

Scottish Mesothelioma Network

Annual Report

2024/25

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Introduction

The Scottish Cancer Network (SCN) currently manages, supports and governs five national cancer networks. The [Scottish Government Cancer Strategy 2023-33](#) ^[68] states:

“The 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 Mesothelioma Network (SMN) was launched as a project in March 2019. The network was initially hosted by NHS Greater Glasgow and Clyde, supported by pump priming funds from Macmillan Cancer Support and Mesothelioma UK. In 2021 the network successfully secured recurrent funding from the Scottish Government and moved into the Scottish Cancer Network (SCN) as of April 2022.

Mesothelioma is an invasive cancer caused by prior exposure to asbestos, usually occurring 30-50 years after inhalation of asbestos dust. Areas of Scotland have the highest incidence of mesothelioma globally. It affects the chest (pleural mesothelioma) in over 90% of patients but can also affect the abdomen (peritoneum), the lining of the heart (pericardium) or the testicles (tunica vaginalis). At present, there is no cure for Mesothelioma and many patients die within a year of diagnosis. However, palliative chemotherapy can prolong life in some patients (Vogelzang et al, JCO 2003) and there are effective means of controlling symptoms such as breathlessness and pain (Woolhouse et al, Thorax 2018). Importantly, there has been a tremendous recent increase in mesothelioma research, resulting in a large number of clinical trials of new treatments, which can be life-changing (Blyth & Murphy, Resp Med 2017). However, access to these requires that patients must be promptly diagnosed and properly informed. This access should be equitable and available to all.

The network that operates a ‘hub and spoke’ model and aligns with the SCN and SG strategic aims once for Scotland and equity of access to care for all patients wherever they live in Scotland. The SMN also provides educational and learning opportunities for clinicians involved in the management of their patients. The network enables Mesothelioma Clinical Nurse Specialists (CNS), who provide enhanced support locally for patients and carers. Patients also have a dedicated Mesothelioma Lead Clinician in each region to improve clinical care and access to clinical trials.

Network staff, based in Glasgow, Edinburgh, Inverness, Dundee and Aberdeen attend a virtual MDT meeting every Friday at 1.30pm via Teams, to represent the patients and feedback clear, high-quality management plans and clinical trial information. This approach aims:

- to provide a forum for clinical teams from across Scotland to share expertise
- to speed up diagnosis and treatment of patients wherever they live
- to develop high quality care plans
- to maximise access to potentially life-changing clinical trials regardless of where a patient lives
- to facilitate optimal care delivery as close to home as possible.
- to ensure patients have access to a dedicated Mesothelioma Clinical Nurse Specialist and dedicated pathways developed by Mesothelioma Lead Clinicians.
- to gather mesothelioma specific patient information which is used for audit and continuous improvements in outcomes, including survival and quality of life

The network has built strong links between acute services and charity support organisations to ensure that patients and their families across Scotland are being offered the most up to date benefits and legal advice, as well as emotional and practical support.

The network also seeks to maximise opportunities for continued medical education and training of professionals involved in the treatment of mesothelioma patients.

Highlights 2024/25

- ✓ Successful SMN 'hub and spoke' MDT model being used as a template for roll out of similar models in England and Wales.
- ✓ Completion of multicentre ambispective cohort study evidencing impact of network since launch suggests that introduction of a specialist mesothelioma network has improved the survival of patients with Pleural Mesothelioma and evidences the benefit of the expert National MDT Model
- ✓ Clinical Audit of Mesothelioma Quality Performance Indicators (QPIs) comparison evidences improvement in the diagnostic pathway (imaging and histopathology) over the four years of QPI reporting
- ✓ Clinical Management Guidelines (CMGs) for mesothelioma have been developed in collaboration with clinical representatives from all specialties and regions across Scotland
- ✓ Successful implementation of KPIs for MDT Coordinator and Audit Facilitator role evidenced the value of the role in coordinating the patient pathway national and delivering high quality care plans
- ✓ Successful in person education event at the Royal College of Physicians in Edinburgh on 6th Feb attended by 80 representatives from the mesothelioma community clinical and support services

Stakeholder Communication and Engagement

An annual review of SMN [website](#) was carried out in line with NSD governance.

The SMN has been collaborating with Mesothelioma UK, Asbestos Action, Maggie's, Action on Asbestos, Macmillan Cancer Support and Clydebank Asbestos Group. Outputs include:

- ✓ Ongoing funding and training from these partners for five Meso UK CNSs across Scotland
- ✓ Ongoing support of delivery of standard patient information pack issued to all patients across Scotland at diagnosis. Including information materials and folder
- ✓ Clinical teams attend and present at conferences and support groups across Scotland to engage with stakeholders including patients and share learning from the network, including Mesothelioma UK Patient and Carer Day, Clydebank Asbestos AGM and Asbestos Action Memorial Day

Education and Training

The SMN held an in person National Education Event on 6th Feb 2025 at the Royal College of Physicians in Edinburgh. Around 70 delegates from across Scotland joined. These delegates were from a range of backgrounds across the mesothelioma community including clinical, charity, administration and audit staff. There were sessions on the network, data intelligence, trials and current research and over 90% of attendees rated the event very relevant to their clinical practice. Highlights included:

- ✓ A presentation by network CNS on specialised role of the mesothelioma CNS
- ✓ Session on palliative care, symptom control and pain management
- ✓ Sessions on clinical trials and the network quality performance indicators

Event Evaluation

- ✓ 77% of attendees found the programme excellent or very good.
- ✓ 82% of attendees thought the event was organised excellently or very well.
- ✓ Attendees thoroughly enjoyed having the event "face to face"
- ✓ The importance of networking and peer support at educational events was stressed.

- ✓ The presentations and speakers were very informative and interesting

Service Development and Delivery

The [Cancer Action Plan for Scotland 2023-2026](#) identifies Quality Performance Indicators 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 Mesothelioma Clinical Audit Report 2023 is available on the network website [Mesothelioma QPI Reports – Scottish Mesothelioma Network](#). This was the fourth year of Mesothelioma QPI reporting since launch in 2019.

The continued support and commitment of the Scottish Mesothelioma Network members ensures the delivery of high-quality care to mesothelioma cancer patients across the country.

Patients with mesothelioma receive high quality care across Scotland and the results of the annual QPI audit reports demonstrate the continued commitment to improve the experience and care received across the patient pathway. Data capture is of a high standard enabling robust assessment of performance against QPIs.

All QPIs presented in this report were subject to evaluation during the first mesothelioma QPI Formal Review in October 2022. Changes identified were implemented in the 2023 reporting. QPI measures that have presented continued and specific challenges (QPIs 4, 5 and 6) were amended to capture and report on newly identified best practice.

The graphs used in this current 2023 audit report show comparison data across 2021-23 where available. This comparison provides evidence of consistent improvement in QPIs 1, 2, 3, 4 and 8 across all Health Boards. QPIs 5 and 6, around Radiotherapy for Uncontrolled Pain Management and Pleural Fluid Management are proving more challenging. Although QPI 5 is showing some improvement since the changes made at formal review in early 2023.

Each NHS Board has provided detailed comments on the results where QPI targets were not met. Board feedback indicates valid clinical reasons and patient locality or co-morbidities that influenced patient management. There are some areas where there are specific challenges that require action either within or out with specific boards/centres which will be discussed later in the report. Additionally, these Boards have indicated where positive action has already been taken at a local level to address any issues highlighted through the QPI data analysis. It is anticipated that these positive changes will result in improved performance going forward.

Mesothelioma Quality Performance Indicators

Patients Diagnosed: 1 January 2023 - 31 December 2023

Number Diagnosed with Pleural Mesothelioma: **132**

Number Diagnosed with Mesothelioma: **138**

Sex:

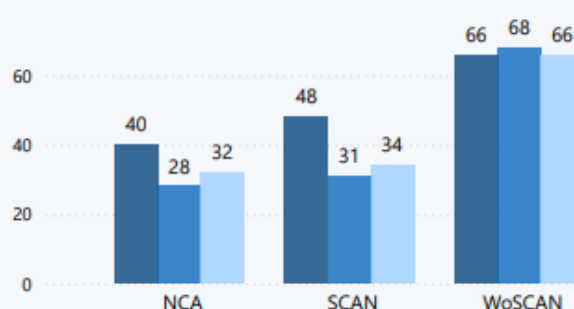
Female 20.5%

Male 79.5%

Median Age: **78**

No. of Patients by Region of Diagnosis

● 2021 ● 2022 ● 2023



QPI Performance

QPI	Target	National	QPI Met
QPI 1(i) - Diagnostic Imaging	90%	93.2%	✓
QPI 1(ii) - Diagnostic Imaging	95%	98.3%	✓
QPI 2(i) - Diagnostic: Histopathology	85%	93.9%	✓
QPI 2(ii) - Diagnostic: Histopathology	95%	99.2%	✓
QPI 2(iii) - Diagnostic: Histopathology	95%	98.7%	✓
QPI 3 - Multidisciplinary Team	95%	97.7%	✓
QPI 4 - Systemic Anti Cancer Treatment	60%	76.3%	✓
QPI 5 - Radiotherapy for Management of Pain	75%	62.5%	✗
QPI 6 - Pleural Fluid Management	90%	73.1%	✗
QPI 8 - Post-Mortem Examination	< 10%	6.3%	✓

Areas for Action

Further analysis will be coordinated by SMN to understand variance in performance:

- QPI 1 (i) and (ii)
- QPI 3
- QPI 5
- QPI 6

Key Achievements

This was the fourth year of the mesothelioma QPI data reporting. QPI data was met nationally on five out of the seven reported QPIs, and performance has improved across all the reported QPIs in all regions with notable improvements in QPI 2 (i) and (iii). QPI 3 continued to improve with ongoing education and engagement with regional MDTs. QPI 5 and 6 did not meet the target despite changes to the measurement criteria at Formal Review in early 2023, although there is improvement shown in QPI 5 and SCAN achieved 100% on QPI 6. QPI 4 showed a marked improvement across all regions.

It should be noted that the denominator numbers for many of the QPIs are small and that impacts percentages. In some cases where QPI targets have not been achieved this has resulted in non compliance in only a single case in some boards.

A multicentre ambispective cohort study was performed, including all cases diagnosed April 2017-April 2022

Equitable delivery of high-quality care is challenging in pleural mesothelioma (PM). Previous UK-audits report variable practice and outcomes. We report outcomes from an embedded impact assessment.

Baseline data, treatment and survival outcomes were collected prospectively in all network cases (April 2019-April 2022) and West of Scotland pre-network cases (April 2017-March 2019). Data were retrieved retrospectively for other cases via cancer networks and Public Health Scotland. Overall survival (OS) was compared between pre-network and network cohorts using Restricted Mean Survival Time (RMST). RMST differences were integrated with baseline features and treatment utilisation, including ipilimumab-nivolumab and surgery. Treatment effects were modelled by Propensity Score Matching.

659 consecutive patients were included (pre-network n=273, network n=386). Cohort demographics were well-balanced. Adjusted RMST was 5.17 months longer in non-epithelioid network cases ($p=0.002$), but did not differ in epithelioid cases or overall. Ipilimumab-nivolumab was used more commonly in network cases (47/279 (16.8%) v 4/154 (2.6%) PS 0-1 pre-network), but similar RMST extension was observed in untreated patients (+5.5 months, $p=0.0016$). RMST differences were associated with improved PS at diagnosis, but not with stage, ipilimumab-nivolumab or surgery (in 17/659 (2.6%)).

Conclusion

This study suggests that introduction of a specialist mesothelioma network has improved the survival of patients with Pleura Mesothelioma. The improved outcomes observed in non-epithelioid patients appeared independent of demographics, stage and receipt of individual therapies. Improved survival was associated with improved PS at diagnosis. These data support wider adoption of specialist mesothelioma networks, including a weekly dedicated MDT meeting and QPIs, underpinning audit that drives local service improvement.

Realistic medicine

1.) Shared decision making

Throughout 2024-25 the network infrastructure continued to enable a 'hub and spoke' model of care with the hub being the Queen Elizabeth University Hospital in Glasgow where the national virtual MDT is hosted. Network staff, based in Glasgow, Edinburgh, Inverness, Dundee and Aberdeen continue to dial into the Once for Scotland MDT to represent the patients and feedback clear, high-quality management plans and clinical trial information. This approach aims to speed up diagnosis and treatment of patients wherever they live whilst ensuring that optimal care is delivered as close to home as possible.

All dial into the virtual MDT, with referring clinicians from across Scotland also encouraged to join and engage in discussion of local cases.

- ✓ Total of 49 MDTs in 2024/25
- ✓ Total of 250 new patient discussions
- ✓ 247 complex case discussions were reported as optimal (all information required available at MDT)
- ✓ 250 high quality patient care plans were generated

Macmillan Scottish Mesothelioma Network

NSD6

Glasgow Mesothelioma Hub



Pleural Disease Unit, Queen



2.) Personalised approach to care

In 2024/25 the continued funding of Meso UK CNSs meant all 132 newly diagnosed patients in Scotland had access to a dedicated nurse specialist. This also ensures that the patient voice is represented at the national MDT where clinicians are made aware of treatment preferences of patients when carrying out case discussions. All patients receive a high quality individually tailored care plan agreed by consensus at the national MDT sent back to the referring clinician within 24 hours of MDT discussion.

3.) Reduce unwanted variation

National clinical management guidelines and optimal mesothelioma pathway developed. Once for Scotland MDT proforma for collection of data to better enable service audit and national QPI collection universally adopted.

4.) Managing risk better

All 275 repeat and newly diagnoses cases in 2023/24 were discussed by a team of expert clinicians at the national virtual MDT. Treatment pathways and care plans agreed in real time by expert consensus at MDT and care plans sent back to local teams to minimise the risk of variation in treatment.

5.) Become Improvers and Innovators

- As referred to above, in 2024/25 there was ongoing utilisation and improvement of Once for Scotland national MDT proforma for referring patients, creating 360 patient care plans and collecting high quality national data for service audit
- The SMN National MDT Model is now being used as the best practise standard temple for the care of mesothelioma patients across England and Wales where similar models are being rolled out.
- The 2024 SMN National Clinical Management Guidelines outlining the optimal treatment and diagnostic pathways is also being adopted across England and Wales.
- Clinical trial referral built into patient pathway as standard via the national MDT and recorded on the MDT proforma. This ensures equity of access to clinical trials for all patients in Scotland.
- Links to research and innovation via PREDICT Meso [Home - PREDICT-Meso \(predictmeso.com\)](https://predictmeso.com) where network clinical lead is the lead investigator.

Financial sustainability

From April 24- 31st March 25 NSS funded 1 wte MDT Coordinator and Audit Facilitator role after a successful KPI review meeting of KPIs for the post. 1PA Clinical Lead session was also funded.

The annual education event was cost neutral to NSS as it was funded via sponsorship obtained by the clinical team.

Climate sustainability

Throughout 24/25 SMN continued to adopt a digital first approach as standard with 100% of network business meetings (including steering group meetings, annual performance appraisals, working groups, weekly virtual MDT and data meetings) carried out online.

Workforce sustainability

Throughout 24/25 the SMN continued to enable strong workforce resilience and commitment from clinical leads in each of the five cancer centres in Scotland at no additional cost to NSS. See table below:

SMN leads	Board	MDT	Radiology subgroup	Pathology subgroup	Long term subgroup	Oncology subgroup	Surgery subgroup	Other (CNS)
5	5	103	6	5	6	6	2	6
TOTAL: 103								

*There are 5 owners of the MESO MDT and 98 members = 103 total members / specialists

A partnership with the charity Meso UK, who fund five dedicated Mesothelioma UK nurse specialists across Scotland via SLAs with regional health boards is ongoing for the fifth year.

The hub and spoke SMN infrastructure with a national audit and coordination role at the centre has enabled the ongoing rapid flow of patient information and efficient cross boundary communication with all of the clinical teams involved in the network throughout 2024/25. There continues to be four dedicated regional clinical leads in each of the cancer centres. As well as five radiologists, four pathologists, SMN lead oncologist and a palliative care doctor all of whom attend the national MDT on a weekly basis, and the Steering Group, QPI and data and Short Life Working Group meetings. All the MDT clinical team above have remained members since the launch of the MDT in March 2019.

Looking forward – 2025/26

Key deliverables until 30th Sept 2025:

- Publication of SMN MDT Impact Evaluation launch (March 2019-present)
- Final review, consultation and publication of the national clinical management guidelines
- Patient Reported Outcome Measures Working Group and Meso DAX PROMS tool
- QPI reporting process and production of the Annual Clinical Audit Report 2024
- Weekly national multi disciplinary team meeting

Finance

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No additional costs were incurred by the network in 2024/25. All NSS costs were incurred by agreed network staffing of 1PA Clinical Lead and National Audit Facilitator and MDT Co-ordinator to support the weekly National MDT, national patient pathway and hub co-ordination, and data and audit for QPI and service audit. Total cost 65k.