

Scottish Adult Neuro-Oncology Network

Annual Report 2024/25

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Introduction

The Scottish Cancer Network (SCN) was established in 2021 and governs, manages and supports the five national cancer networks. 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 Adult Neuro-Oncology Network (SANON) was established in November 2006 to deliver equitable high-quality clinical care to all brain and central nervous system (CNS) cancer patients across Scotland. SANON successfully moved to the SCN during 2022/23. SCN [Clinical Management Pathway for Neuro-Oncology](#) is available on the Healthcare Improvement Scotland (HIS) Right Decision Service (RDS) website, which includes the [SANON Clinical Management Guideline for Radiotherapy \(XRT\) and Systemic Anti-Cancer Therapy \(SACT\)](#).

SANON continues to support and develop the clinical service for brain and CNS cancer. A small community of clinical specialists work collaboratively to support the Scottish Government and SCN strategic aim to provide efficient and effective care founded on national clinical consensus ensuring people with cancer will be informed about their treatment and care and possible outcomes. The majority of cases in Scotland are gliomas and treatment is mainly non-curative. More than half of patients are assigned tumour grade 4 on diagnosis. Brain cancer, as one of the less-survivable cancers, has been identified as an area for focus within the Scottish Government Strategic Priorities in the aim to strive for consistency through a Once for Scotland approach, where appropriate, to reduce inequalities and ensure services are sustainable.

The effective management of patients throughout Scotland relies on co-ordinated delivery of treatment and care that requires close collaboration of professionals from a range of specialties. Most brain/CNS cancer patients are discussed initially in one of the five centres across Scotland (Aberdeen, Dundee, Inverness, Edinburgh and Glasgow) and referred to one of the four multi-disciplinary teams (MDTs). Aberdeen and Inverness hold a joint MDT meeting. Small numbers of brain/CNS cancer patients are managed by other MDT meetings (e.g. pituitary), with the support of the brain/CNS cancer MDTs. Edinburgh pathologists support the MDTs in the north. Edinburgh is responsible for the pathology and molecular stratification of tumours that come from Inverness and Dundee. Each centre covers a similar proportion of population. During 2024/25 all regions continued working to ensure that all appropriate patients are discussed at MDT and improved documentation of these discussions. All regions have continued to strive towards improving timely access to oncological treatments over the year and were very close to reaching the aspirational goal set by the Quality Performance Indicators (QPIs).

Neurosurgery is currently delivered in four centres: Aberdeen, Dundee, Edinburgh and Glasgow. Second opinions are offered proactively to patients through the MDTs. Neurosurgeons in Glasgow and Edinburgh have a subspecialist neuro-oncology team. Four of the five centres have dedicated Clinical Oncologists and CNS, with the Inverness population being served by Aberdeen.

Highlights 2024/25

- ✓ Highly successful in-person National Education Event at The Vine, Dundee attended by neuro-oncology clinical and support staff from across Scotland with contributions from partners and charities in Scotland and the UK
- ✓ Patient and Carer Subgroup was convened and met regularly throughout 2024/25
- ✓ Neuro-Oncology Short Life Working Group to discuss unlicensed medicines offered under the Early Access to Medicines Scheme (EAMS) was convened and completed
- ✓ [Clinical Audit of Brain/CNS cancer Quality Performance Indicators \(QPIs\)](#) was reported for the tenth consecutive year and evidenced improvements across the diagnostic and treatment pathway
- ✓ SANON delivered on all key pieces of work planned for 2024/25

Stakeholder Communication and Engagement

Annual review of the [SANON website](#) was conducted which complies with NSS requirements for safety and security of content and associated links.

SANON Steering Group identified the need for a dedicated patient and carer subgroup. The newly formed Patient and Carer Subgroup held their inaugural meeting on 11th October 2024 and met twice more in 2024/25. This group enables the patient/carers voice to be represented at the network steering group and partnership working with Brainstrust, the brain tumour charity helps empower the group to identify areas of work they would like to progress, routes for support and education around realistic expectations. The group has recently expanded in size and after the initial introductory session have been scoping the potential for future areas of interest.

Links with other partners continue and include:

- ✓ Tessa Jowell Foundation - who featured in the SANON Education Event to present on their Centre for Excellence programme
- ✓ Macmillan - who attended the education event
- ✓ Brain Tumour Charity who invited SANON Clinical Lead to attend a roundtable discussion on barriers to brain tumour diagnosis and Brain Tumour Awareness Month Parliamentary Reception
- ✓ Maggie's offer support services to newly diagnosed patients and their families

Education and Training

SANON held the annual National Education Event at The Vine, Dundee on 25th October 2024. There was strong attendance from this small community with almost 50 delegates from around Scotland. The delegates comprised of clinical specialists, clinical support, admin and audit staff, and associated networks and charities. This was a popular and collaborative day containing specialty updates and lively discussions on neuropathology, low grade gliomas and QPIs in addition to research and innovation plenaries on neurology, glioma care in surgery and spinal cord tumours and the Tessa Jowell Centre of Excellence programme. In the evaluation of the event attendees expressed their appreciation for having the event in-person noting the importance for small teams or single-handed practitioners to meet with colleagues from other boards and regions

as well as highlighting the value for new consultants being able to conduct first face-to-face introductions with the wider network. A common theme of the feedback was the increased learning from data-driven, evidence-based presentations, informative and nuanced discussions, the variety of topics and the collaborative atmosphere.

- ✓ 78% of the attendees found the event extremely useful
- ✓ 80% of attendees thought the event was organised very well or excellently
- ✓ Attendees thoroughly enjoyed the event being “*face to face*”
- ✓ The importance of networking and peer support at educational events was stressed
- ✓ The combination of Scottish and National speakers worked very well
- ✓ All the presenters were well-received, and their presentations were engaging

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 [Brain/CNS cancer Clinical Audit Report 2023](#) is published and available on the SANON website and is based on HIS [Brain and CNS cancer quality performance indicators](#), updated April 2024.

Thanks to the continued commitment of the clinical teams, patients with brain or CNS cancer receive high quality care across Scotland. The clinical audit results demonstrate their continued commitment to improving the experience and care received across the patient pathway. Case ascertainment and data capture is of a high standard enabling robust assessment of performance against QPIs.

All QPIs were subject to recent evaluation during the third cycle of the Brain and CNS cancers Formal Review. Indicators identified for archiving will be removed for the next cohort of patients diagnosed during 2024, with amendments being introduced for the subsequent cohort diagnosed during 2025. QPI measures that have continued to present specific challenges were amended to:

- capture and report on newly identified best practice for molecular analysis (QPI 3)
- set more realistic and clinically appropriate timelines for seizure management (QPI 11)

or archived due to:

- definition and documentation challenges for key worker (QPI 12)
- consistent achievement of target over preceding years for neuropathological diagnosis (QPI 4)

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 outwith, specific boards/centres which are discussed in the report. Additionally, 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.

National audit data (Table 1) indicates that there were 392 patients diagnosed with Brain/CNS cancer in 2023, a return to similar levels observed in 2021. The distribution of new Brain/CNS cancer diagnoses were over a third in both the West (36.7%) and South-East (39.8%) and almost one quarter in the North of Scotland (23.5%), whilst 59% of new patients were male and 41% female.

Table 1: Brain/CNS cancer QPI Patients Diagnosed Jan – Dec 2023

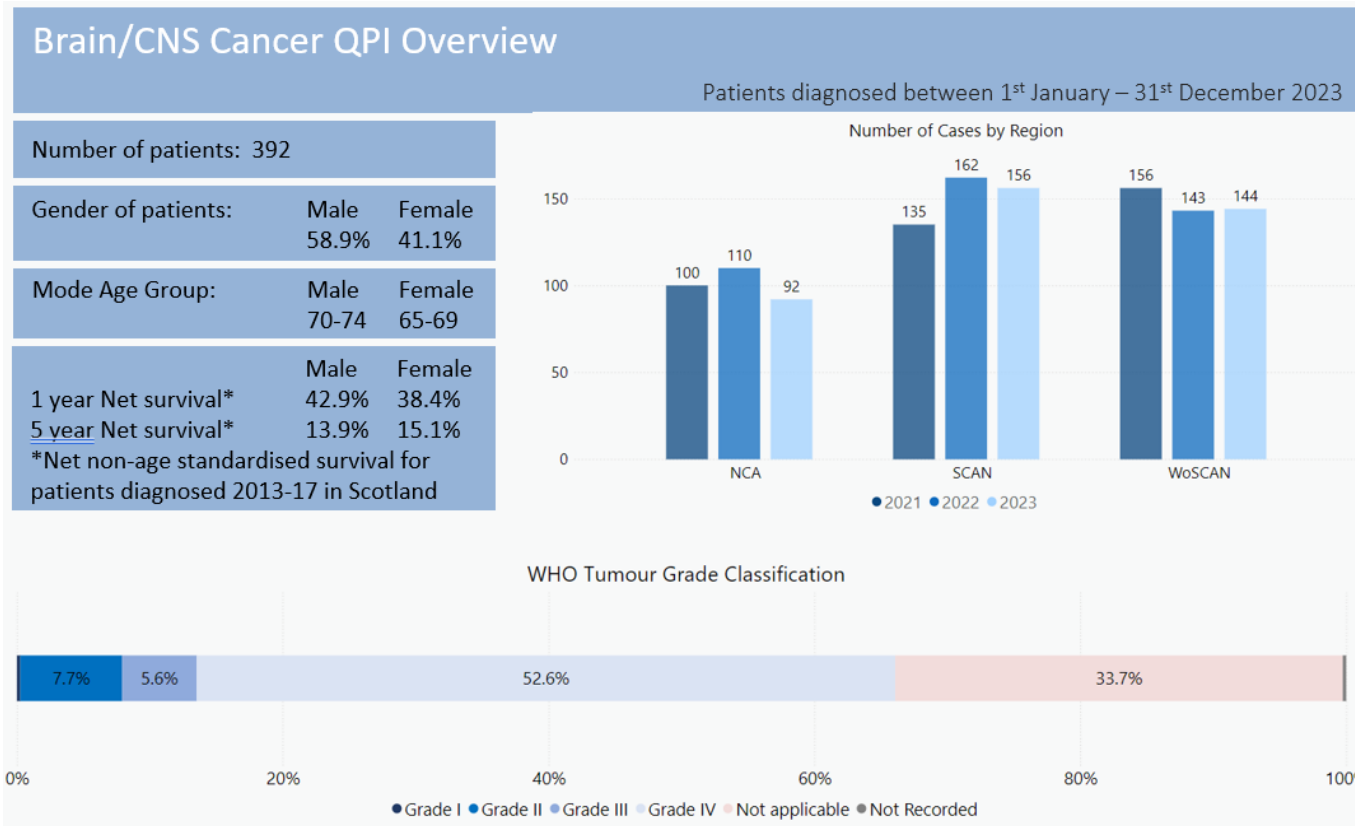
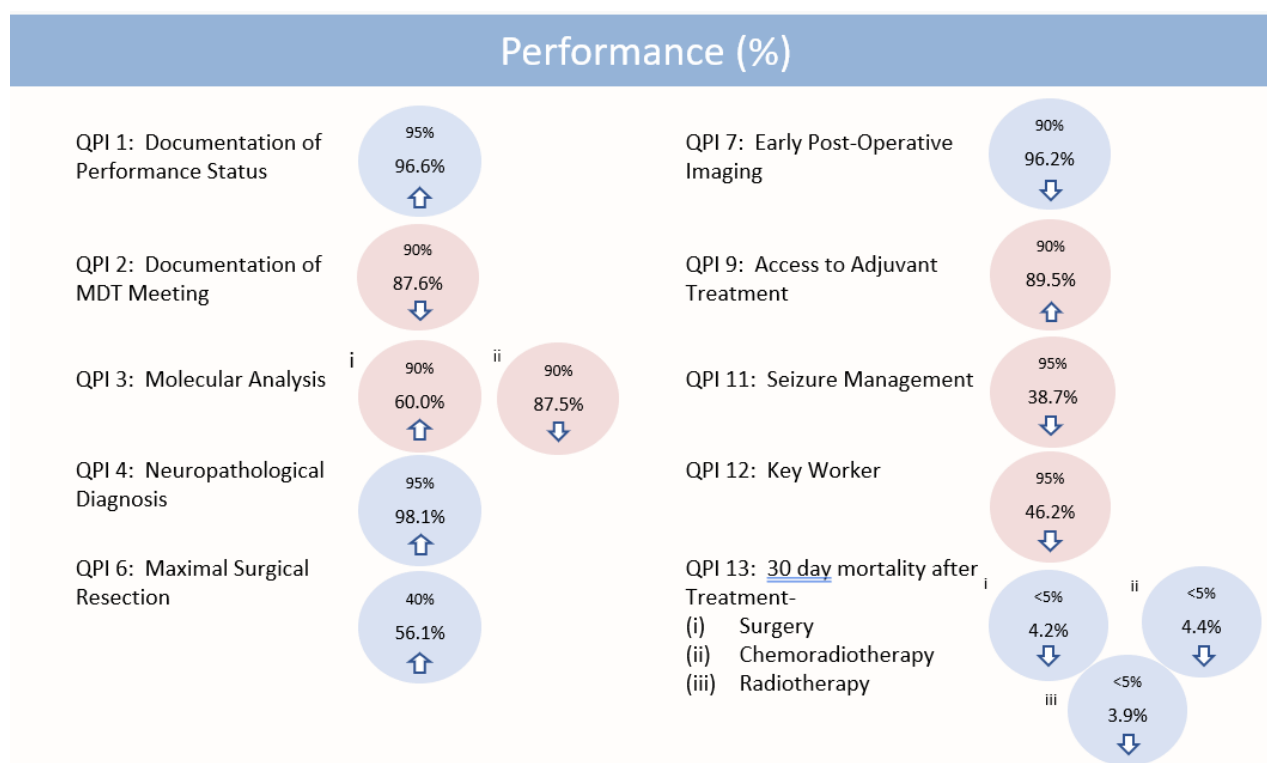


Table 2 illustrates the performance against target for the QPIs used to assess the Brain/CNS cancer services across Scotland. Although the majority of cases occur in older individuals for both sexes, it is notable that one quarter (24.5%) of Brain and CNS cancers were diagnosed in individuals younger than 55 years. Further analysis would help understand this trend.

Table 2: Brain/CNS Cancer QPI Performance Percentage for Patients Diagnosed Jan – Dec 2023



Key areas of achievement are documentation of performance status, neuropathological diagnosis, maximal surgical resection, early post-operative imaging and 30-day mortality after treatment. Improvements against historical results have been noted for molecular analysis and access to adjuvant treatment. Specific challenges exist in all units, in particular for, molecular analysis, access to adjuvant treatment, seizure management and key worker which all remained challenging across Scotland.

Become improvers and innovators

Scottish Government's [Cancer Action Plan for Scotland 2023-2026](#) highlighted that the SCN is at the centre of the work to develop national clinical management pathways (CMPs) for all people with cancer. [SANON Clinical Management Guideline for Radiotherapy \(XRT\) and Systemic Anti-Cancer Therapy \(SACT\)](#) is available on the HIS RDS website.

The Scottish Medicines Consortium (SMC) advise on the clinical and cost-effectiveness of all new medicines for NHS Scotland. In today's research environment, advances in clinical trials can accelerate quickly which can provide new and exciting, potential treatments for patients with terminal illness. This may also promote an urgency at the expense of oversight and risk assessment which can compromise quality. The network steering group are aware that patients can bring questions to consultation about unlicensed medicines that have received media coverage in advance of these being considered by SMC. A neuro-oncology short life working group was convened to discuss an unlicensed medicine that might be a future option for a subset of brain tumour patients (with WHO Grade 2 IDH mutated tumours who were ineligible for radiotherapy or chemotherapy).

The objective of the SLWG was to develop clinical consensus to support clinicians with conversations that might arise when discussing options with patients. There were limitations to this work as the medicine might not gain approval, or necessarily be available through the early access to medicines scheme (EAMS). Whilst recognising this the group worked towards developing consensus, avoiding the need to rush without due consideration, in the event that the medicine was approved. Discussions were fruitful and led to a document being drafted that could be considered through standard governance routes if the SMC review of the drug during 2025/26 was favourable.

Financial sustainability

SANON has had excellent leadership and has a high level of maturity within the network development. The Clinical Lead role has continued at 0.1WTE for 2024/25 in line with other networks at a similar level of maturity.

The annual education event was held in-person as it was an important objective for this small, but highly specialised clinical community. This resulted in minimal cost for NSS as the clinical team obtained sponsorship from the Brain Tumour Charity.

Climate sustainability

Throughout 2024/2025 the national network took a digital first approach with all steering group, MDT, data and subgroup meetings being conducted virtually. The exception to this was the in-person education event, viewed as critical for the progression of key activities for this small, but disparate clinical community. The event was hosted in a central location and accessible by public transport to minimise the environmental impact.

Workforce sustainability

There are five cancer centres across Scotland (Aberdeen, Dundee, Inverness, Edinburgh and Glasgow) and four multi-disciplinary teams (MDTs) as Aberdeen and Inverness have joint MDTs. The MDTs also support other MDTs (e.g. pituitary) for the small number of brain/CNS cancer patients managed outwith the specialist team.

Edinburgh pathologists support the north MDTs and are responsible for the pathology and molecular stratification of tumours from Inverness and Dundee. Each centre covers a similar proportion of population.

Neurosurgery is delivered in four centres (Aberdeen, Dundee, Edinburgh and Glasgow) with Glasgow and Edinburgh having subspecialist neuro-oncology teams. Second opinions are offered proactively to patients by the MDTs. Four centres have dedicated Clinical Oncologists and Clinical Nurse Specialists, with Aberdeen providing the service for Inverness.

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 this proactive network.

Looking forward – 2025/26

Key deliverables by 30th September 2025:

- Hosting a National Education Event
- QPI reporting process and 2024 Brain/CNS Cancer Clinical Audit Report publication
- Patient and Carer Subgroup quarterly meetings

Finance

Network core business and activities were achieved whilst contributing to savings for NSS, with a total spend of £21K.

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