Scottish Cancer Taskforce
National Cancer Quality Steering Group

Sarcoma
Clinical Quality Performance Indicators
Engagement Document

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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 indictors 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 to overcome existing issues relating to the reporting of small volumes in any one year.

In the intervening years tumour specific QPIs are monitored on an annual basis through established Regional Cancer Network and local governance processes, with analysed data submitted to 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 Sarcoma QPI Development Group was convened in March 2012, chaired by Mr James Powell, Consultant Hepato-Pancreato-Biliary (HPB) Surgeon. Membership of this group included clinical representatives drawn from the three Regional Cancer Networks, Healthcare Improvement Scotland, ISD and patient/carer representatives. Membership 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 Sarcoma QPIs was undertaken in January 2018.

A formal Review Group was convened, chaired by Mr Param Mariappan, Consultant Urologist. Membership of this group included Clinical Leads from the three Regional Cancer Networks as well as the National 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 are kept under review and revised as necessary, if further evidence or data becomes available.

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

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

5. Sarcoma QPI Inclusion Criteria

The Sarcoma QPI Development Group agreed that the QPIs would focus on extremity sarcomas in the first instance, unless otherwise specified within the measurability specifications of indicators. Data will however continue to be collected on all sarcomas.

Extremity sarcoma is defined as sarcoma of the: upper limb, shoulder girdle to fingers or lower extremity, iliac crest/buttock to toes. Extremity sarcomas account for 50-60% of all sarcomas[2].
The Sarcoma QPIs are applicable to patients of all ages, from infancy to old age, unless otherwise stated in the QPI.

6. 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 Sarcoma QPIs. The updated document will be implemented for patients diagnosed with Sarcoma on, or after, 1st April 2018.

7. Quality Performance Indicators for Sarcoma

QPI 1: Histological Diagnosis

QPI Title:	Patients with extremity sarcoma should have a histological diagnosis before undergoing a planned surgical resection.
Description:	Proportion of patients with extremity sarcoma who have a histological diagnosis before undergoing a planned surgical resection.
Rationale and Evidence:	Histological typing of extremity sarcomas is essential for planning appropriate treatment and to provide important information relating to prognosis[3]. A histological diagnosis should be obtained before a planned surgical resection takes place. Unplanned surgery has been shown to affect morbidity and mortality[4, 5].
Specifications:	**Numerator:** Number of patients with extremity sarcoma who undergo a planned surgical resection who have a histological diagnosis before surgical resection takes place. **Denominator:** All patients with extremity sarcoma who undergo a planned surgical resection. **Exclusions:** • Patients with cutaneous sarcomas.
Target:	90% The tolerance within this target is designed to account for small superficial lesions where the diagnosis of sarcoma may not be reasonably suspected clinically.

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

QPI 2: Multi-Disciplinary Team (MDT) Meeting

QPI Title:	Patients with extremity sarcoma should be discussed by a multidisciplinary team (MDT) prior to definitive treatment.
Description:	Proportion of patients with extremity sarcoma who are discussed at a MDT meeting before definitive treatment.
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[6]. Discussion prior to definitive treatment decisions being made provides reassurance that patients are being managed appropriately.
Specifications:	**Numerator:** Number of patients with extremity sarcoma discussed at the MDT before definitive treatment. **Denominator:** All patients with extremity sarcoma. **Exclusions:** • Patients with cutaneous sarcomas. • Patients who died before first treatment.
Target:	95% The tolerance within this target is designed to account for situations where patients require treatment urgently.

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

QPI 3: Clinical Staging

QPI Title:	Patients with extremity soft tissue sarcoma should be staged by CT scan and the Tumour Node Metastases (TNM) staging system should be used.	
Description:	Proportion of patients whose extremity soft tissue sarcoma is staged by CT scan prior to definitive treatment, and are clinically staged using the TNM staging system. Please note: The specifications of this QPI are separated to ensure clear measurement of both patients who: (i) Undergo staging CT scan prior to definitive treatment; and (ii) Are clinically staged using the TNM staging system	
Rationale and Evidence:	Staging has an important role in determining the most effective treatment for soft tissue sarcoma and provides information on prognosis[7-10]. Patients with a confirmed soft tissue sarcoma should be staged with a CT chest to exclude pulmonary metastases prior to definitive treatment.[10] Clinical staging should follow the principles of TNM classification; this aids the determination of prognosis and choice of therapy[3]	
Specification (i):	**Numerator:**	Number of patients with extremity soft tissue sarcoma who undergo staging CT scan prior to definitive treatment.
	Denominator:	All patients with extremity soft tissue sarcoma.
	Exclusions:	• Patients with cutaneous sarcomas. • Patients with rhabdomyosarcomas.
Specification (ii):	**Numerator:**	Number of patients with extremity soft tissue sarcoma who are clinically staged using the TNM staging system.
	Denominator:	All patients with extremity soft tissue sarcoma.
	Exclusions:	• Patients with cutaneous sarcomas. • Patients with rhabdomyosarcomas.
Target:	95% The tolerance within this target accounts for the fact that some patients may present with very advanced disease therefore may not be fit for investigation and/or treatment. It also accounts for emergency situations.	

Revision(s):	***QPI separated into 2 parts*** ***(i) Staging CT scan prior to definitive treatment*** ***(ii)Clinically staged using the TNM staging system*** ***TNM no longer required to be recorded prior to treatment.***

QPI 4: Surgical Margins

QPI Title:	Patients with extremity sarcoma undergoing surgical resection should have their tumour adequately excised.
Description:	Proportion of patients with extremity sarcoma, who undergo surgical resection where R0* resection is achieved.
Rationale and Evidence:	The surgical margin achieved within surgical resection impacts on local recurrence rates and survival of patients. To ensure a patient has low recurrence rates surgeons should completely excise the tumour to achieve R0 surgical resection to ensure the surgical margin is clear of microscopic disease[11-13]. It is important that surgical procedures are planned in advance of surgery[13.] This will allow for the necessary treatment planning to take place before the initiation of treatment.
Specifications:	**Numerator:** Number of patients with extremity sarcoma who undergo surgical resection where R0* resection is achieved. **Denominator:** All patients with extremity sarcoma who undergo surgical resection. **Exclusions:** • Patients with cutaneous sarcomas.
Target:	85% The tolerance within this target is designed to account for situations where it is agreed due to anatomical constraints a planned positive surgical margin is acceptable.

Revision(s):	***Changed to include all surgical resections rather than only those with 'curative intent'.***

* R0 resection is a surgical resection where surgical margins are clear of microscopic disease.

QPI 5: Molecular Staging of Gastrointestinal Stromal Tumour (GIST)

QPI Title:	Patients with gastrointestinal stromal tumours (GISTs) should have mutational analysis within 3 months of diagnosis.
Description:	Proportion of patients with GISTs who have mutational analysis within 3 months of diagnosis.
Rationale and Evidence:	All small bowel GISTs and all intermediate and high risk GISTs, regardless of location, should have mutational analysis[14]. This will provide information on the tumour and will allow for a more detailed prognosis. In addition, mutational analysis can provide important information that will influence the type of treatment to use[15-17]. Mutational analysis should include at least assessment of KIT exons 9 and 11, and PDGFRA exons 12 and 18 for mutations. If apparently wildtype, additional exons will need to be examined to rule out rare primary mutations[14].
Specifications:	**Numerator:** Number of patients with GISTs who have mutational analysis within 3 months of diagnosis. **Denominator:** All patients with GISTs. **Exclusions:** • Patients with low risk non metastatic GISTs.
Target:	90% The tolerance within this target is designed to account for situations where the patient died before the clinical features of GIST, small bowel GISTs and primary metastatic GIST were identified and reported.

Revision(s):	***Changed to focus on all GISTs excluding low risk non-metastatic GISTs.***

QPI 6: Limb Sparing Surgery

QPI Title:	Patients with extremity sarcoma should have primary limb-sparing surgery.
Description:	Proportion of patients with extremity sarcoma who undergo a primary limb-sparing surgery.
Rationale and Evidence:	Studies have shown that surgical treatment for approximately 90-95% of patients involves limb sparing surgery[18-20]. Rates of amputation have decreased over the years and this is typically reserved for patients with locally advanced disease that cannot be managed by limb sparing surgery[21, 22]. Patients who undergo limb sparing surgery have reportedly improved quality of life post treatment, uncompromised survival rates and local tumour control. As well as, an asymptomatic and functional limb[20, 22, 23].
Specifications:	**Numerator:** Number of patients with extremity sarcoma who undergo a primary limb-sparing surgery. **Denominator:** All patients with extremity sarcoma undergoing surgery. **Exclusions:** • Patients with cutaneous sarcomas. • Patients who died before first treatment.
Target:	85% The tolerance within this target accounts for those patients with advanced disease that cannot be managed by limb sparing surgery and also to reflect factors of patient choice.

Please Note: varying evidence exists regarding the most appropriate target level therefore this may need to be redefined in the future, to take account of new evidence or when baseline data becomes available.

Revision(s):	***Denominator changed to account only for those patients who undergo surgery.*** ***Target tolerance statement been updated to account for those patients with advanced disease that cannot be managed with limb sparing surgery.***

QPI 7: Primary Flap Reconstruction

QPI Title:	Patients with extremity sarcoma should have successful† primary flap reconstruction following surgical resection.
Description:	Proportion of patients with extremity sarcoma who undergo successful† primary flap reconstruction following surgical resection.
Rationale and Evidence:	After surgical resection, reconstructive surgery may be needed to cover wounds, preserve function and/or improve the cosmetic outcome[24]. When conducting reconstructive surgery, surgeons should consider the flap success rate as one factor in choosing the best construction for any individual patient[25].
Specifications:	**Numerator:** Number of patients with extremity sarcoma who undergo successful† primary flap reconstruction. **Denominator:** All patients with extremity sarcoma who undergo primary flap reconstruction. **Exclusions:** • Patients with cutaneous sarcomas
Target:	85% The tolerance within this target is designed to account for situations where re-exploration of flaps is undertaken due to vascular insufficiency.

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

† Successful has been defined as patients who do not need to return to theatre for unplanned surgical debridement of a sufficient volume of the flap reconstruction such that secondary reconstruction is required.

QPI 8: Post Operative Radiotherapy

QPI Title:	Patients with extremity sarcoma should receive radiotherapy within 3 months of surgery.
Description:	Proportion of patients with an extremity sarcoma who receive post operative radiotherapy within 3 months of surgery.
Rationale and Evidence:	Post operative radiotherapy is advocated for those with a deep tumour (any size, grade 2 or 3), who have had an R0 or R1 excision. R2 excision may warrant re operation followed by radiotherapy. (Note these specific features are not the focus of measurement within this QPI). Post operative radiotherapy should start within 3 months of surgery[10]. Local recurrence rate after wide local excision plus radiotherapy is equivalent to amputation[10]. **Please note:** This QPI is applicable to patients aged 16 years and over.
Specifications:	**Numerator:** Number of patients aged 16 and over, with extremity sarcoma who commenced post operative radiotherapy within 3 months of surgery. **Denominator:** All patients aged 16 and over, with extremity sarcoma who undergo post operative radiotherapy. **Exclusions:** • Patients with cutaneous sarcomas. • Patients with osteosarcomas. • Patients with Ewing's sarcoma. • Patients with chondrosarcomas.
Target:	90% The tolerance within this target is designed to account for situations where co-morbidities, severe post-operative complications or frailty can mean the patient is not suitable for post operative radiotherapy.

Revision(s):	***Denominator changed to focus specifically on those patients that have undergone post operative radiotherapy.*** ***Removed the requirement for a planned marginal or wide local excision (R0 or R1).*** ***Added exclusions for: osteosarcomas, Ewing's sarcoma, chondrosarcomas***

QPI 9: Multi-agent Chemotherapy for Osteosarcoma or Ewing's sarcoma

QPI Title:	Patients with osteosarcoma or Ewing's sarcoma should receive multi-agent chemotherapy when clinically indicated.
Description:	Proportion of patients with osteosarcoma or Ewing's sarcoma who receive multi-agent chemotherapy. **Please note:** This QPI measures two distinct elements to ensure clear measurement of each sarcoma type: i. Patients under the age of 40 with osteosarcoma who receive multi-agent chemotherapy. ii. Patients under the age of 50 with Ewing's sarcoma who receive multi-agent chemotherapy.
Rationale and Evidence:	Treatment is not restricted by age and is considered on an individual patient basis. Evidence suggests patients with Osteosarcoma or Ewing's sarcoma should be given combination neoadjuvant SACT[26]. Due to the intensity and toxicity of this neoadjuvant combination chemotherapy it may not be clinically indicated for patients over the age of 40/50[26]. This is due to a number of factors including performance status. Patients who are unsuitable for this type of treatment are considered for alternative treatment plans. To ensure focussed measurement and a QPI examining expected outcomes the age range <40/<50 has been selected. This represents the majority of patients where this treatment is clinically indicated and therefore provides a good proxy measure for access to multi-agent chemotherapy for the whole patient population.
Specification (i):	**Numerator:** Number of patients with osteosarcoma who are under the age of 40 who undergo multi-agent chemotherapy. **Denominator:** All patients with osteosarcoma who are under the age of 40. **Exclusions:** • Patients undergoing emergency primary surgery or radiotherapy.
Target:	90% The tolerance within this target is designed to account for factors of patient choice, co-morbidities and fitness for treatment.

(Continued overleaf…)

QPI 9: Multi-agent Chemotherapy for Osteosarcoma or Ewing's sarcoma (continued…)

Specification (ii):	**Numerator:**	Number of patients with Ewing's sarcoma who are under the age of 50 who undergo multi-agent chemotherapy.
	Denominator:	All patients with Ewing's sarcoma who are under the age of 50.
	Exclusions:	• Patients undergoing emergency primary surgery or radiotherapy.
Target:	90% The tolerance within this target is designed to account for factors of patient choice, co-morbidities and fitness for treatment.	

Revision(s):	***Removed the reference to 'neoadjuvant' to ensure that all appropriate chemotherapy is being picked up.*** ***Changed combination SACT to multi-agent chemotherapy.***

QPI 10: Adjuvant Oncological Treatment for Gastrointestinal Stromal Tumour (GIST)

QPI Title:	Patients with high risk[‡] Gastrointestinal Stromal Tumour (GIST) should commence adjuvant imatinib within 3 months of surgery.
Description:	Proportion of patients with high risk[§] GIST who commence adjuvant imatinib within 3 months of surgery.
Rationale and Evidence:	Adjuvant imatinib therapy given for a period of three years compared to one year, significantly improved the recurrence free survival in adult patients at significant risk of relapse following resection of GIST[27]. Patients with PDGFRA (platelet-derived growth factor receptor-alpha) D842V mutation demonstrate no benefit from imatinib therefore it is not recommended for this clinical cohort[28]. GISTs are extremely rare in children and young people. Current data is derived from an older population and may not be applicable to this age group due to molecular differences in GIST in younger people. In addition there may be concerns about prolonged biological therapy in growing children. **Please note:** This QPI is applicable to patients aged 16 years and over.
Specifications:	**Numerator:** Number of patients, aged 16 and over, with high risk[§] GIST who receive adjuvant imatinib and commence this within 3 months of surgery. **Denominator:** All patients aged 16 and over, with high risk[§] GIST who receive adjuvant imatinib. **Exclusions:** • Patients who are enrolled in a clinical trial.
Target:	85% The tolerance within this target accounts for the fact that due to co-morbidities and fitness not all patients will be suitable for imatinib following complete macroscopic resection. It also accounts for those patients with PDGFRA D842V mutation GIST where imatinib is not recommended.

Revision(s):	***Changed the denominator to focus only on those patients who receive adjuvant imatinib.*** ***Removed complete macroscopic resection and replaced with all surgery – this removes the requirement to capture all individual resection codes.***

[‡] High risk GIST is defined as: patients with large GIST tumours that have a high chance of recurring

QPI 11: 30 Day Mortality

QPI Title:	30 day mortality following treatment for sarcoma.	
Description:	Proportion of patients who die within 30 days of surgical resection or oncological treatment with curative intent for sarcoma.	
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)[6]. 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.	
Specification (i):	**Numerator:**	Number of patients with sarcoma who undergo surgical resection or oncological treatment with curative intent who die within 30 days of treatment.
	Denominator:	All patients with sarcoma who undergo surgical resection or oncological treatment with curative intent.
	Exclusions:	• No exclusions.
	Please Note:	This indicator will be reported by treatment modality i.e. surgery, neoadjuvant radiotherapy, SACT etc. as opposed to a single figure.
Target:	<10%	
Specification (ii):	**Numerator:**	Number of patients with sarcoma who undergo palliative oncological treatment who die within 30 days of treatment.
	Denominator:	All patients with sarcoma who undergo palliative oncological treatment.
	Exclusions:	• No exclusions.
	Please Note:	This indicator will be reported by treatment modality i.e. palliative radiotherapy, SACT etc. as opposed to a single figure.
Target:	<15%	

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

QPI 12: 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 Sarcoma QPI document.***

8. Survival

Improving survival forms an integral part of the national cancer quality improvement programme. Sarcoma survival analysis will be reported and analysed on a 3 yearly basis by Information Services Division (ISD). The specific issues which will be addressed will be identified by an expert group ahead of any analysis being undertaken, as per the agreed national cancer quality governance and improvement framework.

The Sarcoma QPI Group has identified; during the QPI development process, the following issues for survival analysis.

- 5 year overall survival

To ensure consistent application of survival analysis, it has been agreed that a single analyst on behalf of all three regional cancer networks undertakes this work. Survival analysis 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.

9. Areas for Future Consideration

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

The following area for future consideration has been raised across the lifetime of the Sarcoma QPIs.

- Patients with non-extremity sarcoma.

10. 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 5 and 6 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.

10.1 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 three tumour types per annum and specified generic QPIs as part of the rolling programme of reporting.

10.2 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.

10.3 Local – NHS Boards

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

11. How to participate in the engagement process

In order to ensure wide inclusiveness of clinical and management colleagues from across NHSScotland, patients affected by Sarcoma 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.

11.1 Submitting your comments

You can submit your comments on the Revised Sarcoma QPIs via the Scottish Government Consultation Hub (website link below):

https://consult.gov.scot/nhs/sarcoma-qpis

All responses should be submitted by **Friday 11th May 2018.**

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

Email: SarcomaQPIPublicEngagement@gov.scot

11.2 Engagement feedback

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

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13. 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 Sarcoma QPIs and a search narrative were defined and agreed by the Sarcoma QPI Development Group. The table below shows the final search criteria used in the literature search.

Inclusion	Exclusion

• Primary bone sarcomas
  ○ Chondrosarcoma,
  ○ Ewing's sarcoma,
  ○ Osteosarcoma (osteogenic sarcoma).
• Soft tissue sarcomas
  ○ Liposarcomas,
  ○ Synovial sarcomas, Rhabdomyosarcomas, Leiomyosarcomas,
  ○ Pleomorphic sarcoma.
• Children/Young People Sarcomas
  ○ Rhabdomyosarcomas,
  ○ Extraosseous Ewing's sarcoma (primitive neuroectodermal tumours (PNET).
• Gastrointestinal Stromal Tumours (GIST)
 	
• Diagnosis
• Staging
• Surgical management
• Non-surgical management
• Prosthetics and orthotics
 	
• Adults only
• 2005 to present day
• English only
• Clinical guidelines
	• Benign bone and soft tissue tumours
	• Metastases to bone and soft tissues from tumours at other primary sites / secondary bone cancers.
	• Kaposi's sarcoma, Uterine leiomyosarcoma, Benign fibromas, Chordoma, CNS sarcomas, Head and neck sarcomas, Skin sarcomas, Fibrosarcomas, Myxofibrosarcomas, Desmoid tumours,
	• Malignant peripheral nerve sheath tumours (MPNST) – schwannomas, neurofibromatosis (von Recklinghausen's disease)
	• Angiosarcomas (haemangiosarcomas, lymphangiosarcomas),
	• Rare sarcomas (including: alveolar soft part sarcoma, dermatofibrosarcoma protuberans (DFSP), desmoplastic small round cell tumours, epithelioid sarcomas,extraskeletal myxoid chondrosarcomas, giant cell fibroblastoma (GCF)
	• Prevention, Screening, Primary care/referral
	• Communication, information sharing and support
	• Long-term follow up
	• Management of recurrence/relapsed disease
	• Symptom management (nausea and vomiting, neutropenic sepsis)
	• Palliative/end of life care (pain management, end of life counselling, hospice management)
	• Clinical trials recruitment and protocols

Table 1 – Sarcoma 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.

Twenty nine identified guidelines were appraised for quality using the AGREE II instrument[29]. This instrument assesses the methodological rigour used when developing a guideline. Eight guidelines were recommended for use with consideration of their applicability or currency.

Indicator Development

The Sarcoma 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 November 2013 where the Sarcoma QPIs, along with accompanying draft minimum core dataset and measurability specifications, were made available on the Scottish Government website. During the engagement period clinical and management colleagues from across NHSScotland, patients affected by Sarcoma and the wider public were given the opportunity to influence the development of Sarcoma 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 Sarcoma QPI Development Group and used to produce and refine the final indicators.

Appendix 2: Sarcoma QPI Development Group Membership (2012)

Name	Designation	Cancer Network/Base
James Powell (Chair)	Consultant Hepato-Pancreato-Biliary (HPB) Surgeon	SCAN/ NHS Lothian
Lorna Bruce	SCAN Audit Manager	SCAN
David Boddie	Consultant Surgeon	NOSCAN/ NHS Grampian
Jacquie Campbell	General Manager	WoSCAN/ NHS Greater Glasgow and Clyde
Peter Chong	Consultant Surgeon	WoSCAN/ NHS Greater Glasgow and Clyde
Fiona Cowie	Consultant Oncologist	WoSCAN/ NHS Greater Glasgow and Clyde
Dawn Currie	Clinical Nurse Specialist	WoSCAN/ NHS Greater Glasgow and Clyde
Fiona Dawson	Clinical Nurse Specialist	SCAN/ NHS Lothian
Sinclair Dundas	Consultant Pathologist	NOSCAN/ NHS Grampian
Stuart Hamilton	Consultant Surgeon	SCAN/ NHS Lothian
Larry Hayward	Consultant Oncologist	SCAN/ NHS Lothian
Michelle Hilton Boon	Programme Manager	Healthcare Improvement Scotland
Derek King	Consultant Paediatric Haematologist	MSN for Children and Young People with Cancer
Kelly Macdonald	Project Manager	National Cancer QPI Development Programme
Julie McMahon	Information Officer	WoSCAN
Ashish Mahendra	Consultant Surgeon and Audit Lead	WoSCAN/ NHS Greater Glasgow and Clyde
John Miller	Consultant Radiologist	NOSCAN/ NHS Highland
Brian Murray	Principle Information Development Manager	Information Services Division
Chris Nicholas	Consultant Radiologist	WoSCAN/ NHS Greater Glasgow and Clyde
Daniel Porter	Consultant Surgeon	SCAN/ NHS Lothian
Nancy Rattray	Clinical Nurse Specialist	NOSCAN/ NHS Tayside
Milind Ronghe	Consultant Paediatric Oncologist	WoSCAN/ NHS Greater Glasgow and Clyde
Donald Salter	Consultant Pathologist	SCAN/ NHS Lothian
Evelyn Thomson	Regional Manager (Cancer)	WoSCAN
Stuart Watson	Consultant Surgeon	WoSCAN/ NHS Greater Glasgow and Clyde

Name	Designation	Cancer Network/Base
Jeff White	Consultant Oncologist and Scottish Sarcoma Network Clinical Lead	WoSCAN/ NHS Greater Glasgow and Clyde

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

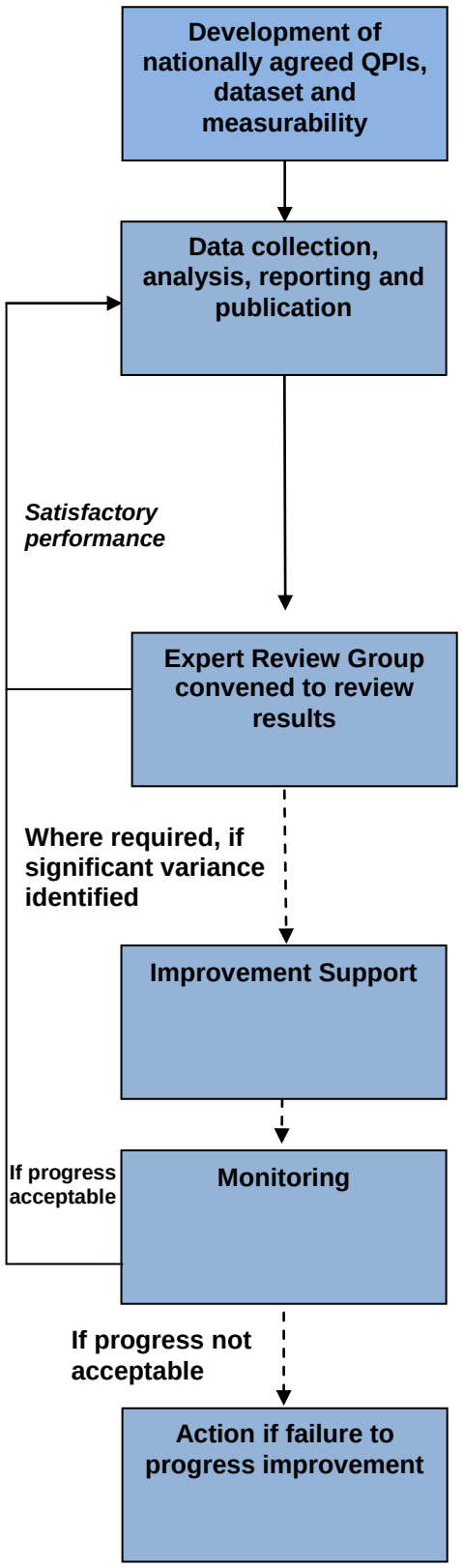
Appendix 3: Sarcoma QPI Formal Group Membership (2018)

Name	Designation	Cancer Network/Base
Param Mariappan (Chair)	Consultant Urologist	SCAN
David Boddie	Consultant Surgeon	NOSCAN
Lorna Bruce	Cancer Audit Manager	SCAN
Peter Chong	Consultant Surgeon	WoSCAN
Fiona Cowie	Consultant Clinical Oncologist	WoSCAN
Jen Doherty	Project Co-ordinator	National Cancer Quality Programme
Michelle Ferguson	Consultant Medical Oncologist	NOSCAN
Larry Hayward	Consultant Medical Oncologist	SCAN
Steven Lo	Consultant Surgeon	WoSCAN
Carol Marshall	Audit Manager	WoSCAN
Walter Mmeka	Consultant Medical Oncologist	NOSCAN
Ioanna Nixon	Sarcoma National Clinical Lead	WoSCAN
Donald Salter	Consultant Pathologist	SCAN
Lorraine Stirling	Project Officer	WoSCAN

Formal review of the Sarcoma 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:

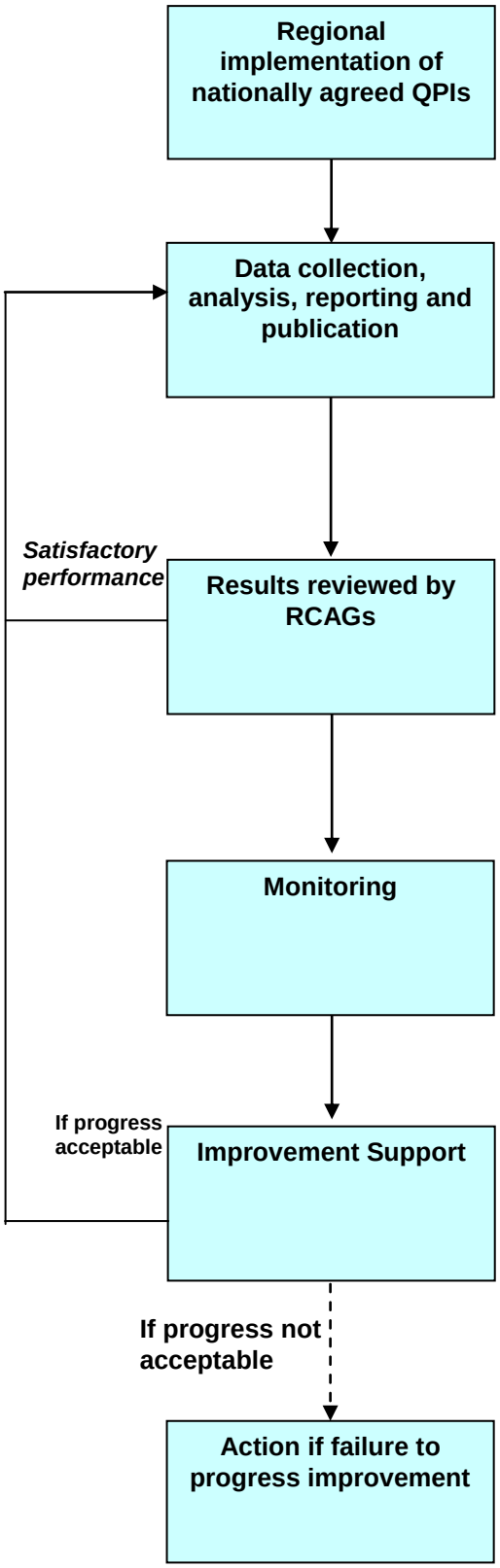
- RCAGs work with Boards to progress outstanding actions, monitor improvement plans and submit progress report to Healthcare Improvement Scotland.
- Healthcare Improvement Scotland report to Scottish Cancer Taskforce as to whether progress is acceptable**.**

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

Adjuvant Treatment	Treatment such as chemotherapy, or radiotherapy that is given after a surgical procedure to reduce the risk of the cancer coming back.
Amputation	An operation to remove a limb.
Compartmentectomy	A wide excision of the whole muscle compartment e.g. hamstring.
Chemotherapy	The use of drugs used to kill cancer cells, to prevent or slow their growth.
Co-morbidity/Co-morbidities	Other conditions and symptoms prevalent other than the primary diagnosis.
Curative Treatment	Treatment given to cure the illness.
Definitive Treatment	Treatment designed to potentially cure cancer using one or a combination of interventions.
Diagnosis	The process of identifying a disease, such as cancer, from its signs and symptoms.
Ewing's Sarcoma	A type of bone cancer that usually forms in the middle of large bones. It occurs most frequently in children and young adults.
Extremity	The upper limb, shoulder girdle to fingers or lower extremity, iliac crest/buttock to toes.
Extremity Sarcoma	Sarcoma of the extremity.
Gastrointestinal Stromal Tumour (GIST)	An unusual and specific type of tumour that usually begins in cells in the wall of the gastrointestinal tract (stomach, small bowel).
Gastrointestinal tract	The part of the digestive system that includes the mouth, oesophagus, stomach, and intestines.
Grade	The degree of malignancy of a tumour, i.e. how closely the cancer cells look like normal cells.
Histological / Histopathogical	The study of the structure, composition and function of tissues under the microscope, and their abnormalities.
Imatinib	A drug used in the treatment of patients with sarcoma.
Limb Sparing Surgery	Surgery where the tumour is removed while retaining the limb.
Metastatic	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).
Morbidity	How much ill health a particular condition causes.
Mortality	Either (1) the condition of being subject to death; or (2) the death rate, which reflects the number of deaths per unit of population in and specific region, age group disease or other classification, usually expressed as deaths per 1,000, 10,000 or 100,000.
Multidisciplinary Team	Team which consists of various specialities and may be different depending on disease. For example, pathologist, surgeon, etc.
Multidisciplinary 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 agreed.
Mutational Analysis	A test that is carried out to detect the presence of a specific mutation, a specific type of mutation or set of mutations.
Neoadjuvant Systematic Anti Cancer	SACT which is given before surgical resection with the aim of improving the results of surgery and preventing the development

Therapy (SACT)	of metastases.
Negative Surgical Margin	A negative surgical margin is when there are no cancer cells at the edge of the tissue that has been removed.
Osteosarcoma	A cancer of the bone that usually affects the large bones of the arm or leg. It occurs most commonly in young people.
Palliative Treatment	Treatment which serves to alleviate symptoms due to the underlying cancer but is not expected to cure it.
Pathologist	A doctor who examines cells and identifies them.
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 a post mortem.
Positive Surgical Margins	A positive surgical margin is when there are cancer cells at the edge of the tissue that has been removed.
Postoperative Complication	Postoperative complications are unexpected problems that arise following surgery, these can range from minor to major complications.
Primary Tumour	Tumours that originate in the area e.g. primary brain tumour will reside in the brain.
Radiotherapy	The use of radiation (such as x-rays) to diagnose or treat disease.
Reconstructive Surgery	Surgery that is done to reshape or rebuild (reconstruct) a part of the body changed by previous surgery.
Resection Margin	The rim of normal tissue surrounding a cancer after removal. These can be distal, proximal, or radial.
Rhabdomyosarcoma	A malignant tumour of muscle tissue.
Sarcoma	One of a group of tumours usually arising from connective tissue. Most sarcomas are malignant. Many types are named after the type of cell, tissue, or structure involved.
Soft tissue Sarcoma	A cancer of the soft tissues of the body.
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.
Systematic Anti Cancer Therapy (SACT)	Treatment of cancer using drugs which prevent the replication or growth of cancer cells. This encompasses biological therapies and cytotoxic chemotherapy.
Toxicity	The extent to which something is poisonous or harmful.
Tumour Node Metastases (TNM)	'TNM' stands for Tumour, Node, Metastasis. This system can describe the size of a primary tumour, whether the cancer has spread to the lymph nodes and whether the cancer has spread to a different part of the body (metastasised). The system uses numbers to describe the cancer.
Unplanned Positive Resection	A positive margin following surgical resection which was not planned for/expected prior to surgical resection.