NHS SCOTLAND

Scottish Cancer Taskforce
National Cancer Quality Steering Group

Renal Cancer Clinical Quality Performance Indicators

Engagement Document

July 2016

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1. National Cancer Quality Programme

Better Cancer Care[1] states that a wide ranging approach to quality improvement is required to ensure that services improve performance across all dimensions of quality. The NHS Scotland Healthcare Quality Strategy[2] (launched in May 2010) further expands upon this by articulating three quality ambitions:

- Mutually beneficial partnerships between patients, their families and those delivering healthcare services which respect individual needs and values and which demonstrate compassion, continuity, clear communication and shared decision-making.

- No avoidable injury or harm from the healthcare they receive, and that they are cared for in an appropriate, clean and safe environment at all times.

- The most appropriate treatments, interventions, support and services will be provided at the right time to everyone who will benefit, with no wasteful or harmful variation.

The quality strategy aims to put quality at the very heart of the NHS, building upon the excellent foundations already in place. A quality measurement framework has been developed which sets out measures and targets which will be used to monitor, challenge, manage and report progress towards the three quality ambitions. This framework also allows for supplementary national indicators that will underpin progress towards the quality ambitions[2].

Under the auspices of the Scottish Cancer Taskforce, National Cancer Quality Performance Indicators (QPIs) have been developed to drive continuous quality improvement in cancer care across NHSScotland. The QPIs are small sets of cancer-specific outcome focussed, evidence-based indicators. These are underpinned by Patient Experience QPIs that are applicable to all, irrespective of cancer type. QPI implementation ensures that activity is focussed on those areas that are most important in terms of improving survival and patient experience whilst reducing variance and ensuring the most effective and efficient delivery of care.

A QPI is defined as a proxy measure of quality care. QPIs are kept under regular review and are responsive to changes in clinical practice and emerging evidence.

1.1 Quality Assurance and Continuous Quality Improvement

The ultimate aim of the programme is to develop a framework, and foster a culture of continuous quality improvement, whereby real time data is reviewed regularly at an individual Multidisciplinary Team/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 Board/Multidisciplinary Team level across NHS Scotland, 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 Renal Cancer QPI Development Group was convened in May 2010, chaired by Dr Robert Masterton (Chair of the National Cancer Quality Steering Group). Membership of this group included clinical representatives drawn from the three regional cancer networks, Healthcare Improvement Scotland, Information Services Division (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 Renal Cancer QPIs was undertaken in February 2016. A formal review group was convened, chaired by Dr Val Doherty (South East Cancer Network Lead Cancer Clinician). Membership of this group included Clinical Leads from the three Regional Cancer Networks. Full 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, which dictates the level 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 influence the target level.

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

5. Supporting Documentation

A national minimum core dataset and a measurability specification document have been developed in parallel with the indicators to support the monitoring and reporting of Renal Cancer QPIs. These were implemented for all patients diagnosed with renal cancer on, or after, 1st January 2012. All relevant updates will be made to the supporting documentation following formal review of the QPIs.

6. Renal Cancer Definition

Approximately 90% of renal cancers are Renal Cell Carcinomas[4] (RCC), various different subtypes of RCC exist, the most common being clear cell. Rarer types of renal cancer include cancer of the ureter and Transitional Cell Carcinoma (TCC). The treatment of these cancers is different from RCC, and more similar to that of bladder cancer therefore these tumour types are included in the QPIs for bladder cancer.

The Renal Cancer QPI Development Group therefore agreed that all QPIs developed by them would focus on Renal Cell Carcinoma (RCC) and these two terms (RCC and renal cancer) are used interchangeably throughout this document.

7. Quality Performance Indicators for Renal Cancer

QPI 1 - Radiological Diagnosis

QPI Title:	Patients with renal cancer should have cross sectional imaging for staging of Renal Cell Carcinoma (RCC).
Description:	Proportion of patients with RCC who undergo pre-treatment cross-sectional imaging of the chest, abdomen +/- pelvis.
Rationale and Evidence:	Although definitive diagnosis of renal cell carcinoma requires pathological assessment, radiology suggests the diagnosis in almost all cases and is the first line of investigation. Patients with renal cell carcinoma should undergo CT with contrast to assess the extent of local and distant metastatic disease[5]. MRI is also an alternative option for patients who require further imaging, or have allergies to intravenous CT contrast media[6].
Specifications:	**Numerator:** Number of patients receiving active treatment[1] with a diagnosis of RCC who undergo cross-sectional imaging (CT or MRI) of the chest, abdomen +/- pelvis (with contrast) before first treatment. **Denominator:** All patients receiving active treatment[1] with a diagnosis of RCC. **Exclusions:** • No exclusions
Target:	95% The tolerance within this target is to account for those patients with contraindications due to renal impairment, allergies to contrast media, and also where renal cancer is an incidental finding following surgery.

[1] Active treatment is defined as partial or radical nephrectomy, cryotherapy, radio frequency ablation or systemic therapy

QPI 2 - Histological Diagnosis

QPI Title:	Patients with renal cancer not undergoing surgery should have a histological diagnosis prior to commencing treatment.
Description:	Proportion of patients with RCC where surgery is not the primary treatment who have a histological diagnosis before treatment, via biopsy. Please note: the specifications of this QPI are separated to ensure clear measurement of patients undergoing the following treatments: (i) Cryotherapy / Radiofrequency ablation (ii) Systemic Anti-Cancer Therapy (SACT)
Rationale and Evidence:	With alternative minimally invasive therapies such as radio frequency ablation (RFA) and cryotherapy where the primary tumour is not resected, it is essential to make a histological or cytological diagnosis of renal carcinoma prior to treatment to avoid treating a non-malignant lesion[5,7]. In patients who are being considered for expensive medical anti-cancer therapy, histological confirmation of the diagnosis is essential as other cell types will not benefit from this treatment[8].
Specification (i):	**Numerator:** Number of patients with RCC undergoing cryotherapy or radiofrequency ablation as their first treatment who have a histological diagnosis (confirmed by biopsy) before commencing treatment. **Denominator:** All patients with RCC undergoing cryotherapy or radiofrequency ablation as their first treatment. **Exclusions:** • Histology not assessable.
Target:	90% The tolerance within this target accounts for situations where patients may require treatment urgently.
Specification (ii):	**Numerator:** Number of patients with RCC undergoing SACT as their first treatment who have a histological diagnosis (confirmed by biopsy) before commencing treatment. **Denominator:** All patients with RCC undergoing SACT as their first treatment. **Exclusions:** • Histology not assessable.
Target:	90% The tolerance within this target accounts for situations where patients may require treatment urgently.

QPI 3 - Clinical Staging – TNM

QPI Title:	The TNM staging system should be used to stage patients with Renal Cell Carcinoma (RCC).	
Description:	Proportion of patients whose RCC is staged pre-treatment using the TNM staging system.	
Rationale and Evidence:	The TNM stage of disease will aid in determining prognosis, choice of therapy and follow up[9]. The TNM staging system is widely recommended for staging of renal cell carcinoma as it[6,9].	
Specifications:	**Numerator:**	Number of patients diagnosed with RCC who were clinically staged using TNM staging system before first treatment.
	Denominator:	All patients diagnosed with RCC.
	Exclusions:	• No exclusions
	Please Note:	For a patient to be recorded as having been clinically staged using the TNM staging system, cT, cN and cM *all* require to be recorded.
Target:	100%	

QPI 4 – Multi-Disciplinary Team (MDT) Meeting

QPI Title:	Patients with renal cell carcinoma should be discussed by a multidisciplinary team prior to definitive treatment.
Description:	Proportion of patients with renal cell carcinoma who are discussed at 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[8]. Discussion prior to definitive treatment decisions being made provides reassurance that patients are being managed appropriately.
Specifications:	**Numerator:** Number of patients with renal cell carcinoma discussed at the MDT before definitive treatment. **Denominator:** All patients with renal cell carcinoma. **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 or where renal cancer has been an incidental finding following surgery.

QPI 5 - Nephron Sparing Surgery

QPI Title:	Patients with T1a renal cancer should receive Nephron Sparing Surgery (NSS).
Description:	Proportion of patients with T1aN_0M_0 RCC who undergo NSS (laparoscopic partial nephrectomy or open partial nephrectomy).
Rationale and Evidence:	When compared with radical nephrectomy, NSS can achieve preserved renal function, decreased overall mortality, reduced frequency of cardiovascular events and increased quality of life for patients. Patients should be informed of these potential advantages of nephron sparing surgery[5]. Surgical resection is the gold standard of care for curative treatment of RCC. Patients with T1a tumours should undergo nephron sparing surgery where appropriate, as clinical trials have shown that long term survival rates are comparable to those following radical surgery[5,7,9].
Specifications:	**Numerator:** Number of patients with T1a N_0M_0 RCC undergoing NSS (laparoscopic partial nephrectomy or open procedure partial nephrectomy). **Denominator:** All patients with T1a N_0M_0 RCC. **Exclusions:** • Patients who refuse treatment. • Patients who receive RFA/Cryotherapy • Patients receiving supportive care only (not for active treatment). • Patients receiving active surveillance (no active treatment). • Patients who died before treatment
Target:	40% This target reflects the fact that some patients opt for a laparoscopic radical nephrectomy (LRN) rather than nephron sparing surgery (NSS) due to factors such as shorter convalescence period and decreased complications associated with LRN compared to NSS. Including this patient group in the exclusion criteria noted above would by default make the target meaningless as 100% would be achieved.

QPI 6 - Leibovich Score

QPI Title:	Patients with clear cell Renal Cell Carcinoma (RCC) should be assigned a Leibovich score following surgical resection.	
Description:	Proportion of patients with clear cell RCC who are assigned a Leibovich score following surgical resection.	
Rationale and Evidence:	Various prognostic scores exist to predict the likelihood of developing metastatic disease following surgery. Evidence shows that the Leibovich score is an accurate model of prediction and assists clinicians and patients in making decisions regarding treatment plans, follow up and selection for clinical trials[10].	
Specifications:	**Numerator:**	Number of patients with clear cell RCC who undergo surgical resection assigned a Leibovich score following surgical resection.
	Denominator:	All patients with clear cell RCC who undergo surgical resection.
	Exclusions:	• Patients undergoing partial nephrectomy • Patients with metastatic disease (TanyNanyM1)
Target:	100%	

QPI 7 - Volume of Cases per Centre / Surgeon

QPI Title:	Renal resectional surgery should be performed in hospitals where there are an appropriate annual volume of such cases.
Description:	Number of renal surgical resections performed by a specialist centre, and surgeon, over a 1 year period.
Rationale and Evidence:	A number of studies have demonstrated the relationship between the number of patients operated on at a particular hospital and the outcome of surgery. The literature demonstrates that there is a relationship between increasing surgical volume and lower complication rates for surgeons undertaking partial nephrectomy for renal cell carcinoma[11].
Specifications:	Number of renal surgical resections performed by each centre / surgeon in a given year. **Exclusions:** • No exclusions
Target:	Minimum 25 procedures per centre, with a minimum of 8 procedures per surgeon, in a 1 year period. This is a minimum target level and is designed to ensure that all surgeons performing renal surgery perform a minimum of 8 procedures per year. **Please Note:** Varying evidence exists regarding the most appropriate target level for surgical case volume. In order to ensure that the target level takes account of level 1 evidence and will drive continuous quality improvement as intended this performance indicator must be kept under regular review.

Please note:
SMR01 data will be utilised to support reporting and monitoring of this QPI rather than clinical audit. This will maximise the use of data which are already collected and remove the need for any duplication of data collection. Standard reports are currently being specified and direct access for each Board to run these reports is being investigated to ensure nationally consistent analysis and reporting.

QPI 8 - Trifecta Rate

QPI Title:	Trifecta Rate in Partial Nephrectomy T1a Renal Cell Carcinoma (RCC) patients.
Description:	Proportion of patients with T1a RCC undergoing partial nephrectomy who achieve trifecta (warm ischaemic time less than 25 minutes, negative surgical margins and no complications*).
Rationale and Evidence:	Trifecta is regarded as a surrogate measure of surgical quality. The combination of achieving negative margins, minimal surgical complications and a reduced warm ischaemic time (associated with improved renal function) is associated with better outcomes for patients undergoing partial nephrectomy[12]. *Length of stay is being used as a surrogate measure for the quality of surgery and post operative care including post operative complications.
Specifications:	**Numerator:** Number of patients with T1a RCC undergoing partial nephrectomy who have warm ischaemic time less than 25 minutes, negative surgical margins and no complications (length of stay ≤7days). **Denominator:** All patients with T1A RCC undergoing partial nephrectomy. **Exclusions:** • No exclusions
Target:	60% The tolerance within this target takes account of the fact that it is not always possible to achieve trifecta due to patient fitness, complex lesions and in solitary kidneys. It may also not always be safe or practical for patients to go home within 7 days of surgery.

QPI 9 – 30 / 90 Day Mortality

QPI Title:	30 and 90 Day Mortality following treatment for RCC.
Description:	Proportion of patients who die within 30 or 90 days of treatment for RCC.
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). However, all causes of death have been used in this indicator as the recording of cause of death by the certifying medical practitioner is not always as specific as the recording of a cancer diagnosis. "For clinicians to restore and retain public confidence, they need to show that effective mechanisms exist for assessing events such as death and to justify patients' faith in the delivery of care" [13].
Specifications:	**Numerator:** Number of patients with RCC who undergo minimally invasive (RFA, cryotherapy, SACT) or operative treatment who die within 30 / 90 days of treatment. **Denominator:** All patients with RCC who undergo minimally invasive (RFA, cryotherapy, SACT) or operative treatment. **Exclusions:** • Patients who undergo emergency surgery (nephrectomy). **Please Note:** This QPI will be reported separately as 30 day mortality and 90 day mortality as opposed to a single figure. In addition, this QPI will be reported by treatment type as opposed to a single figure for all treatment options covered by the indicator (i.e. RFA, cryotherapy, SACT or surgery).
Target:	<5% for patients receiving SACT <2% for patients receiving operative treatment, RFA and cryotherapy. This target reflects the fact that death from any cause, rather than death from renal cancer is being measured by this indicator.

QPI 10 - Prognostic Scoring in Metastatic Disease

QPI Title:	Patients with metastatic renal cell carcinoma (RCC) should be assigned a valid prognostic score[2] prior to starting treatment.
Description:	Proportion of patients with metastatic RCC who are assigned a valid prognostic score[2] prior to starting treatment.
Rationale and Evidence:	Various models exist to predict the survival and prognosis for patients with metastatic RCC. These are key in making decisions about the most appropriate treatment plan for patients, particularly with the use of targeted therapies[14].
Specifications:	**Numerator:** Number of patients with metastatic RCC who are assigned a valid prognostic score prior to starting treatment. **Denominator:** All patients diagnosed with metastatic RCC. **Exclusions:** • No exclusions
Target:	90% The tolerance within this target is to account for situations where patients are deemed unfit to undergo active treatment.

[2] Valid prognostic scoring can be assigned using various models including MSKCC/Motzer, or Heng scoring tools.

QPI 11 – Systemic Therapy

QPI Title:	Patients with advanced and/or metastatic renal cell carcinoma (RCC) should receive systemic therapy between diagnosis and death.
Description:	Proportion of patients presenting with advanced and/or metastatic RCC who receive systemic anti-cancer therapy (SACT) for RCC within 12 months of diagnosis.
Rationale and Evidence:	Sunitinib is currently recommended for use in Scotland as a first-line treatment option for people with advanced and/or metastatic RCC who are suitable for immunotherapy and have an Eastern Cooperative Oncology Group (ECOG) performance status of 0 or 1[15]. Pazopanib is recommended by the Scottish Medicines Consortium (SMC) as a first line treatment option for people with advanced RCC[16,17] Although the SMC advice does not restrict patients according to ECOG performance status, the clinical trial supporting its use was restricted to ECOG PS 0 or 1 patients. Large randomised clinical trials have demonstrated clinical effectiveness of a variety of agents in this setting. Cost effectiveness analysis has demonstrated that sunitinib and pazopanib are considered cost effective in this setting within NHS Scotland. In some cases it is reasonable to delay systemic therapy and the assumption is that 100% of suitable patients should receive systemic therapy between diagnosis and death. We estimate that at least 40% of these patients would be expected to die within 12 months of diagnosis in the absence of systemic treatment and therefore have chosen this time period as suitable for assessing this aspect of practice.
Specifications:	**Numerator:** Number of patients with RCC which is advanced and / or metastatic at time of diagnosis[3] where at least 12 months have elapsed since diagnosis irrespective of whether or not they have died who receive first treatment with SACT, within 12 months of diagnosis[4]. **Denominator:** All patients with RCC which is advanced and / or metastatic at time of diagnosis where at least 12 months have elapsed since diagnosis irrespective of whether or not they have died. **Exclusions:** • Patients documented to have performance status 2, 3 or 4 at time of diagnosis. • Patients documented to have refused systemic treatment. Patients enrolled in clinical trials.
Target:	70% The target reflects the following facts: i. some patients will decline very quickly and systemic therapy is inappropriate; ii. some will have very indolent disease and systemic therapy is not appropriate within 12 months of diagnosis; iii. some patients will die of unrelated causes within 12 months of diagnosis without the need for systemic anti-cancer therapy; iv. some patients will have specific medical contra-indications to systemic therapy; v. some patients with isolated metastatic disease may undergo surgical resection.

[3] Advanced/ metastatic disease defined as T4NanyMany; TanyNanyM1.
[4] Systemic anti-cancer treatments will include any drug which is licensed in this indication; the accompanying data standard contains relevant information about appropriate treatments.

8. Survival

Improving survival forms an integral part of the national cancer quality improvement programme. Renal cancer survival analysis is reported and analysed on a 3 yearly basis by Information Services Division (ISD). The specific issues which will be addressed, for example 1 year or 5 year survival rates, will be identified by an expert group ahead of any analysis being undertaken, as per the agreed national cancer quality governance and improvement framework.

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

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 NHS Scotland.
  - 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 approximately three tumour types per annum as part of the rolling programme of reporting.

9.2 Regional – Regional Cancer Networks

- Annual regional comparative analysis and reporting against tumour specific QPIs.
- Support national comparative reporting of specified generic QPIs.
- Identify and share good practice.

- In conjunction with constituent NHS Boards identify regional and local actions required to develop an action plan to address regional issues identified.
- Review and 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 (generic and tumour specific QPIs).
- Utilise local governance structures to review performance, develop local action plans and monitor delivery.
- Demonstrate continual improvements in quality of care through on-going review, analysis and feedback of clinical audit data at an individual multidisciplinary team (MDT) or unit level.

10. Areas for Future Consideration

The Renal Cancer 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 renal cancer, and therefore in improving the quality of care for patients affected by renal cancer.

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

- Minimally invasive treatments, e.g. RFA, cryotherapy
- Metastasectomy/Cytoreductive nephrectomy
- Palliative radiotherapy
- Management of brain metastases

11. How to participate in the engagement process

In order to ensure wide inclusiveness of clinical and management colleagues from across NHS Scotland, patients affected by renal cancer and the wider public, several different methods of engagement are being pursued:

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

- Wide circulation of the draft documentation for comment and feedback

Patient representative groups:

- Organised patient focus group sessions to be held

11.1 Submitting your comments

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

https://consult.scotland.gov.uk/nhs/renal-cancer-qpis

All responses should be submitted by **Friday 26th August 2016**.

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

Email: RenalQPIPublicEngagement@gov.scot

11.2 Engagement feedback

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

12. References

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13. Appendices

Appendix 1: QPI Development Process

Preparatory Work and Scoping

The preparatory work involved the development of a structured briefing paper by Healthcare Improvement Scotland (formerly NHS Quality 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 renal cancer QPIs and a search narrative were defined and agreed by the Renal Cancer QPI Development Group. The table below shows the final search criteria.

Inclusion		Exclusion	
Renal cell carcinoma, clear cell and other cell carcinoma, renal parenchyma renal cortical lesions Adults only (over 16 years of age) *Date:* 2000 or later *Language:* All *Topics*: Referral, diagnosis, staging, management of non-metastatic (organ confined or locally advanced) and metastatic (advanced) disease, follow up, management of genetic risk.		*Topics:*	Prevention and palliative/end of life care related cancers such as bladder and urethra, pelvis tumours, Wilms tumours nephroblastoma.

Table 1 – Renal 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.

Nineteen guidelines were appraised for quality using the AGREE II instrument[3]. This tool assesses the methodological rigour and precision used when developing a guideline. Six of the guidelines were not recommended for use, of the remaining 13 guidelines, 5 were recommended for use and 8 recommended for use with modifications.

Indicator Development

The Renal 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 2011 where the Renal Cancer QPIs, along with the accompanying draft minimum core dataset and measurability specifications, were made available of the Scottish Government website.

During the engagement period clinical and management colleagues from across NHSScotland, patients affected by renal cancer and the wider public were given the opportunity to influence the development of renal cancer QPIs.

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

Appendix 2: Renal Cancer QPI Development Group Membership

Name	Designation	Cancer Network/Base
Michael Aitchison	Consultant Urologist	WoSCAN (Gartnavel General Hospital, Glasgow) – *until Oct 2010*
David Brewster	Director – Scottish Cancer Registry	ISD, National Services Scotland
Emma Brown	Consultant Clinical Oncologist	NOSCAN (Ninewells Hospital, Dundee)
John Brush	Consultant Radiologist	SCAN (Western General Hospital, Edinburgh)
Jacqueline Campbell	Clinical Nurse Specialist	WoSCAN (Stobhill Hospital, Glasgow)
Maria Doherty	Patient Representative	
Rachael Dunk	Team Leader - Cancer Strategies	Scottish Government Health Department
Clare Echlin	Acting Head of Standards Development	Healthcare Improvement Scotland
Jenny Fleming	Service Manager	SCAN (Western General Hospital, Edinburgh)
Grahame Howard	Consultant Oncologist	SCAN (Western General Hospital, Edinburgh)
Rob Jones	Consultant Oncologist	WoSCAN (Beatson West of Scotland Cancer Centre)
Andrew Martindale	Consultant Urologist	NOSCAN (Ninewells Hospital, Dundee)
Robert Masterton (CHAIR)	Chair – National Cancer Quality Steering Group	
Christine McIntosh	Highland Cancer Network Manager	NOSCAN (Raigmore Hospital, Inverness)
Frances McLinden	Clinical Service Manager	WoSCAN (Royal Infirmary, Glasgow)
Rita O'Dea	Clinical Nurse Specialist	SCAN (Western General Hospital, Edinburgh)
Marie O'Donnell	Consultant Pathologist	SCAN (Western General Hospital, Edinburgh)
Khaver Qureshi	Consultant Urologist	WoSCAN (Gartnavel General Hospital, Glasgow) – *from October 2010*
Tony Riddick	Consultant Urologist	SCAN (Western General Hospital, Edinburgh)
Iona Scott	Project Manager	
Evelyn Thomson	Regional Manager (Cancer)	WoSCAN

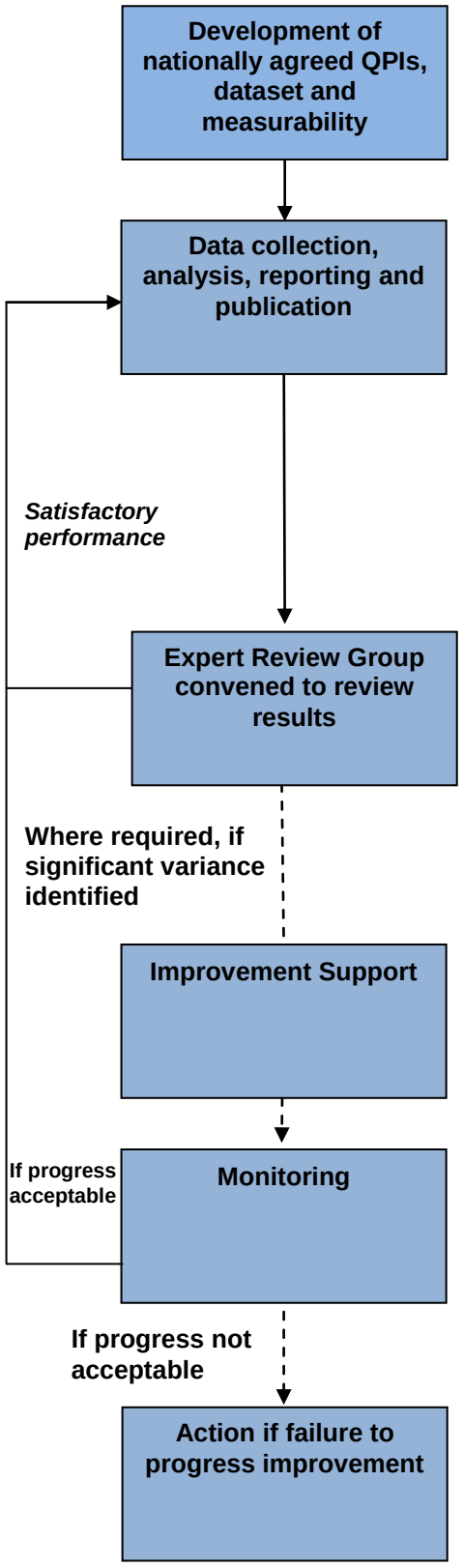
NOSCAN - North of Scotland Cancer Network
SCAN – South East Scotland Cancer Network
WoSCAN – West of Scotland Cancer Network

Appendix 3: Renal Cancer QPI Formal Review Group Membership

Name	Designation	Cancer Network/Base
Val Doherty	Lead Cancer Clinician	SCAN
Evelyn Thomson	Regional Manager (Cancer)	WoSCAN
Iona Scott	Quality & Improvement Manager	WoSCAN
Grenville Oades	Clinical Lead Urological Cancers MCN	WoSCAN / NHS Greater Glasgow & Clyde
Prasad Bollina	Clinical Lead Urological Cancers MCN	SCAN / NHS Lothian
Kevin O'Connor	Consultant Urologist	SCAN / NHS Lothian
Chris Goodman	Clinical Lead Urological Cancers MCN	NOSCAN / NHS Tayside *(until April 2016)*
Nicholas Cohen	Consultant Urologist	NOSCAN / NHS Grampian
Steve Leung	Consultant Urologist	SCAN / NHS Fife
Lorna Bruce	Audit & Information Manager	SCAN
Jen Doherty	Project Co-ordinator	National Cancer Quality Programme

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 section 2.
- Submit yearly reports to ISD for collation and publication every 3 years.
- ISD produce comparative, publicly available, national report consisting of trend analysis of 3 years data and survival analysis.
- National comparative report approved by NHS Boards and RCAGs.

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:

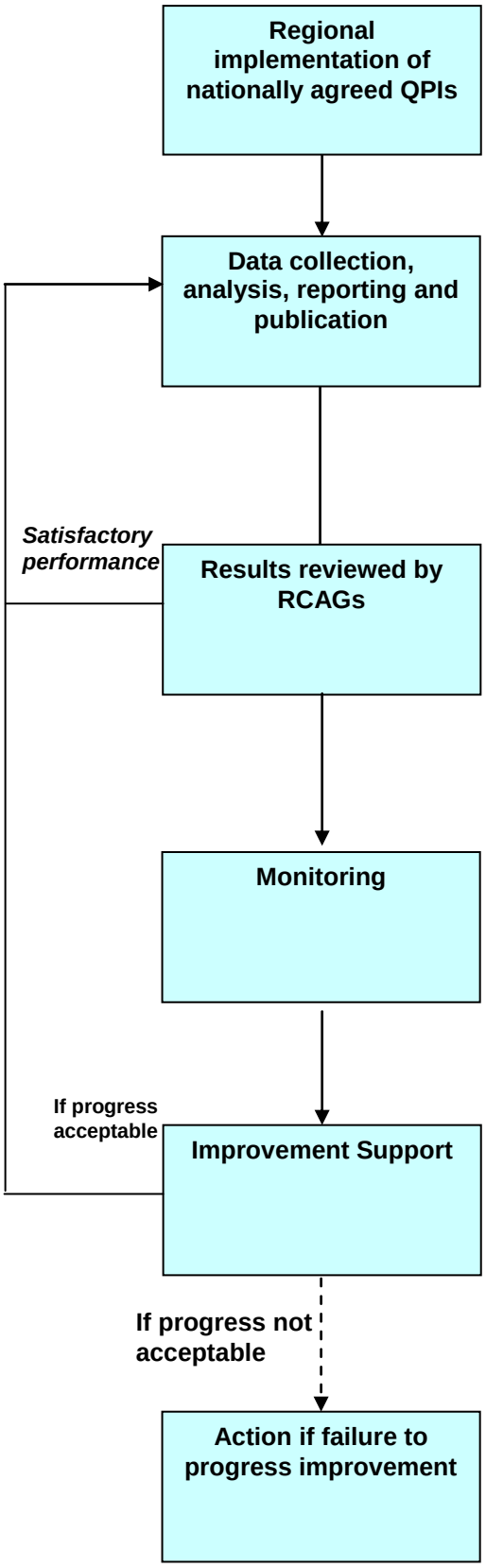
- RCAGs work with Boards to progress outstanding actions, monitor improvement plans and submit progress report to Healthcare Improvement Scotland.
- Healthcare Improvement Scotland report to Scottish Cancer Taskforce as to whether progress is acceptable**.**

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

Ablative therapy	See *Cryotherapy* and *Radiofrequency Ablation*
Active surveillance	Closely watching a patient's condition but not giving treatment unless there are changes in test results. It is used to find early signs that the condition is getting worse.
Active treatment	Treatment directed to cure the disease.
Anatomy	The study of the structure of a plant or animal.
Angiomyolipoma	A benign (non-cancerous) tumour of the kidney.
Anti-cancer therapy	Any treatment which is designed to kill cancer cells.
Biopsy	Removal of a sample of tissue from the body to assist in diagnosis of a disease.
Cardiovascular	Having to do with the heart and blood vessels.
Chronic kidney disease	Long term kidney problems.
Clear cell renal cell carcinoma/renal cancer	The most common subtype of renal cell carcinoma/renal cancer.
Clinical effectiveness	Measure of the extent to which a particular intervention works.
Clinical trials	A type of research study that tests how well new medical approaches or medicines work. These studies test new methods of screening, prevention, diagnosis, or treatment of a disease.
Computed Tomography (CT)	An x-ray imaging technique, which allows detailed investigation of the internal organ of the body.
Contralateral	Referring to the opposite side of the body.
Convalescence	The gradual return to health and strength after an illness.
Cost effectiveness	Value for money
Cross sectional imaging	The term used to cover different techniques (e.g. CT) which produce cross-sectional images of the body. See *Computed Tomography (CT)*
Cryotherapy	A treatment which aims to eradicate cancer by freezing.
Curative intent	Treatment which is given with the aim of curing the cancer.
Cytological / Cytopathological	The study of the structure and function of cells under the microscope, and of their abnormalities.
Diagnosis	The process of identifying a disease, such as cancer, from its signs and symptoms.
Dialysis	The process of filtering the blood when the kidneys are not able to cleanse it.
Elective	An elective procedure is one that is chosen by the patient or doctor that is advantageous to the patient but is not urgent.
First-line / Primary treatment	Initial treatment used to reduce a cancer.
Fuhrman grading system	A specific grading system for clear cell renal cancer. See *Grading*.

Grading	The degree of malignancy of a tumour, i.e. how closely the cancer cells look like normal kidney cells.
Histological / Histopathogical	The study of the structure, composition and function of tissues under the microscope, and their abnormalities.
Immunotherapy	Treatment to stimulate or restore the ability of the immune system to fight infection and disease. Also used to lessen the side-effects that may be caused by some cancer treatments.
Intravenous (IV) contrast	A substance administered intra venously (directly into bloodstream) to enhance the visibility of structures on imaging.
Invasive	Cancer that can or has spread from its histological original site.
Kidney	One of a pair of organs in the abdomen. Kidneys remove waste from the blood (as urine), produce erythropoietin (a substance that stimulates red blood cell production), and play a role in blood pressure regulation.
Laparoscopic nephrectomy	Surgery performed using a laparoscope; a special type of endoscope inserted through a small incision in the abdominal wall.
Lesion	Tumour, mass, or other abnormality.
Licensed indication	Approved use of a drug/treatment (by the Scottish Medicines Consortium or National Institute for Health and Clinical Excellence).
Magnetic Resonance Imaging (MRI)	A procedure in which radio waves and a powerful magnet linked to a computer are used to create detailed pictures of areas inside the body. These pictures can show the difference between normal and diseased tissue.
Malignant	Cancerous. Malignant cells can invade and destroy nearby tissue and spread to other parts of the body.
Metastases/Metastatic disease	Spread of cancer away from the primary site to somewhere else via the bloodstream or the lymphatic system.
Minimally invasive procedure	A procedure undertaken with only a small incision or no incision at all.
Morbidity	How much ill health a particular condition causes.
Morphology	The science of the form and structure of organisms (plants, animals, and other forms of life).
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 any specific region, age group, disease or other classification, usually expressed as deaths per 1000, 10,000 or 100,000.
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.
National Institute for Clinical Effectiveness (NICE)	An independent organisation responsible for providing NHS England with guidance on promoting good health and preventing and treating ill health.
Needle aspirate	Fluid withdrawn from a lump (often a cyst) using a needle.
Nephrectomy	Surgery to remove all or part of a kidney. Radical nephrectomy removes the entire kidney, nearby lymph nodes and other surrounding tissue.

Nephron sparing surgery (NSS)	Partial nephrectomy (also known as Nephron sparing surgery) removes only the tumour and part of the kidney surrounding it.
Non-metastatic	Cancer which has not metastasised. Cancer which has not spread to any other part of the body other than primary site in kidney.
Open resection	Surgery to remove part or all of an organ or a tumour and nearby lymph nodes. The incision is large enough to let the surgeon see into the body.
Palliative	Anything which serves to alleviate symptoms due to the underlying cancer but is not expected to cure it.
Partial nephrectomy	Partial nephrectomy (also known as nephron sparing surgery) removes only the tumour and part of the kidney surrounding it.
Pathological	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.
Performance status	A measure of how well a patient is able to perform ordinary tasks and carry out daily activities. (PS WHO score of 0=asymptomatic, 4=bedridden).
Primary Tumour	The original tumour.
Prognosis	An assessment of the expected future course and outcome of a person's disease.
Radical nephrectomy	Radical nephrectomy removes the entire kidney, nearby lymph nodes and other surrounding tissue.
Radiofrequency ablation (RFA)	A procedure that uses radio waves to heat and destroy abnormal cells.
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.
Renal	Having to do with the kidneys.
Renal Cell Carcinoma / Renal Cancer	Cancer of the kidney/s.
Renal function	An indication of how well the kidney is working.
Scottish Medicines Consortium (SMC)	The purpose of the SMC is to accept for use those newly licensed drugs that clearly represent good value for money to NHSScotland. SMC analyses information supplied by the drug manufacturer on the health benefits of the drug and justification of its price.
Space-occupying lesion	Substantial physical lesions which occupy space.
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.
Supportive care	Care given to improve the quality of life of patients who have a serious or life-threatening disease. The goal of supportive care is to prevent or treat as early as possible the symptoms of a disease, side effects caused by treatment of a disease, and psychological, social, and spiritual problems related to a disease or its treatment.
Surgery / Surgical resection	Surgical removal of the tumour/lesion.

Systemic Anti Cancer Therapy (SACT)	Treatment of cancer using drugs which induce a reduction in tumour cell population, for example cancer chemotherapy or hormone therapy.
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.
TNM staging system	TNM classification provides a system for staging the extent of cancer. T refers to the size of the primary tumour. N refers to the involvement of the lymph nodes. M refers to the presence of metastases or distant spread of the disease.
Transitional Cell Carcinoma (TCC)	Cancer which develops in cells, known as transitional cells, which form the lining of the bladder, ureters and renal pelvis.
Tumour excision	Removal of the tumour mass.
Unresectable	Unable to be removed by surgery.
Ureter	Hollow muscular tubes that carry urine from the kidneys to the bladder.
Vasculature	Arrangement of blood vessels in the body.

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