

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

**Sarcoma
National Managed Clinical Network**



Annual Report

April 2020 – March 2021

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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 2020 and March 2021. It also reports on the findings and resultant actions required from the 2018/19 clinical audit report, as well as looking forward from April 2021 to March 2022.

The COVID-19 pandemic

The Sarcoma NMCN supported Scottish sarcoma patients and carers throughout the pandemic by quickly developing 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 sarcoma multi-disciplinary team (MDT) continued to improve, and was a Cancer Care Team of the Year finalist in the [2020 British Medical Journal Awards](#) (congratulations to Oxford). The Beatson West of Scotland Cancer Centre team were a finalist in the [Health Service Journal Partnership Awards 2021](#), for their chemotherapy service improvement project in partnership with Lilly UK.
- **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 in progress.

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](#) has improved through a clinically-led sub-group, with NMCN members being surveyed twice, choosing the new logo and website activity analysed from December 2020 onwards.
- **Guideline Development and Review**
Scottish and West of Scotland (WoS) guidelines are being developed or reviewed as planned, with the West of Scotland breast sarcoma clinical management guideline published in the [Journal of Plastic, Reconstructive & Aesthetic Surgery](#).
- **Service Map**
The WoS sarcoma service map is being split into 4 components, to match the MDT teams; musculoskeletal (MSK) oncology, gastrointestinal (GI), skin/breast and head & neck.
- **Education**

Education events were quarterly before the pandemic, the last being the British Sarcoma Group 2020 conference in Glasgow. The first virtual event was organised for 21st April 2021 but participation was low due to the pandemic.

- **National Clinical Audit**

Assessment of quality performance indicators (QPIs) using the [2019 audit data](#) shows improvements in the quality of care across Scotland with four of the twelve indicators achieved, three better than 2018 and five poorer than 2018.

- **Newsletter**

The NMCN published its first [newsletter](#) in July 2020 and the second issue is in progress.

- **Clinical Lead**

Dr Ioanna Nixon extended her role until October 2021 to lead the NMCN during the pandemic through the NMCN's rapid response group. The next Clinical Lead is being recruited.

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 (2019 estimated population of 5.463 million¹).

The sarcoma NMCN continues to support and develop the clinical service for sarcoma patients (bone, soft tissue and gastrointestinal stromal tumour (GIST)). The 2019/20 national audit data indicates the number of sarcomas in that year was 341. 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. Bone and soft tissue sarcoma patients are managed by the Scottish sarcoma or South East of Scotland (SEoS) 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), and West of Scotland (WoS) patients are initially managed by the WoS musculoskeletal (MSK)-oncology virtual clinic before being referred to the Scottish sarcoma MDT. GIST patients are managed by the colorectal, hepatopancreatobiliary or upper gastrointestinal MDTs in the North of Scotland (NoS) and SEoS, and by the Scottish sarcoma MDT in the West. 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 2019/20 the audit identified 341 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 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.

¹ <https://www.nrscotland.gov.uk/statistics-and-data/statistics/stats-at-a-glance/infographics-and-visualisations>

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/>

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

Summary statistics for bone and connective tissue cancer

Scotland	Males	Females	Persons
Rank - incidence (2017)	19	23	24
Rank - mortality (2018)	17	19	20
Percentage frequency of all cancers - incidence (2017)	0.6%	0.5%	0.6%
Percentage frequency of all cancers - mortality (2018)	0.8%	0.7%	0.7%
Number of new cases diagnosed in 2017	103	85	188
Number of deaths recorded in 2018	63	55	118
Change in incidence from 2007 to 2017	+0.0%	+10.5%	+3.9%
Change in mortality from 2008 to 2018	+3.1%	-5.3%	-0.3%

Cancer Waiting Times

Sarcoma patients are not reported against the 31 and 62 day standards.

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 Scottish sarcoma MDT, SEoS sarcoma MDT and WoS MSK-oncology virtual clinic annually.

Current Service Configuration and Service Delivery

Whilst the logistics of delivering a safe sarcoma service for both patients and clinical staff during the COVID-19 pandemic remains challenging, clinical teams throughout Scotland have worked flexibly and collaboratively to maintain sarcoma services.

The NMCN created a COVID-19 WhatsApp group to agree guidelines and coordinate changes. Surgery in the WoS was delivered from the Golden Jubilee National Hospital when Glasgow Royal Infirmary was unavailable.

Systemic anti-cancer therapy and radiotherapy continued to be delivered from Aberdeen, Dundee, Inverness, Edinburgh and Glasgow centres.

Use of telemedicine is emerging and in response a survey of patient and professional views was carried out. The survey was led by Dr Ioanna Nixon in collaboration with Strathclyde University and the Royal Marsden Hospital, London. The NMCN surveyed 75 patients/carers and 30 Clinicians between 8th June and 25th August 2020 on the use of telemedicine. Patients/Carers preferred face-to-face appointments for diagnosis and poor prognosis consultations, and phone or video consultations for routine follow-up appointments. Clinicians were comfortable with any consultations but Clinic Rooms need facilitated correctly (computer with camera and headset and fast internet connection). The analysis has been [published in the JCO Global Oncology journal](#), shared with the WoS Cancer Network (WoSCAN) Clinical Leads group in March 2021 and presented at the British Sarcoma Group conference 2021 as an oral presentation.

Referrals

The NMCN monitors the changes in diagnoses during the pandemic, comparing 2020 to 2019, and there has been a small decrease (less than 10%).

The 2020 activity analysis of both MDTs and the virtual clinic is in progress.

Clinics

All clinics have continued to run either in person, by telephone consultation or by video consultation. The survey of patients/carers and Clinicians indicated the continuing implementation of video consultation (e.g. Near Me) into clinic rooms will be beneficial to all.

Diagnostics

Diagnostic imaging has continued throughout the pandemic, along with triple reporting of bone and soft tissue sarcoma pathology between the Aberdeen, Edinburgh and Glasgow centres.

MDTs

The Scottish sarcoma MDT, SEoS sarcoma MDT and WoS MSK-oncology virtual clinic continue to operate weekly, with the Scottish MDT and virtual clinic switching to Microsoft Teams for their video conferencing in May 2020 (Edinburgh MDT remained with National video conference service that now includes participants using Microsoft Teams).

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.

Systemic Anti-Cancer Therapies (SACT)

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

The NMCN monitors the changes in activity during the pandemic and activity has recovered to pre-pandemic levels.

Radiotherapy

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

The NMCN monitors activity during the pandemic and there have been no changes.

Follow-up

The survey of patients/carers and Clinicians has indicated personal consultations are preferred for initial diagnosis and poor prognosis (including relapse or metastases).

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, is in her sixth year 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](#).

2. NMCN Work plan and Activities (04/2020 to 03/2021)

Multi-disciplinary Team Working

The quality improvement commenced in 2019 led by Dr Ioanna Nixon, Scottish Quality and Safety Fellow, and Dr Mark McCleery, MSK Radiologist, completed a review of the MDTs; with duplication of effort between the Scottish and SEoS sarcoma MDTs eliminated (small number of patients re-discussed), minimising the number of patients who cannot be discussed due to lack of referral information (referral form improved and referring Clinician presents patient), Radiologist preparation time minimised (minimised late additions), and improved communication of outcomes (WoSCAN Lead GP observed MDT and recommended improvements). A different day for the MDT was considered but not possible (still Mondays) while an earlier start was implemented (3.45PM) and the deadline for referrals was extended as late in the week as possible (Thursday 5:00PM). Improvements were achieved through a workshop and online surveys. The referral forms for the Scottish and SEoS sarcoma MDTs were reviewed, the structure of the MDT continues to change to reflect the sections (MSK, gastrointestinal, skin/breast and head & neck) and participants dial in depending on the section they are presenting in (gastrointestinal is first due to Radiologist availability). Activity has increased due to care complexities, especially metastases. All this resulted in the Scottish sarcoma MDT being shortlisted in the Cancer Care Team category for the [2020 British Medical Journal awards](#), and congratulations to Oxford on their win. The Beatson West of Scotland Cancer Centre team were finalists in the [Health Service Journal Partnership Awards 2021](#), for their chemotherapy service improvement project in partnership with Lilly UK (and their [presentation](#) is available on the SSN website).

The next improvements are being made in conjunction with the WoSCAN MDT improvement programme. The NMCN is currently reviewing the Scottish sarcoma MDT constitution and operational policy to reflect the 4 teams; MSK, GI, skin/breast and head & neck. The Glasgow centre is considering a weekly GI virtual clinic to streamline referrals through it to the Scottish sarcoma MDT. The Aberdeen centre is considering a weekly MSK-Oncology virtual clinic to streamline referrals through it to the Scottish sarcoma MDT.

The Scottish sarcoma MDT Coordinator also audits WoS sarcoma patients and continues to be co-located with the WoS MSK-Oncology 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. Due to the COVID-19 pandemic most of the Clinicians participate individually by video conference and in preparation for Microsoft 365 being rolled out across Scotland the first MDT was conducted using Microsoft Teams on 18th May 2020. Dr Fiona Cowie, Dr Ioanna Nixon and Dr Jeff White continue to co-chair the Scottish sarcoma MDT.

On average the Edinburgh centre 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-oncology 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 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.

The Aberdeen centre is considering an MSK-oncology virtual clinic to collaborate with North of Scotland Orthopaedic services in investigating and staging North of Scotland patients (as their

surgery would be delivered from Aberdeen), before referring to the Scottish sarcoma MDT. This is being led by Miss Louise McCullough while Mr David Boddie continues to lead the Aberdeen centre.

Dr Michelle Ferguson continues to lead the Dundee centre.

Dr Walter Mmekwa was single-handed in the Inverness centre until June 2021, when Walter left NHS Highland. The Aberdeen centre is supporting the Inverness centre while NHS Highland deal with the vacancy.

Research and Innovation

During 2019 7.9% 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 (previously known as GIST Support 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 for 2021/22.

[Researchers at The Institute of Cancer Research, London, and The Royal Marsden NHS Foundation Trust, working alongside collaborators from around the globe, begin work on the world's largest digital hub of sarcoma clinical and research data after receiving a £2.5m grant.](#) Dr Robin Jones at The Royal Marsden NHS Foundation Trust and the ICR will lead the five-year project aiming to produce the digital hub, as well as 3D cell and animal models of sarcoma, that will help predict and test patient response to drugs for high-risk sarcomas using artificial intelligence. The Glasgow centre is having one of the leading roles in the Consortium, with Dr Ioanna Nixon, Dr Jeff White and the Clinical Trials Unit leading on the clinical data work stream. Dr Larry Hayward and Prof Val Brunton in the Edinburgh centre are also part of the collaborative. Co-Investigators on the project include teams based at University of Birmingham, Instituto Nazionale dei Tumori-Milano, and Instituto de Biomedicina de Sevilla.

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.

The NMCN is initiating a quality improvement and innovation collaborative, with Dr Ioanna Nixon, co-Lead for WoS QI Group, as the lead. This collaborative aims at driving and coordinating quality improvement and innovation across the NMCN. This is acknowledgment of the importance of quality improvement and innovation to patient care and also the necessity for leadership embracing and enabling quality improvement and innovation.

Website

The [SSN website](#) has been updated through a clinically-led improvement group, led by Dr Jeff White (Glasgow Medical Oncologist) and Alan Abraham (Glasgow Clinical Nurse Specialist (CNS)). Improvements were identified through online surveys of members, with the second survey choosing the new SSN logo. The latest improvement added the contact list of Scottish sarcoma CNSs, NHS Highland Cancer Support Workers and the other NHS Board CNSs to the [For Patients & Carers page](#). The activity of the website can be analysed from December 2020 onwards and this will be included in future newsletters and annual reports.

Guideline Development and Review

The Scottish pathology guidelines for bone and soft tissue sarcoma, and GIST were reviewed in May 2019.

The Scottish clinical management guideline (CMG) for GIST was reviewed in October 2019.

Scottish CMGs for bone (review), soft tissue (review) and fibromatosis (development) are nearing completion following extensive consultation on what can/cannot be included.

The WoS CMG for breast sarcoma is nearing completion in collaboration with the WoS Breast MCN (and published in the [Journal of Plastic, Reconstructive & Aesthetic Surgery \(sciencedirect.com\)](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7111111/)).

The Scottish CMG for head and neck sarcoma is in development, based on the survey of UK units and in collaboration with the British Sarcoma Group and British Association of Head and Neck Oncology.

The WoS cutaneous (skin) sarcoma CMG is in review, starting with an audit of practice for the four years of version one, and will hopefully expand to the rest of Scotland.

Dr Ioanna Nixon became a member of the Scottish Medicines Consortium's New Drugs Committee in April 2020.

Follow-up guidance is being included in each of the CMGs and the Scottish follow-up guideline will be retired.

The NMCN constitution is being updated to reflect the partnership working with the Scottish managed service network for Children and Young People.

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 and is separating them into maps to match the 3 teams in the MDT; MSK, GI and skin/breast (head & neck map will be developed in parallel with the CMG).

Isolated limb perfusion ceased in Glasgow Queen Elizabeth University Hospital in early 2020 and Scottish patients suitable for this treatment are now referred down to the London Royal Marsden Hospital.

Dr Craig Wheelans' national review of abdominal sarcoma surgery was completed in 2020, and surgery carries on in the two centres in Edinburgh (SEoS) and Glasgow (NoS and WoS).

The Glasgow centre started reporting molecular pathology for WoS GIST patients in April 2020, completing this regional implementation (Dundee centre for the NoS and Edinburgh for the SEoS).

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. The NMCN is preparing to analyse 2017-2020 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.

The first virtual education day was 21st April 2021 but participation was very low due to the pandemic.

February is reserved for the [British Sarcoma Group conference](#) and in 2020 the conference was held in Glasgow. The NMCN hosted the conference and there were over 350 delegates (some from Europe and Africa), and 88 poster presentations (13 from Scotland) over the 2 days. The 2020 conference started with a civic reception at Glasgow City Chambers and for the first time included a session for Patients and Carers chaired by a Patient and the Beatson Cancer Charity. Feedback from the conference was excellent and it was passed to the Cardiff team for the first virtual conference in 2021. Delegates also sowed a stitch into the [Scottish Cancer Tapestry](#) during the conference.

The NMCN held its first patient and carer day in Falkirk (NHS Forth Valley hosted) in October 2018, with 35 participants, including Andrew Crummy launching the Scottish Cancer Tapestry project. The second day has been delayed due to the pandemic.

The NMCN held its first nurse and allied health professional day in Glasgow in March 2019, with 55 participants. The second day has been delayed due to the pandemic.

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 2019/20 was issued to NHS Boards in June 2021 and is available on the [NMCN website](#). Action plans for the 2018 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; four of the twelve indicators achieved, three better than 2018 and five poorer than 2018. The details are:

Achieved

- QPI 4 of patients with extremity sarcoma undergoing surgical resection should have their tumour adequately excised (92.3% against a target of 85% compared to 80.7% in 2018).
- QPI 6 of patients with extremity sarcoma should have primary limb-sparing surgery (89.6% against a target of 85% compared to 93.2% in 2018).
- 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 2018).
- 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 2018).
- QPI 10i of patients with high risk Gastrointestinal Stromal Tumour (GIST) who undergo surgery that receive post-operative Imatinib and 10ii of patients with high risk Gastrointestinal Stromal Tumour (GIST) who undergo surgery that receive post-operative Imatinib and commence this within 3 months of surgery (100% and 93.3% against a target of 90% compared to 84.6% and 100% in 2018).

Better

- QPI 3ii of patients with extremity soft tissue sarcoma who are clinically staged using the TNM staging system (73.3% against a target of 95% compared to 63.2% in 2018).
- QPI 5 of patients with gastrointestinal stromal tumours (GISTs) should have mutational analysis within 3 months of diagnosis (69.8% against a target of 90% compared to 59.0% in 2018)
- QPI 11i of patients who die within 30 days of surgical resection or oncological (Radical Radiotherapy, Neo-adjuvant Radiotherapy, Adjuvant Radiotherapy and Biological Therapy) treatment with curative intent (0% or 0%/0%/3.0%/0% against a target of less than 10% compared to 0% or 100.0%/0%/0%/0% in 2018).
- QPI 12 of all patients diagnosed with sarcoma who are consented for a clinical trial / research study, wherever eligible (7.9% against a target of 15% compared to 3.7% in 2018).

Poorer

- QPI 1 of patients with extremity sarcoma should have a histological diagnosis before undergoing a planned surgical resection (85.5% against a target of 90% compared to 91.2% in 2018).

- QPI 2 of patients with extremity sarcoma should be discussed by a multidisciplinary team (MDT) prior to definitive treatment (87.0% against a target of 95% compared to 87.5% in 2018).
- QPI 3i of patients with extremity soft tissue sarcoma who undergo staging CT scan where the results are available prior to definitive treatment (83.3% against a target of 95% compared to 87.2% in 2018).
- QPI 8 of patients with extremity sarcoma should receive radiotherapy within 3 months of surgery (57.1% against a target of 90% compared to 71.4% in 2018).
- QPI 9i of patients under the age of 40 with osteosarcoma who receive multi-agent chemotherapy (71.4% against a target of 90% compared to 75% in 2018).
- QPI 11ii of patients who die within 30 days of palliative oncological treatment (24.1% against a target of less than 15% compared to 8.3% in 2018).

The NMCN is further analysing GIST molecular pathology reporting, starting with WoS patients who were prescribed imatinib between January 2017 and August 2019. 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 2019 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 [first issue of the NMCN newsletter](#) was published in July 2020, led by Dr Ioanna Nixon. The second issue is in progress (but has been delayed by the pandemic).

Clinical Lead

Dr Ioanna Nixon extended her term as Clinical Lead for a further year (until October 2021) to provide continuity during the COVID-19 pandemic.

The recruitment of the next Clinical Lead is in progress.

External Scrutiny

The NMCN reports annually to the three regional cancer networks (advisors to the fourteen territorial NHS Boards) and National Services Division (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, Teenager Cancer Trust, 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 and formally Information Services Division (ISD)).

The NMCN reported six years of QPIs with its 2019/20 report and the second formal review of the QPIs through the national programme is scheduled to start in December 2021.

Audit and Governance Process

The clinical audit process captured 341 new cases of sarcoma for 2019/20 (53.4% 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 2019/20 clinical audit data was published in June 2021 and can be found on the [NMCN website](#).

Following publication of the report and in accordance with agreed governance procedure, the five specialist centres and the NMCN will produce an Action/Improvement Plan for 2019/20 in response to the key findings and actions identified in the report;

QPI 3: Clinical Staging

- National MCN to consider an amendment to the QPI at formal review to account for patients who die before treatment.
- All regions to ensure that TNM is documented at MDT for all patients.

QPI 8 – Post Operative Radiotherapy

- NHS Grampian to review local processes and determine the administration support required to improve the patient pathway.
- NMCN to review access to radiotherapy to facilitate more timely access to adjuvant treatment

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 2018/19 audit report and their actions are completed apart from;

QPI 5:- Molecular Staging of Gastrointestinal Stromal Tumours (GISTs)

- *The audit of West of Scotland GIST patients treated with imatinib completed the capture of data and Dr Ioanna Nixon is analysing this cohort so further improvements are agreed and implemented. The regional reporting of molecular pathology is expected to result in the target being met in 2022/23.*

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

Molecular pathology is now reported by the Glasgow centre for West of Scotland GIST patients from April 2020 which will improve the turnaround time (as samples no longer need to be sent to the Dundee centre). The Glasgow centre is expected to become fully operational by 2022/23.

4. Key Priority Areas for the NMCN in 2021/22

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 COVID-19 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.