Scottish Cancer Strategic Board
National Cancer Quality Steering Group

Brain and Central Nervous System Cancer Clinical Quality Performance Indicators

Engagement Document

January 2024

Scottish Government
Riaghaltas na h-Alba

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1. National Cancer Quality Programme

Beating Cancer: Ambition and Action (2016)[1] details a commitment to delivering the National Cancer Quality Programme across NHSScotland, with a recognised need for national cancer QPIs to support a culture of continuous quality improvement. Addressing variation in the quality of cancer services is pivotal to delivering improvements in quality of care. This is best achieved if there is consensus and clear indicators for what good cancer care looks like.

Small sets of cancer specific outcome focussed, evidence based indicators are in place for 19 different tumour types. These QPIs ensure that activity is focused on those areas that are most important in terms of improving survival and individual care experience whilst reducing variation and supporting the most effective and efficient delivery of care for people with cancer. QPIs are kept under regular review and are responsive to changes in clinical practice and emerging evidence.

A programme to review and update the QPIs in line with evolving evidence is in place as well as a robust mechanism by which additional QPIs will be developed over the coming years.

1.1 Quality Assurance and Continuous Quality Improvement

The ultimate aim of the programme is to develop a framework, and foster a culture of continuous quality improvement, whereby real time data is reviewed regularly at an individual Multidisciplinary Team (MDT)/Unit level and findings actioned to deliver continual improvements in the quality of cancer care. This is underpinned and supported by a programme of regional and national comparative reporting and review.

NHS Boards are required to report against QPIs as part of a mandatory, publicly reported, programme at a national level. A rolling programme of reporting is in place, with approximately three national tumour specific summary reports published annually. These reports highlight the publication of performance data in the Cancer QPI Dashboard held within the Scottish Cancer Registry and Intelligence Service (SCRIS). The dashboard includes comparative reporting of performance against QPIs at MDT/Unit level across NHSScotland, trend analysis and survival. This approach helps to overcome existing issues relating to the reporting of small volumes in any one year.

In the intervening years, tumour specific QPIs are monitored on an annual basis through established Regional Cancer Network and local governance processes, with analysed data submitted to Public Health Scotland (PHS) for inclusion in the Cancer QPI Dashboard and subsequent national summary reports. This ensures that timely action is taken in response to any issues that may be identified through comparative reporting and systematic review.

2. Quality Performance Indicator (QPI) Development Process

The QPI development process was designed to ensure that indicators are developed in an open, transparent and timely way.

The Brain/Central Nervous System (CNS) Cancer QPI Development Group was convened in May 2012, chaired by Dr Hilary Dobson, Deputy Director, Innovative Healthcare Delivery Programme. Membership of this group included representatives drawn from the three regional cancer networks, Healthcare Improvement Scotland, Information Services Division (ISD) and patient/carer representatives.

The development process and membership of the development group can be found in appendix 1.

3. QPI Formal Review Process

As part of the National Cancer Quality Programme, a systematic rolling programme of national review process has been developed. This ensures all tumour specific QPIs are subject to formal review following every 3rd year of comparative QPI data analysis.

The formal review process is clinically driven with proposals for change sought from specialty specific representatives in each of the Regional Cancer Networks. It is designed to be flexible in terms of the extent of review required with tumour specific Regional Clinical Leads undertaking a key role in this decision making. Formal review meetings to further discuss proposals are arranged where deemed necessary. The review builds on existing evidence using expert clinical opinion to identify where new evidence is available, and a full public engagement exercise will take place where significant revisions have been made or new QPIs developed.

During formal review QPIs may be archived and replaced with new QPIs. Triggers for doing so include significant change to clinical practice, targets being consistently met by all Boards, and publication of new evidence. Where QPIs have been archived, associated data items will continue to be collected where these are utilised for other indicators, or measures such as survival analysis.

Any new QPIs are developed in line with the following criteria:

- **Overall importance** – does the indicator address an area of clinical importance that would significantly impact on the quality and outcome of care delivered?
- **Evidence based** – is the indicator based on high quality clinical evidence?
- **Measurability** – is the indicator measurable i.e. are there explicit requirements for data measurement and are the required data items accessible and available for collection?

Three formal reviews of the Brain/CNS Cancer QPIs have been undertaken to date. Further information can be found in appendix 2.

4. Format of the Quality Performance Indicators

QPIs are designed to be clear and measurable, based on sound clinical evidence whilst also taking into account other recognised standards and guidelines.

- Each QPI has a **short title** which will be utilised in reports as well as a fuller **description** which explains exactly what the indicator is measuring.

- This is followed by a brief overview of the **evidence base and rationale** which explains why the development of this indicator was important.

- The measurability **specifications** are then detailed; these highlight how the indicator will actually be measured in practice to allow for comparison across NHSScotland.

- Finally a **target** is indicated, this dictates the level which each unit should be aiming to achieve against each indicator.

In order to ensure that the chosen target levels are the most appropriate and drive continuous quality improvement as intended they are kept under review and revised as necessary, if further evidence or data becomes available.

Rather than utilising multiple exclusions, a tolerance level has been built into the QPIs. It is very difficult to accurately measure patient choice, co-morbidities and patient fitness therefore target levels have been set to account for these factors. Further detail is noted within QPIs where there are other factors which influenced the target level.

Where 'less than' (<) target levels have been set the rationale has been detailed within the relevant QPI. All other target levels should be interpreted as 'greater than' (>) levels.

5. Supporting Documentation

A national minimum core dataset and a measurability specification have been developed in parallel with the indicators to support the monitoring and reporting of the Brain/CNS Cancer QPIs. The latest version of these documents can be found at:

Public Health Scotland Cancer Audit

6. Quality Performance Indicators for Brain/CNS Cancer

QPI 1: Documentation of Performance Status

QPI Title:	Patients with newly-diagnosed brain/central nervous system (CNS) cancer should have a world health organisation (WHO) performance status documented at time of multi-disciplinary team (MDT) discussion.
Description:	Proportion of newly-diagnosed patients with brain/CNS cancer who have a documented WHO performance status at the time of multi-disciplinary team (MDT) discussion.
Rationale and Evidence:	Performance status is an important prognostic indicator in patients with brain/CNS cancer. Accurate communication of performance status is vital in guiding complex management decisions, including recruitment into clinical trials[2]. In patients referred from other sites, who have not yet met a member of the neuro-oncology MDT, an estimated performance status should be given, based on the available information from the referring site. For ease of measurability within this QPI, it is specifically the WHO performance status that is used. It is recognised that other tools exist and more complex decision making may be undertaken in order to inform treatment options for patients.
Specification:	**Numerator:** Number of newly-diagnosed patients with brain/CNS cancer discussed at MDT meeting with a documented WHO performance status at the time of MDT discussion. **Denominator:** All newly-diagnosed patients with brain/CNS cancer discussed at MDT meeting. **Exclusions:** • No exclusions.
Target:	95% The tolerance within this target is designed to account for situations where there is insufficient information available from the referring site to estimate the WHO performance status.

Please note: The MDT Chair should try to ensure that a valid performance status is documented on MDT outcome.

Revision(s): No change to QPI or measurement

QPI 2: Multi-disciplinary Team Meeting

QPI Title:	Patients with brain/CNS cancer should be discussed by a multidisciplinary (MDT) team prior to any surgical procedure[1].
Description:	Proportion of patients with brain/CNS cancer who are discussed at MDT meeting before surgery.
Rationale and Evidence:	Evidence suggests that patients with cancer managed by a multi-disciplinary team have a better outcome. There is also evidence that the multidisciplinary management of patients increases their overall satisfaction with their care[3]. Discussion prior to definitive management decisions being made provides reassurance that patients are being managed appropriately. In the majority of cases, patients with Brain / CNS Cancer will undergo surgery (biopsy or resection) as their initial intervention prior to any further treatment. The measurement of this QPI will therefore focus on discussion of patients at this initial point within the clinical pathway.
Specification:	**Numerator:** Number of patients with brain/CNS cancer discussed at the MDT before surgery. **Denominator:** All patients with brain/CNS cancer undergoing surgery. **Exclusions:** • Patients who died before first treatment.
Target:	90% The tolerance within this target is designed to account for situations where patients require treatment urgently.

Revision(s): No change to QPI or measurement

[1] Please note that surgical procedures include diagnostic biopsies.

QPI 3: Molecular Analysis

QPI Title:	Patients with biopsied or resected gliomas should have molecular analysis performed on the tumour tissue within 28 days of surgery to inform diagnosis and treatment decision making.
Description:	Proportion of patients with biopsied or resected gliomas who undergo relevant molecular analysis[2] of tumour tissue within 28 days of surgery. **Please note:** This QPI measures 3 distinct elements: (i): Patients with IDH-wildtype diffuse astrocytic gliomas lacking microvascular proliferation and necrosis who have EGFR gene amplification testing, chromosome 7 and 10 copy number analysis, and TERT gene promotor mutation testing; and (ii): Patients with IDH-mutant and ATRX-wildtype diffuse gliomas who have 1p/19q co-deletion status confirmed; and (iii): Patients with IDH-mutant astrocytomas who have testing for homozygous deletion of CDKN2A/B.
Rationale and Evidence:	Identifying genetic alterations in brain tumours is crucial for accurate diagnosis and informing subsequent clinical management. To identify tumours associated with the most aggressive behaviour, there is strong evidence to support EGFR testing, chromosome 7 and 10 copy number analysis, and TERT gene promotor mutation testing. Whole chromosome 7 gain together with whole chromosome 10 loss, EGFR amplification or TERT promoter mutation are strong markers in identifying IDH-wildtype diffuse astrocytic gliomas with grade 4 clinical behaviour[4,5]. It is also recommended that CDKN2A/B homozygous deletion testing should be performed on IDH-mutant astrocytomas. CDKN2A/B deletion has been shown to be an adverse prognostic factor in these specific tumour types[4]. Combined loss of 1p/19q in gliomas is associated with a more favourable response to therapy (chemotherapy or radiotherapy) and is associated with considerably better prognosis when compared to tumours with intact 1p/19q. As such, where indicated, 1p/19q analysis should be

[2] WHO Classification of CNS tumours (2021) uses molecular parameters in addition to histology to define tumour entities.

(Continued overleaf….)

	carried out to help determine treatment and provide information on predicted tumour response to therapy and prognosis[2,6,7]. The group have added a 28 day timeframe to allow for initial IDH testing and ensure that the molecular analysis is undertaken and reported before treatment takes place.

Molecular Analysis (cont…)

Specification (i):	**Numerator:**	Number of patients with IDH Wildtype diffuse astrocytic gliomas lacking microvascular proliferation and necrosis who have EGFR gene amplification testing, chromosome 7 and 10 copy number analysis, and TERT gene promotor mutation testing within 28 days of surgery.
	Denominator:	All patients with IDH Wildtype diffuse astrocytic gliomas lacking microvascular proliferation and necrosis undergoing surgery
	Exclusions:	• No exclusions.
Specification (ii):	**Numerator:**	Number of patients with IDH-mutant and ATRX-wildtype diffuse gliomas who have 1p/19q co-deletion status confirmed within 28 days of surgery.
	Denominator:	All patients with IDH-mutant and ATRX-wildtype diffuse gliomas undergoing surgery.
	Exclusions:	• No exclusions.
Specification (iii):	**Numerator:**	Number of patients with IDH-mutant astrocytomas who have testing for homozygous deletion of CDKN2A/B within 28 days of surgery.
	Denominator:	All patients with IDH-mutant astrocytomas undergoing surgery.
	Exclusions:	• No exclusions.
Target:	Specifications (i), (ii) and (iii) 90% The tolerance within this target level is designed to account for cases in which there is insufficient viable tissue	

	for molecular analysis.

Revision(s):

- QPI has been amended to reflect advances in molecular testing and tumour diagnostics.
- Clinical cohorts and tests have been revised. Comprises of 3 separate specifications.

QPI 4: Neuropathological Diagnosis

Revision(s):

- This QPI has been archived – the QPI target has been consistently met across all regions over the previous 3 years. This is considered standard practice across Scotland.

QPI 6: Maximal Surgical Resection

QPI Title:	Where considered consistent with a safe outcome, patients should undergo maximal surgical resection of malignant gliomas[3] with the use of surgical techniques[4] to aid the extent of resection.
Description:	Proportion of patients with malignant glioma (with enhancing component on pre-operative imaging) who undergo surgical resection where ≥90%[5] reduction in tumour volume is achieved and one or more surgical techniques have been used to aid the extent of resection. **Please Note**: the specifications of this QPI are separated to ensure clear measurement of patients with malignant glioma (with enhancing component on pre-operative imaging) who undergo surgical resection: (i) Where ≥90% reduction in tumour volume is achieved; and (ii) Where ≥90% reduction in tumour volume is achieved and one or more surgical technique has been used to aid the extent of resection.
Rationale and Evidence:	The extent of surgical resection is an independent prognostic factor in Grade III and Grade IV malignant gliomas. Maximal safe surgical resection (≥90%) prolongs time to tumour recurrence[8] and is associated with prolonged survival[9]. Maximum safe surgical resection is recommended by several published guidelines[10]. Evidence has shown that the use of 5-ALA guided resection is more likely to result in complete or near-complete removal of the tumour and therefore improve progression free survival[11,12]. Intraoperative MRI or intraoperative ultrasound are other techniques which should be considered to help achieve surgical resection, and awake craniotomy to preserve neurological function[12]. **Please refer to all footnotes for further information around the measurement of this QPI.**

(Continued overleaf….)

[3] Malignant gliomas include:
Glioblastoma multiforme- GBM and its variants e.g. gliosarcoma
Anaplastic Astrocytoma- AA
Anaplastic pleomorphic xanthoastrocytoma
Aanaplastic oligodendrogliomas
Anaplastic (High-grade) ependymoma

[4] Surgical techniques to aid the extent of resection include: 5ALA, Ultrasound, Intraoperative MRI, Intraoperative monitoring and awake craniotomy.

[5] Percentage tumour reduction should be assessed by comparing pre-surgical imaging to post-surgical 72hr Magnetic Resonance Imaging (MRI).

QPI 6: Maximal Surgical Resection (continued)

Specification (i):	**Numerator:**	Number of patients with malignant glioma (with enhancing component on pre-operative imaging) undergoing surgical resection where ≥90% reduction in tumour volume is achieved.
	Denominator:	All patients with malignant glioma (with enhancing component on pre-operative imaging) undergoing surgical resection.
	Exclusions:	• Patients undergoing biopsy only.
Target:	40%	
Specification (ii)	**Numerator**:	Number of patients with malignant glioma (with enhancing component on pre-operative imaging) who undergo surgical resection where ≥90% reduction in tumour volume is achieved and one or more surgical techniques have been used to aid the extent of resection.
	Denominator:	All patients with malignant glioma (with enhancing component on pre-operative imaging) who undergo surgical resection where ≥90% reduction in tumour volume is achieved.
	Exclusions:	• Patients undergoing biopsy only.
Target:	50%	

Please note: Additional information on the total number of patients with high grade glioma who undergo surgical resection/partial debulking will be reported alongside this QPI. This information will be reviewed to identify whether there is variation in practice between these surgical management options for patients across the regions.

Revision(s):

- Current QPI is now Specification (i) – no change
- Specification (ii) added to capture the use of one or more techniques to aid the extent of resection.
- Additional information to be reported alongside this QPI on the total number of high grade glioma patients undergoing surgical resection / partial debulking.

QPI 7: Early Post-Operative Imaging

QPI Title:	Patients with malignant glioma[e] (with enhancing component on pre-operative imaging) undergoing surgical resection should be subject to early post-operative imaging.	
Description:	Proportion of patients with malignant glioma (with enhancing component on pre-operative imaging), who receive early post operative imaging with Magnetic Resonance Imaging (MRI) within 3 days (72hrs) of surgical resection.	
Rationale and Evidence:	Post operative imaging: (i) provides a measurement of surgical performance; (ii) helps to determine if further treatment is required; (iii) helps determine what further treatment might be appropriate; (iv) estimates residual tumour to help target radiotherapy when needed; and (v) helps to assess prognosis Imaging should be carried out within 72hrs to enable reliable assessment of the extent of the resection[13-17]. MRI is the preferred imaging method for patients with glioma. After this time period, changes in the tumour resection bed confound estimation. Delaying assessment until these changes settle is inappropriate as regrowth of high-grade tumours can occur rapidly and also post operative treatments such as radiotherapy and chemotherapy are normally instituted rapidly which could further affect the images.	
Specifications:	**Numerator:**	Number of patients with malignant glioma (with enhancing component on pre-operative imaging), undergoing surgical resection who receive MRI within 3 days (72hrs) of surgical resection.
	Denominator:	All patients with malignant glioma (with enhancing component on pre-operative imaging), undergoing surgical resection.

	Exclusions:	• Patients unable to undergo an MRI scan[6] e.g.-
		  ○ Pacemaker or other MRI incompatible implanted device.
		  ○ Cerebral aneurysm clip.
		  ○ Contraindication to intravenous contrast medium.
		• Patients who refuse MRI.
		• Patients undergoing biopsy only.

[6] Where it is not possible to image with MRI an attempt should be made to image with computerised tomography (CT).

QPI 7: Early Post-Operative Imaging (continued)

Target:	90% The tolerance within this target is designed to account for situations where patients are deemed unfit to attend for imaging within the stated timeframe.

Revision(s):

- No change to QPI

QPI 9: Access to Oncological Treatment

QPI Title:	The maximum time between surgery and oncological treatment for patients with high grade glioma (world health organisation (WHO) grades III and IV) should be 6 weeks.
Description:	Proportion of patients with high grade glioma (WHO grades III and IV) undergoing surgery who commence their oncological treatment (chemotherapy, radiotherapy, or chemoradiotherapy) within 6 weeks of surgery.
Rationale and Evidence:	Evidence demonstrates a negative impact on patient outcome if adjuvant treatment is delayed. It has been reported that by delaying oncological treatment, the risk of death increased by 8.9% for each week from the date of first surgery[18]. In addition, evidence shows that patients commencing radiotherapy within 6 weeks of the date of surgery had improved overall survival[19].
Specifications:	**Numerator:** Number of patients with high grade glioma (WHO grades III and IV) who undergo oncological treatment (chemotherapy, radiotherapy, or chemoradiotherapy) who commence treatment within 6 weeks of surgery. **Denominator:** All patients with high grade glioma (WHO grades III and IV) who undergo oncological treatment (chemotherapy, radiotherapy, or chemoradiotherapy) following surgery. **Exclusions:** • No exclusions.
Target:	90% The tolerance within the target is designed to account for patients with post-operative complications and those situations where oncological treatment may be delayed due to patient choice.

Revision(s):

- No change to QPI

QPI 11: Seizure Management

QPI Title:	Patients with brain/CNS cancer presenting with seizures at diagnosis should be seen by a neurologist and/or a named epilepsy specialist nurse (ESN).
Description:	Proportion of patients with brain/CNS cancer presenting with seizures at diagnosis who are seen by a neurologist or a named ESN within four months of first MDT discussion.
Rationale and Evidence:	Diagnosing epilepsy can be complex and it is crucial that specialists are involved early to avoid misdiagnosis[20]. The diagnosis of epilepsy is more accurate when made by a medical practitioner who specialises in epilepsy, resulting in better patient outcomes. Access to a specialist nurse with expertise in epilepsy management enhances the quality of life for patients and gives a more patient centred approach to care[21,22]. The QPI Formal Review Group agree that a timeframe of 4 months is appropriate for this intervention given the multiple appointments, treatments and abundance of information being provided during the earlier stages of diagnosis.
Specification:	**Numerator:** Number of patients presenting with seizures at diagnosis seen by a neurologist or a named ESN within four months of first MDT discussion. **Denominator:** All brain/CNS cancer patients presenting with seizures at diagnosis. **Exclusions:** • No exclusions
Target:	95% The tolerance within this target is designed to account for factors of patient choice.

Revision(s):

- Timeframe within QPI changed from four weeks to four months.
- The QPI Formal Review Group agree that four weeks is not a realistic timeframe and more importantly is not appropriate for the patient given the multiple appointments, treatments and wealth of information all being provided during the initial stages of diagnosis.

QPI 12: Key Worker

Revision(s):

- This QPI has been archived – performance is consistently low year on year largely due to documentation issues and is not driving improvement for patients.
- The key worker can change over time and measuring the quality of co-ordinated care throughout the pathway is better assessed using a qualitative approach.

QPI 13: 30 Day Mortality after Treatment for Brain/CNS Cancer

QPI Title:	30 day mortality following treatment for brain/CNS cancer.	
Description:	Proportion of patients with brain/CNS cancer who die within 30 days of treatment (surgery, radiotherapy or chemoradiotherapy) for brain / CNS cancer.	
Rationale and Evidence:	Treatment related mortality is a marker of the quality and safety of the whole service provided by the Multi Disciplinary Team (MDT)[3]. Outcomes of treatment, including treatment related morbidity and mortality should be regularly assessed. Treatment should only be undertaken in individuals that may benefit from that treatment, that is, treatments should not be undertaken in futile situations. This QPI is intended to ensure treatment is given appropriately, and the outcome reported on and reviewed. **Please note:** 30 Day Mortality for Systemic Anti-Cancer Therapy (SACT) is measured separately from the QPI process. National SACT data from CEPAS (Chemotherapy Electronic Prescribing and Administration System) is utilised to support reporting and monitoring of this measure rather than audit data. This methodology allows the whole population of patients with brain/CNS cancer undergoing SACT to be captured rather than those newly diagnosed within the audit.	
Specifications:	**Numerator:**	Number of patients with brain/CNS cancer who undergo treatment that die within 30 days of treatment.
	Denominator:	All patients with brain/CNS cancer who undergo treatment (surgery, radiotherapy or chemoradiotherapy).
	Exclusions:	• No exclusions.
	Please note:	This indicator will be reported by treatment modality, i.e. surgery, radiotherapy, chemoradiotherapy as opposed to one single figure.
Target:	<5%	

Revision(s):

- Note added within the rationale to explain why 30 Day Mortality following SACT is not included within the QPI.

- No change to QPI measurement.

QPI 14: Clinical Trials and Research Study Access

Revision(s):

- This QPI has now been removed from the individual tumour specific QPI documents and will be replaced by trials activity measures reported via the Scottish Cancer Research Network.

QPI 15: 30 Day Mortality following Systemic Anti-Cancer Therapy (SACT)

Revision(s):

- This QPI has now been removed from the QPI process and is reported by Public Health Scotland using national SACT data which has been checked and validated across Scotland.

QPI 16: Access to Timely Surgery – NEW QPI

QPI Title:	Patients with high grade glioma (WHO Grades III and IV) should undergo timely surgery.
Description:	Proportion of patients with high grade glioma (WHO Grades III and IV) who undergo surgery within 14 days of MDT discussion.
Rationale and Evidence:	Due to the fact that some patients may present with non-specific symptoms, it is important that once a radiological diagnosis has been established, timely treatment should commence. Patients who may improve should be identified and undergo more urgent resection in order not to hinder Karnofsky Performance Scale (KPS) score improvement[23]. Evidence suggests that glioblastoma surgery should not be delayed for longer than a month from the initial diagnostic scan[24].
Specification:	**Numerator:** Number of patients with high grade glioma (WHO Grades III and IV) who undergo surgery within 14 days of MDT discussion. **Denominator:** All patients with high grade glioma (WHO Grades III and IV) who undergo surgery (biopsy or resection). **Exclusions:** • No exclusions
Target:	75% The tolerance within this target accounts for the fact that not all patients will be suitable for surgery within the optimal timeframe due to co-morbidities or factors of patient choice.

Revision(s):

- NEW QPI

QPI 17: Neuropsychological Assessment - NEW QPI

QPI Title:	Patients with malignant glioma should have access to neuropsychology assessment during their treatment pathway.	
Description:	Proportion of patients with malignant glioma undergoing surgical resection who are seen by a Clinical Neuropsychologist/Clinical Psychologist for assessment prior to and following surgery. **Please note:** The specifications of this QPI are separated to ensure clear measurement of patients who are seen by a Clinical Neuropsychologist/Clinical Psychologist: (i) Within 4 weeks prior to surgery; and (ii) Within 4 weeks after surgery.	
Rationale and Evidence:	Neuropsychological assessment is a key component in the management of patients with brain tumours both pre and post-operatively[25,26,27]. It is an important adjunct to identify cognitive symptoms and can be used to aid treatment planning[25]. Treatment options including surgical resection comes with a risk of cognitive impairment, therefore it is important to assess this both before and after surgery in order to understand the impact with regards to functional outcomes for patients[,26,27]. It has been suggested that cognitive assessment prior to surgery helps predict cognitive outcomes better than tumour topography or tumour volume[26].	
Specification (i):	**Numerator:**	Number of patients with malignant glioma undergoing surgical resection who are seen by a Clinical Neuropsychologist/Clinical Psychologist within 4 weeks prior to surgery.
	Denominator:	All patients with malignant glioma undergoing surgical resection.
	Exclusions:	• Patients who decline assessment. • Patients undergoing biopsy only
Specification (ii):	**Numerator:**	Number of patients with malignant glioma undergoing surgical resection who are seen by a Clinical Neuropsychologist/Clinical Psychologist within 4 weeks after surgery.
	Denominator:	All patients with malignant glioma undergoing surgical resection.
	Exclusions:	• Patients who decline assessment. • Patients undergoing biopsy only.
Target:	80% The tolerance within this target is designed to account for those patients with comorbidities, or very advanced disease who may not be fit for assessment.	

7. Survival

Improving survival forms an integral part of the National Cancer Quality Programme. Brain/CNS cancer survival analysis will be reported and analysed on a 3 yearly basis by Public Health Scotland (PHS). The specific issues which will be addressed will be identified by an expert group ahead of any analysis being undertaken, as per the agreed national cancer quality governance and improvement framework.

The Brain/CNS Cancer QPI Group has identified the following issues for survival analysis:

- 5 and 10 year overall survival

To ensure consistent application of survival analysis, it has been agreed that a single analyst on behalf of all three regional cancer networks undertakes this work. Survival analysis is scheduled as per the national survival analysis and reporting timetable, agreed with the National Cancer Quality Steering Group and Scottish Cancer Strategic Board. This reflects the requirement for record linkage and the more technical requirements of survival analyses which makes it difficult for individual Boards to undertake routinely and in a nationally consistent manner.

8. Areas for Future Consideration

The Brain/CNS Cancer QPI Groups have not able to identify sufficient evidence, or determine appropriate measurability specifications to address all areas felt to be of key importance in the treatment of Brain/CNS Cancer, and therefore in improving the quality of care for patients affected by Brain/CNS Cancer.

The following areas for future consideration have been raised across the lifetime of the Brain/CNS Cancer QPIs:

- Access to Psychology and Psychiatry Services for Assessment and Treatment of Emotional Disorders.
- Access to physical/psychological and cognitive/functional needs assessment.
- Neurological functional needs assessment.
- Access to appropriate palliative care support.
- Compliance with neuro-radiology sequence guidance.
- Further molecular testing (e.g. TERT)
- Use of the Patient Concerns Inventory (PCI) in Brain/CNS cancer patients
- Surgical Volumes

9. Governance and Scrutiny

A national and regional governance framework to assure the quality of cancer services in NHSScotland has been developed; key roles and responsibilities within this are set out below. Appendices 3 and 4 provide an overview of these governance arrangements diagrammatically. The importance of ensuring robust local governance processes are in place are recognised and it is essential that NHS Boards ensure that cancer clinical audit is fully embedded within established processes.

9.1 National

- Scottish Cancer Strategic Board
    - Accountable for overall National Cancer Quality Programme and overseeing the quality of cancer care across NHSScotland.

- Healthcare Improvement Scotland
    - Proportionate scrutiny of performance.
    - Support performance improvement.
    - Quality assurance: ensure robust action plans are in place and being progressed via regions/Boards to address any issues identified.

- Public Health Scotland (PHS)
    - Publish national comparative report on tumour-specific QPIs and survival analysis for approximately three tumour types per annum as part of the rolling programme of reporting.

9.2 Regional – Regional Cancer Networks

- Annual regional comparative analysis and reporting against tumour-specific QPIs.
- Support national comparative reporting of specified generic QPIs.
- Identify and share good practice.
- In conjunction with constituent NHS Boards identify regional and local actions required to develop an action plan to address regional issues identified.
- Review and monitor progress against agreed actions.
- Provide assurance to NHS Board Chief Executive Officers and Scottish Cancer Strategic Board that any issues identified have been adequately and timeously progressed.

9.3 Local – NHS Boards

- Collect and submit data for regional comparative analysis and reporting in line with agreed measurability and reporting schedule (generic and tumour-specific QPIs).
- Utilise local governance structures to review performance, develop local action plans and monitor delivery.
- Demonstrate continual improvements in quality of care through on-going review, analysis and feedback of clinical audit data at an individual multidisciplinary team (MDT) or unit level.

10. How to participate in the engagement process

In order to ensure wide inclusiveness of clinical and management colleagues from across NHSScotland, patients affected by brain/CNS cancer and the wider public, draft documentation will be widely circulated for comment and feedback. This will

include professional groups, health service staff, voluntary organisations and other relevant individuals.

10.1 Submitting your comments

Submission of comments on the Brain/CNS Cancer QPIs are available via the Scottish Government Consultation Hub (website details below):

Website: Citizen Space

If you require any further information regarding the engagement process please use the email address below.

Email: Brain-CNSQPIPublicEngagement@gov.scot

10.2 Engagement feedback

At the end of the engagement period, all comments and responses will be collated for review by the Brain/CNS Cancer QPI Formal Review Group. Those who have participated in the engagement process will receive an overview of the changes made and a copy of the final Brain/CNS Cancer QPI document.

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12. Appendices

Appendix 1: QPI Development Process

The preparatory work involved the development of a structured briefing paper by Healthcare Improvement Scotland. This paper took account of existing, high quality, clinical guidance and provided a basis for the development of QPIs.

The scope for development of Brain/CNS Cancer QPIs and a search narrative were defined and agreed by the Brain/CNS Cancer QPI Development Group. The table below shows the final search criteria used in the literature search.

Inclusion	Exclusion
Topics (**population/patient**): Brain and Central Nervous System (CNS) tumours, including: • Glial tumours/gliomas (including: astrocytomas, oligodendrogliomas, ependymomas, medulloblastomas) • Spinal cord tumours • Pineal tumours • Intracranial germ cell tumours • Neuronal tumours Topics **(intervention)**: • Diagnosis • Staging • Surgical management of disease • Non-surgical management of disease (chemotherapy, radiotherapy, biological/targeted therapies; palliation e.g. management of seizures) Adults only Date: 2005 to present day Language: English only	Topics: Related cancers, including: • Metastatic brain/CNS tumours • Meningiomas • Cranial nerve tumours • Pituitary tumours • Primary CNS lymphomas Communication/information, end of life care, pain management, prevention, and screening. Primary care diagnosis and referral. Guidelines for the conduct of clinical trials (topic for generic QPI development).

Table 1 – Brain/CNS Cancer Search Criteria

A systematic search was carried out by Healthcare Improvement Scotland using selected websites and two primary medical databases to identify national and international guidelines.

Nine guidelines were appraised for quality using the AGREE II instrument[28]. This instrument assesses the methodological rigour and precision used when developing a guideline. Two of the guidelines were not recommended for use. Seven of the guidelines were recommended for use.

Indicator Development

The Brain/CNS Cancer QPI Development group defined evidence based, measurable indicators with a clear focus on improving the quality and outcome of care provided.

The Group developed QPIs using the clinical recommendations set out in the briefing paper as a base, ensuring all indicators met the following criteria:

- **Overall importance** – does the indicator address an area of clinical importance that would significantly impact on the quality and outcome of care delivered?
- **Evidence based** – is the indicator based on high quality clinical evidence?
- **Measurability** – is the indicator measurable i.e. are there explicit requirements for data measurement and are the required data items accessible and available for collection?

Engagement Process

A wide clinical and public engagement exercise was undertaken as part of development in May 2013, where the Brain/CNS Cancer QPIs, along with accompanying draft minimum core dataset and measurability specification, were made available on the Scottish Government website. During the engagement period clinical and management colleagues from across NHSScotland, patient affected by Brain/CNS cancer and the wider public were given the opportunity to influence the development of Brain/CNS QPIs.

Draft documentation was circulated widely to professional groups, health service staff, voluntary organisations and individuals for comment and feedback.

Following the engagement period all comments and responses received were reviewed by the Brain/CNS Cancer QPI Development Group and used to produce and refine the final indicators.

Brain/CNS Cancer QPI Development Group Membership (2013)

Name	Designation	Cancer Network/Base
Hilary Dobson	Regional Lead Cancer Clinician (Chair)	WoSCAN
Anne Addison	Audit Facilitator	SCAN (Western General Hospital, Edinburgh)
Syed A. Al-Haddad	Consultant Neurosurgeon	NOSCAN (Aberdeen Royal Infirmary)
Anthony Chalmers	Clinical Oncologist	WoSCAN (Beatson West of Scotland Cancer Centre)
Susan Chivers	Audit / MDT Coordinator	WoSCAN (Southern General Hospital, Glasgow)
Laurence Dunn	Consultant Neurosurgeon	WoSCAN (Southern General Hospital, Glasgow)
Sam Eljamel	Consultant Neurosurgeon	NOSCAN (Ninewells Hospital, Dundee)

Name	Designation	Cancer Network/Base
Kirsten Forbes	Consultant Radiologist	WoSCAN (Southern General Hospital, Glasgow)
Helen Gooday	Consultant in Rehabilitation Medicine	NOSCAN (Woodend Hospital, Aberdeen)
Robin Grant	Consultant Neurologist	SCAN (Western General Hospital, Edinburgh)
James Ironside	Consultant Pathologist	SCAN (Western General Hospital, Edinburgh)
Jennifer Lee	Audit Facilitator	NOSCAN (Ninewells Hospital, Dundee)
Hannah Lord	Clinical Oncologist	NOSCAN (Ninewells Hospital, Dundee)
Kelly Macdonald	Project Manager	WoSCAN
James MacKenzie	Consultant Pathologist	NOSCAN (Aberdeen Royal Infirmary)
Mairi MacKinnon	Clinical Nurse Specialist	WoSCAN (Beatson West of Scotland Cancer Centre)
Shanne McNamara	Clinical Nurse Specialist	SCAN (Western General Hospital, Edinburgh)
Carol Marshall	Project Manager	WoSCAN
Alison Mitchell	Consultant in Palliative Medicine	WoSCAN (Beatson West of Scotland Cancer Centre)
Brian Murray	Principle Information Development Manager	ISD
Lynn Myles	Consultant Neurosurgeon	SCAN (Western General Hospital, Edinburgh)
Chris Myres	Assistant Service Manager	SCAN (Western General Hospital, Edinburgh)
Shona Olson	Consultant Radiologist	NOSCAN (Aberdeen Royal Infirmary)
Sharon Peoples	Clinical Oncologist	SCAN (Western General Hospital, Edinburgh)
Roy Rampling	SANON Clinical Lead	Scottish Adult Neuro-Oncology Network (SANON)
Margaret Ritchie	Clinical Nurse Specialist	NOSCAN/ (Aberdeen Royal Infirmary)
Ally Rooney	ST4 General Adult Psychiatry	SCAN (Royal Edinburgh Hospital, Edinburgh)
Willie Stewart	Consultant Pathologist	WoSCAN (Southern General Hospital, Glasgow)
David Summers	Consultant Radiologist	WoSCAN (Western General Hospital, Edinburgh)
Evelyn Thomson	Regional Manager (Cancer)	WoSCAN
Antonia Torgeson	Consultant Pathologist	SCAN (Royal Infirmary of Edinburgh, Edinburgh)
Alena Vasianovich	Audit Facilitator	NOSCAN (Aberdeen Royal Infirmary)

NOSCAN - North of Scotland Cancer Network
SCAN - South East Scotland Cancer Network
WoSCAN - West of Scotland Cancer Network

Appendix 2: Brain/CNS Cancer QPI Formal Reviews

Formal review of the Brain/CNS Cancer QPIs was undertaken for the first time in August 2017 following reporting of 3 years of national QPI data. A Formal Review Group was convened, chaired by Dr Hilary Dobson, Deputy Director, Innovative Healthcare Delivery Programme. Membership of this group is outlined below.

Brain/CNS Cancer QPI Formal Review Group Membership (2017)

Name	Designation	Cancer Network
Hilary Dobson	Deputy Director (Chair)	Innovative Healthcare Delivery Programme
Lorna Bruce	Audit Manager	SCAN
Jen Doherty	Project Co-ordinator	National Cancer Quality Programme
Sara Erridge	Consultant Clinical Oncologist	SCAN
Robin Grant	Consultant Neurologist	SCAN
Athanasios Grivas	Consultant Neurosurgeon	WoSCAN
Allan James	Consultant Clinical Oncologist	WoSCAN
Avinash Kanodia	SANON Clinical Lead (until Nov 17) / Consultant Radiologist	NOSCAN
Imran Liaquat	SANON Clinical Lead (from Nov 17) / Consultant Neurosurgeon	SCAN
Lorraine Stirling	Project Officer	National Cancer Quality Programme
Evelyn Thomson	Regional Manager (Cancer)	WoSCAN

Formal review of the Brain/CNS Cancer QPIs has been undertaken in consultation with various other clinical specialties.

NOSCAN - North of Scotland Cancer Network
SCAN - South East Scotland Cancer Network

2nd Cycle Formal Review

The 2nd cycle of formal review commenced in July 2020. This review was more selective and focussed on ensuring the ongoing clinical relevance of the QPIs. A Formal Review Group was convened, with Dr Noelle O'Rourke, Consultant Clinical Oncologist, NHS Greater Glasgow and Clyde appointed as Clinical Advisor/Chair to the group. Membership of this group is outlined below.

Brain/CNS Cancer QPI Formal Review Group Membership – 2nd Cycle (2020/21)

Name	Designation	Cancer Network
Noelle O'Rourke	Consultant Clinical Oncologist (Chair)	WoSCAN
Bobby Alikhani	Regional Manager (Cancer)	SCAN
Lorna Bruce	Audit Manager	SCAN
Jen Doherty	Programme Co-ordinator	National Cancer Quality Programme
Robin Grant	Consultant Neurologist	SCAN
Athanasios Grivas	Consultant Neurosurgeon	WoSCAN
Anne-Marie Hobkirk	Health Intelligence Senior Analyst	NCA
Allan James	Consultant Clinical Oncologist	WoSCAN
Imran Liaquat	Consultant Neurosurgeon and National MCN Clinical Lead	SCAN
Carol Marshall	Audit Manager	WoSCAN
Shona Olson	Consultant Neuroradiologist	NCA
Sharon Peoples	Consultant Clinical Oncologist	SCAN
Anna Solth	Consultant Neurosurgeon	NCA
Colin Smith	Professor of Neuropathology	SCAN
Lorraine Stirling	Project Officer	National Cancer Quality Programme
Antonia Torgersen	Consultant Neuropathologist	SCAN
James Walkden	Consultant Neurosurgeon	NCA

Formal review of the Brain/CNS Cancer QPIs has been undertaken in consultation with various other clinical specialties.

NCA - North Cancer Alliance
SCAN - South East Scotland Cancer Network
WoSCAN - West of Scotland Cancer Network

3rd Cycle Formal Review

The 3rd cycle of formal review commenced in April 2023. Mr Roger Currie, Consultant and Maxillofacial Surgeon, NHS Ayrshire and Arran was appointed as Clinical Advisor/Chair to the group. Membership of this group is outlined below:

Brain/CNS Cancer QPI Formal Review Group Membership – 3rd Cycle (2023/24)

Name	Designation	Cancer Network/Base
Roger Currie	Consultant Oral and Maxillofacial Surgeon (Chair)	WoSCAN
Jen Doherty	Programme Co-ordinator	National Cancer Quality Programme
Jennifer Fleming	Principal Clinical Scientist	SCAN
Allan James	Consultant Clinical Oncologist	WoSCAN
Marie Gallagher	Programme Manager	Scottish Cancer Network
Louise Gilroy	Clinical Scientist in Molecular Pathology	SCAN
Athanasios Grivas	Consultant Neurosurgeon	WoSCAN
Avinash Kanodia	Consultant Radiologist	NCA
Kevin Kinch	Consultant Neuropathologist	SCAN
Claire Lawrie	Senior Programme Manager	National Services Division
Hannah Lord	Consultant Clinical Oncologist	NCA
Imran Liaquat	Consultant Neurosurgeon and National MCN Clinical Lead	SCAN
Noelle O'Rourke	National Clinical Lead	Scottish Cancer Network
Sharon Peoples	Consultant Clinical Oncologist	SCAN
Colin Smith	Professor of Neuropathology	SCAN
Anna Solth	Consultant Neurosurgeon	NCA
Alexandru Stan	Consultant Neuropathologist	WoSCAN
Lorraine Stirling	Project Officer	National Cancer Quality Programme
James Walkden	Consultant Neurosurgeon	NCA

Formal review of the Brain/CNS Cancer QPIs has been undertaken in consultation with various other clinical specialties.

NCA - North Cancer Alliance
SCAN – South East Scotland Cancer Network
WoSCAN – West of Scotland Cancer Network

Appendix 3: 3-Yearly National Governance Process and Improvement Framework for Cancer Care

This process is underpinned by the annual regional reporting and governance framework (see appendix 4).

National QPI Development Stage

- QPIs developed by QPI development groups, which include representation from Regional Cancer Networks, Healthcare Improvement Scotland, PHS, patient representatives and the Cancer Coalition.

2. Data Analysis Stage:

- NHS Boards and Regional Cancer Advisory Groups (RCAGs)* collect data and analyse on yearly basis using nationally agreed measurability criteria and produce action plans to address areas of variance, see appendix 4.
- Submit yearly reports to PHS for collation and publication every 3 years.
- National comparative report approved by NHS Boards and RCAGs.
- PHS produce comparative, publicly available, national report consisting of trend analysis of 3 years data and survival analysis.

3. Expert Review Group Stage (for 3 tumour types per year):

- Expert group, hosted by Healthcare Improvement Scotland, review comparative national results.
- Write to RCAGs highlighting areas of good practice and variances.
- Where required NHS Boards requested to submit improvement plans for any outstanding unresolved issues with timescales for improvement to expert group.
- Improvement plans ratified by expert group and Scottish Cancer Strategic Board.

4. Improvement Support Stage:

- Where required Healthcare Improvement Scotland provide expertise on improvement methodologies and support.

6. Escalation Stage:

- If progress not acceptable, Healthcare Improvement Scotland will visit the service concerned and work with the RCAG and Board to address issues.

Report submitted to Scottish Cancer Strategic Board and escalation with a proposal to take forward to Scottish Government Health Department.

Appendix 4: Regional Annual Governance Process and Improvement Framework for Cancer Care

1. Regional QPI Implementation Stage:

- National cancer QPIs and associated national minimum core dataset and measurability specifications, developed by QPI development groups.
- Regional implementation of nationally agreed dataset to enable reporting of QPIs.

2. Data Analysis Stage:

- NHS Boards collect data and data is analysed on a yearly basis using nationally agreed measurability criteria at local/ regional level.
- Data/results validated by Boards and annual regional comparative report produced by Regional Networks.

- Areas of best practice and variance across the region highlighted.
- Yearly regional reports submitted to PHS for collation and presentation in national report every 3 years.

3. Regional Performance Review Stage:

- RCAGs* review regional comparative report.
- Regional or local NHS Board action plans to address areas of variance developed.
- Appropriate leads identified to progress each action.
- Action plans ratified by RCAGs.

4. Monitoring Stage:

- Where required, NHS Boards monitor progress with action plans and submit progress reports to RCAGs.
- RCAGs review and monitor regional improvement.

5. Improvement Support Stage:

- Where required Healthcare Improvement Scotland maybe requested to provide expertise to NHS Boards/RCAGs on improvement methodologies and support.

6. Escalation Stage:

- If progress not acceptable, RCAGs will escalate any issues to relevant Board Chief Executives. If progress remains unacceptable RCAGs will escalate any relevant issues to Healthcare Improvement Scotland.

*The Regional Cancer Planning Group (South and East of Scotland) and the North Cancer Clinical Leadership Group (North Cancer Alliance) are equivalent to the Regional Cancer Advisory Group (RCAG) in the West of Scotland.

Appendix 5: Glossary of Terms

- Active treatment - Treatment directed to cure the disease.
- Adjuvant therapy - Treatment given in addition to the primary therapy, or a secondary remedy assisting the action of another.
- Biopsy - Removal of a sample of tissue from the body to assist in diagnosis of a disease.
- Brain tumour - A tumour of part of the brain. There are many different types of brain tumour and they are named depending on which type of brain cells are affected.
- Central nervous system - The portion of the nervous system comprising the brain and spinal cord.
- Chemoradiotherapy - Treatment that combines chemotherapy with radiation therapy.
- Chemotherapy - The use of drugs that kill cancer cells, or prevent or slow their growth.
- Clinical trials - A type of research study that tests how well new medical approaches or medicines work. These studies test new methods of screening, prevention, diagnosis, or treatment of a disease.
- Computed Tomography (CT) - An x-ray imaging technique, which allows detailed investigation of the internal organ of the body.
- Contraindication - A symptom or medical condition that makes a particular treatment or procedure inadvisable because a person is likely to have a bad reaction.
- Diagnosis - The process of identifying a disease, such as cancer, from its signs and symptoms.
- Glial - Specialised cells that surround neurones, supporting nerve cells.
- Glioblastoma The most common type of brain tumour found in adults. It is also called grade 4 astrocytoma
- Glioma - A type of brain tumour that grows from glial cells. Glial cells make up the supporting tissue of the brain. Types include astrocytoma, ependymoma and oligodendroglioma.
- Grading - The degree of malignancy of a tumour, i.e. how closely the cancer cells look like normal cells.
- Imaging - The production of a clinical image using radiology, for example, CT, MRI, x-ray or ultrasound.
- Intravenous contrast - A substance administered intra venously (directly into bloodstream) to enhance the visibility of structures on imaging.
- Magnetic Resonance Imaging (MRI) - A procedure in which radio waves and a powerful magnet linked to a computer are used to create detailed pictures of areas inside the body. These pictures can show the difference between normal and diseased tissue.
- Metastases/Metastatic disease - Spread of cancer away from the primary site to somewhere else via the bloodstream or the lymphatic system. Metastatic disease can be local (close to the area where the cancer is) or distant (in another area of the body).
- MGMT - The O (6)-methylguanine-DNA methyltransferase (MGMT) gene. Methyl Guanine Methyl Transferase is a 'suicide' enzyme found in many cells including glioma cells. It acts to reverse toxic damage caused by certain agents including some alkylating agents like Temozolomide making them more resistent

- MGMT promoter methylation - Translation of the MGMT gene is controlled by a promotor. In glioblastoma, methylation of the promoter can lead to reduced production of MGMT and increased sensitivity to Temozolomide. Estimation of the MGMT promoter methylation status can be used as a predictive biomarker
- MHRA - Medicines and Healthcare products Regulatory Authority.
- Morbidity - How much ill health a particular condition causes.
- Molecular Analysis - The process of testing tumours for genetic characteristics and biomarkers. Based on this information, targeted therapies can then be recommended for treatment.
- Multi-disciplinary team meeting (MDT) - A meeting which is held on a regular basis, which is made up of participants from various disciplines appropriate to the disease area, where diagnosis, management, and appropriate treatment of patients is discussed and decided.
- Neuroimaging - Production of images of the brain by non-invasive techniques, for CT, MRI or PET scan
- Neurological - Related to the nervous system.
- Neurologist - A doctor who diagnoses and treats disorders of the central nervous system.
- Neuro-oncology - Medical speciality dealing with tumours of the nervous system.
- Neuropathologist - A pathologist who specializes in the diagnosis of diseases of the brain and nervous system by means of microscopic examination of the tissue etc.
- Oligodendroglial - Cells found in the central nervous system and associated with the formation of myelin.
- Pathological/Pathology - The study of disease processes with the aim of understanding their nature and causes. This is achieved by observing samples of fluid and tissues obtained from the living patient by various methods, or at post mortem.
- Pathologist - A doctor who identifies diseases by studying cells and tissues under a microscope.
- Performance status - A measure of how well a patient is able to perform ordinary tasks and carry out daily activities.
- Post operative complication - A complication or problem experienced following a surgical procedure.
- Progression- In medicine, the course of a disease, such as cancer, as it becomes worse or spreads in the body.
- Radical treatment - Treatment that aims to get to completely get rid of a cancer.
- Radiology - The use of radiation (such as x-rays) or other imaging technologies (such as ultrasound and magnetic resonance imaging) to diagnose or treat disease.
- Resection - Surgical removal of all or part of an organ, tissue, or structure.
- Resectable - When a tumour or part of a structure of organ is surgically removable.
- Seizure - An epileptic episode. It can also be known as a 'fit', 'funny turn' or 'attack'. A seizure occurs when there is excessive electrical activity in the brain. The brains electrical circuit is disrupted and the wrong messages are sent.
- Staging - Process of describing to what degree cancer has spread from its original site to another part of the body. Staging involves clinical, surgical and pathology assessments.

- Surgery / Surgical resection - Surgical removal of the tumour/lesion.
- Survival - The percentage of people in a study or treatment group who are alive for a certain period of time after they were diagnosed with or treated for a disease, such as cancer.
- Systemic therapies - Treatment, usually given by mouth or by injection, that reaches and affects tumour cells throughout the body rather than targeting one specific area.

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