Scottish Cancer Taskforce
National Cancer Quality Steering Group

Brain and Central Nervous System Cancer
Clinical Quality Performance Indicators
Engagement Document

December 2017

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1. National Cancer Quality Programme

Better 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 18 different tumour types. These are underpinned by patient experience QPIs that are applicable to all, irrespective of tumour type. 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 Multi Disciplinary 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 reports published annually. National reports include comparative reporting of performance against QPIs at MDT/Unit level across NHSScotland, trend analysis and survival. This approach helps 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 Information Services Division (ISD) for inclusion in subsequent national reports. This approach 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 Development Process

The QPI development process was designed to ensure that indicators are developed in an open, transparent and timely way. The development process can be found in appendix 1.

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, ISD and patient/carer representatives. Memberships of the development group can be found in appendix 2.

3. QPI Formal Review Process

As part of the National Cancer Quality Programme a systematic national review process has been developed, whereby all tumour specific QPIs published are subject to formal review following 3 years analysis of comparative QPI data.

Formal review of the Brain/CNS Cancer QPIs was undertaken in August 2017.

A Formal Review Group was convened, chaired by Dr Hilary Dobson, Deputy Director, Innovative Healthcare Delivery Programme. Membership of this group included Clinical Leads from the three Regional Cancer Networks as well as the National Clinical Lead. Membership of this group can be found in appendix 3.

The formal review process is clinically driven with comments sought from specialty specific representatives in each of the Regional Cancer Networks for discussion at the initial meeting. This review builds on existing evidence using expert clinical opinion to identify where new evidence is available.

During formal review QPIs may be removed 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.

Any new QPIs have been 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?

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 will be 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 document have been developed in parallel with the indicators to support the monitoring and reporting of Brain/CNS Cancer QPIs. The updated document will be implemented for patients diagnosed with Brain/CNS Cancer on, or after, 1st January 2017.

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 diagnosis.
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):	***Additional information noted within the rationale and evidence section to acknowledge the use of other tools that may be used to inform treatment decision making.***

QPI 2: Multi-Disciplinary Team Meeting

QPI Title:	Patients with brain/CNS cancer should be discussed by a multidisciplinary (MDT) team prior to surgery.*
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 (including biopsy) 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. **Exclusions:** • Patients who died before first treatment.
Target:	95% The tolerance within this target is designed to account for situations where patients require treatment urgently.

*This includes those patients who have undergone biopsy as part of their clinical management.

Revision(s):	***QPI changed to focus on discussion prior to surgery (including patients that have undergone biopsy as part of their clinical management).***

QPI 3: Molecular Analysis

QPI Title:	Patients with biopsied or resected gliomas should have molecular analysis performed on the tumour tissue within 21 days of surgery to inform treatment decision making.
Description:	Proportion of patients with biopsied or resected gliomas who undergo relevant molecular analysis[a] of tumour tissue within 21 days of surgery. **Please note:** This QPI measures 2 distinct elements: (i): Patients with Grade II or III gliomas who have the tumour tested for combined loss of 1p/19q; and (ii): Patients with glioblastomas[b] who have the tumour tested for MGMT[c] promoter methylation status.
Rationale and Evidence:	Combined loss of 1p/19q in gliomas with an oligodendroglial component 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 carried out to help determine treatment and provide information on predicted tumour response to therapy and prognosis[2,4]. Determination of MGMT promoter methylation status predicts response to therapy (chemotherapy or concomitant chemoradiotherapy) in glioblastomas and assists in determination of prognosis. As such, where indicated, MGMT promotor methylation analysis should be carried out to help determine treatment and provide information on predicted tumour response to therapy and prognosis[5]. The group have added a 21 day timeframe to ensure that the molecular analysis is undertaken and reported before treatment takes place.
Specification (i):	**Numerator:** Number of patients with a Grade II or III glioma undergoing surgery where tissue sample is tested for 1p/19q within 21 days of surgery. **Denominator:** All patients with a Grade II or III glioma undergoing surgery. **Exclusions:** • No exclusions.
Target:	90% The tolerance within this target is designed to account for cases in which there is insufficient viable tissue for molecular analysis.

(Continued overleaf…)

[a] WHO Classification of CNS tumours (2016) uses molecular parameters in addition to histology to define tumour entities. In addition to those outlined in the QPI, relevant molecular analysis also include those outlined in 2016 World Health Organisation Classification of Tumours of the Central Nervous System.[6]
[b] Including subtypes (WHO Grade IV)
[c] The O(6)-methylguanine-DNA methyltransferase (MGMT) gene

QPI 3: Molecular Analysis (cont…)

Specification (ii):	**Numerator:**	Number of patients with glioblastomas undergoing surgery where tissue sample is assessed for MGMT promoter hypermethylation status within 21 days of surgery.
	Denominator:	All patients with glioblastomas undergoing surgery.
	Exclusions:	• No exclusions.
Target:	90% The tolerance within this target is designed to account for cases in which there is insufficient viable tissue for molecular analysis.	

Revision(s):	***Removed reference to oligodendroglial component in specification (i)and reference to this in the footnote*** ***Footnote added to clarify that molecular analysis includes all those outlined in the WHO document***

QPI 4: Neuropathological Diagnosis

QPI Title:	All pathology reports for brain/central nervous system (CNS) cancer should contain full pathology information (including tumour type as described in World Health Organisation (WHO) Classification of CNS tumours (2016) and (WHO) grade where appropriate) to inform patient management.
Description:	Proportion of patients with brain/CNS cancer where the pathology report contains a full set of data items (as defined by the Royal College of Pathologists).
Rationale and Evidence:	Accurate and robust standardisation of tumour diagnosis is required for appropriate patient management. As such, Neuropathologists should report to the standards defined by the Royal College of Pathologists in 'Standards and Datasets for Reporting Cancers: Dataset for Tumours of the Central Nervous System, including Pituitary Gland[2].
Specifications:	**Numerator:** Number of patients with a histological diagnosis of brain/CNS cancer where histological pathology report contains all data items (as defined by relevant Royal College of Pathologists). **Denominator:** All patients with a histological diagnosis of brain/CNS cancer. **Exclusions:** • No exclusions.
Target:	95% The tolerance within this target is designed to account for tumour specimens where insufficient tissue is available for a definitive neuropathological diagnosis.

Revision(s):	***Appendix 7 (Royal College of Pathologists Dataset) removed from the QPI document and relevant changes made to the audit dataset (Type of procedure and Tumour subtype not a requirement for a complete pathology report.*** ***Increased the target to 95%***

QPI 5: Pre-Treatment Magnetic Resonance Imaging (MRI)

QPI Title:	Patients with brain/central nervous system (CNS) cancer should have contrast enhanced Magnetic Resonance Imaging (MRI) prior to treatment.
Description:	Proportion of patients with brain/CNS cancer undergoing surgery and/or radical radiotherapy, who have a contrast enhanced MRI prior to treatment. **Please note:** The specification of this QPI are separated to ensure clear measurement of both: (i) Patients undergoing contrast enhanced MRI prior to surgery (ii) Patients undergoing contrast enhanced MRI prior to radical radiotherapy
Rationale and Evidence:	MRI is the established investigation for patients with presumed low grade tumours[2, 7]. Although contrast enhanced Computed Tomography (CT) will often be the initial investigation suggesting the diagnosis of CNS tumour, MRI provides additional information in many cases. Revised response assessment criteria for high grade gliomas suggest that MRI is the preferred modality used to assess response and progression, therefore pre-treatment MRI is essential for this[2, 8].

Specification (i):	**Numerator:** Number of patients with brain/CNS cancer undergoing surgery who receive a contrast enhanced MRI prior to treatment.
	
	Denominator: All patients with brain/CNS cancer undergoing surgery.
	
	Exclusions:
	• Patients unable to undergo a contrast enhanced MRI scan e.g.:
	  ○ Pacemaker or other MRI incompatible implanted device.
	  ○ Claustrophobia.
	  ○ Contraindication to intravenous contrast medium.
	• Patients who refuse MRI.

Target:	90% The tolerance within the target takes account of those situations where patients require surgical intervention as an emergency.

(Continued overleaf…)

QPI 5: Pre-Treatment Magnetic Resonance Imaging (MRI) (cont…..)

Specification (ii):	**Numerator:**	Number of patients with brain/CNS cancer undergoing radical radiotherapy who receive a contrast enhanced MRI prior to treatment.
	Denominator:	All patients with brain/CNS cancer undergoing radical radiotherapy.

	Exclusions:	• Patients unable to undergo a contrast enhanced MRI scan e.g.:
		  ○ Pacemaker or other MRI incompatible implanted device.
		  ○ Claustrophobia.
		  ○ Contraindication to intravenous contrast medium.
		• Patients who refuse MRI.

Target:	90% The tolerance within this target is to account for other situations where patients are deemed clinically unsuitable or unfit to undergo MRI.	

Revision(s):	***QPI separated into 2 specifications to focus on different times within the treatment pathway:*** ***(i) MRI prior to surgery*** ***(ii) MRI prior to radical radiotherapy***

QPI 6: Maximal Surgical Resection

QPI Title:	Wherever possible patients should undergo maximal surgical resection of malignant gliomas[d].	
Description:	Proportion of patients with malignant gliomad[d] (with enhancing component on pre-operative imaging) who undergo surgical resection where >90% reduction in tumour volume is achieved provided it is considered consistent with safe outcome.	
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[9] and is associated with prolonged survival[10]. Maximum safe surgical resection is recommended by several published guidelines[4, 11]. **Measurement of this QPI will focus on those patients with the intention for maximal safe surgical resection.** This will be identified pre-operatively and documented at the MDT.	
Specification:	**Numerator:**	Number of patients with resectable malignant gliomad[d] (with enhancing component on pre-operative imaging) undergoing surgical resection where >90%* reduction in tumour volume is achieved.
	Denominator:	All patients with malignant glioma[d] (with enhancing component on pre-operative imaging) undergoing surgical resection.
	Exclusions:	• Patients undergoing biopsy only. • Patients in whom surgeons intent is partial resection / debulking surgery.
Target:	40%	

*Percentage tumour reduction should be assessed by comparing pre surgical imaging to post surgical 72hr Magnetic Resonance Imaging (MRI)

Revision(s):	***QPI changed to focus on those patients where the intention for safe maximal resection has been agreed pre-operatively by MDT.***

[d] Malignant gliomas include:
Glioblastoma multiforme- GBM and its variants e.g. gliosarcoma
Anaplastic Astrocytoma- AA
Aanaplastic oligodendrogliomas
Mixed tumours e.g. oligoastrocytoma, glioblastoma with oligodenroglial component
High-grade ependymoma

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[e] (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[12-16]. 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[e] (with enhancing component on pre-operative imaging), undergoing surgical resection receiving MRI within 3 days (72hrs) of surgical resection.
	Denominator:	All patients with malignant glioma[e] (with enhancing component on pre-operative imaging), undergoing surgical resection.

	Exclusions:	• Patients unable to undergo an MRI scan[f] 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.

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.	

[e] Malignant gliomas include:
Glioblastoma multiforme- GBM and its variants e.g. gliosarcoma)
Anaplastic Astrocytoma- AA)
Anaplastic oligodendrogliomas
Mixed tumours e.g. oligoastrocytoma, glioblastoma with oligodenroglial component
High-grade ependymoma

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

	No changes to QPI

QPI 8: Specialist Neuro-Oncology Access

QPI Title:	Patients with brain/central nervous system (CNS) cancer undergoing oncological treatment should be managed by a site specialist neuro-oncologist.
Description:	Proportion of patients with brain/CNS cancer undergoing oncological treatment (chemotherapy or radiotherapy) who are managed by a specialist neuro-oncologist.
Rationale and Evidence:	Non-surgical management of patients with brain and CNS tumours is increasingly complex. Radiotherapy and systemic therapy are evolving rapidly, particularly with regard to the emergence of (a) new radiotherapy technologies and (b) novel prognostic and predictive molecular markers. Psychosocial aspects of care are also complex. All patients should therefore be under the care of a clinical oncologist with a special interest in tumours of the brain and CNS[2].
Specifications:	**Numerator:** Number of patients with brain/CNS cancer undergoing oncological treatment (chemotherapy or radiotherapy) who are managed by a specialist neuro-oncologist. **Denominator:** All patients with brain/CNS cancer undergoing oncological treatment (chemotherapy or radiotherapy). **Exclusions:** • No exclusions.
Target:	100%

Revision(s):	***No changes to QPI.***

QPI 9: Access to Adjuvant 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[17]. In addition, evidence shows that patients commencing radiotherapy within 6 weeks of the date of surgery had improved overall survival[18].
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:	95% 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 changes to QPI.***

QPI 10: Radical Radiotherapy Planning Process

QPI Title:	The radical[g] radiotherapy planning process for patients with brain/Central Nervous System (CNS) cancer should include Magnetic Resonance Imaging (MRI) fusion.
Description:	Proportion of patients with brain/CNS cancer undergoing radical radiotherapy for whom the radiotherapy planning process includes MRI fusion.
Rationale and Evidence:	Determining the Gross Target Volume is a critical process in the radiotherapy planning of patients with primary brain/CNS cancer. Radiotherapy planning Computed Tomography (CT) scans provide very limited information on the extent of the primary tumour, and attempts to utilise anatomical MRI information by 'side-by-side' visual assessment are usually inaccurate[19]. MRI fusion enables the superior anatomical and physiological information provided by MRI to be accurately combined with planning CT data sets in order to optimise gross tumour volume (GTV) delineation. MRI fusion has been shown to reduce inter-observer variation in target delineation of high grade gliomas[19] and a number of studies have shown that target volumes determined by CT alone frequently underestimate tumour extent[20].

Specifications:	**Numerator:** Number of patients with brain/CNS cancer undergoing radical radiotherapy for whom radiotherapy planning includes MRI fusion.
	
	Denominator: All patients with brain/CNS cancer undergoing radical radiotherapy.
	
	Exclusions:
	• Patients unable to undergo an MRI scan e.g.-
	  ○ Pacemaker or other MRI incompatible implanted device.
	  ○ Cerebral aneurysm clip.
	  ○ Contraindication to intravenous contrast medium.
	• Patients who refuse MRI.

Target:	95% The tolerance within this target is designed to account for factors of patient choice.

Revision(s):	***Footnote added to change the definition of radical radiotherapy from ≥20 fractions to ≥15 fractions.***

[g] Radical is defined as radiotherapy courses where ≥15 fractions are delivered.

QPI 11: Seizure Management

QPI Title:	Patients with brain/central nervous system (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 weeks of diagnosis.
Rationale and Evidence:	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].
Specification:	**Numerator:** Number of patients presenting with seizures at diagnosis seen by a neurologist or a named ESN within four weeks of diagnosis. **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):	***QPI updated to include reference to an appropriate timescale for being seen by the neurologist / nurse with expertise in epilepsy management.*** ***Wording has been changed from nurse with expertise in epilepsy management to named epilepsy specialist nurse (ESN).***

QPI 12: Key Worker

QPI Title:	Patients with brain/central nervous system (CNS) cancer should have an identified key worker to co-ordinate care across the patient pathway.
Description:	Proportion of patients with brain/CNS cancer who have an identified key worker by the first MDT meeting.
Rationale and Evidence:	It is recommended that all patients with CNS tumours should have an identified key worker. Having a clearly identified key worker is important to ensure that care is adequately co-ordinated for patients with CNS tumours[23]. While the patient is being managed under the care of the neuroscience or oncology / radiotherapy centre the key worker is likely to be the Clinical Nurse Specialist[23].
Specifications:	**Numerator:** Number of patients with brain/CNS cancer who have an identified key worker by the first MDT meeting. **Denominator:** All patients with brain/CNS cancer **Exclusions:** • No exclusions.
Target:	95% The tolerance within this target is designed to account for factors of patient choice.

Revision(s):	***New QPI***

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 and chemotherapy) 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 intented to ensure treatment is given appropriately, and the outcome reported on and reviewed.
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 chemotherapy). **Exclusions:** • No exclusions. **Please note:** This indicator will be reported by treatment modality, i.e. surgery, radiotherapy and chemotherapy as opposed to one single figure.
Target:	Surgery <3% Chemotherapy / Radiotherapy / Chemoradiotherapy <5%

Revision(s):	***New QPI***

QPI 14: Clinical Trials and Research Study Access

Revision(s):	***The revised Clinical Trial Access QPI which is applicable to all tumour sites will be included with the final Brain / CNS Cancer QPI document.***

7. Survival

Improving survival forms an integral part of the national cancer quality improvement programme. Brain/CNS Cancer survival analysis will be reported and analysed on a 3 yearly basis by Information Services Division (ISD). The specific issues which will be addressed, for example 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, during the QPI development process, the following issues for survival analysis:

- Overall 1, 2 and 5 year 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 will be scheduled as per the national survival analysis and reporting timetable, agreed with the National Cancer Quality Steering Group and Scottish Cancer Taskforce. This reflects the requirement for record linkage and the more technical requirements of survival analyses which would make 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.
- The use of techniques aimed at safe surgical resection (e.g. 5-ALA)
- Further molecular testing (e.g. TERT)

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 4 and 5 provide an overview of these governance arrangements diagrammatically. The importance of ensuring robust local governance processes are in place is recognised and it is essential that NHS Boards ensure that cancer clinical audit is fully embedded within established processes.

9.1 National

- Scottish Cancer Taskforce
    - Accountable for overall national cancer quality programme and overseeing the quality of cancer care across NHSScotland.
    - Advising Scottish Government Health and Social Care Directorate (SGHSCD) if escalation required.

- 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.

- Information Services Division (ISD)
    - Publish national comparative report on tumour specific QPIs and survival for 3 tumour types per annum and specified generic QPIs 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 monitoring of progress against agreed actions.
- Provide assurance to NHS Board Chief Executive Officers and Scottish Cancer Taskforce 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 (patient experience 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, several different methods of engagement are being pursued:

Professional groups, health service staff, voluntary organisations and individuals:

- Wide circulation of the draft documentation for comment and feedback.

Patient representative groups:

- Organised patient focus group sessions to be held.

10.1 Submitting your comments

You can submit your comments on the revised Brain/CNS Cancer QPIs via the Scottish Government Consultation Hub (website link below):

https://consult.gov.scot/nhs/brain-cns-cancer-qpisbrain-cns-cancer-qpis

All responses should be submitted by **Friday 26th January 2017.**

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

Email: BrainCNSQPIPublicEngagement@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 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.

11. References

1. Scottish Government (2016). Beating Cancer: Ambition and Action Available from: http://www.scotland.gov.uk/Resource/Doc/242498/0067458.pdf. (accessed December 2016).
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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[24]. 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.

Appendix 2: 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)
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	
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	
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)

Name	Designation	Cancer Network/Base
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)

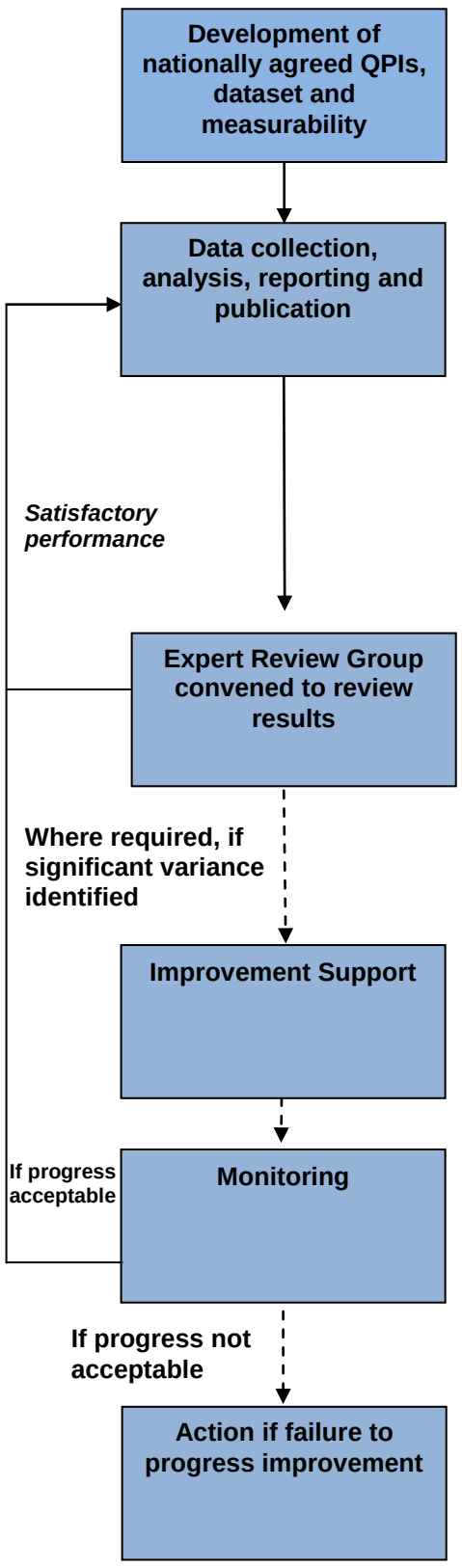
NOSCAN - North of Scotland Cancer Network
SCAN - South East Scotland Cancer Network
WoSCAN - West of Scotland Cancer Network

Appendix 3: Brain/CNS Cancer QPI Development Group Membership (2017)

Name	Designation	Cancer Network/Base
Hilary Dobson	Deputy Director, 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 / Consultant Radiologist	NOSCAN
Imran Liaquat	Consultant Neurosurgeon	SCAN
Lorraine Stirling	Project Officer	WoSCAN
Evelyn Thomson	Regional Manager (Cancer)	WoSCAN

Appendix 4: 3 Yearly National Governance Process & Improvement Framework for Cancer Care

This process is underpinned by the annual regional reporting and governance framework (see appendix 5).



1. National QPI Development Stage

- QPIs developed by QPI development groups, which include representation from Regional Cancer Networks, Healthcare Improvement Scotland, ISD, 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 6.
- Submit yearly reports to ISD for collation and publication every 3 years.
- National comparative report approved by NHS Boards and RCAGs.
- ISD 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 Taskforce.

4. Improvement Support Stage:

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

5. Monitoring Stage:

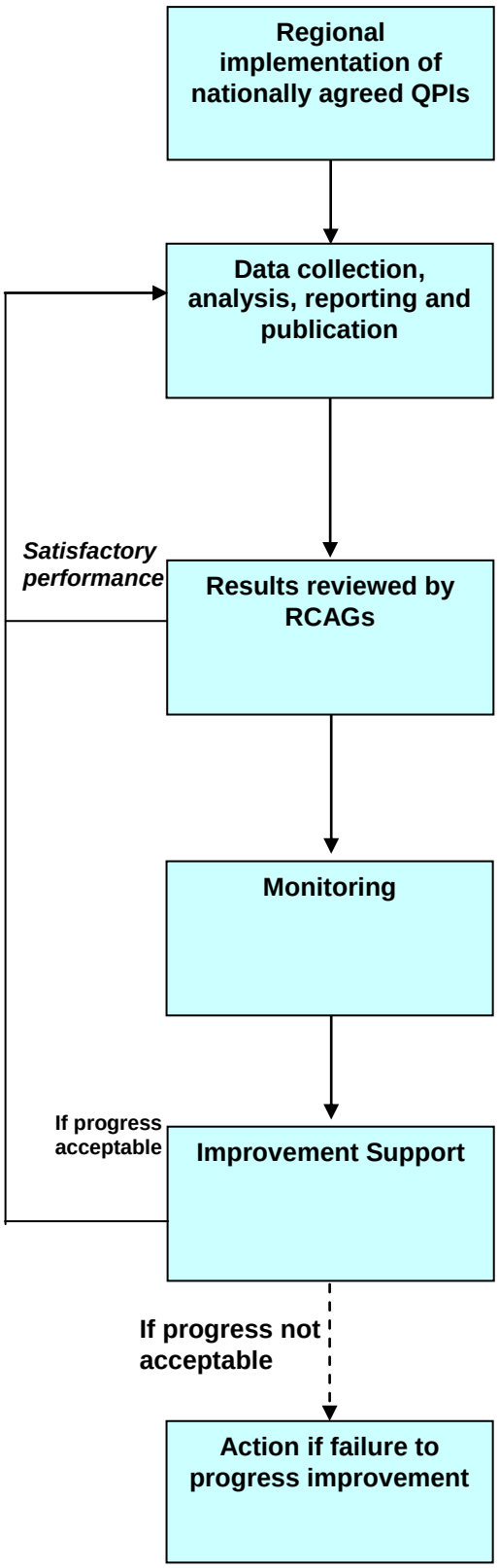
- RCAGs work with Boards to progress outstanding actions, monitor improvement plans and submit progress report to Healthcare Improvement Scotland.
- Healthcare Improvement Scotland report to Scottish Cancer Taskforce as to whether progress is acceptable**.**

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 Taskforce and escalation with a proposal to take forward to Scottish Government Health Department.

*In the South and East of Scotland Cancer Network (SCAN) the Regional Cancer Planning Group is the equivalent group to Regional Cancer Advisory Group (RCAG).

Appendix 5: 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 ISD 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.

*In the South and East of Scotland Cancer Network (SCAN) the Regional Cancer Planning Group is the equivalent group to Regional Cancer Advisory Group (RCAG).

Appendix 6: 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.
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.