Renal Cancer

Data Definitions for the National Minimum Core Dataset to Support the Introduction of Renal Quality Performance Indicators

Definitions developed by ISD Scotland in collaboration with the Renal Quality Performance Indicator Development Group

Version 4.1: June 2020

To be used in conjunction with:

1. Renal Cancer Clinical Quality Performance Indicators V4.0
2. Renal Cancer QPI Dataset Validations (latest published version)
3. Renal Cancer Measurability of Quality Performance Indicators (latest published version)
Title: Renal Cancer – Data Definitions for Minimum Core Dataset for Quality Performance Indicators (QPIs)

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Renal Cancer Measurability of Quality Performance Indicators

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PREFACE

Following the completion of the Scottish Urological Cancer Audit (SUCA) in 2004 and as a requirement of the Cancer in Scotland: Action for Change, a national urological cancer data set was developed by ISD in collaboration with the three cancer networks.

Following the publication of ‘Better Cancer Care: An Action Plan’ in October 2008, the Scottish Government established the Scottish Cancer Taskforce to oversee its implementation. The NHS Scotland Healthcare Quality Strategy in 2010 expands on this by articulating quality ambitions. A quality measurement framework has been developed setting out measures and targets which will be used to monitor, challenge, manage and report progress. Part of this strategy is the development of national cancer quality performance indicators (QPIs) to drive quality improvement in cancer care throughout NHS Scotland.

As high quality data are required to enable comparisons over time and between regions, it is important that national data definitions are used to facilitate consistent data collection. National data definitions already in use have been used as much as possible to allow electronic data capture, thereby minimising duplication of data collection. Where national data definitions do not already exist, definitions used in other systems have been incorporated.

To ensure that findings are comparable across Scotland, the national dataset and data definitions in conjunction with the final quality performance indicators and the accompanying measurability document were agreed in public engagement and are now ready for implementation for patients diagnosed from 01/01/2012.

Dr John Brush, Consultant Radiologist, NHS Lothian
Dr Rob Jones, Consultant Oncologist, NHS Greater Glasgow and Clyde
Mr Andrew Martindale, Consultant Urologist, NHS Tayside

Renal Cancer QPI Development Group Subgroup Lead Clinicians
NOTES FOR IMPLEMENTATION OF CHANGES

The following changes should be implemented for all patients who are diagnosed with renal cancer on or after 1st January 2019, who are eligible for inclusion in the renal cancer audit.

Changes to definitions fall into the following categories:

- to address problems with ongoing audit and standardise data definitions, where feasible, between different cancer sites
- to address problems with existing definitions
- to allow Quality Performance Indicators to be measured and reported against

General enquiries on the collection of the National Minimum Core Dataset:

If you have any difficulties in using individual definitions within this document, or any comments on the data definitions, ISD would welcome your feedback.

Please contact: phs.canceraudit@nhs.net

CONVENTIONS

The layout for each item is standard as shown below where it is applicable:

Common Name(s):
Main Source of Data Item Standard:
Definition:
Field Name:
Field Type:
Field Length:
Notes for Users:
Codes and Values:
Related Data Item(s):
Notes by Users:

In addition the following two conventions have been used in the document:

- {curly brackets} - definition relates to one specific named data set
- 'described elsewhere' - indicates there is a definition for the named item within this document
REVISIONS TO DATASET

Addition to Dataset during COVID 19 Pandemic (June 2020)

Database Specification

Date of Referral - add new Data item, Field Name: REFERDATE, Field Type: Date (DD/MM/CCYY), Field Length: 10

COVID 19 impact - add new Data item, Field Name: COVID, Field Type: Integer, Field Length: 2

Dataset

Date of Referral - add new data item - implement from 1 March 2020

COVID 19 Impact - add new Data item – implemented from 1 January 2019

Changes outwith Review (June 2020)

Leibovich Score – Codes and Values table remove leading ‘0’

Date of Definitive Treatment {Renal Cancer} Notes for Users add SABR radiotherapy

Revision to Dataset agreed at Formal Review (August 2019)

Database Specification

Inherited Genetic Renal Cancer – add new data item, Field Name: GENREN, Field Type: Integer, Field Length: 2

Location Code {SACT Treatment} - add new data item Field Name: HOSPSACT, Field Type: Characters, Field Length: 5

Dataset

Staging Investigations Complete (Pre-treatment) - Title remove ‘(Pre-treatment)’; Notes for Users remove ‘but before first treatment’, ‘Complete staging should be within 3 months of treatment.’

Date Staging Investigations Complete (Pre-treatment) - Title remove ‘(Pre-treatment)’; Notes for Users remove ‘but before first treatment’, amend ‘10/10/1010’ to ‘10/10/1900’, ‘09/09/0909’ to ‘09/09/1900’

Contrast Agent Administered Status (Pre-treatment) - Title remove ‘(Pre-treatment)’

TNM Tumour Classification (Clinical) (Kidney) (Pre-treatment) - Notes for Users remove ‘Required for QPI ‘6’, remove ‘If in any doubt, check with pathology.’
TNM Nodal Classification (Clinical) (Kidney) (Pre-treatment) - Notes for User remove ‘Required for QPI ‘6’, remove ‘If in any doubt, check with pathology.’

TNM Metastasis Classification (Clinical) (Kidney) (Pre-treatment) - Notes for Users remove ‘Required for QPI ‘6’, remove ‘If in any doubt, check with pathology.’

Date of Diagnosis - Notes for Users amend ‘09/09/0909’ to ‘09/09/1900’

Date of Histological Diagnosis - Notes for Users amend 10/10/1010’ to ‘10/10/1900’, ‘09/09/0909’ to ‘09/09/1900’

Date Discussed by Care Team (MDT Pre-treatment) - Title remove ‘(MDT Pre-treatment)’; definition remove ‘prior to treatment’; Notes for Users amend 10/10/1010’ to ‘10/10/1900’, ‘09/09/0909’ to ‘09/09/1900’

Inherited Genetic Renal Cancer - add new data item

Prognostic Score (Pre-treatment) - Title remove ‘(Pre-treatment)’; Definition amend ‘prior to commencing treatment’ to ‘following diagnosis’; Notes for Users amend ‘prior to commencing treatment’ to ‘at any point during the initial treatment plan. This should also include patients where the treatment plan is ‘no active treatment’.’, remove ‘For patients undergoing no active treatment (e.g. supportive care only) code as 96 ‘Not applicable’.’, Codes and Values table remove code, value and explanatory notes for code ‘1’ and code ‘2’, add code, value and explanatory notes for code ‘3’, code ‘4’ and code ‘5’, explanatory note for code 96 amend ‘Patients undergoing no active treatment’ to ‘Patients with no metastatic disease’

Type of First Cancer Treatment – Notes for Users remove ‘Required for QPI ‘6’

Date of First Cancer Treatment - Notes for Users amend 10/10/1010’ to ‘10/10/1900’, ‘09/09/0909’ to ‘09/09/1900’

Date of Definitive Treatment - Notes for Users amend 10/10/1010’ to ‘10/10/1900’, ‘09/09/0909’ to ‘09/09/1900’

Definitive Operative Procedure – Notes for Users remove ‘Required for QPI ‘5, 6’

Date of Definitive Surgery - Notes for Users amend 10/10/1010’ to ‘10/10/1900’, ‘09/09/0909’ to ‘09/09/1900’

Date of Discharge {Cancer Surgery} - Notes for Users amend 10/10/1010’ to ‘10/10/1900’, ‘09/09/0909’ to ‘09/09/1900’

Surgical Procedure Type – Codes and Values table add code ‘3 Robotic’

Date of Cryotherapy - Notes for Users amend 10/10/1010’ to ‘10/10/1900’, ‘09/09/0909’ to ‘09/09/1900’

Morphology of Tumour - remove ‘Required for QPI ‘1, 2, 3, 4, 5, 6, 7, 8, 10’, remove ‘As there is currently no ICD code for Tubulocystic Carcinoma, record as Collecting Duct (M.8319/3) meantime. As there is currently no ICD code for Translocation Carcinomas, record as Renal Cell Carcinoma (M.8312/3) meantime.’, add ‘Please note that clear cell papillary RCC is distinct from papillary RCC. The clear cell variant does not have a malignant (/3) behaviour code and is therefore not
included'; Codes and Values table add code and value for ’8311/3, 8480/3, 8510/3, amend value for 8316/3, 8318/3, 8319/3

Fuhrman Grade (Kidney) - Notes for Users remove ‘Required for QPI ’5’, add ‘Required for: national comparative analysis and sub analysis’

Location Code (SACT Treatment) - add new data item

Systemic Anti Cancer Therapy Agent (Renal Cancer) - Notes for Users remove ‘Required for QPI ’8 and’

Date Treatment Started (Systemic Anti Cancer Therapy) - Notes for Users amend 10/10/1010’ to ’10/10/1900’, ’09/09/0909’ to ’09/09/1900’

Date Treatment Completed (Systemic Anti-Cancer Therapy) - Notes for Users remove ‘Required for QPI ’8’, amend 10/10/1010’ to ’10/10/1900’, ’09/09/0909’ to ’09/09/1900’

Date of Death - Notes for Users amend 10/10/1010’ to ’10/10/1900’, ’09/09/0909’ to ’09/09/1900’

Revision to Dataset outwith review (August 2018)

Definitive Operative Procedure – Codes and Values table add M02.9 Total excision of kidney – unspecified

Revisions to Dataset outwith review (January 2018)

TNM Tumour Classification (Clinical) (Kidney) (Pre-treatment) - Main Source of Data Item Standard and definition changed from Seventh Edition, 2009 to Eighth Edition 2017; change ‘Tumour invades’ to ‘Tumour extends’ in value for T3, value for T3a changed to ‘Tumour extends into the renal vein or its segmental branches, or tumour invades the pelvicalyceal system or tumour invades peritrenal and/or renal sinus fat (peropelviv) fat but not beyond Gerota fascia’, change ‘Grossly extends’ to ‘Tumour extends’ in value for T3b and T3c, insert ‘contiguous’ to value for T4

TNM Nodal Classification (Clinical) (Kidney) (Pre-treatment) - Main Source of Data Item Standard and definition changed from Seventh Edition, 2009 to Eighth Edition 2017; change value for N1 to ‘Metastasis in regional lymph mode(s)’; delete code and value for N2

TNM Metastases Classification (Clinical) (Kidney) (Pre-treatment) - Main Source of Data Item Standard and definition changed from Seventh Edition, 2009 to Eighth Edition 2017

TNM Tumour Classification (Pathological) (Kidney) - Main Source of Data Item Standard changed from Seventh Edition, 2009 to Eighth Edition 2017; change ‘Tumour invades’ to ‘Tumour extends’ in value for pT3, value for pT3a changed to ‘Tumour extends into the renal vein or its segmental branches, or tumour invades the pelvicalyceal system or tumour invades peritrenal and/or renal sinus fat (peropelviv) fat but not beyond Gerota fascia’, change ‘Grossly extends’ to ‘Tumour extends’ in value for pT3b and pT3c, insert ‘contiguous’ to value for pT4
TNM Nodal Classification (Pathological) (Kidney) - Main Source of Data Item
Standard changed from Seventh Edition, 2009 to Eighth Edition 2017; change value for pN1 to ‘Metastasis in regional lymph mode(s)’; delete code and value for pN2

TNM Metastases Classification (Pathological) (Kidney) - Main Source of Data Item Standard changed from Seventh Edition, 2009 to Eighth Edition 2017

Prognostic Score (Pre-Treatment) - The explanatory note for the code 01 – yes changed to ‘A valid prognostic score has been assigned i.e. Good, Intermediate, Poor’.

Date of First Cancer Treatment - Notes for Users add ‘Where this has subsequently been confirmed at MDT, the date of MDT should be recorded

Date of Definitive Treatment {Renal Cancer} - Notes for Users add ‘Where this has subsequently been confirmed at MDT, the date of MDT should be recorded

Revisions to Dataset outwith Review (September 2017)

Person Family Name – Link updated
Person Given Name – Link updated
Patient Postcode at Diagnosis – Link updated
Date of Birth – Link updated

Staging Investigations Complete – Notes for Users add ‘Complete staging should be within 3 months of treatment.’

Date of Discharge – Notes for Users add, ‘In cases where date of death is prior to discharge, record as 10/10/1010 (Not applicable).’

Warm Ischaemia Time – Field length amended from 3 to 4; Notes for Users added ‘For those patients who undergo cold ischaemia rather than warm ischaemia code as 1010 (Not applicable)’

Cold Ischaemia Time – New Data Item added; Database Specification updated.

Revisions to Dataset From Formal Review (November 2016)

Staging Investigations Complete (Pre-treatment) - Definition: add ‘(or MRI)’ and delete ‘and’. Notes for Users: add ‘(or MRI) of the’, delete ‘and’ and add ‘MRI of the kidney alone is insufficient and chest imaging must be completed’.

Date Staging Investigations Complete (Pre-treatment) - Definition: add ‘(or MRI)’ and delete ‘and’. Notes for Users: add ‘(or MRI) of the’, delete ‘and’.

Contrast Agent Administered Status (Pre-treatment) - Definition: delete ‘three’, add ‘/ MRI’, add ‘and’, delete ‘and’ and add ‘+/–’. Notes for Users: add ‘(or MRI)’ x3, add ‘and’, delete ‘and’ and add ‘+/–’, delete ‘three’, delete ‘and’ and add ‘+/–’, delete ‘CT’ and add ‘If complete staging has not been undertaken, record as 96 (Not applicable)’. Codes and Values: code 2 – correct ‘imaging’. 
TNM Tumour Classification (Clinical) (Kidney) (Pre-treatment) - Main Source of Data Item Standard and Definition: change: replace sixth edition 2002 with seventh edition 2009. Notes for Users: add ‘and 13’. Codes and values: add or delete as appropriate:
- T2a/ Tumour > 7cm to 10cm – add
- T2b/ Tumour > 10cm: limited to the kidney – add
- T3/ Add ‘or perinephric tissues but not into ipsilateral adrenal gland’ delete ‘adrenal or perinephric invasion not’ and add ‘and not’
- T3a/ Add ‘Grossly extends into renal vein or its segmental branches, or invades perirenal and/or’ and delete ‘Directly invades adrenal gland or perinephric tissues (includes)’
- T3b/ Delete ‘renal vein(s) or’ and add ‘below’ and delete ‘or its wall beyond’ and delete ‘(includes segmental (muscle-containing) branches)’
- T3c/ Delete ‘or its wall’ and add ‘or invades the wall of the vena cava’
- T4/ Add (including extension into the ipsilateral adrenal gland.


TNM Metastasis Classification (Clinical) (Kidney) (Pre-treatment) – Main Source of Data Item Standard & Definition replace sixth edition 2002 with seventh edition 2009. Notes for Users: Required for QPI(s): add 10, 11. Add ‘Where there is no evidence of metastasis record as M0’. Codes and Values: delete: MX/ Presence of distant metastasis cannot be assessed

Date of Diagnosis - Notes for Users: Required for QPI(s): replace ‘9’ with ‘13’.

Date Discussed by Care Team (MDT Pre-treatment) - Notes for Users Required for QPI: add ‘(s)’.

Prognostic Score (Pre-Treatment) – add New Data Item

Date of First Cancer Treatment - Notes for Users: Required for QPI(s): add ‘and’.

Date of Definitive Treatment (Renal Cancer) - Notes for Users: Required for QPI: add ‘(s)’.

Definitive Operative Procedure - Notes for Users: Required for QPI(s): add ‘11 and 13’.

Date of Definitive Surgery - Notes for Users: Required for QPI(s): add ‘8 and 13’. Related Data Item(s): add ‘Date of Discharge, Operating Consultant Surgeon, Location Code’.

Date of Discharge {Cancer Surgery} – add new data item.

Location Code {Cancer Surgery} – Add related Data Item(s): ‘Definitive Operative Procedure, Operating Consultant Surgeon, Date of Discharge’.

Operating Consultant Surgeon (1-2) – add new data item.

Date of Cryotherapy - Notes for Users: add ‘Required for QPI(s): 8’.
Leibovich Score - add new data item.

Warm Ischaemia Time – add new data item.

Morphology of Tumour - Notes for Users: Required for QPI(s): add ‘10, 11’.

TNM Tumour Classification (Pathological) (Kidney) (pT) - Main Source of Data Item Standard: replace sixth edition 2002 with seventh edition 2009. Codes and values: add or delete following:
- pT2a/ Tumour > 7cm to 10cm: add
- pT2b/ Tumour > 10cm: limited to the kidney – add
- pT3/ Add ‘or perinephric tissues but not into ipsilateral adrenal gland and’ and delete ‘: adrenal or perinephric invasion’
- pT3a/ Add ‘Grossly extends into renal vein or its segmental branches, or invades perirenal and/or’ and delete ‘Directly invades adrenal gland or perinephric tissues (includes’
- pT3b/ delete ‘renal vein(s) or’ and delete ‘or its wall beyond’ and add ‘below’ and delete ‘(includes segmental (muscle-containing) branches’
- pT3c/ Delete ‘or its wall’ and add ‘or invades the wall of the vena cava’
- pT4/ Add ‘(including extension into the ipsilateral adrenal gland).’


TNM Metastasis Classification (Pathological) (Kidney) - Main Source of Data Item Standard: replace sixth edition 2002 with seventh edition 2009. Notes for Users: Add ‘If no distant metastasis are present record as ‘not applicable’. Table of Codes and values – add or delete as appropriate:
- pM0/ No distant metastasis - delete
- pM1/ Delete ‘present’ and add ‘microscopically confirmed’
- pMX/ Presence of distant metastasis cannot be assessed – delete

Margin Status – add new data item.

Systemic Anti Cancer Therapy Agent (Renal Cancer) - Notes for Users: Required for QPI(s): add ‘8 and’. Related Data Item(s): add ‘Date Treatment Ended (Systemic Anti Cancer Therapy)’.

Date Treatment Started (Systemic Anti Cancer Therapy) - Related Data Item(s): add Date Treatment Ended (Systemic Anti Cancer Therapy).

Date Treatment Completed (Systemic Anti-Cancer Therapy) – add new data item.

Date of Death - Notes for Users: Required for QPI(s): ‘and 9’.

Underlying Cause of Death - Notes for Users: Required for cause-specific sub-analysis of QPI: replace 7 with 8.

Revisions to Dataset from Baseline Review (April 2015)

Staging Investigations Complete (Pre-treatment) & Date Staging Investigations Complete - Definition updated to state ‘+/- pelvis’ as per Baseline Review.

Location of Diagnosis {Cancer} – add code for not recorded as per query 608 on query log.
Location Code {Cancer Surgery} – update link to reference files.

Revisions to Dataset out-with Review (June 2014)

Database Specification

Date of Definitive Treatment {Renal Cancer} – add new Data Item: Field Name: DEFTREATDATE, Field Type: Date, Field Length: 10.

Dataset

Date of Definitive Treatment {Renal Cancer} - add new Data Item

Staging Investigations Complete (Pre-treatment) - Notes for Users revised to “When in any doubt about whether staging of a patient can be considered complete, this should be checked with radiology using the criteria outlined in the dataset.”

Date Staging Investigations Complete (Pre-treatment) - Notes for Users revised to “ALL” and added “When in any doubt about whether staging of a patient can be considered complete, this should be checked with radiology using the criteria outlined in the dataset.”

Date of Diagnosis - Notes for Users revised to “This may be the date of the CT scan where suspicion of renal cancer was raised and subsequently confirmed.”

Laterality - Notes for Users’ removed Two tumours of the same morphology diagnosed simultaneously in paired organs should be recorded separately (i.e. right and left) unless stated to have originated from a single primary tumour. Tumours in paired organs of completely different histology should be recorded separately (i.e. right and left). If there are two tumours in the same kidney, record only the details of the tumour with the worst prognosis e.g. highest TNM stage.” Added “In cases where there are multiple tumours, the tumour with the worst prognosis should be used e.g. highest TNM stage.”

Definitive Operative Procedure - ‘Notes for Users’ removed “Please note that only surgery occurring within six months of diagnosis should be included in the analysis against the relevant QPI” Added ‘Patients treated within 6 months of a patient initially refusing investigation or whose initial treatment is ‘Watch and Wait’ can also be recorded.’

Date of Definitive Surgery - Notes for Users’ removed “Please note that only surgery occurring within six months of diagnosis should be included in the analysis against the relevant QPI” Added ‘Patients treated within 6 months of a patient initially refusing investigation or whose initial treatment is ‘Watch and Wait’ can also be recorded.

Fuhrman Grade (Kidney) - Notes for Users’ revised to “As of 1st April 2014 this is also known as ISUP (Vancouver) Grading System.

Codes and Values Table Inserted - New Codes and Values 1st April 2014 – to date
1/ Grade 1/ Nucleoli: None
2/ Grade 2/ Nucleoli: Visible at high power x 400 magnification.
3/ Grade 3/ Nucleoli: Prominent visible at x 100 magnification.
4/ Grade 4/ Nuclear shape: Bizarre and multilobed nuclei +/- spindle or rhabdoid shaped cells.
Nucleoli: Prominent.
96/ Not applicable/ e.g. Non-clear cell or Non Papillary carcinomas
99/ Not recorded

Revisions To Dataset Following 9-Month Review (September 2013)

The following changes have been made following the 9-month review of Renal Cancer Data Definitions for the National Minimum Core Data Set. Changes to take effect for patients diagnosed from 01/01/2014.

Criteria For Inclusion of Patients in Audit: - Inclusion criteria removed:
- ‘Multiple independent primary tumours should be recorded separately’
- ‘Patients diagnosed within NHS Scotland but who have received any part of their treatment privately or outwith Scotland’
- ‘All patients aged 16 years and over’
Exclusion criteria added:
- ‘Patients with other tumour types, such as sarcoma or lymphoma’
- ‘Patients with carcinoma in situ’
- ‘Patients where the only record of their cancer is from a death certificate (DCO)’
- ‘Patients whose definitive cancer treatment was privately funded or undertaken outwith Scotland’
Exclusion criteria removed:
- ‘Patients with tumour types other than renal cell carcinomas’
- ‘Patients diagnosed in the private sector’
- ‘Death Certificate Only (DCO) cases’

Database Specification:

Date of Histological Diagnosis data item added: Field Name: HDIAG, Field Type: Date, Field Length: 10.

Dataset:

Date of Histological Diagnosis – add New Data Item

Person Sex at Birth –Codes and Values Table amended code ‘99: Not known’ to ‘99: Not recorded’.


Staging Investigations Complete (Pre-treatment) – Codes and Values Table Amended code ‘99: Not known’ to ‘99: Not recorded’, in table of codes and values.
Date Staging Investigations Complete (Pre-treatment) - Amended code '10/10/1010: inapplicable' to '10/10/1010: Not applicable’.

Contrast Agent Administered Status (Pre-treatment) - Notes for Users revised to: “Although imaging investigations may be done separately at different times, it is usual practice for CT of chest, abdomen and pelvis to be carried out together and for contrast to be administered for all three imaging procedures. If contrast is administered for CT of abdomen and CT pelvis, but not for CT chest, record as ‘2: Imaging with contrast agent’”. Codes & Values Table amended code ‘99: Not known’ to ‘99: Not recorded’, and amended code ‘96: inapplicable’ to ‘96: Not applicable’.

TNM Tumour Classification (Clinical) (Kidney) (Pre-treatment) AND TNM Nodal Classification (Clinical) (Kidney) (Pre-treatment) AND TNM Metastasis Classification (Clinical) (Kidney) (Pre-treatment) Notes for Users' updated to reflect changes to QPI numbering. Notes for Users’ revised to: “Clinical TNM is derived from all clinical, radiological and biochemical results prior to treatment, including clinical examination and imaging. N.B. Pathological classification for this data item refers to those made from biopsies only.

In cases where there are multiple tumours, the tumour with the worst prognosis should be used for TNM classification. If in any doubt, check with pathology.

If stage is unable to be definitively determined from information in case notes/clinical systems, do not deduce from other information and record as ‘not recorded’.”
Codes & Values table amended code ‘99: Not known’ to ‘99: Not recorded’.

Date of Diagnosis - Notes for Users updated to reflect changes to QPI numbering & amended code '10/10/1010: inapplicable' to ‘10/10/1010: Not applicable’.

Location of Diagnosis - Notes for Users’ revised to “Required for analysis purposes & clarifying responsibility for data collection.” And amended code ‘X1010: inapplicable’ to ‘X1010: Not applicable’.

Most Valid Basis of Diagnosis – Codes and Values Table amended code ‘99: Not known’ to ‘99: Not recorded’

Date Discussed by Care Team (MDT Pre-treatment) - Notes for Users updated to reflect changes to QPI numbering. ‘Notes for Users’ amended to remove requirement for MDT date to be recorded as inapplicable if date is after the date of first treatment. Amended code '10/10/1010: inapplicable' to ‘10/10/1010: Not applicable’.

Type of First Cancer Treatment - Notes for Users updated to reflect changes to QPI numbering.
Note appended to ‘notes for users’: “‘Supportive care only’ includes watchful waiting, but not palliative chemotherapy and/or radiotherapy.”
Codes & Values table added ‘radiofrequency ablation’, and ‘embolisation’ to explanatory notes for ‘supportive care only’.
Added ‘refusal of primary therapies’ to explanatory notes for ‘patient refused all therapies’.
Added code ‘99: not recorded’ to list of codes and values.

Date of First Cancer Treatment - Notes for Users’ updated to reflect changes to QPI numbering. Notes for Users’ amended to “If type of first cancer treatment is
'supportive care only', the date recorded should be the date of the MDT that this decision was made.” Amended code '10/10/1010: inapplicable' to '10/10/1010: Not applicable'.

**Definitive Operative Procedure** - Notes for Users’ updated to reflect changes to QPI numbering.
Codes and Values table:
- added 'M02.2: Nephroureterectomy NEC',
- Amended '99: Not known' to '99: Not recorded'
- Amended code '96: inapplicable' to '96: Not applicable'.

**Date of Definitive Surgery** - ‘Notes for Users’ updated to reflect changes to QPI numbering and amended code '10/10/1010: inapplicable' to '10/10/1010: Not applicable'.

**Location Code {Cancer Surgery}** - Main Source of Data Item Standard updated
‘Notes for Users’ updated to reflect changes to QPI numbering.
‘Notes for Users’ updated with correct links to location codes and ‘LOC-NEW’ form.
Codes and Values Table amended code '96: inapplicable' to '96: Not applicable'.

**Surgical Procedure Type** - Notes for Users’ updated to reflect changes to QPI numbering.
Codes and Values Table amended code '99: Not known' to '99: Not recorded',

**Surgical Presentation Type** - Notes for Users’ updated to reflect changes to QPI numbering.

**Date of Cryotherapy** - Notes for Users’ updated to reflect changes to QPI numbering.
Amended code '10/10/1010: inapplicable' to '10/10/1010: Not applicable’.

**Morphology of Tumour** - Notes for Users updated to reflect changes to QPI numbering. Notes for Users’ updated with correct email address to request morphology codes from.

**Fuhrman Grade (Kidney)** - Notes for Users updated to reflect changes to QPI numbering.
Codes and Values Table amended code '99: Not known' to '99: Not recorded'.

**TNM Tumour Classification (Pathological) (Kidney) AND TNM Nodal Classification (Pathological (Kidney) AND TNM Metastasis Classification (Pathological) (Kidney)** - Notes for Users revised to: “In the case of multiple tumours, the tumour with the worst prognosis should be used for classification. If in doubt, check with pathology.”
Pathology taken within 6 months of a patient initially refusing further investigation or whose initial treatment is ‘Watch and Wait’ can also be recorded.
If stage is unable to be definitively determined from information in case notes/clinical systems, do not deduce from other information and record as ‘not recoded’.
Codes and Values Table amended code '99: Not known' to '99: Not recorded'.

**Systemic Anti Cancer Therapy Agent (Renal Cancer)** - Definition amended to “The type of cytotoxic or biological agent used either alone or in combination to treat renal cancer. Notes for Users’ updated to reflect changes to QPI numbering.
Codes and Values Table amended code '99: Not known' to '99: Not recorded'.
Date Treatment Started (Systemic Anti Cancer Therapy) - Notes for Users updated to reflect changes to QPI numbering. Amended code ‘10/10/1010: inapplicable’ to ‘10/10/1010: Not applicable’.

Patient Entered into Clinical Trial (Renal Cancer) - Notes for Users updated to reflect changes to QPI numbering. Codes and Values Table amended code ’99: Not known’ to ’99: Not recorded’.

Date of Death - Notes for Users updated to reflect changes to QPI numbering. Amended code ’10/10/1010: inapplicable’ to ’10/10/1010: Not applicable’.

Underlying Cause of Death - Notes for Users updated to reflect changes to QPI numbering.

Date Record Considered Complete - Notes for Users updated to reflect changes to QPI numbering. Notes for Users revised: “This relates only to patients with advanced and/or metastatic disease at diagnosis, as SACT may be given to locally advanced disease without metastases.” Codes and Values Table added ’96: Not applicable’ option.
CRITERIA FOR INCLUSION OF PATIENTS IN AUDIT

To facilitate national comparisons the same patients must be audited throughout Scotland. The following eligibility criteria have been documented for this purpose.

Include

- All patients with a confirmed new primary renal cell carcinoma of the kidney (See Morphology of Tumour in dataset).
- Including, all patients who have had a previous primary malignancy of any site or a concurrent primary malignancy of another site.

Exclude

- Patients where the origin of the primary is uncertain.
- Patients with other tumour types, such as sarcoma or lymphoma.
- Patients with recurrent disease (as opposed to a new primary).
- Patients with carcinoma in situ.
- Patients, at date of diagnosis, under 16 years of age i.e. up to 15 years 364 days.
- Patients where the only record of their cancer is from a death certificate (DCO).
- Patients with normal residence outwith Scotland.
- Patients whose definitive cancer treatment was privately funded or undertaken outwith NHS Scotland.
DOWNLOAD FORMAT
To assist with downloading data to ISD for the National Quality Assurance Programme and other agreed activities, all sites should be able to export data according to the following specification.

DATABASE SPECIFICATION

<table>
<thead>
<tr>
<th>Section 1: Demographic Items</th>
<th>Field name</th>
<th>Field type</th>
<th>Size</th>
<th>Page</th>
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<td>Person Given Name</td>
<td>PATFNAME</td>
<td>Characters</td>
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<td>Date</td>
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<tr>
<td>Person Sex at Birth</td>
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<td>CHI Number</td>
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<th>Section 2: Pre-treatment Imaging &amp; Staging Investigations</th>
<th>Field name</th>
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<td><strong>Section 5: Systemic Anti-Cancer Therapy</strong></td>
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<td>Date Treatment Complete (Systemic Anti-Cancer Therapy)</td>
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<td><strong>Section 6: Clinical Trials and Death Details</strong></td>
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<td>Date of Death</td>
<td>DOD</td>
<td>Date</td>
<td>10</td>
<td>60</td>
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<td>Underlying Cause of Death</td>
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<td>Character</td>
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<tr>
<td>Date Record Considered Complete</td>
<td>DATECOMP</td>
<td>Date</td>
<td>10</td>
<td>62</td>
</tr>
</tbody>
</table>
Section 1: Demographic Items
Person Family Name (at Diagnosis)

Common Name(s): Surname, Family name

Main Source of Data Item Standard: Government Data Standards Catalogue

Definition: That part of a person's name which is used to describe family, clan, tribal group, or marital association at the time of diagnosis.

Field Name: PATSNAME
Field Type: Characters
Field Length: 35

Notes for Users:
Required, in association with other demographic items, in order to locate patients records and as a means of linking to other patient level data sources, such as inpatient records and death information.

The surname of a person represents that part of the name of a person indicating the family group of which the person is part.

It should be noted that in Western culture this is normally the latter part of the name of a person. However, this is not necessarily true of all cultures. This will, of course, give rise to some problems in the representation of the name. This is resolved by including the data item Name Element Position in the structured name indicating the order of the name elements.

From SMR Definitions and Codes

Notes by Users:
**Person Given Name**

**Common Name(s):** Forename, Given Name, Personal Name

**Main Source of Data Item Standard:** [Government Data Standards Catalogue](#)

**Definition:** The forename or given name of a person.

**Field Name:** PATFNAME  
**Field Type:** Characters  
**Field Length:** 35

**Notes for Users:**
Required, in association with other demographic items, in order to locate patient records and as a means of linking to other patient level data sources, such as inpatient records and death information.

The first forename of a person represents that part of the name of a person which after the surname is the principal identifier of a person.

Where the person's preferred forename is not the first forename, the related data item 'Preferred Forename' should be used to indicate this.

**Notes by Users:**
Patient Postcode at Diagnosis (Cancer)

Main Source of Data Item Standard: Government Data Standards Catalogue

Definition: Postcode of patient's usual place of residence on the date of diagnosis

Field Name: PATPCODE
Field Type: Characters
Field Length: Maximum 8

Notes for Users:
Required, in association with other demographic items, in order to locate patient records and as a means of linking to other patient level data sources, such as inpatient records and death information.

Postcode is included in BS7666 Address (GDSC) but there is also a separate Post Code standard which will be populated from BS7666 Address Post Code.

This item can be derived from the date of diagnosis and patient address at that time.

Related Data Items:
Date of Diagnosis

Notes by Users:
Date of Birth

Main source of Data Item Standard: Government Data Standards Catalogue

Definition: The date on which a person was born or is officially deemed to have been born, as recorded on the Birth Certificate.

Field Name: DOB
Field Type: Date (DD/MM/CCYY)
Field Length: 10

Notes for Users:
Required, in association with other demographic items, in order to locate patient records and as a means of linking to other patient level data sources, such as inpatient records and death information.

If the patient's date of birth is recorded differently on different occasions, the most frequently used or latest date should be recorded.

The patient's full date of birth inclusive of the century should be recorded. The format should be DD/MM/CCYY e.g. 01/02/2011.

Related Data Items:
CHI Number

Notes by Users:
**Person Sex at Birth**

Common Name(s): Sex at Birth

Main Source of Data Item Standard: Derived from the nearest equivalent Government Data Standards Catalogue standard 'Person Gender at Registration'

Definition: This is a factual statement, as far as is known, about the phenotypic (biological) sex of the person at birth

Field Name: SEX
Field Type: Integer
Field Length: 2

Notes for Users:
Required, in association with other demographic items, in order to locate patient records and as a means of linking to other patient level data sources, such as inpatient records and death information.

A person’s sex has clinical implications, both in terms of the individual’s health and the health care provided to them.

In the majority of cases, the phenotypic (biological) sex and genotypic sex are the same and the phenotypic sex is usually easily determined. In a small number of cases, accurate determination of genotype may be required.

Codes and Values:

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
<th>Explanatory Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Male</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Female</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Not specified/Indeterminate</td>
<td>Where it has not been possible to determine if the person is male or female at birth, e.g. intersex / hermaphrodite.</td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
<td></td>
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</table>

Related Data Items:
CHI Number

Notes by Users:
**CHI Number**

**Main Source of Data Item Standard:** Scottish Executive Health Department.

**Definition:** The Community Health Index (CHI) is a population register, which is used in Scotland for health care purposes. The CHI number uniquely identifies a person on the index.

**Field Name:** CHINUM
**Field Type:** Integer
**Field Length:** 10

**Notes for Users:** Required, in association with other demographic items, in order to locate patient records and as a means of linking to other patient level data sources, such as inpatient records and death information.

The Community Health Index (CHI) is a computer based population index whose main function at present is to support primary care services. CHI contains details of all Scottish residents registered with a General Practitioner and was originally envisaged and implemented as a population-based index to help assess the success of immunisation and screening programmes. It is therefore closely integrated with systems for child health, cervical cytology and breast screening call and recall. It is intended that this number, the Scottish equivalent of the new NHS number in England and Wales, should become the Unique Patient Identifier throughout the NHS in Scotland.

From Designed to Care - Scottish Office

The CHI number is a unique numeric identifier, allocated to each patient on first registration with the system. The CHI number is a 10-character code consisting of the 6-digit date of birth (DDMMYY), two digits, a 9th digit which is always even for females and odd for males and an arithmetical check digit (ISD, Information Services, NHS National Services Scotland).

The CHI number should always be used to identify a patient. However, Health record identifiers, such as hospital numbers in Patient Administration Systems (PAS), may be used locally, in conjunction with the CHI number or in the absence of the CHI number, to track patients and their records.

Although there may be no number when a patient presents for treatment, there must be an allocation at some point in the episode of care as CHI is mandatory on all clinical communications.

Non-Scottish patients and other temporary residents can have a CHI number allocated if required but it is envisaged that future development may allow the identifying number used in other UK countries to be used in Scotland.

**Related Data Items:**
Date of Birth
Person Sex at Birth

**Notes by Users:**
Section 2: Pre-treatment Imaging & Staging Investigations
Date of Referral

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: The date on which the patient referral to secondary care for the investigation and/or treatment of renal cancer was received.

Field Name: REFERDATE
Field Type: Date (DD/MM/CCYY)
Field Length: 10

Notes for Users: Required for national survival analysis and national comparative analysis.

The referral date is the date of receipt of initial referral into secondary care.

Where referral is through a screening programme, referral date is the date a request for further diagnostic intervention is received.

Where presentation is via A & E or other direct referral to hospital the referral date is the date the patient presents to hospital.

If the exact date is not documented, record as 09/09/1900.

Notes by Users:
**WHO/ECOG Performance Status at Time of Diagnosis**

**Main Source of Data Item Standard:** WHO (World Health Organisation) and Eastern Cooperative Oncology Group (ECOG)

**Definition:** An overall assessment of the functional/physical performance of the patient at the time of diagnosis, and before first treatment.

**Field Name:** PSTATUS

**Field Type:** Integer

**Field Length:** 1

**Notes for Users:** Required for QPI(s): 9.

The WHO/ECOG performance status is a grade on a five point scale (range 0 to 4) at the time of investigation in which '0' denotes normal activity and '4' a patient who is 100% bedridden. If it is not documented in case notes do not deduce from other information and record as 'Not known'.

**Codes and Values:**

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<thead>
<tr>
<th>Code</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
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<td>Fully active, able to carry on all pre-disease performance without restriction</td>
</tr>
<tr>
<td>1</td>
<td>Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g. light housework, office work</td>
</tr>
<tr>
<td>2</td>
<td>Ambulatory and capable of self care but unable to carry out any work activities: up and about more than 50% of waking hours</td>
</tr>
<tr>
<td>3</td>
<td>Capable of only limited self care, confined to bed or chair more than 50% of waking hours</td>
</tr>
<tr>
<td>4</td>
<td>Completely disabled, cannot carry on any self care, totally confined to bed or chair</td>
</tr>
<tr>
<td>9</td>
<td>Not recorded</td>
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</table>

**Notes by Users:**
Staging Investigations Complete

Definition: An indication of whether or not staging investigations were completed by CT (or MRI) of the chest and abdomen, +/- pelvis.

Field Name: SINVEST
Field Type: Integer
Field Length: 2

Notes for Users: Required for QPI(s): 1.

Complete staging is CT (or MRI) of the chest and abdomen +/- pelvis (and no other combination). These investigations may be done separately at different times. MRI of the kidney alone is insufficient and chest imaging must be completed.

When in any doubt about whether staging of a patient can be considered complete, this should be checked with radiology using the criteria outlined in the dataset.

Codes and Values:

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Yes</td>
</tr>
<tr>
<td>2</td>
<td>No</td>
</tr>
<tr>
<td>95</td>
<td>Patient refused investigations</td>
</tr>
<tr>
<td>96</td>
<td>Not applicable</td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
</tr>
</tbody>
</table>

Related Data Item(s):
Date Staging Investigations Complete
Contrast Agent Administered Status

Notes by Users:
**Date Staging Investigations Complete**

**Definition:** The date that staging investigations were completed by CT (or MRI) of the chest and abdomen, +/- pelvis.

**Field Name:** SINVESTDATE  
**Field Type:** Date (DD/MM/CCYY)  
**Field Length:** 10

**Notes for Users:** Required for QPI(s): 1.

Complete staging is CT (or MRI) of the chest and abdomen +/- pelvis (and no other combination). These investigations may be done separately at different times. Record the date that **ALL** items are complete, e.g. if done on separate days then record the final date.

**When in any doubt about whether staging of a patient can be considered complete, this should be checked with radiology using the criteria outlined in the dataset.**

If staging investigations were not completed, record as not applicable (10/10/1900).

If the exact date is not documented, record as (09/09/1900).

**Related data item(s):**
Staging Investigations Complete

**Notes by Users:**
**Contrast Agent Administered Status**

**Main Source of Data Item Standard:** The National Cancer Audit Datasets developed by the regional Cancer Networks supported by the Information Services.

**Definition:** An indicator of whether or not a contrast agent was administered for each of the imaging procedures (CT / MRI of chest and abdomen, +/- pelvis).

**Field Name:** CONAGENT  
**Field Type:** Integer  
**Field length:** 2

**Notes for Users:** Required for QPI(s): 1.

Although imaging investigations may be done separately at different times, it is usual practice for CT (or MRI) of chest and abdomen, +/- pelvis to be carried out together and for contrast to be administered for all imaging procedures.

If contrast is administered for CT (or MRI) of abdomen, +/- pelvis, but not for CT (or MRI) chest, record as ‘2: Imaging with contrast agent’.

If complete staging has not been undertaken, record as 96 (Not applicable).

**Codes and Values:**

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Imaging without contrast agent</td>
</tr>
<tr>
<td>2</td>
<td>Imaging with contrast agent</td>
</tr>
<tr>
<td>96</td>
<td>Not applicable</td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
</tr>
</tbody>
</table>

**Related Data Item(s):**  
Staging Investigations Complete

**Notes by Users:**
**TNM Tumour Classification (Clinical) (Kidney) (Pre-treatment)**

**Common Name:** Clinical TNM Tumour Classification (Kidney).

**Main Source of Data Item Standard:** TNM Classification (TNM Classification of Malignant Tumours, Eighth Edition, UICC, 2017).

**Definition:** A record of the size and extent of the tumour of the kidney as determined by pre-treatment investigations (not pathological), coded according to the official TNM Classification (TNM Classification of Malignant Tumours, Eighth Edition, 2017).

**Field Name:** cT  
**Field Type:** Characters  
**Field length:** 3

**Notes for Users:** Required for QPI(s): 3, 7, 9, and 13.

This is a pre/non-operative classification as defined by the Multidisciplinary Team Meeting (MDT) based on best knowledge. This may be at any MDT meeting up until first treatment.

Clinical TNM is derived from all clinical, radiological and biochemical results prior to treatment, including clinical examination and imaging. **N.B. Pathological classification for this data item refers to those made from biopsies only.**

In cases where there are multiple tumours, the tumour with the worst prognosis should be used for TNM classification.

If stage is unable to be definitively determined from information in case notes/clinical systems, do not deduce from other information and record as ‘not recorded’.
### Codes and Values:

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>T0</td>
<td>No evidence of primary tumour</td>
</tr>
<tr>
<td>T1</td>
<td>Tumour 7cm or less: limited to the kidney</td>
</tr>
<tr>
<td>T1a</td>
<td>Tumour ≤ 4cm</td>
</tr>
<tr>
<td>T1b</td>
<td>Tumour &gt; 4cm to 7cm</td>
</tr>
<tr>
<td>T2</td>
<td>Tumour more than 7cm: limited to the kidney</td>
</tr>
<tr>
<td>T2a</td>
<td>Tumour &gt; 7cm to 10cm</td>
</tr>
<tr>
<td>T2b</td>
<td>Tumour &gt; 10cm: limited to the kidney</td>
</tr>
<tr>
<td>T3</td>
<td>Tumour extends into major veins or perinephric tissues but not into ipsilateral adrenal gland and not beyond Gerota’s fascia</td>
</tr>
<tr>
<td>T3a</td>
<td>Tumour extends into the renal vein or its segmental branches, or tumour invades the pelvicalyceal system or tumour invades perirenal and/or renal sinus fat (peripelvic) fat but not beyond Gerota fascia</td>
</tr>
<tr>
<td>T3b</td>
<td>Tumour extends into vena cava below diaphragm</td>
</tr>
<tr>
<td>T3c</td>
<td>Tumour extends into vena cava above the diaphragm or invades the wall of the vena cava</td>
</tr>
<tr>
<td>T4</td>
<td>Tumour invades beyond Gerota’s fascia (including contiguous extension into the ipsilateral adrenal gland).</td>
</tr>
<tr>
<td>TX</td>
<td>Primary tumour cannot be assessed</td>
</tr>
<tr>
<td>96</td>
<td>Not applicable</td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
</tr>
</tbody>
</table>

### Related Data Item(s):
- TNM Nodal Classification (Clinical) (Kidney) (Pre-treatment)
- TNM Metastasis Classification (Clinical) (Kidney) (Pre-treatment)

### Notes by Users:
TNM Nodal Classification (Clinical) (Kidney) (Pre-treatment)

**Common Name:** Clinical TNM Nodal Classification (Kidney).

**Main Source of Data Item Standard:** TNM Classification (TNM Classification of Malignant Tumours, Eighth Edition, UICC, 2017).

**Definition:**
A record of the extent of regional lymph node of the kidney metastasis as determined by pre-treatment investigations (not pathological), coded according to the official TNM Classification (TNM Classification of Malignant Tumours, Eighth Edition, 2017).

**Field Name:** cN
**Field Type:** Characters
**Field length:** 2

**Notes for Users:** Required for QPI(s): 3, and 7.

This is a pre/non-operative classification as defined by the MDT based on best knowledge. This may be at any MDT meeting up until first treatment.

Clinical TNM is derived from all clinical, radiological and biochemical results prior to treatment, including clinical examination and imaging. **N.B. Pathological classification for this data item refers to those made from biopsies only.**

In the case of multiple tumours, the tumour with the worst prognosis should be used for classification.

If stage is unable to be definitively determined from information in case notes/clinical systems, do not deduce from other information and record as ‘not recorded’.

**Codes and Values:**

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>N0</td>
<td>No regional lymph node metastasis.</td>
</tr>
<tr>
<td>N1</td>
<td>Metastasis in regional lymph node(s).</td>
</tr>
<tr>
<td>NX</td>
<td>Regional lymph nodes cannot be assessed (e.g. previously removed).</td>
</tr>
<tr>
<td>96</td>
<td>Not applicable</td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
</tr>
</tbody>
</table>

**Related Data Item(s):**
TNM Tumour Classification (Clinical) (Kidney) (Pre-treatment)
TNM Metastasis Classification (Clinical) (Kidney) (Pre-treatment)

**Notes by Users:**
TNM Metastasis Classification (Clinical) (Kidney) (Pre-treatment)

Common Name: Clinical TNM Metastasis Classification (Kidney).


Definition: A record of the extent of metastatic spread of the tumour of the kidney as determined by pre-treatment investigations (not pathological), coded according to the official TNM Classification (TNM Classification of Malignant Tumours, Eighth Edition, 2017).

Field Name: cM
Field Type: Characters
Field length: 2

Notes for Users: Required for QPI(s): 3, 7, 9, 10, 11.

This is a pre/non-operative classification as defined by the MDT based on best knowledge. This may be at any MDT meeting up until first treatment.

Clinical TNM is derived from all clinical, radiological and biochemical results prior to treatment, including clinical examination and imaging. N.B. Pathological classification for this data item refers to those made from biopsies only.

In the case of multiple tumours, the tumour with the worst prognosis should be used for classification.

If stage is unable to be definitively determined from information in case notes/clinical systems, do not deduce from other information and record as ‘not recorded’.

Where there is no evidence of metastasis record as M0.

Codes and Values:

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>M0</td>
<td>No distant metastasis.</td>
</tr>
<tr>
<td>M1</td>
<td>Distant metastasis.</td>
</tr>
<tr>
<td>96</td>
<td>Not applicable</td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
</tr>
</tbody>
</table>

Related Data Item(s):
TNM Tumour Classification (Clinical) (Kidney) (Pre-treatment)
TNM Nodal Classification (Clinical) (Kidney) (Pre-treatment)

Notes by Users:
**Date of Diagnosis**

**Main Source of Data Item Standard:** The National Audit Cancer Datasets developed by the regional Cancer Networks supported by Information Services.

**Definition:** The date of diagnosis is the date on which there was first confirmation of the diagnosis of renal cancer whether by histology, cytology or clinical (including radiological) methods.

**Field Name:** DIAGDATE  
**Field Type:** Date (DD/MM/CCYY)  
**Field Length:** 10

**Notes for Users:** Required for QPI(s): 1 - 13.

The date recorded is the date of the first investigative procedure that confirms a diagnosis of kidney cancer whether done radiologically or histologically. The date recorded is the date the procedure was performed, not the date the report was issued.

This may be the date of the CT scan where suspicion of renal cancer was raised and subsequently confirmed.

If the exact date is not documented, record as (09/09/1900).

**Related Data Item(s):**  
Location of Diagnosis {Cancer}

**Notes by Users:**
Location of Diagnosis {Cancer}

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: The patient's hospital of investigation in which the diagnosis of cancer was first made

Field Name: HOSP
Field Type: Characters
Field Length: 5

Notes for Users: Required for analysis purposes & clarifying responsibility for data collection.

This may also be a GP surgery code if a biopsy was taken by a GP. This will be the hospital/GP surgery where the sample was taken or the hospital at which the patient was managed when the diagnosis was made.

Details of location codes for hospitals can be found in the "Definitions and Codes for the NHS in Scotland" manual produced by ISD Scotland.

Location codes for hospitals are five character codes maintained by ISD Scotland and the General Register Office (Scotland). The first character denotes the health board, the next three are assigned and the fifth denotes the type of location (H=hospital) e.g.

A111H=Crosshouse Hospital
G107H=Glasgow Royal Infirmary
X9999=Not recorded

If a patient was diagnosed through imaging at one hospital but transferred to another for confirmation of the diagnosis, the first hospital should be recorded as the Location of diagnosis.

Related Data Item(s):
Date of Diagnosis

Notes by Users:
**Date of Histological Diagnosis**

**Main Source of Data Item Standard:** The National Audit Cancer Datasets developed by the regional Cancer Networks supported by Information Services.

**Definition:** The date of histological diagnosis is the date on which there was confirmation of the diagnosis of cancer by histology.

**Field Name:** HDIAG  
**Field Type:** Date (DD/MM/CCYY)  
**Field Length:** 10

**Notes for Users:** Required for QPI(s): 2

The date recorded is the date the procedure was performed, not the date the report was issued.

If the exact date is not documented, record as (09/09/1900).

If no invasive diagnostic procedures were undertaken, record as Not applicable (10/10/1900),

**Related Data Item(s):**  
Most Valid Basis of Diagnosis

**Notes by Users:**
Most Valid Basis of Diagnosis {Cancer}


Definition: The best evidence in support of the diagnosis of cancer.

Field Name: VALID
Field Type Integer
Field Length: 2

Notes for Users: Required for QPI(s): 2.

The conclusion of a diagnosis of cancer may be based on one or several procedures; clinical findings or as a report on the death certificate. Histological confirmation is considered as the most valid basis of diagnosis.

If a patient is diagnosed on a CT scan but then goes on to have surgery and there is histology available then you would record Histology of Primary, as this is the most valid, regardless of the fact the diagnosis was made on CT scan.

NB: With the emergence of molecular markers etc., there are plans to review the definition of this variable in the context of updating the IARC monograph, Cancer Registration Principles and Methods.

Codes and Values:

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
<th>Explanatory Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Clinical only</td>
<td>The diagnosis is based solely on clinical findings (history and/or physical examination). This is made before death but without the benefit of the following:</td>
</tr>
<tr>
<td>2</td>
<td>Clinical investigation</td>
<td>The diagnosis is supported by investigations such as x-ray, CT scan, ultrasound etc.</td>
</tr>
<tr>
<td>3</td>
<td>Exploratory surgery/endoscopy/autopsy (without concurrent or previous histology)</td>
<td>The tumour has been visualised or palpated but there is no confirmatory microscopic evidence</td>
</tr>
<tr>
<td>4</td>
<td>Tumour specific markers (biochemical/immunological tests)</td>
<td>The diagnosis is supported by specific tests</td>
</tr>
<tr>
<td>5</td>
<td>Cytology</td>
<td>The diagnosis is supported by cytology (the examination of cells whether from a primary or secondary site).</td>
</tr>
<tr>
<td>6</td>
<td>Histology of metastasis</td>
<td>The diagnosis is based on the histology of a metastasis (secondary deposit), e.g. resulting from a lymph node biopsy</td>
</tr>
<tr>
<td>7</td>
<td>Histology of primary</td>
<td>The diagnosis is based on the histology of the primary either resulting from a biopsy or from complete resection of the tumour.</td>
</tr>
<tr>
<td>8</td>
<td>Autopsy (with histology)</td>
<td>The diagnosis is based on the findings at autopsy supported by concurrent or previous histology.</td>
</tr>
<tr>
<td>10</td>
<td>Death Certificate only</td>
<td>The only information available to the registry is from a death certificate.</td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
<td></td>
</tr>
</tbody>
</table>

Notes by Users:
Laterality

**Main Source of Data Item Standard:** The National Audit Cancer Datasets developed by the regional Cancer Networks supported by Information Services.

**Definition:** This indicates the side or laterality (i.e. left or right) of the body in which the tumour is located.

**Field Name:** SIDE  
**Field Type:** Integer  
**Field Length:** 2

**Notes for Users:**

Clinically relevant data item which can influence treatment decisions and prognosis. Required for sub-group analysis as incidence and survival may be associated with laterality.

It is important that this be recorded for paired organs (e.g. kidney, testis). Only the following codes to be used:

In cases where there are multiple tumours, the tumour with the worst prognosis should be used e.g. highest TNM stage.

**Codes and Values:**

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
<th>Explanatory notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Right</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Left</td>
<td></td>
</tr>
<tr>
<td>96</td>
<td>Not applicable</td>
<td>e.g. Congenital fusion anomalies for example, horseshoe kidney.</td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
<td></td>
</tr>
</tbody>
</table>

**Notes by Users**
Date Discussed by Care Team

Common Name: Date discussed by multidisciplinary team (MDT) {Cancer}

Main Source of Data Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: This denotes the date the care team meeting was held to discuss the management of the patient's care.

Field Name: MDTDATE
Field Type: Date (DD/MM/CCYY)
Field Length: 10

Notes for Users: Required for QPI(s): 4

A cancer multidisciplinary care team may include surgeons, oncologists, radiologists, pathologists, nurses, speech language therapists, physiotherapists and others relevant to the treatment of a specific cancer. The team meets on a regular basis to discuss optimal patient management. Documentation of the discussion should be included in the case-note or other formal documentation.

The first MDT meeting date will be recorded.

If the patient has not been discussed by the MDT, record as Not applicable (10/10/1900).

If the date of the MDT meeting is unknown record as (09/09/1900).

Notes by Users:
COVID 19 Impact

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: A record of whether COVID 19 has impacted on treatment decisions.

Field Name: COVID
Field Type: Integer
Field Length: 2

Notes for Users: Required for national survival analysis and national comparative analysis.

The COVID 19 pandemic will have an impact on the patient pathways of some patients, potentially affecting the treatment they will receive. This may affect treatment decisions from the outset or plans may change part way through treatment. MDTs will record when the recommendations of the MDT for management are made on the basis of emergency COVID 19 management guideline and differ from what would otherwise be advised.

Where there is a record of a patients treatment being amended due to the emergency COVID 19 management guidelines elsewhere, for example amendments to treatment after MDT discussion, then this can also be recorded under ‘Yes – other’, however it is acknowledged that this information may not be complete.

Codes and Values:

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
<th>Explanatory Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Yes - plan developed by MDT</td>
<td>MDT record treatment as determined by emergency COVID 19 management guidelines from the outset</td>
</tr>
<tr>
<td>2</td>
<td>Yes - plan amended by MDT</td>
<td>MDT record amendment to existing treatment plan due to emergency COVID 19 management guidelines</td>
</tr>
<tr>
<td>3</td>
<td>Yes – Other</td>
<td>Other record of amendment to treatment due to emergency COVID 19 management guidelines e.g. clinic letter about alteration of treatment plan</td>
</tr>
<tr>
<td>4</td>
<td>No</td>
<td>No evidence of patient treatment being affected by COVID 19</td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
<td>Where documentation of part of the patient pathway is unavailable, e.g. for patients diagnosed outwith NHS Scotland, or where the patient moves away while treatment is still ongoing</td>
</tr>
</tbody>
</table>
Inherited Genetic Renal Cancer

Main Source of Data Item Standard: The National Audit Cancer Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: This is a record of whether a patient has inherited genetic renal cancer.

Field Name: GENREN
Field Type: Integer
Field Length: 2

Notes for Users: Required for QPI: 2

Renal cell carcinoma can be inherited although these cancers are rare and account for a small number of cases overall.

If the patient has inherited genetic renal cancer this may be noted within the family history in the clinical notes.

If it is documented that the patient has the presence of any of the following inherited conditions this should be coded as 1 (Yes): Von Hippel-Lindau Syndrome (VHL); Birt-Hogg-Dube Syndrome (BHD); tuberous sclerosis.

These are the most common inherited conditions however this list is not exhaustive. If there is any doubt, this should be checked with the relevant clinician.

Codes and Values:

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
<th>Explanatory Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
<td></td>
</tr>
</tbody>
</table>
Prognostic Score

Main Source of Data Item Standard: The National Audit Cancer Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: This is a record of whether a patient with metastatic disease has been assigned a valid prognostic score following diagnosis.

Field Name: PROGSCORE
Field Type: Integer
Field Length: 2

Notes for Users: Required for QPI: 10

Valid prognostic scoring can be assigned using various models including MSKCC/Motzer, or Heng scoring tools. The score should be assigned at any point during the initial treatment plan. This should also include patients where the treatment plan is 'no active treatment'.

This field should only be completed for patients with metastatic disease. If the patient does not have metastatic disease code as 96 'Not applicable'

If there is no score assigned do not deduce from other information and record as 99 'Not recorded'.

Codes and Values:

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
<th>Explanatory Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>Good</td>
<td>e.g. good / favourable risk</td>
</tr>
<tr>
<td>4</td>
<td>Intermediate</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Poor</td>
<td>e.g. high risk / poor risk</td>
</tr>
<tr>
<td>96</td>
<td>Not applicable</td>
<td>e.g. Patients with no metastatic disease</td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
<td></td>
</tr>
</tbody>
</table>
Type of First Cancer Treatment

Common Name: Mode of First Treatment

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: This denotes the first specific treatment modality administered to a patient.

Field Name: FIRSTTREATMODE
Field Type: Integer
Field length: 2

Notes for Users: Required for QPI(s): 1, 2, 4, 7, and 8.

For any particular modality it is the first treatment and not specifically the definitive treatment i.e. this does not include purely diagnostic biopsies such as incisional biopsies, needle biopsies or core biopsies. It also does not include open and close procedures. Some biopsies, such as excisional biopsies and cone biopsies, may be included as these may have some therapeutic benefits i.e. the removal of the tumour.

Record patients as having ‘supportive care only’ if a decision was taken not to give the patient any active treatment as part of their primary therapy. ‘Supportive care only’ includes watchful waiting, but not palliative chemotherapy and/or radiotherapy.

Steroids etc should not be recorded as first treatment if more substantive treatment such as surgery is given. If no further treatment is given, then record as supportive care only.
<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
<th>Explanatory notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Surgery</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Radiotherapy</td>
<td>Includes Teletherapy (external beam radiotherapy, proton beam therapy) and Brachytherapy.</td>
</tr>
<tr>
<td>7</td>
<td>Supportive Care Only</td>
<td>Not for active treatment. May include: terminal care patients, radiofrequency ablation, embolisation, and watchful waiting</td>
</tr>
<tr>
<td>11</td>
<td>Other therapy</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Active Surveillance</td>
<td>Scheduled follow-up including repeat clinic visits, tests and biopsies after an interval until the disease progresses or the grade of the tumour changes.</td>
</tr>
<tr>
<td>13</td>
<td>Systemic Anti-Cancer Therapy (SACT)</td>
<td>Includes biological therapies: Sunitinib (Sutent), Pazopanib (Votrient), Bevacizumab (Avastin), Interferon (Roferon or Intron), Temsirolimus (Torisel)</td>
</tr>
<tr>
<td>14</td>
<td>Patient died before treatment</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>Radiofrequency Ablation</td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>Cryotherapy</td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>Embolisation</td>
<td></td>
</tr>
<tr>
<td>95</td>
<td>Patient refused all therapies</td>
<td>Refusal of Primary Therapies.</td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
<td></td>
</tr>
</tbody>
</table>

**Related Data Item(s):**
Date of First Cancer Treatment

**Notes by Users:**
**Date of First Cancer Treatment**

**Main Source of Data Item Standard:** The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

**Definition:** This denotes the date the type of first cancer treatment was given to the patient.

**Field Name:** FIRSTTREATDATE  
**Field Type:** Date (DD/MM/CCYY)  
**Field Length:** 10

**Notes for Users:** Required for QPI(s): 1, 2, and 8.

This field should be recorded for all patients including those with ‘supportive care only’ (see below).

If type of first cancer treatment is ‘supportive care only’, the date recorded should be the date of the MDT that this decision was made. Where this has subsequently been confirmed at MDT, the date of MDT should be recorded. The aim of this date is to distinguish between patients who have initially had no treatment but receive some therapy when symptoms develop.

The date recorded should be that of the first type of cancer treatment.

If the patient died before treatment or the patient refused treatment, record as (10/10/1900).

If the exact date is not documented, record as (09/09/1900).

**Related Data Item(s):**  
Type of First Cancer Treatment

**Notes by Users:**
**Date of Definitive Treatment {Renal Cancer}**

**Main Source of Data Item Standard:** The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

**Definition:** This denotes the date definitive cancer treatment was given to the patient.

**Field Name:** DEFTREATDATE  
**Field Type:** Date (DD/MM/CCYY)  
**Field Length:** 10

**Notes for Users:** Required for QPI(s): 4

For patients with renal cancer definitive treatment will be either:

- Surgery;
- Radiofrequency Ablation (RFA);
- Cryotherapy; or
- Systemic Anti Cancer Therapy (SACT);
- SABR radiotherapy.

It is the date of this treatment that should be recorded.

If a patient receives more than one of the treatments listed it is the first which should be recorded.

For patients undergoing no active treatment (e.g. active surveillance or supportive care only) the date recorded should be the first date the decision was taken not to give the patient treatment as part of their primary therapy. Where this has subsequently been confirmed at MDT, the date of MDT should be recorded. This will therefore be the same date as the First Treatment Date for these patients.

If the exact date is not documented, record as 09/09/1900 (Not recorded).

If the patient died before treatment or the patient refused treatment, record as 10/10/1900 (Not applicable).

**Related Data Item(s):**
Section 3: Surgery
**Definitive Operative Procedure**

**Main Source of Data Item Standard:** The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services

**Definition:** This denotes the surgical procedure(s) performed for investigation and treatment of cancer. This also includes nodal and reconstructive surgery performed on the patient for treatment of cancer.

**Field Name:** OPCODE1

**Field Type:** Characters

**Field Length:** 5

**Notes for Users:** Required for QPI(s): 1, 7, 8, 11 and 13.

Only the definitive procedure i.e. main type of surgery should be recorded here. For example; if patient has partial nephrectomy followed by radical nephrectomy it is the radical nephrectomy that should be recorded (if this occurs within six months of first treatment).

Patients treated within 6 months of a patient initially refusing investigation or whose initial treatment is ‘Watch and Wait’ can also be recorded.

If a palliative operation such as a bypass is the only operation performed, the code for that operation should be entered in this field.

However if an operation to relieve symptoms and a further operation which aims to remove the tumour is performed the second operation is the one that should be coded in this field.

If any operation is not listed then please contact ISD Scotland as described elsewhere so that standard codes can be allocated throughout Scotland.

Operation is coded to the 4-digit code according to the Fourth Revision of the OPCS Classification of Surgical Operations (OPCS4). Centres using READ codes may continue provided the codes can be mapped to OPCS.

Coding instructions and a full list of codes are included in the OPCS4 manual. It should be noted that it may be necessary to record two or more codes in order to fully specify the operation. **If only one operative procedure is performed then OPCODE2 should be set to 96 by default.**

If the patient’s first treatment was ‘active surveillance’, then subsequently proceeds to active treatment at a later date, record if surgery occurs within six months of diagnosis.

The most radical surgical procedure received during the first six months following diagnosis should be recorded.
### Codes and Values:

<table>
<thead>
<tr>
<th>OPCS4 Code 1</th>
<th>OPCS4 Code 2</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>M02.1</td>
<td></td>
<td>Nephrectomy &amp; excision of perirenal tissue</td>
</tr>
<tr>
<td>M02.2</td>
<td></td>
<td>Nephroureterectomy NEC</td>
</tr>
<tr>
<td>M02.3</td>
<td></td>
<td>Bilateral nephrectomy</td>
</tr>
<tr>
<td>M02.4</td>
<td></td>
<td>Excision of half of horseshoe kidney</td>
</tr>
<tr>
<td>M02.5</td>
<td></td>
<td>Radical nephrectomy</td>
</tr>
<tr>
<td>M02.5</td>
<td>B22.3</td>
<td>Radical nephrectomy with adrenalectomy</td>
</tr>
<tr>
<td>M02.5</td>
<td>T87.9</td>
<td>Radical nephrectomy with lymphadenectomy</td>
</tr>
<tr>
<td>M02.9</td>
<td></td>
<td>Total excision of kidney - unspecified</td>
</tr>
<tr>
<td>M03.9</td>
<td></td>
<td>Partial nephrectomy</td>
</tr>
<tr>
<td>M04.2</td>
<td></td>
<td>Open excision of lesion of kidney NEC (Tumour enucleation)</td>
</tr>
<tr>
<td>M04.3</td>
<td></td>
<td>Open destruction of lesion of kidney</td>
</tr>
<tr>
<td>M10.1</td>
<td></td>
<td>Endoscopic extirpation of lesion of kidney</td>
</tr>
<tr>
<td>M13.7</td>
<td></td>
<td>Percutaneous radiofrequency ablation of lesion of kidney</td>
</tr>
<tr>
<td>95</td>
<td></td>
<td>Patient refused surgery</td>
</tr>
<tr>
<td>96</td>
<td></td>
<td>Not applicable</td>
</tr>
<tr>
<td>99</td>
<td></td>
<td>Not recorded</td>
</tr>
</tbody>
</table>

### Related Data Item(s):
- Date of Definitive Surgery
- Surgical Procedure Type

### Notes by Users:
Date of Definitive Surgery

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: This is the date of the operative procedure described elsewhere.

Field Name: SURGDATE
Field Type: Date (DD/MM/CCYY)
Field Length: 10

Notes for Users: Required for QPI(s): 8 and 13

The date format should be DD/MM/CCYY.

If no surgical procedure is carried out, code as 10/10/1900 (Not applicable).

If the exact date is not documented, record as 09/09/1900.

If the patient’s first treatment was ‘active surveillance’, then subsequently proceeds to active treatment at a later date, record if surgery occurs within six months of diagnosis.

Patients treated within 6 months of a patient initially refusing investigation or whose initial treatment is ‘Watch and Wait’ can also be recorded.

Related Data Item(s):
Definitive Operative Procedure
Date of Discharge
Operating Consultant Surgeon
Location Code

Notes by Users:
Date of Discharge (Cancer Surgery)

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: This is the date of discharge following the operative procedure described elsewhere.

Field Name: DISCDATE
Field Type: Date (DD/MM/CCYY)
Field Length: 10

Notes for Users: Required for QPI(s): 13

The date format should be DD/MM/CCYY.

If no surgical procedure is carried out, code as 10/10/1900 (Not applicable).

If the exact date is not documented, record as 09/09/1900.

In cases where date of death is prior to discharge, record as 10/10/1900 (Not applicable).

If the patient’s first treatment was ‘active surveillance’, then subsequently proceeds to active treatment at a later date, record if surgery occurs within six months of diagnosis.

Patients treated within 6 months of a patient initially refusing investigation or whose initial treatment is ‘Watch and Wait’ can also be recorded.

Related Data Item(s):
Date of Definitive Surgery
Definitive Operative Procedure
Operating Consultant Surgeon
Location Code

Notes by Users:
Location Code (Cancer Surgery)

Common Name(s): Location, Location of Contact.


Definition: This is the reference number of any building or set of buildings where events pertinent to NHS Scotland take place. Locations include hospitals, health centres, GP surgeries, clinics, NHS board offices, nursing homes, schools and patient/client's home.

Field Name: HOSPSURG
Field Type: Characters
Field Length: 5

Notes for Users: May be used for sub-analysis presentation of QPI(s) 7 and 8.

This is the hospital of definitive surgery which removes the primary renal tumour. This may be a planned excision even if close margins are found and further surgery is required. On occasion, this result will be achieved by excision biopsy. This should be included as site of definitive surgery.

Each location has a location code, which is maintained by ISD:

http://www.isd-n3.scot.nhs.uk/National-Reference-Files/Nat-Ref-Files/location?84577144
Location must be viewed as an address and not a code. If any new locations arise where NHS healthcare is delivered/administered, please ensure that the Reference Files Team at ISD is informed using form LOC-NEW (which can be downloaded from the website below) so that a new code may be issued as appropriate.

http://www.isdscotland.org/Products-and-Services/Data-Definitions-and-References/National-Reference-Files/SMR-Reference-Files/

Information about location should be electronically stored, managed and transferred using the relevant location code. IT systems should allow the recording and display of locations on the user interface as the relevant location name and associated address, etc.

If the patient’s first treatment was ‘active surveillance’, then subsequently proceeds to active treatment at a later date, record if surgery occurs within six months of diagnosis.

If surgery has not been performed or the patient has refused surgery, record as Not applicable, X1010.

If the location code is not documented, record as X9999.
Examples of codes are given below.

<table>
<thead>
<tr>
<th>Code</th>
<th>Institution</th>
</tr>
</thead>
<tbody>
<tr>
<td>A111H</td>
<td>CROSSHOUSE HOSPITAL</td>
</tr>
<tr>
<td>C418H</td>
<td>ROYAL ALEXANDRA HOSPITAL</td>
</tr>
<tr>
<td>F704H</td>
<td>VICTORIA HOSPITAL, KIRKCALDY</td>
</tr>
<tr>
<td>G107H</td>
<td>GLASGOW ROYAL INFIRMARY</td>
</tr>
<tr>
<td>G405H</td>
<td>SOUTHERN GENERAL HOSPITAL, GLASGOW</td>
</tr>
</tbody>
</table>

Related Data Item(s):
Date of Definitive Surgery
Definitive Operative Procedure
Operating Consultant Surgeon
Date of Discharge

Notes by Users:
Operating Consultant Surgeon (1-2)

Main Source of Data Item Standard: The National Audit Cancer Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: The surgeon performing the definitive surgery as described elsewhere.

Field Name: OPSURG1
Field Name: OPSURG2
Field Type: Characters
Field Length: 20

Notes for Users: Required for QPI(s): 12

The surname and forename of each consultant should be recorded to distinguish between surgeons with common surnames. Consultants’ names should be stored in databases as General Medical Council (GMC) number.

If two consultant surgeons share an operation each operating surgeon code should be recorded.

If the patient is operated on by a clinician who is working as a locum consultant, record only that the clinician is a locum consultant 'LOCUM'.

If the operating surgeon is not a consultant record as non-consultant grade '8889' regardless of whether the surgeon was a locum or not.

If the clinician’s name is not recorded code as 9999.

If no surgery was performed record as Not applicable (1010).

Related Data Item(s):
Location Code (Cancer Surgery)
Definitive Operative Procedure
Date of Definitive Surgery
Date of Discharge

Notes by Users:
Surgical Procedure Type

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by the Information Services.

Definition: The type of surgical procedure(s) performed for investigation and/or treatment of cancer. This also includes nodal and reconstructive surgery performed on the patient for treatment of cancer.

Field Name: SURGTYPE
Field Type: Characters
Field Length: 2

Notes for Users:
If the patient’s first treatment was ‘active surveillance’, then subsequently proceeds to active treatment at a later date, record if surgery occurs within six months of diagnosis.

Please note that only surgery occurring within six months of diagnosis should be included in the analysis against the relevant QPI.

Codes and Values:

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
<th>Explanatory Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Open</td>
<td></td>
</tr>
<tr>
<td>2A</td>
<td>Laparoscopic - Completed</td>
<td></td>
</tr>
<tr>
<td>2B</td>
<td>Laparoscopic - Converted</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Robotic</td>
<td></td>
</tr>
<tr>
<td>96</td>
<td>Not applicable</td>
<td>e.g. Surgery not performed.</td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
<td></td>
</tr>
</tbody>
</table>

Related Data Item(s):
Definitive Operative Procedure
Date of Definitive Surgery

Notes by Users:
Surgical Presentation Type

**Main Source of Data Item Standard:** The National Cancer Audit Datasets developed by the regional Cancer Networks supported by the Information Services.

**Definition:** How the patient presented for surgery.

**Field Name:** PRESENT  
**Field Type:** Integer  
**Field Length:** 2

**Notes for Users:** Required for QPI(s): 8.

Both categories incorporate:  
1. Transfer from another consultant and/or significant facility and/or specialty and/or hospital in the same or another trust where the patient was already undergoing hospital care for treatment.  
2. A patient presenting for surgery while undergoing hospital care for an unrelated condition (incidental finding).

If the patient’s first treatment was ‘active surveillance’, then subsequently proceeds to active treatment at a later date, record if surgery occurs within six months of diagnosis.

**Please note that only surgery occurring within six months of diagnosis should be included in the analysis against the relevant QPI.**

**Codes and Values:**

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
<th>Explanatory Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Elective (routine)</td>
<td>A patient who presents for surgery as planned.</td>
</tr>
<tr>
<td>2</td>
<td>Emergency</td>
<td>A patient, who for clinical reasons, presents unplanned for surgery.</td>
</tr>
<tr>
<td>96</td>
<td>Not applicable</td>
<td>If no operation was performed.</td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
<td></td>
</tr>
</tbody>
</table>

**Related Data Item(s):**  
Definitive Operative Procedure  
Date of Definitive Surgery

**Notes by Users:**
Date of Cryotherapy

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: This is the date Cryotherapy was performed.

Field Name: CRYODATE
Field Type: Date (DD/MM/CCYY)
Field Length: 10

Notes for Users: Required for QPI(s): 8

This is freezing of the tumour.

Please note that only cryotherapy received within six months of diagnosis should be included in the analysis against the relevant QPI.

If cryotherapy is not carried out, code as (10/10/1900) (Not applicable).

If the exact date is not documented, record as (09/09/1900).

Notes by Users:
Leibovich Score

Main Source of Data Item Standard: The National Audit Cancer Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: This is the score used to help predict survival for patients with clear cell Renal Cell Carcinoma (RCC)

Field Name: LEIBOVICH
Field Type: Integer
Field Length: 2

Notes for Users: Required for QPI: 11

The Leibovich score (also sometimes referred to as the Mayo Clinic score) is calculated from the following components: primary tumour / T-stage, tumour size, Regional Lymph Node status, Nuclear Grade and Tumour Necrosis.

Documentation of the score can be found in pathology reports, clinical records or MDT notes. This should only be recorded for those patients with clear cell RCC who undergo radical nephrectomy.

For those patients with known metastatic disease or who do not undergo radical nephrectomy code as 96 ‘Not applicable’.

If the overall score is not documented do not deduce from other information and record as 99 ‘Not recorded’.

Codes and Values:

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
<th>Explanatory Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>0 - 2</td>
<td>Low Risk</td>
</tr>
<tr>
<td>2</td>
<td>3 – 5</td>
<td>Intermediate Risk</td>
</tr>
<tr>
<td>3</td>
<td>≥6</td>
<td>High Risk</td>
</tr>
<tr>
<td>96</td>
<td>Not applicable</td>
<td>E.g. Patient does not have clear cell RCC, patient has not undergone radical nephrectomy, patient has known metastatic disease</td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
<td></td>
</tr>
</tbody>
</table>

Related Data Items:

Notes by Users:
**Warm Ischaemia Time**

**Main Source of Data Item Standard:** The National Audit Cancer Datasets developed by the regional Cancer Networks supported by Information Services.

**Definition:** This is a record of the warm ischaemia time in minutes for patients undergoing partial nephrectomy.

**Field Name:** ISCTIME  
**Field Type:** Integer (nnnn)  
**Field Length:** 4

**Notes for Users:** Required for QPI: 13

Warm ischemia time (WIT) in surgery is the time a tissue, organ or body part remains at body temperature after its blood supply has been reduced or cut off but before it is cooled or reconnected to the blood supply. In this context it is the time the renal artery remains clamped during a partial nephrectomy.

WIT is an important determinant of kidney function recovery after partial nephrectomy. The time in minutes will be documented on the operation note.

For those patients who do not undergo partial nephrectomy code as 1010 (Not applicable).

For those patients who undergo cold ischaemia rather than warm ischaemia code as 1010 (Not applicable).

If the warm ischaemia time is unknown code as 9999 (Not recorded).

**Related Data Items:**

**Notes by Users:**
**Cold Ischaemia Time**

**Main Source of Data Item Standard:** The National Audit Cancer Datasets developed by the regional Cancer Networks supported by Information Services.

**Definition:** This is a record of the cold ischaemia time in minutes for patients undergoing partial nephrectomy.

**Field Name:** CISCTIME  
**Field Type:** Integer  
**Field Length:** 4

**Notes for Users:** Required for QPI: 13

Cold ischemia time (CIT) in surgery is the time between the chilling of a tissue, organ or body part after its blood supply has been reduced or cut off and the time it is warmed by having its blood supply restored.

This is often used in open partial nephrectomy surgery. The time in minutes will be documented on the operation note.

For those patients who do not undergo partial nephrectomy code as 1010 (Not applicable).

For those patients who undergo warm ischaemia rather than cold ischaemia code as 1010 (Not applicable).

If the cold ischaemia time is unknown code as 9999 (Not recorded).

**Related Data Items:**

**Notes by Users:**
Section 4: Pathology Details
**Morphology of Tumour**

**Main Source of Data Item Standard:** The National Audit Cancer Datasets developed by the regional Cancer Networks supported by Information Services.

**Definition:** This is the morphology of the tumour according to the International Classification of Diseases for Oncology (ICD-O (3)).

**Field Name:** MORPHOL  
**Field Type:** Characters  
**Field Length:** 6

**Notes for Users:** Required for QPI(s): 11.

The morphology terms have five-digit code numbers which run from 8000/0 to 9989/1; the first four digits indicate the specific histologic terms and the fifth digit, after the slash, is a behaviour code.

If material supplied cannot be assessed or if the pathology report is negative then record as 6666/6 (Clinical/Radiological only diagnosis of renal cell carcinoma).

If two descriptions/qualifiers (and possibly two morphology codes) are given by the pathologist, e.g. clear cell/sarcomatoid renal cell carcinoma, use the higher morphology rule. The exception to this is renal cell/clear cell renal cell carcinoma. This should be coded as M_8310/3.

Please note that clear cell papillary RCC is distinct from papillary RCC. The clear cell variant does not have a malignant (/3) behaviour code and is therefore not included.

Morphology codes are shown below. This list is not exhaustive and if a code is not on the list please contact phs.canceraudit@nhs.net for advice.

**Codes and Values:**

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
<th>Explanatory Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>8310/3</td>
<td>Clear Cell Renal Cell Carcinoma; Clear cell carcinoma; clear cell adenocarcinoma, mesonephroid</td>
<td>Conventional renal cell carcinoma.</td>
</tr>
<tr>
<td>8311/3</td>
<td>Hereditary leiomyomatosis and RCC syndrome associated renal cell carcinoma / MiT family translocation RCCs / Succinate dehydrogenase-deficient RCC.</td>
<td></td>
</tr>
<tr>
<td>8260/3</td>
<td>Papillary Renal Cell Carcinoma</td>
<td></td>
</tr>
<tr>
<td>8312/3</td>
<td>Renal cell carcinoma; renal cell adenocarcinoma; Grawitz tumour; Hypernephroma</td>
<td></td>
</tr>
<tr>
<td>8316/3</td>
<td>Cyst-associated renal cell carcinoma / Tubilocystic renal cell carcinoma</td>
<td></td>
</tr>
<tr>
<td>8317/3</td>
<td>Chromophobe cell renal carcinoma</td>
<td></td>
</tr>
<tr>
<td>8318/3</td>
<td>Sarcomatoid renal cell carcinoma</td>
<td></td>
</tr>
<tr>
<td>8319/3</td>
<td>Collecting duct carcinoma</td>
<td></td>
</tr>
<tr>
<td>8480/3</td>
<td>Mucinous renal cell carcinoma</td>
<td></td>
</tr>
<tr>
<td>8510/3</td>
<td>Renal Medullary carcinoma</td>
<td></td>
</tr>
<tr>
<td>6666/6</td>
<td>Clinical/Radiological only diagnosis of renal cell carcinoma, not assessable or negative</td>
<td>Code only to be used if there is no histology.</td>
</tr>
<tr>
<td>9999/9</td>
<td>Not Recorded</td>
<td></td>
</tr>
</tbody>
</table>

**Notes by Users:**

*Data Definitions for the National Minimum Core Dataset for Renal Cancer.*  
*Developed by ISD Scotland, 2013*
Fuhrman Grade (Kidney)


Definition: Application of the Fuhrman grading system

Field Name: FUHRMAN
Field Type: Integer
Field Length: 2

Notes for Users: Required for: national comparative analysis and sub analysis

As of 1st April 2014 this is also known as ISUP (Vancouver) Grading System.

This is a qualitative assessment of nuclear pleomorphism.

Fuhrman Grade should be recorded for clear cell renal carcinoma (M-8310/3) only.

Grade should be assigned according to the worst grade regardless of extent.

Original Codes and Values 1st January 2014 – 31st March 2014

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
<th>Explanatory Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Grade 1</td>
<td>Nuclear shape: Round, uniform. Nucleoli: None</td>
</tr>
<tr>
<td>2</td>
<td>Grade 2</td>
<td>Nuclear shape: Slightly irregular. Nucleoli: Visible at high power x 400 magnification.</td>
</tr>
<tr>
<td>3</td>
<td>Grade 3</td>
<td>Nuclear shape: Very irregular outlines. Nucleoli: Prominent visible at x 100 magnification.</td>
</tr>
<tr>
<td>4</td>
<td>Grade 4</td>
<td>Nuclear shape: Bizarre and multilobed spindle shaped cells. Nucleoli: Prominent.</td>
</tr>
<tr>
<td>96</td>
<td>Not applicable</td>
<td>e.g. Non-clear cell carcinoma</td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
<td></td>
</tr>
</tbody>
</table>

New Codes and Values 1st April 2014 – to date

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
<th>Explanatory Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Grade 1</td>
<td>Nucleoli: None</td>
</tr>
<tr>
<td>2</td>
<td>Grade 2</td>
<td>Nucleoli: Visible at high power x 400 magnification.</td>
</tr>
<tr>
<td>3</td>
<td>Grade 3</td>
<td>Nucleoli: Prominent visible at x 100 magnification.</td>
</tr>
<tr>
<td>4</td>
<td>Grade 4</td>
<td>Nuclear shape: Bizarre and multilobed nuclei +/- spindle or rhabdoid shaped cells. Nucleoli: Prominent.</td>
</tr>
<tr>
<td>96</td>
<td>Not applicable</td>
<td>e.g. Non-clear cell or Non Papillary carcinomas</td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
<td></td>
</tr>
</tbody>
</table>

Related Data Item(s):
Morphology of Tumour
**TNM Tumour Classification (Pathological) (Kidney)**

**Common Name:** Pathological TNM Tumour stage (Kidney)

**Main Source of Data Item Standard:** TNM Classification (TNM Classification of Malignant Tumours, Eighth Edition, UICC, 2017).

**Definition:** A record of the size and extent of the tumour of the kidney following resection of the primary cancer. **This classification only applies to renal cell carcinoma.**

**Field Name:** pT  
**Field Type:** Characters  
**Field Length:** 4

**Notes for Users:** Required to allow adjustments for stage when undertaking survival analysis.

In the case of multiple tumours, the tumour with the worst prognosis should be used for classification. If in doubt, check with pathology.

Pathology taken within 6 months of a patient initially refusing further investigation or whose initial treatment is ‘Watch and Wait’ can also be recorded.

If stage is unable to be definitively determined from information in case notes/clinical systems, do not deduce from other information and record as ‘not recorded’.

**Codes and Values:**

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>pT0</td>
<td>No evidence of primary tumour</td>
</tr>
<tr>
<td>pT1</td>
<td>Tumour 7cm or less: limited to the kidney</td>
</tr>
<tr>
<td>pT1a</td>
<td>Tumour ≤ 4cm</td>
</tr>
<tr>
<td>pT1b</td>
<td>Tumour &gt; 4cm to 7cm</td>
</tr>
<tr>
<td>pT2</td>
<td>Tumour more than 7cm: limited to the kidney</td>
</tr>
<tr>
<td>pT2a</td>
<td>Tumour &gt; 7cm to 10cm</td>
</tr>
<tr>
<td>pT2b</td>
<td>Tumour &gt; 10cm: limited to the kidney</td>
</tr>
<tr>
<td>pT3</td>
<td>Tumour extends into major veins or perinephric tissues but not into ipsilateral adrenal gland and not beyond Gerota fascia</td>
</tr>
<tr>
<td>pT3a</td>
<td>Tumour extends into renal vein or its segmental branches, or tumour invades the pelvicalyceal system or tumour invades perirenal and/or renal sinus (peripelvic) fat but not beyond Gerota fascia</td>
</tr>
<tr>
<td>pT3b</td>
<td>Tumour extends into vena cava below diaphragm</td>
</tr>
<tr>
<td>pT3c</td>
<td>Tumour extends into vena cava above diaphragm or invades the wall of the vena cava</td>
</tr>
<tr>
<td>pT4</td>
<td>Tumour invades beyond Gerota’s fascia (including contiguous extension into the ipsilateral adrenal gland).</td>
</tr>
<tr>
<td>pTX</td>
<td>Primary tumour cannot be assessed</td>
</tr>
<tr>
<td>96</td>
<td>Not applicable</td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
</tr>
</tbody>
</table>

**Related data items:**

- TNM Nodal Classification: (Pathological) (Kidney),
- TNM Metastasis Classification (Pathological) (Kidney)

**Notes by Users:**
TNM Nodal Classification (Pathological) (Kidney)

Common Name: Pathological TNM Nodal stage (Kidney)


Definition: A record of the extent of regional lymph node metastases. This classification only applies to renal cell carcinoma.

Field Name: pN
Field Type: Characters
Field Length: 3

Notes for Users:
Required to allow adjustments for stage when undertaking survival analysis.

In the case of multiple tumours, the tumour with the worst prognosis should be used for classification. If in doubt, check with pathology.

Pathology taken within 6 months of a patient initially refusing further investigation or whose initial treatment is ‘Watch and Wait’ can also be recorded.

If stage is unable to be definitively determined from information in case notes/clinical systems, do not deduce from other information and record as ‘not recorded’.

Codes and Values:

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
<th>Explanatory Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>pN0</td>
<td>No regional lymph node metastases</td>
<td></td>
</tr>
<tr>
<td>pN1</td>
<td>Metastasis in regional lymph node(s)</td>
<td></td>
</tr>
<tr>
<td>pNX</td>
<td>Regional lymph nodes cannot be assessed</td>
<td></td>
</tr>
<tr>
<td>96</td>
<td>Not applicable</td>
<td>e.g. if nodal dissection not performed.</td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
<td></td>
</tr>
</tbody>
</table>

Related Data items:
TNM Tumour Classification (Pathological) (Kidney)
TNM Metastasis Classification (Pathological) (Kidney)

Notes by Users:
**TNM Metastasis Classification (Pathological) (Kidney)**

**Common Name:** Pathological TNM Metastasis Classification (Kidney)

**Main Source of Data Item Standard:** TNM Classification (TNM Classification of Malignant Tumours, Eighth Edition, UICC, 2017).

**Definition:** A record of the extent of metastatic spread of the tumour as detected by microscopy. This classification only applies to renal cell carcinoma.

**Field Name:** pM  
**Field Type:** Characters  
**Field length:** 3

**Notes for Users:**  
Required to allow adjustments for stage when undertaking survival analysis.

In the case of multiple tumours, the tumour with the worst prognosis should be used for classification. If in doubt, check with pathology.

Pathology taken within 6 months of a patient initially refusing further investigation or whose initial treatment is ‘Watch and Wait’ can also be recorded.

If stage is unable to be definitively determined from information in case notes/clinical systems, do not deduce from other information and record as ‘not recorded’.

If no distant metastasis are present record as ‘not applicable’.

**Codes and Values:**

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>pM1</td>
<td>Distant metastasis microscopically confirmed.</td>
</tr>
<tr>
<td>96</td>
<td>Not applicable</td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
</tr>
</tbody>
</table>

**Related data items:**  
TNM Tumour Classification (Pathological) (Kidney)  
TNM Nodal Classification (Pathological) (Kidney)

**Notes by Users:**
**Margin Status**

**Main Source of Data Item Standard:** The National Audit Cancer Datasets developed by the regional Cancer Networks supported by Information Services.

**Definition:** The presence or absence of margin involvement following partial nephrectomy.

**Field Name:** MARGIN  
**Field Type:** Integer  
**Field length:** 2

**Notes for Users:** Required for QPI(s): 13

If the patient does not undergo partial nephrectomy code as 96 (Not applicable).

**Codes and Values:**

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
<th>Explanatory Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Positive</td>
<td>Tumour present at the surgical margin.</td>
</tr>
<tr>
<td>2</td>
<td>Negative</td>
<td>Tumour not present at the surgical margin.</td>
</tr>
<tr>
<td>3</td>
<td>Uncertain</td>
<td>E.g. Very difficult to assess</td>
</tr>
<tr>
<td>96</td>
<td>Not applicable</td>
<td></td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
<td></td>
</tr>
</tbody>
</table>

**Notes by Users:**
Section 5: Systemic Anti-Cancer Therapy
Location Code {SACT Treatment}

Common Name(s): Location


Definition: This is the reference number of any building or set of buildings where events pertinent to NHS Scotland take place. Locations include hospitals, health centres, GP surgeries, clinics, NHS board offices, nursing homes, schools and patient/client’s home.

Field Name: HOSPSACT
Field Type: Characters
Field Length: 5

Notes for Users: Required for regional/national analysis

This is the hospital in which the patient received the majority of their SACT treatment.

Each location has a location code, which is maintained jointly by ISD and General Register Office (Scotland). [http://www.natref.scot.nhs.uk/](http://www.natref.scot.nhs.uk/)

Location must be viewed as an address and not a code. If any new locations arise where NHS healthcare is delivered/administered, please ensure that the Reference Files Team at ISD is informed using form LOC-NEW (which can be downloaded from the website below) so that a new code may be issued as appropriate.


Information about location should be electronically stored, managed and transferred using the relevant location code. IT systems should allow the recording and display of locations on the user interface as the relevant location name and associated address, etc.

If the location code is not documented, record as X9999.

If SACT has not been performed or the patient has refused SACT, record as inapplicable, X1010.

Related Data Item(s):
Systemic Anti Cancer Therapy Agent (Renal Cancer)

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: The type of cytotoxic or biological agent used either alone or in combination to treat renal cancer.

Field Name: SYSTAGENT
Field Type: Integer
Field length: 2

Notes for Users: Required for QPI(s): 9.

If the patient’s first treatment was ‘active surveillance’, then subsequently proceeds to active treatment at a later date, record if systemic therapy occurs within one year of diagnosis.

Please note that only systemic anti-cancer therapy received within twelve months of diagnosis should be included in the analysis against the relevant QPI.

If any systemic anti cancer therapy agent is not listed then please contact ISD Scotland as described elsewhere so that standard codes can be allocated throughout Scotland. NB: Non-licensed therapies are not included in the national dataset.

Codes and values:

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
<th>Explanatory notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Sunitinib</td>
<td>Sutent</td>
</tr>
<tr>
<td>2</td>
<td>Pazopanib</td>
<td>Votrient</td>
</tr>
<tr>
<td>3</td>
<td>Bevacizumab *</td>
<td>Avastin</td>
</tr>
<tr>
<td>4</td>
<td>Interferon</td>
<td>Roferon or Intron</td>
</tr>
<tr>
<td>5</td>
<td>Temsirolimus</td>
<td>Torisel</td>
</tr>
<tr>
<td>95</td>
<td>Patient refused systemic anti-cancer therapy</td>
<td></td>
</tr>
<tr>
<td>96</td>
<td>Not applicable</td>
<td></td>
</tr>
<tr>
<td>98</td>
<td>Other</td>
<td>Including clinical trials</td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
<td></td>
</tr>
</tbody>
</table>

* If used in combination with another agent, record only Bevacizumab.

Related Data Item(s):
Date Treatment Started (Systemic Anti Cancer Therapy)
Date Treatment Ended (Systemic Anti Cancer Therapy)

Notes by Users:
**Date Treatment Started (Systemic Anti Cancer Therapy)**

**Main Source of Data Item Standard:** The National Cancer Audit Datasets developed by the regional Cancer Networks supported by the Information Services.

**Definition:** The date systemic treatment course commenced.

**Field Name:** SYSTDATE  
**Field Type:** Date (DD/MM/CCYY).  
**Field Length:** 10

**Notes for Users:** Required for QPI(s): 9.

If the patient’s first treatment was ‘active surveillance’, then subsequently proceeds to active treatment at a later date, record if systemic therapy occurs within one year of diagnosis.

Please note that only systemic anti-cancer therapy received within twelve months of diagnosis should be included in the analysis against the relevant QPI.

This is the first dose of the first cycle of a course of chemotherapy or biological therapy.

If treatment has not been given, record as not applicable, 10/10/1900.

If the date treatment started is unknown, record as 09/09/1900.

**Related Data Item(s):**  
Systemic Anti-Cancer Therapy Agent (Renal Cancer)  
Date Treatment Ended (Systemic Anti Cancer Therapy)

**Notes by Users:**
**Date Treatment Completed (Systemic Anti-Cancer Therapy)**

**Main Source of Data Item Standard:** The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

**Definition:** The date systemic treatment course ended.

**Field Name:** SYSTENDATE  
**Field Type:** Date (DD/MM/CCYY).  
**Field Length:** 10

**Notes for Users:** Required for QPI(s):

This is the first day of the last cycle of a course of chemotherapy or biological therapy.

It should be noted that this can be the same day as the day the therapy started.

If treatment has not been given or the patient has refused treatment, record as 10/10/1900 (Not applicable).

If the date treatment completed is unknown, record as 09/09/1900 (Not recorded).

**Related Data Item(s):**  
Systemic Anti Cancer Therapy Agent (Renal Cancer)  
Date Treatment Started (Systemic Anti Cancer Therapy)
Section 6: Clinical Trials and Death Details
Patient Entered into Clinical Trial [Renal Cancer]

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: An indication of whether or not the patient received treatment within the context of a clinical trial.

Field Name: TRIAL
Field Type: Characters
Field Length: 2

Notes for Users: Required for QPI(s): 9.

This would be during a specified time period – one year after diagnosis.

This relates only to participation in clinical trials which may be national or international multi-centred trials. This is restricted to clinical trials which involve administration of systemic anti-cancer drugs for renal cancer.

The majority of non-commercial multi-centred trials available in Scotland are National Cancer Research Network (NCRN) badged or equivalent.

Some academic and university units may have ongoing local trials which should not be included here. These can be recorded on local trials databases.

Codes and Values:

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
<th>Sub-values</th>
</tr>
</thead>
<tbody>
<tr>
<td>1A</td>
<td>Yes - Systemic therapy</td>
<td>Entered into a clinical trial involving systemic therapy</td>
</tr>
<tr>
<td>1B</td>
<td>Yes - Non-systemic therapy</td>
<td>Entered into a clinical trial not involving systemic therapy</td>
</tr>
<tr>
<td>1C</td>
<td>Yes - Not known</td>
<td>Entered into a clinical trial but type of therapy not known</td>
</tr>
<tr>
<td>2</td>
<td>No</td>
<td>Not entered into a clinical trial</td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
<td>Not recorded whether or not patient received treatment within the context of a clinical trial</td>
</tr>
</tbody>
</table>

Notes by Users:
**Date of Death**

**Main Source of Data Item Standard:** The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

**Definition:** This is the certified date of death as recorded by the National Records of Scotland (NRS) (previously General Register Office Scotland (GRO(S))).

**Field Name:** DOD  
**Field Type:** DATE (DD/MM/CCYY)  
**Field Length:** 10

**Notes for Users:** Required for QPI(s): 8 and 9.

If the patient is still alive, record as 10/10/1900 (Not applicable).

If the exact date is not documented, record as 09/09/1900.

**Related Data Item(s):**  
Underlying Cause of Death

**Notes by Users:**
Underlying Cause of Death

Common name: Cause of Death

Main Source of Data Item Standard: National Records of Scotland (NRS) (previously General Register Office Scotland (GRO(S)))

Definition: The underlying cause of death as recorded by NRS in Part I of the death certificate.

Field Name: COD
Format: Character. (ICD10 code, ann.n or ann.a e.g. C34.9).
Field length: 5

Notes for Users: Required for cause-specific sub-analysis of QPI 8.

This refers only to the underlying cause of death, which is the condition recorded in the lowest completed line of Part I of the death certificate and is shown in the first column in the NRS download.

In cases where a post mortem examination has been performed, the underlying cause of death recorded by the pathologist should replace any preceding entry. In cases where the Procurator Fiscal has been involved, the final underlying cause of death recorded by them should supersede any previous entry.

The mode of dying, such as cardiac arrest or asphyxia, should not be recorded here. Other significant conditions contributing to the death but not related to the disease or condition causing it, as recorded in Part II of the death certificate, should not be recorded here.

If the patient is still alive, record as not applicable (96).
If the cause of death is unknown record as (99).

Related Data Item(s):
Date of Death

Notes by Users:
**Date Record Considered Complete**

**Definition:** The date the auditor considers all relevant information is completed and can validate that 12 months have elapsed.

**Field Name:** DATECOMP  
**Format:** Date (DD/MM/CCYY)  
**Field length:** 10

**Notes for Users:** Required for QPI(s): 9.

This relates only to patients with advanced and/or metastatic disease at diagnosis, as SACT may be given to locally advanced disease without metastases. Therefore only these patients would require to be followed up for a maximum of 12 months after diagnosis to establish whether they had received Systemic Anti-Cancer Therapy (SACT) or died. However, not all of these patients will require a full 12 months follow-up as this would cease when they either received SACT or died and these dates were established. The completion of this data item ensures that the person extracting the data has confidence that all relevant patients have been followed-up for the required time period at the time of data extraction.

However, this may be a useful data item for all patients depending on how the data validations were being implemented locally. For example not all the individual validations for individual data items could be run at data entry as some rely on the completed values for other fields across the data set, which may be entered later. Therefore, this data item could be used to indicate batches of records where the auditor is satisfied that all the required information has been recorded fully before running the full data validations across all data items.

**Related Data Item(s):**  
Date of Diagnosis

**Notes by Users:**