

Professional Edition

# Kidney Cancer UK

# Accord

## Consensus statement

***The UK's leading kidney cancer charity,  
here to listen, inform and support patients  
and their families.***



**Kidney  
Cancer UK**

The UK's leading kidney cancer charity

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# About us.

Kidney Cancer UK and sister charity Kidney Cancer Scotland, are the UK's leading kidney cancer charities; here to listen, inform and support patients, carers and their families.

We seek to reduce the harm caused by kidney cancer by increasing knowledge and awareness, providing patient support and information and by funding research into the causes, prevention and treatment of the disease.

For support or more information relating to kidney cancer visit our website

[www.kcuk.org.uk](http://www.kcuk.org.uk)



# Cancer Patient Quality Improvement Group

## Consensus Statement

### England and Wales Kidney Cancer Services

#### Introduction

Kidney cancer is the 7<sup>th</sup> commonest cancer in the UK and 50% of all sufferers will die from it. Of the 6 cancers that are more common than kidney cancer, only lung cancer is more lethal to those who develop it. As such, kidney cancer is a significant cancer in an important organ within the body. However, there is a low level of awareness of kidney cancer and the symptoms that patients may present with. Also, although there are pockets of excellence, there is significantly less research and funding for research into this cancer compared to other cancers – particularly in the area of non-metastatic disease. These factors are reflected in the lack of an agreed quality framework around key aspects of the patient pathway. This Consensus Statement aims to develop the key elements of good quality in kidney cancer care. In due course this will be supported by a set of Quality Performance Indicators. The aim is the development of an overarching NICE Clinical Guideline for kidney cancer, similar to the other existing NICE guidelines for many comparable conditions.

#### Statement of need

The Cancer Strategy Implementation Plan<sup>1</sup>, produced by NHS England highlighted six priority areas for cancer services:

1. Prevention and Public Health
2. Earlier diagnosis
3. Patient experience
4. Living with and beyond cancer
5. Investment in high quality, modern service
6. Commissioning, accountability and provision

The Cancer Delivery Plan for Wales 2016-2020<sup>2</sup> covers a similar range of areas. Since both are overarching cancer strategies, both address services across all cancers, though they include initiatives in specific types of cancer where these can demonstrate an improvement not only in services for that specific cancer but in the overall performance of cancer services.

The National Institute for Health and Care Excellence (NICE) has produced 15 items that relate directly to kidney cancer, comprising a Pathway, 4 Interventional Procedures Guidances and 10 Technology Appraisals<sup>3</sup>. NICE has also developed 10 additional items that are relevant to kidney cancer, but which are for related conditions or which apply generally to all types of cancer<sup>3</sup>. However, there is no NICE Clinical Guideline or Quality Standard specifically for kidney cancer, in contrast to 10 other cancer types of which 4 (pancreatic, bladder, oesophageal and ovarian) are less common than kidney cancer<sup>4</sup>. Therefore, there is no means of bringing together the 15 individual pieces of guidance on kidney cancer in a way that provides a clear and comprehensive view of the quality requirements for kidney cancer services.

Data on kidney cancer are collected by multiple bodies, but whether these are suitable for the measurement of quality of services remains to be seen as they should ideally be: collected by data managers (not clinicians), complete and audited. As an extension to this consensus statement, KCPQIG is investigating the feasibility of developing and measuring a simple set of quality performance indicators (QPIs), similar to those that have been developed in Scotland. The development of simple QPIs would be a valuable step forward, but ultimately such work needs to be guided by evidence-based quality statements.

### **The concept of quality service values**

Quality service values are aspirational statements, written from the perspective of the patient, that describe what they should expect from kidney cancer services. The statements are based on evidence, where possible, and on expert opinion and good practice.

Together, the quality service values describe:

- The quality of service that people in England and Wales should expect from a good kidney cancer service no matter where they live.
- A consensus that:
  - could be the basis for an evidence-based Clinical Guideline and a Quality Standard from NICE.
  - would support the monitoring of kidney cancer services and underpin the development of measurable Quality Performance Indicators.
  - would support the Cancer Strategy and Implementation plans in England and Wales

### **Using this consensus**

The quality service values should be regarded as aspirational, bringing focus to kidney cancer service quality and its improvement from the patients' perspective. The consensus should therefore be used as the basis for the way in which the commissioning and provision of services are carried out and enhanced, along with the way in which providers engage with patients. They should therefore indicate where services could be improved and how this could be carried out.

The local environment in which kidney cancer services are provided varies according to multiple factors including population dynamics, geography, local policies and funding priorities. Therefore, the way in which the quality service values are fulfilled is likely to be different depending on the part of the United Kingdom considered. The important point is that the end result, as described by the consensus, is the same throughout.

Primarily the quality service values are aimed at systems and services, but they can also be used by individuals as a means of self-monitoring.

The following statements refer to all types of renal cell carcinoma (RCC) unless otherwise stated.

## Consensus statement

### England and Wales Quality Service Values in Kidney Cancer

#### General

##### **Patient perspective**

In all cases, diagnosis, treatment and care of patients with kidney cancer or suspected kidney cancer will be provided by centres and individuals who are experienced in kidney cancer and who frequently diagnose, treat or provide care for the disease.

#### Identification and diagnosis of kidney cancer

##### **Radiology**

##### **Patient perspective**

Patients with suspected kidney cancer have cross sectional imaging with CT +/- MRI scans to assist with diagnosis and initial staging of the disease.

##### **Reasoning**

Treatment options that are provided subsequently should be offered according to the extent to which the cancer has spread. Cross sectional imaging will provide additional information about the diagnosis to health care professionals and patients.

##### **Health care professionals perspective**

All patients with kidney cancer receiving active treatment have been referred for pre-treatment contrast-enhanced CT (unless contraindicated) of the chest, abdomen and pelvis. If there are symptoms or signs suggesting brain metastases, a CT brain should be undertaken.

#### Assessment of diagnosed kidney cancer

##### **Histology**

##### **Patient perspective**

Patients with kidney cancer for whom the recommended treatment is active surveillance, ablation, or drug therapy, and who are fit enough for intervention, have a histological diagnosis prior to commencing treatment (where technically feasible). Patients with small renal masses (<4cm) considering surgical excision should be offered a renal tumour biopsy to determine pathology prior to surgery.

##### **Reasoning**

Histological diagnosis is likely to provide essential information that could guide the management of the patient with small renal masses and those having first-line non-surgical systemic therapy, by confirming the pathology being treated.

##### **Health care professionals perspective**

All patients who are referred for ablation therapy or systemic anti-cancer treatment are first referred for histological diagnosis by biopsy (unless the patient does not give consent, there is a failed biopsy or clinical urgency to treat without histological diagnosis) the results of which are discussed prior to referral for treatment. Patients with small renal masses undergoing active surveillance (who would be suitable for interventional treatment rather than those who would not and would be put on watchful waiting) or considering surgical excision should be offered a biopsy to determine pathology which may alter eventual treatment strategy.

##### **Staging**

##### **Patient perspective**

Patients with kidney cancer should have their tumour staged before first treatment and should be informed of this and how it relates to the available treatment options.

##### **Reasoning**

TNM is the standard staging system and its pre-treatment use provides a baseline from which treatment effectiveness can be measured. Informing patients of the stage of their tumour helps them make informed choices and can be reassuring to many people, provided their preferences to receive such information have been established first.

#### **Health care professionals perspective**

The TNM staging system should be used to stage patients with kidney cancer. Patients should be informed that they can ask for the results and when to do so. When informing patients of their staging, health care professionals must ensure that they also explain their meaning related to potential treatment choices to allow patients to make informed decisions on their treatment.

## **Surgery**

#### **Patient perspective**

Patients whose kidney cancer remains localised to the kidney and immediate surrounding area are offered surgery to remove the whole kidney as their first-line treatment, except where the tumour is small, in which case surgery would aim to remove only part of the kidney or discuss active surveillance or ablative approaches. Patients should be offered minimal access surgery (laparoscopic or robot-assisted) where technically feasible and safe.

#### **Reasoning**

Where the tumour remains localised, surgery normally offers the best treatment outcomes. In tumours less than 4cm in diameter only part of the kidney need normally be removed to preserve as much kidney function as possible. Tumours between 4-7cm should also be assessed for their suitability for kidney preserving surgery. For tumours larger than this, which may also have spread to an adjacent major blood vessel, the adrenal gland or other immediately adjacent tissue, the whole kidney is likely to be removed. It is important that patients understand treatment choices and the reasons for recommending a particular treatment, and that they are included in the decision-making process. Minimal access surgery should be offered where appropriate due to the shorter hospital stay, lower complication rate and more rapid post-operative recovery time.

#### **Health care professionals perspective**

All patients with cT1-3N0M0 suspected kidney cancer are referred to a specialist centre for kidney surgery as first-line treatment and afterwards are assigned a prognostic risk group. Partial nephrectomy should be considered in all patients with cT1-N0M0 tumours. Minimal access surgery should be offered to all patients where appropriate and referral to centres that offer it made if needed.

## **Ablative therapy**

#### **Patient perspective**

Patients should be offered percutaneous ablative treatment (cryoablation or radiofrequency ablation) as a treatment for small kidney cancers; especially in those patients who cannot have surgery or who do not wish to do so.

#### **Reasoning**

Removal of the tumour remains the most effective treatment for these patients. If this cannot be achieved by surgery, ablation of the tumour is the most effective alternative. Patients must be informed so that they are able to participate in this decision and understand the underlying reasons for it.

#### **Health care professionals perspective**

All patients with cT1aN0M0 kidney cancers should be offered percutaneous ablation as a treatment option. This is especially the case for patients who are unsuitable for surgery, or who have expressed a strong desire to avoid surgery.

## Active surveillance

### Patient perspective

Patients who have small renal tumours are considered for active surveillance and have this discussed as a treatment option and the reasons for this are fully explained to them so that they are involved in the decision.

### Reasoning

Kidney cancers may grow extremely slowly and the risk of metastases is low when tumours are smaller than 4cm. It is particularly important to ensure that patients, families and carers are fully informed of the benefits of active surveillance and the reasons for offering it. Patients and their families can become very anxious if they perceive this treatment option as a lack of treatment.

### Health care professionals perspective

In patients with tumours  $\leq 4$ cm active surveillance with regular imaging should be considered as a treatment option, especially in patients with lesions  $< 2$ cm, or who are frail or who have comorbidities that increase the risks of surgery. A biopsy should be offered to patients to identify the aetiology of the lesion and tailor surveillance. Tumours which are growing rapidly or to a size of  $> 4$ cm should be considered for treatment with either ablative methods or surgery. Patients not fit for intervention are therefore not candidates for active surveillance and may not require any further imaging.

## Systemic anti-cancer therapy (SACT)

### Patient perspective

Patients who have locally advanced primary tumours or where the cancer has spread to other parts of the body, will be assessed for systemic therapy. The extent of the metastatic disease will be staged by cross sectional imaging prior to starting treatment. Patients will be informed about the SACT that is being recommended and the reasons for doing so; this will include possible side-effects and any treatments that might be used to combat them.

### Reasoning

Patients with advanced or metastatic kidney cancer have improved survival when treated with SACT (antiangiogenic tyrosine kinase inhibitors and/or immunotherapy) and this will maximise the number of additional life years these patients experience. Patients with slowly progressive kidney cancer may be appropriate for active surveillance for a period before receiving SACT; there is no evidence that this impacts on long term outcome and patients avoid having side effects from treatment, which must be communicated to relevant patients.

### Health care professionals perspective

Patients with advanced or metastatic kidney cancer are referred to an oncologist who specialises in the treatment of kidney cancer patients and receive systemic anti-cancer treatment if medically fit, or are placed on active surveillance prior to SACT. Patients with metastatic disease are assigned a prognostic score (MSKCC or IDMC score) before commencing treatment.

## Supportive and palliative care

### Patient perspective

Patients with incurable kidney cancer are able to receive treatment to control their symptoms and they, their families and carers have access to psychological, social and spiritual support if and when they need it.

### Reasoning

Holistic care for kidney cancer patients, their families and carers is important at all stages of the disease, but particularly so when it has reached an advanced stage. Supportive and palliative care should be provided in a way that is responsive to the varying needs of patients,

families and carers and which is fully integrated into any ongoing cancer treatment provided for the patient.

#### **Health care professionals perspective**

Patients with incurable kidney cancer (regardless of whether they are receiving ongoing cancer treatment or not) are offered access to supportive and palliative care expertise if needed from hospital or community services as appropriate.

### **Patient management and involvement**

#### **Multi-Disciplinary Team**

##### **Patient perspective**

Patients with kidney cancer should be listed/tabeled at a specialist multi-disciplinary team (MDT) before management options are discussed with the patient. Patients should be given timely information about the MDT process and estimated timescales. The MDT should ensure that a holistic approach is taken to their overall wellbeing and that this informs decisions about treatment made in the MDT.

##### **Reasoning**

A multi-disciplinary team is very important in ensuring that patient-centred treatment is provided and that it is optimised to achieve the best possible outcome as well as a high quality of life for the patient. Patients may need reassuring that the timescales needed will not impact on the progress of their disease, and that their holistic needs are being taken into account.

##### **Health care professionals perspective**

All patients who are being considered for treatment for kidney cancer should be listed/tabeled/discussed (as appropriate) by a specialist multi-disciplinary team. In conjunction with clinic assessment the MDT will assess allied services that may benefit the patient's outcome, taking into account individual needs and preferences, quality of life, symptom burden and the presence of co-existing medical conditions.

#### **Patient information**

##### **Patient perspective**

As soon as kidney cancer has been confirmed, patients should be given an overview of what kidney cancer is, what kind of treatment plan they can expect and estimated timescales involved. They should be directed to reliable sources of information (see Addendum) and encouraged to be actively engaged with their treatment. After a period of time to reflect on their diagnosis, they should be asked about the level of information and involvement they want to have. They should be introduced to a named key worker such as a clinical nurse specialist. Following biopsy/surgery an explanation of the pathology results should be offered together with an indication of the future risk of recurrence/spread.

##### **Reasoning**

A diagnosis of cancer can result in significant anxiety and this should be taken into account. Patients are more likely to have lower levels of anxiety and higher levels of trust throughout their treatment if they receive a level of information they are comfortable with and are actively engaged with their medical team.

##### **Health care professionals perspective**

All patients are introduced to a named key worker and are consulted on the level of information and involvement they would like to have, which should be recorded and taken into consideration in future consultations/treatment decisions etc. The level of information and involvement should be reviewed periodically to ensure that it still meets the needs of the patient.

### **Clinical trials**

#### **Patient perspective**

Patients are informed about relevant clinical trials available at their centre and elsewhere and are given the opportunity to take part if eligible.

#### **Reasoning**

Clinical trials are not only an important element in advancing research and the development of new treatments, but also act as a strong motivator for many patients who want to take part and to have the chance of trying new and possibly more effective treatments.

#### **Health care professionals perspective**

All patients are considered for participation in available clinical trials, wherever eligible.

### **Survivorship monitoring**

#### **Patient perspective**

Following successful active treatment, patients should be informed about ongoing monitoring, including how long monitoring will be continued, what form monitoring will take, how frequently it will be carried out and how to access further support in the after-treatment period if they need it.

#### **Reasoning**

Although their treatment has been successful, many patients remain anxious that the cancer might return and if all support is stopped on successful treatment completion, they can feel abandoned. Making patients, carers and families aware of the availability of ongoing support (support groups etc.) is a tremendous help in their holistic recovery from kidney cancer.

#### **Health care professional perspective**

Patients should be given an after-treatment plan at the point of successful treatment completion, explaining to them how and for how long they will continue to be monitored, and signposting access to additional support that may help them during this period.

### **Implementing the Quality Service Values**

The quality service values may be used by individuals to check their own practice, but they are probably more valuable when applied to diagnosis and treatment centres and the services that they provide. They are not intended to be quantitative measures but should rather be used as aspirational statements.

We would like to encourage diagnosis and treatment units to endorse this consensus and it may be useful to display the Patient statements within these units or to make them available to patients via alternative means.

We would also encourage units to identify parts of their services that could be improved and to use the quality service values to guide these improvements.

### **Next steps and recommendations**

We would like to see some simple quality performance indicators introduced and the next stage of development of the quality service values is to assess the feasibility of converting them into statements that can be measured using existing data that are already gathered.

Ultimately, we believe that this work should underpin the development of a Clinical Guideline and Quality Standard, which should be developed by the National Institute for Health and Care Excellence (NICE).

## ADDENDUM

### Common questions from patients and carers

The following is a list of questions that are commonly asked by patients at different stages in their treatment. Health care professionals should be prepared to answer these questions and to direct patients and carers to reliable sources of information that address them.

Whilst not every patient will want to have information on all of these topics, it is important that they are able to ask these questions at any time in their treatment pathway and that they know where to go for further information if they wish to know more.

Please note that this is not intended to be an exhaustive list of questions, but it covers the topics that patients and carers ask about most frequently.

### Newly Diagnosed

I have blood and blood clots in my urine – how will that be treated until I have my nephrectomy?

I have bouts of severe pain – how will that be treated until I have my nephrectomy?

How can kidney cancer be diagnosed from a scan? How do they know it is malignant?

How soon will I see a consultant?

What does my future hold?

Why do some people have biopsies and not others?

What will happen after I've had a biopsy?

How soon should I have my operation?

I've got to wait weeks for before I can see a specialist and start treatment - will the cancer grow while I'm waiting?

How long has the tumour been there?

Is there a support group near me?

Is there any online support?

### General

Lots of confusion over what staging, grading, Leibovich means and how it applies to patients.

Can having kidney cancer cause changes to my menstrual cycle?

Should I chase a scan/consultant appointment if my hospital has not sent an appointment when expected?

Can I get a copy of my scan results report?

Can I get a copy of letters between the hospital and my GP? If I don't get sent copies, what can I do?

Are there any tumour markers for kidney cancer?

Is it realistic to expect a complete cure if a tumour has been caught early and there is no spread?

What is a key worker/CNS?

What is embolization?

What is ablation?

What is a positive margin?

Is there a link between high blood pressure and kidney cancer?

Is it genetic, is my family at increased risk?

### **Monitoring after Treatment**

Why does it take weeks for some people to get scan results and others get them quickly?

Can I continue to work during and after treatment?

Should I have blood tests before I have scans?

What is the contrast used during scans and why is it used?

Why do I have to drink lots of water before a scan?

What side effects can you get from the contrast used during scans?

Why do some people have a CT scan and some an MRI scan?

Why do some people have a CT scan and some have an ultrasound/x-ray?

Why are we only scanned on the chest, abdomen and pelvis? Why do we not get regular brain or bone scans?

How long will I need to be scanned for?

I have read that kidney cancer can return many years later, why am I not being scanned for more than 5 years?

Is there any special diet for someone with kidney cancer/following nephrectomy?

If I get further spread, how will it be treated?

I am always so exhausted, could this be a side effect of kidney cancer? (after diagnosis and months after nephrectomy)

I still have occasional pain over the site of the removed kidney months after nephrectomy – is this normal?

Can I consider myself cured if I am clear of cancer after 5 years of monitoring?

### **Surgery**

What is robotic surgery?

Why do you get wind following nephrectomy?

I'm very constipated after a nephrectomy – why is this and what can I do about it?

How long will I be in hospital assuming no complications?

How long does a nephrectomy take?

How long before the op do you have a pre-op?

### **Drug Treatment**

Can I have treatment breaks?

My oncologist has suggested I go on ..... drug treatment, what can I expect?

Do I need a letter when travelling abroad under treatment?

Do I need to stay out of the sun?

Can I get travel insurance?

Can I take other drugs, such as painkillers and cold treatments while on treatment?

What side effects can I expect?

### **Recurrence/Spread**

I've just been told my cancer has returned, what treatment can I expect?

How long will I have to wait to see an oncologist?

- 
- 1 Achieving World Class Cancer Outcomes: Taking the strategy forward. The National Cancer Transformation Board 2016. <https://www.england.nhs.uk/wp-content/uploads/2016/05/cancer-strategy.pdf>
  - 2 Cancer Delivery Plan for Wales 2016-2020. Wales Cancer Network. 2016. <https://gov.wales/docs/dhss/publications/161114cancerplanen.pdf>
  - 3 NICE Search Engine result on 07-11-18. <https://www.nice.org.uk/guidance/conditions-and-diseases/cancer/renal-cancer#panel-new>
  - 4 Cancer Incidence for Common Cancers – Twenty Most Common Cancers, UK, 2015. Cancer Research UK website. Viewed 07-11-18. <https://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence/common-cancers-compared#heading-Zero>



**0800 002 9002**  
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Free telephone support when you need it  
and the UK's only free kidney cancer  
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KIDNEY CANCER COUNSELLING  
*Here to support*

\*The service is free to call though some networks may charge. Please check with your service provider if in doubt.





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