

# Scottish Sarcoma Network

## Annual Report 2024/25

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## Introduction

The Scottish Cancer Network (SCN) was established in 2021 as part of the Scottish Government's (SG) commitment in [Recovery and Redesign: An Action Plan for Cancer Services](#) (December 2020) and has been highlighted as at the heart of SG ambitions for defining clinical management pathways in [Cancer Action Plan for Scotland 2023-2026](#) (June 2023). The [Scottish Government Cancer Strategy 2023-33](#) states:

*"The Scottish Cancer Network (SCN) will be at the heart of our strategic ambitions... The SCN will also host national networks, where national integration and collaboration for specific cancers can make best use of expert resources and improve outcomes for people with cancer. It will drive 'Once for Scotland' work, where appropriate, and work closely with regional networks where work is better delivered at that level."*

The Scottish Sarcoma Network (SSN), established in 2004 to deliver equitable high quality clinical care to sarcoma patients across Scotland. SSN successfully moved to the SCN during 2022/23. Sarcomas are a rare group of cancers that occur in bone and connective tissue. The effective management of these patients throughout Scotland relies on co-ordinated delivery of treatment and care that requires close collaboration of multi-disciplinary professionals. Bone and soft tissue sarcoma patients are managed by the Scottish sarcoma Multi-disciplinary team (MDT) meeting or south-east of Scotland (SEoS) sarcoma multi-disciplinary meeting (MDM) with the clinicians based in five centres across Scotland (Edinburgh, Aberdeen, Dundee, Inverness and Glasgow). West of Scotland (WoS) patients are initially managed by the WoS Musculoskeletal (MSK)-Oncology Virtual Clinic before referral to the national sarcoma MDT. Gastro-intestinal stromal tumour (GIST) patients in the north of Scotland (NoS) and SEoS are managed by the Colorectal, HepatoPancreatoBiliary (HPB) or Upper Gastrointestinal (UGI) MDTs. GIST patients in the WoS are managed by the Scottish Sarcoma MDT. Small numbers of sarcoma patients are managed by other MDTs (such as breast, gynaecological oncology, head and neck, lung, neuro-oncology, skin and urological) with the support of the Scottish or SEoS Sarcoma MDTs. Scottish Ewing sarcoma patients are re-discussed at the UK Ewing Sarcoma MDT meeting, as appropriate.

## Highlights

- ✓ Successful in-person National Education Event at Malmaison, Dundee on 22-March 2024, attended by 48 delegates from the sarcoma clinical community, associated audit and support staff and partner charities
- ✓ Quarterly Steering group meetings were held throughout 2024/25
- ✓ Improved engagement across the three regions was observed
- ✓ Successful implementation of Key Performance Indicators (KPIs) for the SSN MDT Coordinator and Audit Facilitator role, with the value of this role in national MDT co-ordination of care for sarcoma patients evidenced
- ✓ The majority of key priorities were delivered, with the exception of sarcoma benchmarking which was dependent on case ascertainment by the Scottish Pathology Network (SPaN), paused as part of the prioritisation exercise conducted pending SG network review

## **Stakeholder Communication and Engagement**

Annual review of the [SSN website](#) was conducted. The website complies with NSS requirements for safety and security of content and associated links and is updated regularly.

The [SSN newsletter](#) (August 2024) shared news, staff changes and updates on projects, clinical trials, and information from partner charities with the wider community.

## **Education and Training**

SSN held a National Education Event at Malmaison, Dundee on 22<sup>nd</sup> March 2024. Hosted by the Edinburgh cancer team, there was strong attendance from this small, specialised community with 44 delegates, including clinical representation from all three regions as well as partner charity representation.

The day consisted of a varied programme, including specialty breakout sessions, NHSE presentation on long-term effects of treatment and discussions on Scottish desmoid tumour guideline. Evaluation of the event highlighted:

- ✓ 95% of attendees found the event useful or extremely useful
- ✓ 68% of attendees thought the event organisation was very good or excellent
- ✓ praise for the interesting and multi-disciplinary nature of the programme
- ✓ appreciation for the opportunity to network and hear from a range of professionals
- ✓ breakout sessions, as well as the focus on young adults in the afternoon
- ✓ well-informed and balanced views from all presenters

The network is very small and in-person events are incredibly important for maintaining network, peer support and for single-handed clinicians.

The Network continues with its bimonthly virtual surgical mortality and morbidity meeting to provide surgeons the opportunity to have peer-supported discussions of challenging or difficult cases encountered over the previous year.

In addition to Sarcoma UK, the SSN has links with partner sarcoma charities, including Bone Cancer Research Trust, GIST Cancer UK, Macmillan and Maggie's centres. The latter provide access to psychological support for patients in some health boards.

## **Service Development and Delivery**

The National Sarcoma MDT continues to experience high levels of referrals set against a background of staffing shortages at clinician and clinical nurse specialist level. MDT Co-ordinator and Audit Facilitator role KPIs were developed and implemented in collaboration with the host board to support oversight of the role. The refined MDT referral form has supported streamlining of sarcoma patients, but further work is required to ensure referring clinicians attend the meeting to present, increasingly complex, cases to the national MDT.

The [Cancer Action Plan for Scotland 2023-2026](#) identifies Quality Performance Indicators (QPIs) as a key driver of an overall cancer services improvement agenda, aligning with national clinical management and optimal pathways.

**Audit and Continuous Quality Improvement**

The [2023/24 Sarcoma Clinical Audit Report](#) is available on the SSN website. Data analysis of Sarcoma QPIs for April 2023 to March 2024 focused on sarcoma of soft tissue and the extremities, the most common sites of sarcoma.

National audit data (Table 1) indicates that there were 360 patients diagnosed with a new primary invasive sarcoma in FY2023/24. The majority of new diagnoses were in the West of Scotland (42%), with close to a third in the South-East (32%) and just over one quarter in the North (26.1%). The percentage incidence increased in females (46.1% of new cases) in 2023/24 compared to 53.9% male new cases. Over three quarters of new diagnoses (78.6%) are aged 50 years or over. The SSN continues to support and develop the clinical service for sarcoma patients (bone, soft tissue, gastrointestinal stromal tumour (GIST) and desmoid tumours).

**Table 1: Sarcoma QPI Patients Diagnosed Apr 2023 – Mar 2024**

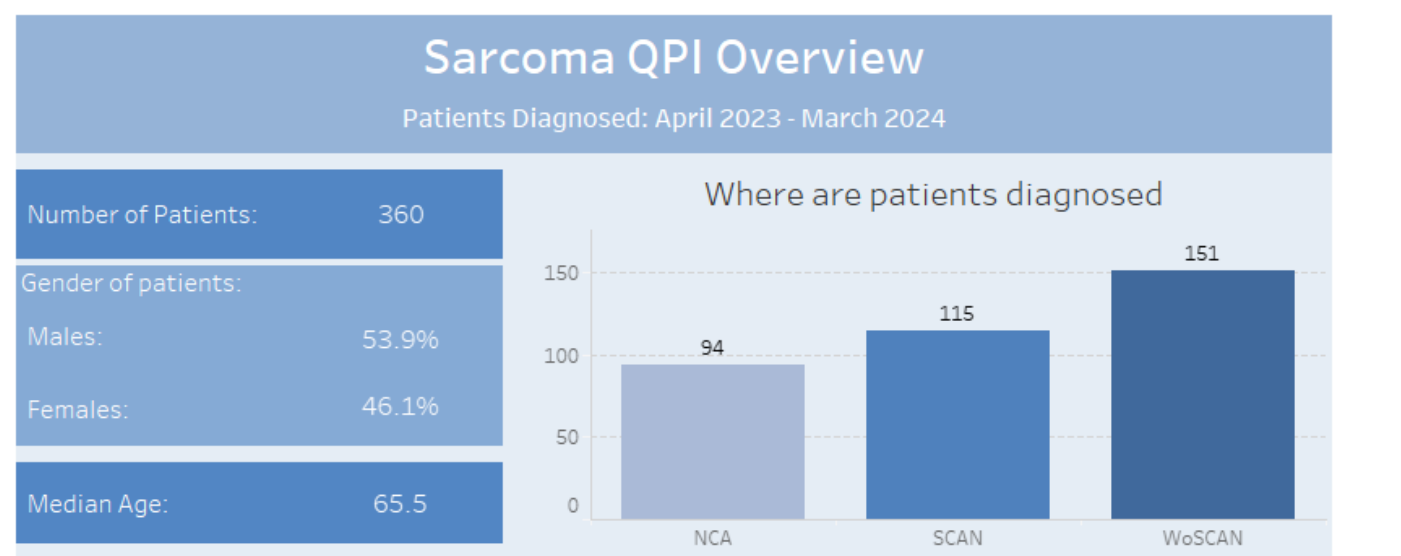
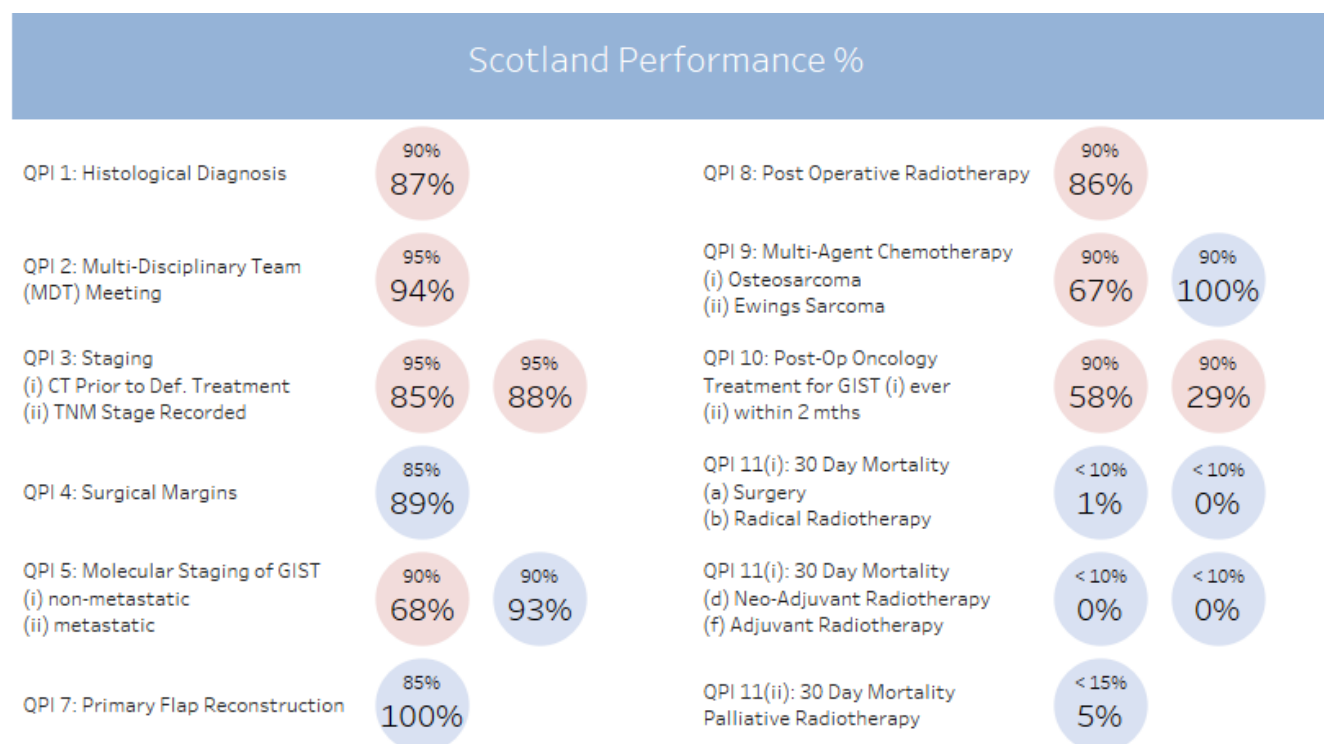


Table 2 illustrates the performance against target for the QPIs used to assess the sarcoma services across Scotland. Although the majority of cases occur in older individuals for both sexes, it is notable that one fifth (21.4%) of sarcomas were diagnosed in individuals younger than 50 years.

**Table 2: Sarcoma QPI Performance Percentage for Patients Diagnosed Apr 2023 – Mar 2024**



## Key Achievements

- ✓ Surgical margins, primary flap reconstruction and 30-day mortality for both curative and palliative treatments continue to be areas of strength
- ✓ Improvements were observed in molecular staging for metastatic GIST and multi-agent chemotherapy for Ewings sarcoma
- ✓ Performance in the service continues to be high, and better than indicated by percentage figures, as low numbers for these rare cancers' skew the data.

## Become improvers and innovators

The SSN Clinical Lead sits on the UK Sarcoma Early Diagnostic Steering Group and UK Sarcoma Advisory Group. The Sarcoma Early Diagnostic Steering Group (UK) develops national guidelines to improve sarcoma referral and diagnostic pathways for patients with these rare cancers. This work is a collaborative effort with NHSE and charity partners, Sarcoma UK, and feeds into the Sarcoma Advisory Group.

The Sarcoma Advisory Group is the primary source of clinical opinion for sarcoma services and provides oversight for guidelines and molecular testing pathways. In addition to developing guidelines, it provides a forum for all clinicians involved in sarcoma care where issues or challenges can be addressed. The group has quarterly online meetings with one in-person meeting per year, which was held in Birmingham in 2024.

## Financial Sustainability

Extension for SSN Clinical Lead (0.1WTE) and SSN MDT Co-ordinator and Audit Facilitator (1WTE) roles were confirmed until 31<sup>st</sup> March 2025. Further funding extensions for both roles were

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confirmed until 30<sup>th</sup> September 2025, on a risk-based approach, pending the outcome of the Scottish Government national network review.

The national education event was held early (22<sup>nd</sup> March) and costs allocated during 2023/24 and therefore there was no incurred cost for this in-person event.

## **Climate sustainability**

Throughout 2024/25 the SSN continued to adopt a digital first approach as standard with 100% network business meetings (including steering group, MDT and data meetings conducted virtually).

## **Workforce sustainability**

The SSN Clinical Lead tenure was extended for ten months to 31<sup>st</sup> March 2025, initially, and further extended to 30<sup>th</sup> September 2025 pending the outcome of the Scottish Government network review. The Steering Group membership has been refreshed to improve cross regional and specialty representation.

The network programme team has had a vacancy for some months at the beginning and end of 2024/25, but the wider SCN Team have supported to enable continued delivery of service for the network.

## **Looking forward – 2025/26**

Key deliverables to be achieved in 2025/26 are:

- Hosting a National Education Event
- QPI reporting process and 2024/25 Sarcoma Clinical Audit Report
- Clinical Management Guidelines finalised and ratified by steering group
- Molecular Pathology for GIST tumours

## **Finance**

Network core business and activities were achieved whilst contributing to savings for NSS, with a total spend of £69K.

Due to current financial constraints being experienced across NHS Scotland, SSN will continue to minimise budgetary spend in the coming financial year, where feasible.