Scottish Cancer Taskforce
National Cancer Quality Steering Group

Brain and Central Nervous System Cancer
Clinical Quality Performance Indicators

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Contents Update Record

March 2018 (v3.0)
This document was updated following formal review of the Brain / CNS Cancer Quality Performance Indicators (QPIs) which took place following analysis of year 3 of the brain / CNS cancer QPI data.

The following QPIs have been updated:

- QPI 1 – Documentation of Performance Status
- QPI 2 – Multidisciplinary Team Meeting
- QPI 3 – Molecular Analysis
- QPI 4 – Neuropathological Diagnosis
- QPI 5 – Pre-Treatment Magnetic Resonance Imaging (MRI)
- QPI 6 – Maximal Surgical Resection
- QPI 10 – Radical Radiotherapy Planning Process
- QPI 11 – Seizure Management

The following new QPIs have been added:

- QPI 12 – Key Worker
- QPI 13 – 30 Day Mortality after Treatment for Brain / CNS Cancer

Please note the revised Clinical Trials and Research Study Access QPI has now been added into each tumour specific QPI document (see QPI 14: Clinical Trials and Research Study Access).

As a result of the changes above, the contents page and page numbering differ from earlier versions of this document. Sections 1 - 10 and the appendices have also been updated.

Please note that this version of the Brain/CNS Cancer QPI Document applies to cases diagnosed from 1st January 2017 onwards. Where amended or new QPIs require new data items for measurement, this will apply for patients diagnosed from 1st January 2018.

Previous Updates:

December 2015 (v2.0)
This document was updated following baseline review of the Brain / CNS Cancer QPIs which took place following analysis of year 1 of the brain / CNS cancer data. As a result, the following QPIs have been updated:

- QPI 1 – Documentation of Performance Status
- QPI 6 – Maximal Surgical Resection
- QPI 7 – Early Post-Operative Imaging
- QPI 9 – Access to Adjuvant Treatment

Please note that this version of the Brain / CNS Cancer QPI document applies to cases diagnosed from 1st January 2015.
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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?

The revised Brain / CNS Cancer QPIs were made available on the Scottish Government Consultation Hub during December 2017 / January 2018, as part of a wide clinical and public engagement exercise. During the engagement period, clinical and management colleagues from across NHSScotland, patients affected by brain / CNS cancer and the wider public were given the opportunity to influence the revised Brain / CNS Cancer QPIs.

Following the engagement period all comments and responses received were reviewed by the Brain / CNS Cancer QPI Formal Review Group and used to produce and refine the final indicators (section 6).

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' (>l) 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

<table>
<thead>
<tr>
<th>QPI Title:</th>
<th>Patients with newly-diagnosed brain/central nervous system (CNS) cancer should have a world health organisation (WHO) performance status documented at time of diagnosis.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Description:</td>
<td>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.</td>
</tr>
<tr>
<td>Rationale and Evidence:</td>
<td>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.</td>
</tr>
<tr>
<td></td>
<td>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.</td>
</tr>
<tr>
<td></td>
<td>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.</td>
</tr>
<tr>
<td>Specification:</td>
<td><strong>Numerator:</strong> 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.</td>
</tr>
<tr>
<td></td>
<td><strong>Denominator:</strong> All newly-diagnosed patients with brain/CNS cancer discussed at MDT meeting.</td>
</tr>
<tr>
<td></td>
<td><strong>Exclusions:</strong> No exclusions.</td>
</tr>
<tr>
<td>Target:</td>
<td>95%</td>
</tr>
<tr>
<td></td>
<td>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.</td>
</tr>
</tbody>
</table>

**Please note:** The MDT Chair should try to ensure that a valid performance status is documented on MDT outcome.
### QPI 2: Multi-Disciplinary Team Meeting

<table>
<thead>
<tr>
<th>QPI Title:</th>
<th>Patients with brain/CNS cancer should be discussed by a multidisciplinary (MDT) team prior to any surgical procedure.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Description:</strong></td>
<td>Proportion of patients with brain/CNS cancer who are discussed at MDT meeting before surgery.</td>
</tr>
</tbody>
</table>
| **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.  
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:** | 95%  
The tolerance within this target is designed to account for situations where patients require treatment urgently. |

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*a* 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 21 days of surgery to inform treatment decision making.

Description: Proportion of patients with biopsied or resected gliomas who undergo relevant molecular analysis 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 who have the tumour tested for MGMT promoter methylation status.

Rationale and Evidence: 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 carried out to help determine treatment and provide information on predicted tumour response to therapy and prognosis.

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 promoter methylation analysis should be carried out to help determine treatment and provide information on predicted tumour response to therapy and prognosis.

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…)

b 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 includes those outlined in 2016 World Health Organisation Classification of Tumours of the Central Nervous System.

c Including subtypes (WHO Grade IV)

d The O(6)-methylguanine-DNA methyltransferase (MGMT) gene
### QPI 3: Molecular Analysis (cont…)

<table>
<thead>
<tr>
<th>Specification (ii):</th>
<th>Numerator: Number of patients with glioblastomas undergoing surgery where tissue sample is assessed for MGMT promoter hypermethylation status within 21 days of surgery.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Denominator: All patients with glioblastomas undergoing surgery.</td>
</tr>
<tr>
<td>Exclusions:</td>
<td>• No exclusions.</td>
</tr>
</tbody>
</table>

**Target:**

90%

The tolerance within this target is designed to account for cases in which there is insufficient viable tissue for molecular analysis.
### QPI 4: Neuropathological Diagnosis

<table>
<thead>
<tr>
<th>QPI Title:</th>
<th>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.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Description:</td>
<td>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).</td>
</tr>
<tr>
<td>Rationale and Evidence:</td>
<td>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’.</td>
</tr>
</tbody>
</table>
| 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. |
### QPI 5: Pre-Treatment Magnetic Resonance Imaging (MRI)

<table>
<thead>
<tr>
<th><strong>QPI Title:</strong></th>
<th>Patients with brain/central nervous system (CNS) cancer should have contrast enhanced Magnetic Resonance Imaging (MRI) prior to treatment.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Description:</strong></td>
<td>Proportion of patients with brain/CNS cancer undergoing surgery who have contrast enhanced MRI prior to treatment.</td>
</tr>
</tbody>
</table>
| **Rationale and Evidence:** | MRI is the established investigation for patients with presumed low grade tumours.  
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.

The focus of this QPI is on those patients undergoing surgery. MRI for patients undergoing radical radiotherapy is covered by QPI 10 – Radical Radiotherapy Planning Process. |

| **Specifications:** | **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.  
  - Cerebral aneurysm clip.  
  - 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. |
## QPI 6: Maximal Surgical Resection

<table>
<thead>
<tr>
<th>QPI Title:</th>
<th>Whenever possible patients should undergo maximal surgical resection of malignant gliomas.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Description:</td>
<td>Proportion of patients with malignant glioma (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.</td>
</tr>
<tr>
<td>Rationale and Evidence:</td>
<td>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 and is associated with prolonged survival. Maximum safe surgical resection is recommended by several published guidelines. 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.</td>
</tr>
</tbody>
</table>
| Specification: | **Numerator:** Number of patients with resectable 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.  
- 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)

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* Malignant gliomas include:  
  - Glioblastoma multiforme - GBM and its variants e.g. gliosarcoma  
  - Anaplastic Astrocytoma - AA  
  - Anaplastic pleomorphic xanthoastrocytoma  
  - Anaplastic oligodendrogliomas  
  - Anaplastic (High-grade) ependymoma
## QPI 7: Early Post-Operative Imaging

<table>
<thead>
<tr>
<th>QPI Title:</th>
<th>Patients with malignant glioma (with enhancing component on pre-operative imaging) undergoing surgical resection should be subject to early post-operative imaging.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Description:</td>
<td>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.</td>
</tr>
</tbody>
</table>
| 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. 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 e.g.:  
  o Pacemaker or other MRI incompatible implanted device.  
  o Cerebral aneurysm clip.  
  o 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. |

1 Where it is not possible to image with MRI an attempt should be made to image with computerised tomography (CT).
### 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 CNS². |
| **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% |
**QPI 9: Access to Oncological Treatment**

<table>
<thead>
<tr>
<th>QPI Title:</th>
<th>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.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Description:</td>
<td>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.</td>
</tr>
</tbody>
</table>
| 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. In addition, evidence shows that patients commencing radiotherapy within 6 weeks of the date of surgery had improved overall survival.

<table>
<thead>
<tr>
<th>Specifications:</th>
<th><strong>Numerator:</strong> 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.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Denominator:</strong> All patients with high grade glioma (WHO grades III and IV) who undergo oncological treatment (chemotherapy, radiotherapy, or chemoradiotherapy) following surgery.</td>
</tr>
<tr>
<td></td>
<td><strong>Exclusions:</strong> No exclusions.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Target:</th>
<th>95%</th>
</tr>
</thead>
</table>

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.
# QPI 10: Radical Radiotherapy Planning Process

<table>
<thead>
<tr>
<th>QPI Title:</th>
<th>The radical(^9) radiotherapy planning process for patients with brain/Central Nervous System (CNS) cancer should include Magnetic Resonance Imaging (MRI) fusion.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Description:</td>
<td>Proportion of patients with brain/CNS cancer undergoing radical radiotherapy for whom the radiotherapy planning process includes MRI fusion.</td>
</tr>
<tr>
<td>Rationale and Evidence:</td>
<td>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).</td>
</tr>
</tbody>
</table>
| 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.-  
  o Pacemaker or other MRI incompatible implanted device.  
  o Cerebral aneurysm clip.  
  o 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. |

\(^9\) Radical is defined as radiotherapy courses where \(\geq 15\) fractions are delivered.
### QPI 11: Seizure Management

<table>
<thead>
<tr>
<th>QPI Title:</th>
<th>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).</th>
</tr>
</thead>
<tbody>
<tr>
<td>Description:</td>
<td>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.</td>
</tr>
<tr>
<td>Rationale and Evidence:</td>
<td>Diagnosing epilepsy can be complex and it is crucial that specialists are involved early to avoid misdiagnosis. 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.</td>
</tr>
</tbody>
</table>
| 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. |
## QPI 12: Key Worker

<table>
<thead>
<tr>
<th><strong>QPI Title:</strong></th>
<th>Patients with brain/central nervous system (CNS) cancer should have an identified key worker to co-ordinate care across the patient pathway.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Description:</strong></td>
<td>Proportion of patients with brain/CNS cancer who have an identified key worker by the first MDT meeting.</td>
</tr>
</tbody>
</table>
| **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. 

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.

Supportive care patients have been excluded from this QPI as they are managed separately through a palliative care route. |
| **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:** Patients undergoing supportive care. |
| **Target:** | 95%  
The tolerance within this target is designed to account for factors of patient choice. |
### QPI 13: 30 Day Mortality after Treatment for Brain/CNS Cancer

<table>
<thead>
<tr>
<th><strong>QPI Title:</strong></th>
<th>30 day mortality following treatment for brain / CNS cancer.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Description:</strong></td>
<td>Proportion of patients with brain / CNS cancer who die within 30 days of treatment (surgery, radiotherapy and chemotherapy) for brain / CNS cancer.</td>
</tr>
<tr>
<td><strong>Rationale and Evidence:</strong></td>
<td>Treatment related mortality is a marker of the quality and safety of the whole service provided by the Multi Disciplinary Team (MDT). 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.</td>
</tr>
<tr>
<td><strong>Specifications:</strong></td>
<td><strong>Numerator:</strong> Number of patients with brain / CNS cancer who undergo treatment that die within 30 days of treatment. <strong>Denominator:</strong> All patients with brain / CNS cancer who undergo treatment (surgery, radiotherapy or chemotherapy). <strong>Exclusions:</strong> • No exclusions. <strong>Please note:</strong> This indicator will be reported by treatment modality, i.e. surgery, radiotherapy and chemotherapy as opposed to one single figure.</td>
</tr>
<tr>
<td><strong>Target:</strong></td>
<td>&lt;5%</td>
</tr>
</tbody>
</table>
**QPI 14: Clinical Trials and Research Study Access**

<table>
<thead>
<tr>
<th>QPI Title:</th>
<th>All patients should be considered for participation in available clinical trials / research studies, wherever eligible.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Description:</td>
<td>Proportion of patients diagnosed with brain / CNS cancer who are consented(^h) for a clinical trial / research study.</td>
</tr>
<tr>
<td>Rationale and Evidence:</td>
<td>Clinical trials are necessary to demonstrate the efficacy of new therapies and other interventions(^{24}). Evidence suggests improved patient outcomes when hospitals are actively recruiting patients into clinical trials(^{23}). Clinicians are therefore encouraged to enter patients into well-designed trials and to collect longer-term follow-up data. High accrual activity into clinical trials is used as a goal of an exemplary clinical research site. The measurement of this QPI focuses on those patients who have consented in order to reflect the intent to join a clinical trial and demonstrate the commitment to recruit patients. Often patients can be prevented from enrolling within a trial due to stratification of studies and precise inclusion criteria identified during the screening process.</td>
</tr>
</tbody>
</table>
| Specifications: | **Numerator:** Number of patients diagnosed with brain / CNS cancer consented for a clinical trial / research study.  
**Denominator:** All patients diagnosed with brain / CNS cancer.  
**Exclusions:**  
- No exclusions. |
| Target: | 15% |

**Please note:**

The Clinical Trials and Research Study Access QPI is measured utilising SCRN data and ISD incidence data, as is the methodology currently utilised by the Chief Scientist Office (CSO) and NCRI. The principal benefit of this approach is that this data is already collected utilising a robust mechanism.

Utilising SCRN data allows for comparison with CSO published data and ensures capture of all eligible clinical trials and research studies, not solely first line treatment trials, as contained in the clinical audit data. Given that a significant proportion of clinical trials and research studies are for relapsed disease this is felt to be particularly important in driving quality improvement. This methodology utilises incidence as a proxy for all patients with cancer. This may slightly over, or underestimate, performance levels, however this is an established approach currently utilised by NHSScotland.

For further details of definitions, inclusion criteria and methodology used, please see the full Clinical Trials and Research Study Access QPI. This can be found at:

[Healthcare Improvement Scotland - Cancer Quality Performance Indicators](#)

\(^h\) Consented is defined as patients who have given consent to participate in a clinical trial / research study subject to study specific screening for eligibility.
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. References


11. 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.

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

Adults only
Date: 2005 to present day
Language: English only

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\(^2\). 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)

<table>
<thead>
<tr>
<th>Name</th>
<th>Designation</th>
<th>Cancer Network/Base</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hilary Dobson</td>
<td>Regional Lead Cancer Clinician (CHAIR)</td>
<td>WoSCAN</td>
</tr>
<tr>
<td>Anne Addison</td>
<td>Audit Facilitator</td>
<td>SCAN (Western General Hospital, Edinburgh)</td>
</tr>
<tr>
<td>Syed A. Al-Haddad</td>
<td>Consultant Neurosurgeon</td>
<td>NOSCAN (Aberdeen Royal Infirmary)</td>
</tr>
<tr>
<td>Anthony Chalmers</td>
<td>Clinical Oncologist</td>
<td>WoSCAN (Beatson West of Scotland Cancer Centre)</td>
</tr>
<tr>
<td>Susan Chivers</td>
<td>Audit / MDT Coordinator</td>
<td>WoSCAN (Southern General Hospital, Glasgow)</td>
</tr>
<tr>
<td>Laurence Dunn</td>
<td>Consultant Neurosurgeon</td>
<td>WoSCAN (Southern General Hospital, Glasgow)</td>
</tr>
<tr>
<td>Sam Eljamel</td>
<td>Consultant Neurosurgeon</td>
<td>NOSCAN (Ninewells Hospital, Dundee)</td>
</tr>
<tr>
<td>Kirsten Forbes</td>
<td>Consultant Radiologist</td>
<td>WoSCAN (Southern General Hospital, Glasgow)</td>
</tr>
<tr>
<td>Helen Gooday</td>
<td>Consultant in Rehabilitation Medicine</td>
<td>NOSCAN (Woodend Hospital, Aberdeen)</td>
</tr>
<tr>
<td>Robin Grant</td>
<td>Consultant Neurologist</td>
<td>SCAN (Western General Hospital, Edinburgh)</td>
</tr>
<tr>
<td>James Ironside</td>
<td>Consultant Pathologist</td>
<td>SCAN (Western General Hospital, Edinburgh)</td>
</tr>
<tr>
<td>Jennifer Lee</td>
<td>Audit Facilitator</td>
<td>NOSCAN (Ninewells Hospital, Dundee)</td>
</tr>
<tr>
<td>Hannah Lord</td>
<td>Clinical Oncologist</td>
<td>NOSCAN (Ninewells Hospital, Dundee)</td>
</tr>
<tr>
<td>Kelly Macdonald</td>
<td>Project Manager</td>
<td></td>
</tr>
<tr>
<td>James MacKenzie</td>
<td>Consultant Pathologist</td>
<td>NOSCAN (Aberdeen Royal Infirmary)</td>
</tr>
<tr>
<td>Mairi MacKinnon</td>
<td>Clinical Nurse Specialist</td>
<td>WoSCAN (Beatson West of Scotland Cancer Centre)</td>
</tr>
<tr>
<td>Shanne McNamara</td>
<td>Clinical Nurse Specialist</td>
<td>SCAN (Western General Hospital, Edinburgh)</td>
</tr>
<tr>
<td>Carol Marshall</td>
<td>Project Manager</td>
<td></td>
</tr>
<tr>
<td>Alison Mitchell</td>
<td>Consultant in Palliative Medicine</td>
<td>WoSCAN (Beatson West of Scotland Cancer Centre)</td>
</tr>
<tr>
<td>Brian Murray</td>
<td>Principle Information Development Manager</td>
<td>ISD</td>
</tr>
<tr>
<td>Lynn Myles</td>
<td>Consultant Neurosurgeon</td>
<td>SCAN (Western General Hospital, Edinburgh)</td>
</tr>
<tr>
<td>Chris Myres</td>
<td>Assistant Service Manager</td>
<td>SCAN (Western General Hospital, Edinburgh)</td>
</tr>
<tr>
<td>Shona Olson</td>
<td>Consultant Radiologist</td>
<td>NOSCAN (Aberdeen Royal Infirmary)</td>
</tr>
<tr>
<td>Sharon Peoples</td>
<td>Clinical Oncologist</td>
<td>SCAN (Western General Hospital, Edinburgh)</td>
</tr>
<tr>
<td>Roy Rampling</td>
<td>SANON Clinical Lead</td>
<td>Scottish Adult Neuro-Oncology Network (SANON)</td>
</tr>
<tr>
<td>Name</td>
<td>Designation</td>
<td>Cancer Network/Base</td>
</tr>
<tr>
<td>--------------------</td>
<td>-----------------------------------</td>
<td>----------------------------------------------------------</td>
</tr>
<tr>
<td>Margaret Ritchie</td>
<td>Clinical Nurse Specialist</td>
<td>NOSCAN/ (Aberdeen Royal Infirmary)</td>
</tr>
<tr>
<td>Ally Rooney</td>
<td>ST4 General Adult Psychiatry</td>
<td>SCAN (Royal Edinburgh Hospital, Edinburgh)</td>
</tr>
<tr>
<td>Willie Stewart</td>
<td>Consultant Pathologist</td>
<td>WoSCAN (Southern General Hospital, Glasgow)</td>
</tr>
<tr>
<td>David Summers</td>
<td>Consultant Radiologist</td>
<td>WoSCAN (Western General Hospital, Edinburgh)</td>
</tr>
<tr>
<td>Evelyn Thomson</td>
<td>Regional Manager (Cancer)</td>
<td>WoSCAN</td>
</tr>
<tr>
<td>Antonia Torgeson</td>
<td>Consultant Pathologist</td>
<td>SCAN (Royal Infirmary of Edinburgh, Edinburgh)</td>
</tr>
<tr>
<td>Alena Vasianovich</td>
<td>Audit Facilitator</td>
<td>NOSCAN (Aberdeen Royal Infirmary)</td>
</tr>
</tbody>
</table>

NOSCAN - North of Scotland Cancer Network  
SCAN - South East Scotland Cancer Network  
WoSCAN - West of Scotland Cancer Network
### Appendix 3: Brain/CNS Cancer QPI Formal Review Group Membership (2017)

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

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

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Active treatment</strong></td>
<td>Treatment directed to cure the disease.</td>
</tr>
<tr>
<td><strong>Adjuvant therapy</strong></td>
<td>Treatment given in addition to the primary therapy, or a secondary remedy assisting the action of another.</td>
</tr>
<tr>
<td><strong>Biopsy</strong></td>
<td>Removal of a sample of tissue from the body to assist in diagnosis of a disease.</td>
</tr>
<tr>
<td><strong>Brain tumour</strong></td>
<td>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.</td>
</tr>
<tr>
<td><strong>Central nervous system</strong></td>
<td>The portion of the nervous system comprising the brain and spinal cord.</td>
</tr>
<tr>
<td><strong>Chemoradiotherapy</strong></td>
<td>Treatment that combines chemotherapy with radiation therapy.</td>
</tr>
<tr>
<td><strong>Chemotherapy</strong></td>
<td>The use of drugs that kill cancer cells, or prevent or slow their growth.</td>
</tr>
<tr>
<td><strong>Clinical trials</strong></td>
<td>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.</td>
</tr>
<tr>
<td><strong>Computed Tomography (CT)</strong></td>
<td>An x-ray imaging technique, which allows detailed investigation of the internal organ of the body.</td>
</tr>
<tr>
<td><strong>Contraindication</strong></td>
<td>A symptom or medical condition that makes a particular treatment or procedure inadvisable because a person is likely to have a bad reaction.</td>
</tr>
<tr>
<td><strong>Diagnosis</strong></td>
<td>The process of identifying a disease, such as cancer, from its signs and symptoms.</td>
</tr>
<tr>
<td><strong>Gliarial</strong></td>
<td>Specialised cells that surround neurones, supporting nerve cells.</td>
</tr>
<tr>
<td><strong>Glioblastoma</strong></td>
<td>The most common type of brain tumour found in adults. It is also called grade 4 astrocytoma.</td>
</tr>
<tr>
<td><strong>Glioma</strong></td>
<td>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 oligodendroglia.</td>
</tr>
<tr>
<td><strong>Grading</strong></td>
<td>The degree of malignancy of a tumour, i.e. how closely the cancer cells look like normal cells.</td>
</tr>
<tr>
<td><strong>Imaging</strong></td>
<td>The production of a clinical image using radiology, for example, CT, MRI, x-ray or ultrasound.</td>
</tr>
<tr>
<td><strong>Intravenous contrast</strong></td>
<td>A substance administered intravenously (directly into bloodstream) to enhance the visibility of structures on imaging.</td>
</tr>
<tr>
<td><strong>Magnetic Resonance Imaging (MRI)</strong></td>
<td>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.</td>
</tr>
<tr>
<td><strong>Metastases/Metastatic disease</strong></td>
<td>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).</td>
</tr>
<tr>
<td><strong>MGMT</strong></td>
<td>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 resistant</td>
</tr>
<tr>
<td><strong>MGMT promoter methylation</strong></td>
<td>Translation of the MGMT gene is controlled by a promoter. 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</td>
</tr>
</tbody>
</table>
**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.