North, South East and West of Scotland Cancer Networks

Sarcoma
National Managed Clinical Network



Annual Report April 2019 – March 2020

Dr Ioanna Nixon

Consultant Clinical Oncologist

NMCN Clinical Lead

Lindsay Campbell NMCN Manager

CONTENTS

EXECUTIVE SUMMARY		3
1.	INTRODUCTION	6
	NMCN GOVERNANCE	6
2.	NMCN WORK PLAN AND ACTIVITIES (04/2019 TO 03/2020)	6
	MULTI-DISCIPLINARY TEAM WORKING	6
	RESEARCH AND DEVELOPMENT	8
	EDUCATION	8
	NATIONAL CLINICAL AUDIT PROGRAMME	9
	GUIDELINE DEVELOPMENT AND REVIEW	10
	SERVICE MAP	11
	EXTERNAL SCRUTINY	11
	CHARITIES	11
	WEBSITE	12
	NEWSLETTER	12
	CLINICAL LEAD	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 2020/21	14
5.	CONCLUSION	14
ACKNOWLEDGEMENT		15

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 2019 and March 2020. It also reports on the findings and resultant actions required from the 2017/18 clinical audit report, as well as looking forward from April 2020 to March 2021.

NMCN Objectives

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

Multi-disciplinary Team (MDT) Working

The effectiveness and efficiency of the Scottish Sarcoma MDT was continually improved through a survey of MDT participants and a workshop in September 2019, with the referral form being updated in November 2019 and April 2020. Dr Ioanna Nixon nominated the Scotish sarcoma MDT as "cancer team of the year" for the British Medical Journal Awards 2020 with the Quality Improvement Project "National Sarcoma MDT Improvement" and the MDT has been short listed (the Awards have been inpacted by the COVID-19 pandemic). In the context of the project, a robust referral and output process is in place, a referral form has been designed, agreed and used. In addition, Dr Nixon asked Dr Douglas Rigg (Clinical Lead for the West of Scotland Primary Care Network) to peer review the Scottish Sarcoma MDT and his improvements are being implemented during 2020/21 through the West of Scotland Cancer Network's MDT improvement programme.

The teams in the MDT have now expanded to four with the creation of the head and neck sarcomas while the skin team has expanded to include breast sarcomas too.

Research and Development

The Scottish sarcoma research strategy is being implemented in partnership with the Charities and Universities, including the world's largest digital hub of sarcoma research data being led by Dr Robin Jones, at The Royal Marsden NHS Foundation Trust through a 5 year, £2.5 million project. The Glasgow centre (Dr Ioanna Nixon and Dr Jeff White) is leading on the clinical data work-stream for the consortium and the Edinburgh centre (Dr Larry Hayward and Prof Val Brunton) is also a collaborator on the grant.

The Scottish Bone Tumour Registry is awaiting the implementation of Microsoft 365 across Scotland (due September 2020) to enable the Registry to be brought up to date (from September 2018) and the Radiologists and Pathologists to link to their Scottish digital repositories.

The NMCN website has a <u>Clinical Trials page</u> that links to the sarcoma trials available in Scotland and news on the sarcoma trials Scotlish patients participates in.

Education

In May 2019 the NMCN education day was in Aberdeen. In October 2019 Bone Cancer Research Trust held their second patient and carer day in parallel with the NMCN education day in Glasgow. In December 2019 GIST Cancer UK (previously known as GIST Support UK) held their fifth patient and carer day in Edinburgh (the NMCN education day was cancelled to prepare for the 2020 British Sarcoma Group conference). In February 2020 the British Sarcoma Group conference was in Glasgow with the programme formed on the theme

"what matters to you, matters to us", and was extremely well received with feedback as one of the best conferences.

National Clinical Audit

The fifth audit of performance against quality performance indicators (QPIs) (for patients diagnosed between 1st April 2018 and 31st March 2019) was reported in February 2020. The actions from the fourth audit were completed. The Scottish Cancer Registry data for 2000 to 2018 will be requested (estimate September 2020).

• Guideline Development and Review

The Scottish guideline for gastrointestinal stromal tumours (GISTs) was reviewed in October 2019. The Scottish guidelines for bone, soft tissue and fibromatosis are being reviewed through the National Cancer Clinical Management Consensus Group (including medicines not approved by the Scottish Medicines Consortium due to the manufacturer not submitting them). The West of Scotland guideline for breast sarcoma is nearing completion (estimate September 2020) and the Scottish guideline for head and neck sarcoma is in development utilising the analysis of the survey of UK Clinicians.

Service Map

The West of Scotland sarcoma service map is being separated into three maps (bone and soft tissue; gastrointestinal sarcomas; skin and breast sarcomas) and the service maps for the North and South East will be developed with these two regions thereafter.

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). Healthcare Improvement Scotland reviewed the cancer QPIs with the three reginal cancer networks and the NMCN is further investigating QPIs 8 and 9.

Website

The <u>website</u> is being reveiwed led by Dr Jeff White and Alan Abraham, with a survey of the Scottish sarcoma MDT participants completed. A techical problem has meant we are unable to analyse activity so far.

Newsletter

The <u>NMCN's first newsletter</u> was published in June 2020, led by Dr Ioanna Nixon. The aim is to publish bianually.

Clinical Lead

Dr Ioanna Nixon became a member of the British Sarcoma Group in November 2019, visitied the USA in March 2020, and became a member of the Scottish Medicines Consortium's New Drugs Committee in April 2020. Dr Nixon has extended her role until October 2021 to lead the NMCN during the COVID-19 pandemic through the NMCN's rapid response group.

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, review and standardise cancer MDT constitution and operational policies, in order to ensure operational efficiency and sustainability
- 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

- Upgrade 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 2018/19 national audit data indicates the number of sarcomas in that year was 334. 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 Edinburgh centre multi-disciplinary teams (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). GIST patients are managed by the colorectal, hepatopancreatobiliary or 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 the other MDTs (breast, gynaecological oncology, head and neck, lung, neuro-oncology, skin and urological) with the support of the Scottish sarcoma or Edinburgh centre MDTs. The majority of treatment is surgical, with five year survival of 55%.

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 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 fifth year as national Clinical Lead. The <u>membership of the virtual steering group</u> and <u>constitution</u> of the NMCN are detailed on the NMCN website.

2. NMCN Work plan and Activities (04/2019 to 03/2020)

Multi-disciplinary Team Working

Led by Dr Mark McCleery and Dr Ioanna Nixon the participants of the Scottish Sarcoma MDT were surveyed and the analysis utilised for a workshop in September 2019. This resulted in the referral form being updated in November 2019, and again in April 2020. The constitution was reaffirmed as all sarcomas and breast sarcomas have joined skin sarcomas being led by Mr Steven Lo. Mr Jeremy McMahon, Glasgow Oral and Maxillo-Facial Surgeon, has joined the MDT to manage patients with head and neck sarcoma along with Dr Ioanna Nixon (who is leading the development of the head

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

and neck sarcoma guideline). The gynaecological oncology, lung, neuro-oncology and urological MDTs manage patients with sarcoma in that part of the body. Dr Douglas Rigg (West of Scotland Primary Care Clinical Lead) observed the Scottish sarcoma MDT and recommended improvements. 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.

The constitution and operational policy for the Scottish sarcoma MDT is in review to reflect all these improvements in partnership with the West of Scotland Cancer Network MDT improvement programme.

The Edinburgh centre MDT reviewed their referral form in July 2019 and manage patients in the South East of Scotland with bone or soft tissue sarcoma. Patients with gastrointestinal sarcoma (including GIST) are managed by the colorectal, hepatopancreatobiliary or upper gastrointestinal MDTs. Patients with skin sarcoma are managed by the skin MDTs. Patients with breast sarcoma are managed by the breast MDTs. Patients with head and neck sarcoma are managed by the head and neck MDT. The gynaecological oncology, lung, neuro-oncology and urological MDTs manage patients with sarcoma in that part of the body.

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 musculoskeletal oncology virtual clinic investigates and stages West of Scotland 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 (estimated completion September 2020).

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 a musculoskeletal 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.

Dr Michelle Ferguson continues to lead the Dundee centre.

Dr Walter Mmeka is single-handed in the Inverness centre.

Prof Paddy O'Dwyer, General Surgeon in Glasgow, retired in summer 2019. Catriona Graham, Clinical Nurse Specialist in Glasgow, moved on in August and was replaced by Alan Abraham in November 2019. Marnie Black re-joined the NMCN as the Scottish sarcoma MDT Coordinator and West of Scotland sarcoma Auditor (capturing the patient data to calculate the quality performance indicators) in February 2020. Nicola Heymans replaced Gordon McInally (who will specialise in Teenagers and Young Adults with cancer), Clinical Nurse Specialist in Dundee, in June 2020.

The Scottish sarcoma MDT is shortlisted for cancer care team of the year in the British Medical Journal's 2020 awards with the Quality Improvement Project "National Sarcoma MDT Improvement" but the awards have been impacted by the COVID-19 pandemic and delayed until October 2020.

Research and Development

During 2018 3.7% 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 2020/21.

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 Nationale dei Tumoti-Milano, and Instituto de Biomedicina de Sevilla.

The Scottish Bone Tumour Registry is awaiting the implementation of Microsoft 365 across Scotland (due September 2020) to enable the Registry to be brought up to date (from September 2018), the Radiologists and Pathologists to link to their Scottish digital repositories, and be maintained by the Scottish Clinicians and the Scottish sarcoma MDT Coordinator.

The NMCN website has a <u>Clinical Trials page</u> that links to the sarcoma trials available in Scotland and news on the sarcoma trials Scotlish patients participate in.

Education

2019/20 was special for the NMCN as it hosted the British Sarcoma Group conference in Glasgow in February 2020. The education day in Edinburgh planned for December 2019 was cancelled (to enable preparations for the conference) but the NMCN supported GIST Cancer UK's fifth patient and carer day. The education day in Aberdeen was in May while the education day in Glasgow in October was in parallel with Bone Cancer Research Trust's second patient and carer day.

The 28th May 2019 education day in Aberdeen had 27 delegates. Mr Ashish Mahendra presented the review of the first four years of quality performance indicators and why some patients did not achieve an R0 resection. Mr David Boddie then presented the mortality and morbidity for the North of Scotland during 2017/18. Dr Fiona Cowie then presented the highlights of the British Sarcoma Group 2019 conference in London in February 2019 along with an overview of the clinical trials available in the UK. Dr Sinclair Dundas presented the Scottish sarcoma research strategy for approval (and it was published in August 2019). On behalf of Dr Jeff White, Lindsay Campbell presented the first draft of the programme for the British Sarcoma Group conference in Glasgow. On behalf of Dr Ioanna Nixon, Lindsay Campbell presented the Clinical Lead's update that included the launch of the Cancer Tapestry by Andrew Crummy.

The 9th October 2019 education day in Glasgow had 37 delegates. Dr Jeff White and Mr Peter Chong presented the mortality and morbidity for West of Scotland patients during 2017/18, including an update on the Transatlantic Australasian Retroperitoneal Sarcoma Working Group by Peter. Jacqui Frame then discussed her care with Louise Kirby (Patient Support and Engagement Manager, Bone Cancer Research Trust) and answered questions. Garry Hecht then demonstrated the DISCOVERY dashboard that does not include sarcoma patients yet but will work with the NMCN to achieve this. Dr Henry Daebritz then presented the ongoing GIST research in the Glasgow centre North, South East and West of Scotland Cancer Networks

in partnership with the Cambridge centre. Dr Ramesh Bulusu then presented the research and services in the Cambridge centre. Ms Martha Quinn then presented the GIST surgical services across Scotland. Dr Jeff White then presented the latest draft programme for British Sarcoma Group conference in Glasgow. Dr Ioanna Nixon then presented the Clinical Lead's update that included Healthcare Improvement Scotland's review of the sarcoma quality performance indicators.

GIST Cancer UK's fifth patient and carer day in Edinburgh on 3rd December 2019 had 34 participants. On behalf of Dr Ioanna Nixon, Lindsay Campbell presented the NMCN update and answered questions.

Some of the Clinicians travelled to China in November 2019 to present to an international conference and caught up with Mr Daniel Porter. The <u>trip report (including photographs) by Dr Jeff White</u> is available on the NMCN website.

The British Sarcoma Group 2020 conference was held on 26th and 27th February in Glasgow with 356 attendees, 23 free talks and 88 posters. On the evening of 25th there was a civic reception at Glasgow City Chambers to welcome everyone. The dinner on the 26th was attended by 139 people and included a video update from Camera Obscura made by Sarcoma UK, and Prof lan Judson's reflections of his time in New Zealand. The second day included the first patient and carer session hosted by Shelagh Allison and Martin Cawley (CEO of the Beatson Cancer Charity) and the feedback is being utilised by the British Sarcoma Group for their 2021 conference in Cardiff. Throughout the conference Andrew Crummy's Cancer Tapestry was available for everyone to add a stitch, supported by Heather Swinson (cancer survivor and lead for the first panel of the tapestry). On the morning of the 27th a 5km walk was hosted by Dr Fiona Cowie, a 5km run by Dr Jeff White, and a mindfulness session by Dr Ioanna Nixon and Dr Avinash Basdibe (mindfulness instructor). The programme and abstract book are available on their website with photographs and report on the NMCN website. Dr Ioanna Nixon and Dr Jeff White led the programme organising committee and the NMCN Clinicians reviewed the 112 abstracts. The theme of the conference was "what matters to you, matters to us", and the conference was extremely well received with feedback as one of the best conferences yet.

National Clinical Audit Programme

A key area of the sarcoma NMCN was to effectively utilise audit findings to inform and drive service improvement. A comprehensive clinical audit report of performance against quality performance indicators (QPIs) for 2018/19 (our fifth year of reporting) was issued to NHS Boards in February 2020 and is available on the About the SSN page of the NMCN website. The two indicators related to GIST (5 and 10) could not be reported due to data definition and measurability issues while there were again small number of patients reported against the indicators for radiotherapy (8) and systemic anti-cancer therapy (9). The actions from the fourth year were completed. The sarcoma NMCN is encouraged by the performance of NHS Boards and centres against the national QPIs with results demonstrating that patients with a sarcoma receive a consistent and improving standard of care across all geographical locations; three of the twelve indicators achieved, two better than 2017/18, three poorer, two measured for the first time (due to new data items being introduced) and the two that could not be reported. The details are:

Achieved

- QPI 1 of patients with extremity sarcoma should have a histological diagnosis before undergoing a planned surgical resection (91.2% against a target of less than 90%).
- QPI 6 of patients with extremity sarcoma should have primary limb-sparing surgery (93.2% against a target of 85%).
- QPI 7 of patients with extremity sarcoma should have successful primary flap reconstruction following surgical resection (100% against a target of 85%).

Better

- QPI 3ii of patients with extremity soft tissue sarcoma who are clinically staged using the TNM staging system (63.2% against a target of 95% compared to 58.9%) with 3i measured for the first time
- QPI 8 of patients with extremity sarcoma should receive radiotherapy within 3 months of surgery (71.4% against a target of 90% compared to 52.4%).
- QPI 11i of patients who die within 30 days of surgical resection or oncological treatment with curative intent (0.5% against a target of less than 10% compared to 1.2%) and QPI 11ii of patients who die within 30 days of palliative oncological treatment (6.2% against a target of less than 15% compared to 8.3%)

Poorer

- QPI 2 of patients with extremity sarcoma should be discussed by a multidisciplinary team (MDT) prior to definitive treatment (87.5% against a target of 95% compared to 94.3%).
- QPI 4 of patients with extremity sarcoma undergoing surgical resection should have their tumour adequately excised (80.7% against a target of 85% compared to 84.5%).
- QPI 12 of all patients should be considered for participation in available clinical trials / research studies, wherever eligible (3.7% against a target of 15% compared to 8.2%)

Measured for the first time

- QPI 3i of patients with extremity soft tissue sarcoma who undergo staging CT scan where the results are available prior to definitive treatment (87.2% against a target of 95%)
- QPI 9i of patients under the age of 40 with osteosarcoma who receive multi-agent chemotherapy (75% against a target of 90%) and 9ii of patients under the age of 50 with Ewing's sarcoma who receive multi-agent chemotherapy (100% against a target of 90%)

Could not be measured

- QPI 5 of patients with gastrointestinal stromal tumours (GISTs) should have mutational analysis within 3 months of diagnosis (target of 90% but data definition and measurability issues mean it will not be reported until 2019/20)
- 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 (both target of 90% but data definition and measurability issues mean it will not be reported until 2019/20)

The NMCN is auditing West of Scotland patients with GIST to ensure both QPIs are able to be reported.

The NMCN will be requesting Scottish Cancer Registry data for patients diagnosed with a sarcoma between 2000 and 2018 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).

The 31 and 62 days waiting times standards are not reported for sarcoma but the fourteen territorial Boards track each sarcoma patient to ensure equity of care.

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 GIST CMG was reviewed in October 2019 to incorporate the review of the GIST pathology CGD in May 2019.
- The reviews of the Scottish bone and Scottish soft tissue CMGs and the development of the Scottish fibromatosis CMG (led by Dr Jeff White and Dr Ioanna Nixon) have restarted after

Medical Directors and Directors of Pharmacy confirmed medicines not approved by the Scottish Medicines Consortium due to the manufacturer not submitting them cannot be included. These medicines perform well in clinical trials and Oncologists are able to request them for a patient through the Peer Approved Clinical System Tier 2 (PACS 2) process (that replaced Individual Patient Treatment Requests (IPTRs)). The NMCN is a member of the National Cancer Clinical Management Consensus Group that is reviewing cancer CMGs for the future. The NMCN is tracking the requests to ensure equity of care across Scotland; with the second analysis in progress for patients prescribed during 2017-2019 (first analysis was 2008-2016).

- The development of the West of Scotland breast sarcoma CMG (led by Mr Steven Lo) in partnership with the West of Scotland breast managed clinical network is nearing completion (estimated by September 2020).
- The development of the Scottish head and neck sarcoma CMG (led by Dr Ioanna Nixon) in partnership with the three regional head and neck managed clinical networks is making good progress with the UK Clinicians surveyed with the support of the British Sarcoma Group and the British Association of Head and Neck Oncologists.
- The review of the West of Scotland cutaneous (skin) sarcoma CMG has started (led by Mr Steven Lo) with an audit of practice over the 3 years of version one led by Dr Ruth Blair.
- The review of the Scottish sarcoma follow-up guideline has started (led by Dr Ioanna Nixon) with a survey of patients, carers and Clinicians on the use of telemedicine (virtual clinic appointments) which has been accelerated by the COVID-19 pandemic.
- The constitution of the NMCN is being reviewed (led by Dr Ioanna Nixon) in partnership with the Managed Service Network for Children and Young People with Cancer to ensure it remains applicable to all ages.

CMGs can be accessed from the <u>sarcoma page of the West of Scotland Cancer Network intranet</u> <u>site</u> (when connected to the NHS network). CGDs can be accessed from the <u>NMCN website</u>.

Service Map

The West of Scotland service map is being separated into 3; bone/soft tissue, gastrointestinal and skin/breast to reflect the 3 teams in the Scottish sarcoma MDT. This requires the activity data to be separated too and Julie McMahon is preparing this based on the 2019/20 QPI data. The service maps for the North and South East of Scotland will be developed with each region thereafter.

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).

Healthcare Improvement Scotland audited the three reginal cancer networks and the cancer QPIs, with Dr Ioanna Nixon presenting the sarcoma QPIs to the West of Scotland meeting. The NMCN has been asked to further review QPIs 8 and 9 performance and implement any improvements.

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 and #hellomynameis continue to be active members of the NMCN and participated in the British Sarcoma Group conference in Glasgow in February 2020.

Website

Lorraine Striling (Network Administrator) has taken over from Debi Kirk (patient and entrepreneur) as the Webmaster for the <u>Scottish Sarcoma Network website</u>, with Lindsay Campbell as her deputy. Dr Jeff White (Oncologist) and Alan Abraham (Clinical Nurse Specialist) are leading the review of the website and have surveyed the Scottish sarcoma MDT participants. The improvements have been split into two phases with phase one in April to September 2020 and phase two October 2020 to March 2021.

A technical problem has meant the website activity cannot be analysed yet, but this will hopefully be resolved during 2020.

Newsletter

The <u>first issue of the NMCN newsletter</u> was published in June 2020, led by Dr Ioanna Nixon. The newsletter will be published biannually and Dr Ioanna Nixon is working with NMCN members on the second issue planned to be published in December 2020.

Clinical Lead

Dr Ioanna Nixon joined the British Sarcoma Group in November 2019 and the Scottish Medicines Consortium's New Drugs Committee in April 2020. In March 2020 Dr Ioanna Nixon travelled to NASA, Microsoft and MD Anderson in the USA in the context of a quality improvement and safety study trip. Dr Ioanna Nixon will extend her term as Clinical Lead for a further year (until October 2021) to provide continuity during the COVID-19 pandemic.

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 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 334 new cases of sarcoma (35 of bone, 164 of soft tissue, 60 of GIST and 75 of other) for 2018/19. 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.

Following publication of the report and in accordance with agreed governance procedure, the five specialist centres have produced an Action/Improvement Plan for 2018/19 in response to the key findings and actions identified in the report;

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

- MCN to further explore with ISD and Information Managers the data recording and measurability issues raised via the ISD Query Log to ensure national agreement on how to measure this indicator going forward.
- Glasgow centre to share any learning from the ongoing GIST imatinib audit with other Scottish centres to ensure the accurate capture of GIST patients going forward.

QPI 8:- Post Operative Radiotherapy

 NHS Grampian and NHS Tayside to report back to the MCN the findings of the audit to identify discrepancies in numbers.

QPI 11:- 30 day Mortality Following Palliative Chemotherapy/Radiotherapy

 NCA should discuss cases where patients died within 30 days of palliative chemotherapy and radiotherapy at Morbidity and Mortality meeting and provide feedback to MCN.

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

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

- The audit of West of Scotland GIST patients treated with imatinib is completing the capture of pathology data and Dr Amy Young will then analyse this cohort with Dr Ioanna Nixon.
- Dr Amy Young and Dr Ioanna Nixon will then present the analysis to the first virtual NMCN education day so improvements are agreed and implemented.

QPI 8:- Post Operative Radiotherapy

 NHS Grampian and NHS Tayside reported back to the MCN the findings of the audit that identified the discrepancies in numbers. Dr Ioanna Nixon is reviewing the findings with the North of Scotland centres to agree improvements and implement them.

QPI 11:- 30 day Mortality Following Palliative Chemotherapy/Radiotherapy

 As the education days have been impacted by the COVID-19 pandemic the North of Scotland centres will present their Morbidity and Mortality at the next available virtual education day.

Action/Improvement Plan Progression

All three Regions returned their action/improvement plans in response to the 2017/18 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

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). This means each region is self-sufficient (Dundee centre for the North and Edinburgh centre for the South East).

As surgery for sarcoma is performed by the appropriate Surgeon participating in the appropriate MDT the NMCN re-confirmed the Surgeons and MDTs to ensure care is provided as effectively and efficiently as possible (GIST through the review of the CMG and head and neck through the survey). Aberdeen, Edinburgh and Glasgow centres continue to perform the majority of the surgery for bone and soft tissue sarcomas and the Scottish Pathologists continue to triple report patients managed by the Scottish sarcoma MDT and Edinburgh centre MDT. During the first wave of the COVID-19 pandemic the Glasgow Surgeons operated at the Golden Jubilee National Hospital instead of Glasgow Royal Infirmary.

The Scottish sarcoma MDT, Edinburgh centre MDT and Glasgow virtual clinic had Clinicians participating from their office or home during the COVID-19 pandemic. This is planned to continue for the foreseeable future and the switch to Microsoft Teams will better enable this (the Edinburgh centre MDT is continuing with NHS Scotland video conferencing until the South East migrates to Microsoft 365 in September 2020).

Dr Ioanna Nixon utilised WhatsApp to work with the Scottish sarcoma Clinicians during the COVID-19 pandemic (as guidelines were developed so quickly across the UK), forming a rapid response COVID-19 group. The group has representation from all centres and all disciplines and WhatsApp continues to be used to keep everyone up to date on all the work of the NMCN.

4. Key Priority Areas for the NMCN in 2020/21

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, review and standardise cancer MDT constitution and operational policies, in order to ensure operational efficiency and sustainability (continuing the Scottish Sarcoma MDT data collection to enable monitoring of performance and allow for improvements)
- 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
- Upgrade 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, the Scottish Cancer Research Network, the Scottish Primary Care Cancer Group, the Scottish Clinical Imaging Network, the Scottish Pathology Network (especially the Scottish Molecular Pathology Consortium) and NHS Education for Scotland for their support and collaboration.