to monitor the changes in diagnoses during the pandemic and the 2020 and 2021 activity of the MDTs and virtual clinics is being analysed.

Clinics

All clinics have continued to run either in person, by telephone consultation or by video consultation.

Diagnostics

Diagnostic imaging has continued throughout the pandemic. Triple reporting of bone and soft tissue sarcoma pathology between the Aberdeen, Edinburgh and Glasgow centres has continued. GIST molecular pathology is fully operational in the Dundee, Edinburgh and Glasgow centres.

MDTs

The Scottish sarcoma MDT, SEoS sarcoma MDT and WoS MSK virtual clinic continue to operate weekly. The NoS MSK virtual clinic started in October 2021 and operates bi-weekly (weeks 2 and 4).

Surgery

Bone and soft tissue sarcoma surgery continues to be delivered from Aberdeen (NoS patients), Edinburgh (SEoS) and Glasgow (WoS) centres.

GIST surgery continues to be delivered from Edinburgh (SEoS) and Glasgow (NoS and WoS) centres.

Surgery was delivered from an alternative location when the normal location was unavailable (e.g. in Golden Jubilee National Hospital rather than Glasgow Royal Infirmary).

Systemic Anti-Cancer Therapies (SACT)

SACT continues to be delivered from Aberdeen, Dundee, Inverness, Edinburgh and Glasgow centres.

Radiotherapy

Radiotherapy continues to be delivered from Aberdeen, Dundee, Inverness, Edinburgh and Glasgow centres.

Follow-up

Follow-up clinics have continued to run either in person, by telephone consultation or by video consultation.

Workforce

The pandemic has meant unpredictable workforce challenges (e.g. short notice leave to self-isolate) but each centre is coping with this as best they can, and mutual aid is always available.

NMCN Governance

The NMCN normally meets three times per annum with representation from patients, carers, charities, external companies, local authorities, universities and NHS Boards and all relevant specialities 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 Greater Glasgow and Clyde, stepped down in October 2021 and Miss Louise McCullough, Consultant Orthopaedic and Trauma Surgeon, NHS Grampian started in November 2021 as national Clinical Lead. The [membership of the NMCN virtual steering group](#) is detailed on the NMCN website. The [constitution](#) of the NMCN is being updated to reflect the partnership working with the [Children and Young People with Cancer managed service network](#) and the transition of the NMCN to the Scottish Cancer Network (SCN) from the West of Scotland Cancer Network (WoSCAN).

2. NMCN Work plan and Activities (04/2021 to 03/2022)

Multi-disciplinary Team Working

To ensure efficient MDT working across Scotland the NMCN has focused on improving the operation of MDTs as well as identifying Scotland-wide IT applications. Improvements are being made in conjunction with the WoSCAN MDT improvement programme.

The Scottish sarcoma MDT Coordinator also audits WoS sarcoma patients and continues to be co-located with the WoS MSK team.

On average the Scottish sarcoma MDT discusses 1150 patients (a patient can be discussed multiple times) per year, comprised of 20 Clinicians and lasting an hour and a half per MDT. A rota for the Chair of the Scottish sarcoma MDT was implemented in March 2022. This is being reflected in the review of Scottish sarcoma MDT constitution and operational policy currently in progress.

On average the SEoS sarcoma MDT discusses 650 patients (a patient can be discussed multiple times) per year. Dr Aisling Hennessy continues to chair the Edinburgh centre MDT.

The Glasgow centre MSK virtual clinic investigates and stages WoS patients in collaboration with the local Orthopaedic services, referring patients with bone and soft tissue sarcomas (and appropriate benign conditions) to the Scottish sarcoma MDT. This clinic is developing their referral form and on average this clinic discusses 700 patients per year. Mr Ashish Mahendra continues to chair this clinic.

The Aberdeen MSK virtual clinical started in October 2021 and investigates and stages NoS patients in collaboration with the local Orthopaedic services, referring patients with bone and soft tissue sarcomas (and appropriate benign conditions) to the Scottish sarcoma MDT. This is being reflected in the review of Scottish sarcoma MDT constitution and operational policy currently in progress. The

virtual clinic is chaired by Miss Louise McCullough while Mr David Boddie continues to lead the Aberdeen centre.

The Glasgow centre is considering a gastrointestinal sarcoma virtual clinic to collaborate with local gastrointestinal services in investigating and staging North and West of Scotland patients (as their surgery would be delivered from Glasgow), before referring to the Scottish sarcoma MDT. This is being led by Mr Peter Chong and Ms Martha Quinn.

Dr Michelle Ferguson stepped down as lead for Dundee centre in December 2021 and Dr Fay Tough started in January 2022.

Dr Walter Mmekaka left NHS Highland in June 2021 and Dr Ute MacGregor started as the lead for the Inverness centre in July 2021.

The analysis of 2020 and 2021 MDT and virtual clinic activity is in progress (delayed due to the pandemic).

Research and Innovation

During 2020/21 5.9% of patients were consented for participation in a clinical trial. The two challenges for sarcoma are its rarity and clinical trials increasingly including molecular pathology criteria, with both minimising the number of patients who can participate.

In collaboration with Sarcoma UK, Bone Cancer Research Trust, GIST Cancer UK, the Beatson Cancer Charity and the Universities the Scottish sarcoma research strategy is gathering momentum with a second day devoted to research being planned once the pandemic allows.

The Scottish bone tumour registry was parked in September 2018, with the retirement of the Data Manager. The NMCN is working with eHealth to network the 4 computers in the Aberdeen, Dundee, Edinburgh and Glasgow centres before migrating to a wholly digital solution based on Microsoft 365. The Scottish Pathologists have confirmed the pathology solution and the Radiologists are working with the national Radiology team on their solution (PACS or OSIRIX). The registry was started in 1952, has data on over 5000 bone sarcoma patients, and integration with the bio-banking service has been completed (adding blood and tissue samples to the registry).

The NMCN website has a [Clinical Trials page](#) that links to the sarcoma trials available in Scotland and news on the sarcoma trials Scottish patients participate in.

Website

The [SSN website](#) continues to be updated through a clinically-led improvement group, led by Dr Jeff White (Glasgow Medical Oncologist) and Alan Abraham (Glasgow Clinical Nurse Specialist (CNS)). Improvements continue to be identified through an annual online surveys of members. Lorraine Stirling (Network Administrator) is the Webmaster and Lindsay Campbell is the deputy webmaster. From 1st April 2021 to 31st March 2022 an average of 16 people visited the website every day. 69% of the people were in the UK, 13% in the USA and the rest from around the world. 60% of people viewed the website from a computer, 36% from a mobile and 4% from a tablet.

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 pandemic has impacted their development or review and the NMCN is progressing them as fast as possible.

The Scottish pathology guideline for bone and soft tissue sarcoma is in review, led by Dr Elaine MacDuff.

The Scottish pathology guideline for GIST is in review, led by Dr Shaun Walsh.

The Scottish CMG for GIST is in review, and the lead for this review is being confirmed.

The Scottish CMG for bone is in review, led by Dr Trevor McGoldrick.
The Scottish CMG for soft tissue is in review, led by Dr Ioanna Nixon.
The Scottish CMG for fibromatosis is in development, led by Dr Larry Hayward and Dr Helen Creedon.
The WoS CMG for breast sarcoma is in development, led by Mr Steven Lo.
The Scottish CMG for head and neck sarcoma is in development, led by Mr Jeremy McMahon.
The WoS cutaneous (skin) sarcoma CMG is in review, led by Mr Steven Lo.
Follow-up guidance is being included in each of the CMGs and the Scottish follow-up guideline will be retired.

CMGs can be accessed from the [sarcoma page of the West of Scotland Cancer Network intranet site](#) (when connected to the NHS network). Other guidelines can be accessed from the [Guidelines page of the NMCN website](#).

Service Map

The NMCN is reviewing the WoS service map based on the 2020/21 QPI results and is separating them into 4 maps to match the 4 teams in the MDT; MSK, gastrointestinal, skin/breast and head & neck.

The NMCN analysed the prescribing of medicines not approved by the Scottish Medicine Consortium across Scotland between 2008 and 2016, and the NoS prescribed less than the other 2 regions. In partnership with the SCN the NMCN is preparing to analyse 2017 onwards to determine if anything has changed, and continue the support given to the Consortium on ultra-orphan and orphan medicines.

Education

The NMCN was holding three education events per year before the pandemic, May in the NoS, September in the WoS and December in the SEoS.

Events were in parallel with a sarcoma Charity (Bone Cancer Research Trust, Sarcoma UK or GIST Cancer UK) patient and carer day to maximise collaboration.

On 15th April 2021 Dr Ioanna Nixon and Alan Abraham presented to the GIST Cancer UK first virtual patient and carer meeting and the recording is available at <https://youtu.be/z7FaBom-KC0>.

On 3rd March 2022 a virtual education event devoted to molecular pathology was successfully held by Microsoft Teams and the [recording can be viewed on the NMCN website](#).

The [British Sarcoma Group conference](#) was held in Liverpool on 23rd and 24th March 2022 and 9 Scottish posters were presented, and the posters will be added to the NMCN website.

In partnership with Maggie's Glasgow the sarcoma patient and carer support group meet every 2 months.

National Clinical Audit Programme

A key activity of the NMCN is to effectively utilise audit findings to inform and drive service improvement. A comprehensive clinical audit report of performance against QPIs for 2020/21 was issued to NHS Boards in May 2022 and is available on the [NMCN website](#). Action plans for the 2019/20 data were completed by the five centres and the NMCN.

The sarcoma NMCN is encouraged by the performance of NHS Boards and centres against the national QPIs with results demonstrating that patients with sarcoma receive a consistent and improving standard of care across all geographical locations; five of the twelve indicators achieved, three improved, one the same and three declined compared to 2019/20. The details are:

Achieved

- QPI 1 of patients with extremity sarcoma should have a histological diagnosis before undergoing a planned surgical resection (92.5% against a target of 90% compared to 85.5% in 2019/20).
- QPI 4 of patients with extremity sarcoma undergoing surgical resection should have their tumour adequately excised (90.9% against a target of 85% compared to 92.3% in 2019/20).
- QPI 6 of patients with extremity sarcoma should have primary limb-sparing surgery (85.3% against a target of 85% compared to 69.8% in 2019/20).
- QPI 7 of patients with extremity sarcoma should have successful primary flap reconstruction following surgical resection (100% against a target of 85% compared to 100% in 2019/20).
- QPI 9ii of patients under the age of 50 with Ewing's sarcoma who receive multi-agent chemotherapy (100% against a target of 90% compared to 100% in 2019/20).
- QPI 10ii of patients with high risk GIST who commence post-operative imatinib within 3 months of surgery (100% against a target of 90% compared to 93.3% in 2019/20).
- QPI 11i of patients who die within 30 days of surgical resection or oncological treatment with curative intent (Radical Radiotherapy, Neo-adjuvant Radiotherapy, Adjuvant Radiotherapy and Biological Therapy) (1.3% or 0%/0%/0%/0% against a target of less than 10% compared to 0% or 0%/0%/3.0%/0% in 2019/20).
- QPI 11ii of patients who die within 30 days of palliative oncological treatment (12.5% against a target of less than 15% compared to 24.1% in 2019/20).

Improved

- QPI 2 of patients with extremity sarcoma should be discussed by a multidisciplinary team (MDT) prior to definitive treatment (90.6% against a target of 95% compared to 87.0% in 2019/20).
- QPI 5 of patients with gastrointestinal stromal tumours (GISTs) should have mutational analysis within 3 months of diagnosis (78.1% against a target of 90% compared to 69.8% in 2019/20)
- QPI 8 of patients with extremity sarcoma should receive radiotherapy within 3 months of surgery (77.8% against a target of 90% compared to 57.1% in 2019/20).

Same

- QPI 3i of patients with extremity soft tissue sarcoma who undergo staging CT scan where the results are available prior to definitive treatment (91.7% against a target of 95% compared to 83.3% in 2019/20).
- QPI 3ii of patients with extremity soft tissue sarcoma who are clinically staged using the TNM staging system (66.7% against a target of 95% compared to 73.3% in 2019/20).

Declined

- QPI 9i of patients under the age of 40 with osteosarcoma who receive multi-agent chemotherapy (50% against a target of 90% compared to 71.4% in 2019/20).
- QPI 10i of patients with high risk GIST who commence post-operative imatinib (86.1% against a target of 90% compared to 100% in 2019/20).
- QPI 12 of all patients diagnosed with sarcoma who are consented for a clinical trial / research study, wherever eligible (5.9% against a target of 15% compared to 7.9% in 2019/20).

The NMCN is further analysing GIST molecular pathology reporting, starting with WoS patients who were prescribed imatinib. This will confirm the Pathologists requesting molecular pathology (to ensure they are represented at the MDT), the time to report the molecular pathology to the MDT (QPI 5 target is within 3 months of diagnosis) and how the MDT outcome is communicated to the patient (QPI 10 target is imatinib should be prescribed within 3 months of surgery). This is challenging given the number of Pathologists requesting molecular pathology (over 30) and the molecular pathology test not yielding a result and requires to be retested (possibly requiring more tissue to be provided first).

The NMCN will be requesting Scottish Cancer Registry data for patients diagnosed with a sarcoma between 2000 and 2020 but as the data includes patient identifiers (Community Health Index or CHI) this needs approval by the Public Benefit and Privacy Panel for Health and Social Care (and patients with an hepatopancreatobiliary cancer have been requested first).

Newsletter

The [second issue of the NMCN newsletter](#) was published in August 2021, led by Dr Ioanna Nixon.

Clinical Lead

Dr Ioanna Nixon stepped down in October and Miss Lousie McCullough started in November 2021.

External Scrutiny

The NMCN reports annually to the three regional cancer networks (advisors to the fourteen territorial NHS Boards) and National Services Scotland (commissioners of the NMCNs on behalf of the fourteen territorial NHS Boards).

Charities

Sarcoma UK, Bone Cancer Research Trust, GIST Cancer UK, Ewing's Sarcoma Research Trust, EHE Rare Cancer Charity (UK), Chordoma UK, Macmillan, Maggie's, Changing Faces, Finding Your Feet, Trekstock, Beatson Cancer Charity, Amputee Football Scotland, #hellomynameis, Cancer Support Scotland and CLAN Cancer Support continue to be active members of the NMCN.

3. Quality Assurance / Service Development / 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 survival analysis will be produced by Public Health Scotland (PHS).

The NMCN reported seven years of QPIs with its 2020/21 report and the second formal review of the QPIs through the national programme started in December 2021.

Audit and Governance Process

The clinical audit process captured 299 new cases of sarcoma for 2020/21 (54.8% of patients were male, the median age of patients was 64 and the majority of sarcoma patients received surgery as their first treatment). These data have been used to measure quality of clinical care provided, utilising national cancer QPIs.

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.

The report of the 2020/21 clinical audit data was published in May 2022 and can be found on the [NMCN website](#).

Following publication of the report and in accordance with agreed governance procedure, the five specialist centres were asked to produce an Action/Improvement Plan in response to the key findings and actions identified in the report;

QPI 3 – Clinical Staging

- All centres to ensure recording of TNM for all sarcomas.

Initial responses will be submitted to the WoSCAN Information Manager within two months of publication of the audit report. All actions will be progressed and monitored via local Board governance structures and by the NMCN.

Action/Improvement Plan Progression

All three Regions returned their action/improvement plans in response to the 2019/20 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

The GIST pathology guideline review, CMG review and second formal review of the sarcoma QPIs are collaborating to ensure patients are risk assessed and treated appropriately.

The target of 95% of patients with extremity sarcoma who are discussed at a MDT meeting before definitive treatment is challenging (QPI 2 and improved in 2020/21) given some patients are diagnosed after surgery and some patients need surgery urgently.

The target of 95% of patients with extremity soft tissue who undergo staging CT where the results are available prior to definitive treatment is challenging (QPI 3i and improved in 2020/21) given some patients need surgery urgently. The target of 95% of patients with extremity soft tissue sarcoma who are clinically staged using the TNM staging system is challenging (QPI 3ii and declined in 2020/21) given some patients need surgery urgently and all centres are improving the recording on TNM by the MDT.

The target of 90% of patients with GISTs who have a mutational analysis within 3 months of diagnosis (QPI 5 and improved in 2020/21) is challenging given some patients did not have it performed as they were unfit for surgery. The second formal review of the QPIs is considering which patients require mutational analysis and will update the definition accordingly.

The target of 90% of patients aged 16 and over, with extremity sarcoma who commenced post-operative radiotherapy within 3 months of surgery is challenging (QPI 8 and improved in 2020/21) given some patients take longer to recover from their surgery.

The target of 90% of patients with osteosarcoma who receive multi-agent chemotherapy (QPI 9i and declined in 2020/21) is challenging given the very small number of patients per year.

The target of 90% of patients with high risk GIST who commence post-operative imatinib is challenging (QPI 10i and declined in 2020/21) and the NMCN is further investigating why with improvements aiming to be made for 2022/23.

The target of 15% of patients diagnosed with sarcoma who are consented for a clinical trial / research study is challenging (QPI 12 and declined in 2020/21) and the NMCN's research strategy aims to improve this, with the NMCN expecting this target to be achieved in 2022/23.

4. Key Priority Areas for the NMCN in 2022/23

The NMCN work plan has been developed with an emphasis on identifying outcomes that improve the quality of patient care and overall efficiency:

- In conjunction with the Regional MDT Improvement Programme, complete FIT activity and implement Microsoft Teams application
- Migrate the Scottish Bone Tumour Registry to a digital and networked solution ensuring robust governance is in place to manage the registry in line with NHS Greater Glasgow and Clyde requirements (SBTR “parked” in September 2018)
- Sustain SSN website to ensure it meets requirements for patients and healthcare professionals and raises network profile through sharing information and education events
- Develop and maintain regional / national clinical guidelines
- Maintain regional service map to support planning functions
- Deliver national sarcoma education events to promote shared learning of current best practice and innovation
- Use clinical data to drive improvement in quality of care and outcomes.

The work plan is published on the [About the SSN page of 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 and cope with the pandemic.

Ongoing development and review 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. Microsoft 365 will be a key enabler of this collaborative working, as the use of Microsoft Teams for the Scottish sarcoma MDT has already demonstrated.

Looking ahead the membership welcomes the opportunity to continue improving sarcoma pathways and treatments locally, regionally and nationally while increasing international collaborations in research.

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, NHS Research Scotland, the Scottish Primary Care Cancer Group, the Scottish Clinical Imaging Network, the Scottish Pathology Network (especially the Scottish Molecular Pathology Consortium), Public Health Scotland and NHS Education for Scotland for their support and collaboration.