NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Guideline

Kidney cancer

Draft for consultation, September 2025

This guideline covers diagnosing and managing renal cell carcinoma (the most common type of kidney cancer) in adults. It aims to improve care by helping healthcare professionals offer people the right treatments and support, taking into account the person's individual preferences.

Who is it for?

- healthcare professionals
- commissioners and providers of kidney cancer services
- people with renal cell carcinoma, their families and carers.

What does it include?

- the recommendations
- recommendations for research
- rationale and impact sections that explain why the committee made the recommendations and how they might affect practice
- the guideline context.

Information about how the guideline was developed is on the guideline's webpage. This includes the evidence reviews, the scope, details of the committee and any declarations of interest.

This guideline refers to NHS England commissioning policies. In Wales and Northern Ireland, follow Welsh or Northern Irish commissioning positions if applicable.

Contents

People have the right to be involved in discussions and make informed decisions about their care, as described in NICE's information on making decisions about your care.

Making decisions using NICE guidelines explains how we use words to show the strength (or certainty) of our recommendations, and has information about prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

Health and social care professionals should follow our general guidelines for people delivering care:

- Patient experience in adult NHS services
- Service user experience in adult mental health
- People's experience in adult social care services
- Shared decision making
- Medicines adherence
- Medicines optimisation
- Multimorbidity
- Decision making and mental capacity.

Information and support

1.1 General information for people with suspected or confirmed renal cell carcinoma

1.1.1 When referring someone for investigations for suspected renal cell carcinoma (RCC), follow the recommendations in the section on patient information and support in NICE's guideline on suspected cancer.

1.1.2 Healthcare professionals in all settings (including primary care, genetics services and specialist multidisciplinary services) should provide ongoing information and support to people with suspected or confirmed RCC, based on a personalised assessment of what the person needs at different times, in line with:

- NICE's guideline on patient experience in adult NHS services, particularly the recommendations on:
  - patient views and preferences
  - patient concerns
  - communication
  - information
  - knowing the patient as an individual
  - continuity of care and relationships
  - an individualised approach to services
  - involvement of family members and carers
- NICE's guideline on shared decision making, particularly the recommendations on:
  - putting shared decision making into practice
  - communicating risks, benefits and consequences
- NICE's guideline on workplace health
- NICE's guideline on people's experience in adult social care services, particularly the recommendations on co-production and enabling people to make decisions.

See also section 3.5 (management communication and shared decision making) in the Getting It Right First Time (GIRFT) guide Urology: Towards better care for patients with kidney cancer.

1.1.3 Offer clinical nurse specialist support in secondary care to people with RCC – from diagnosis, during management and during follow-up or palliative care – and give them the clinical nurse specialist's contact details.

1.1.4 Ensure that the clinical nurse specialist supporting the person with RCC:

- acts as the key worker to address the person's information and care needs **and**
- has training and experience in kidney cancer care.

1.1.5 Ensure the person with RCC is given the contact details for a cancer care navigator, if available, in addition to the clinical nurse specialist (see recommendations 1.1.3 and 1.1.4).

1.1.6 Discuss with the person with RCC how they are coping with emotions such as sadness, depression and anxiety, and feeling out of control over the outcome of the disease and treatment. Signpost or refer the person to mental health support services, if appropriate.

See also NICE's guideline on depression in adults with a chronic physical health problem.

1.1.7 Offer support to help people with RCC who currently smoke to stop smoking, in line with NICE's guideline on tobacco.

1.1.8 Discuss involvement in clinical trials and other types of research with people with RCC, including:

- where to find information, for example, Be Part of Research, Action Kidney Cancer and ISRCTN: The UK's Clinical Study Registry
- opportunities for research involvement in their centre and others
- the benefits and risks of entering clinical trials and other studies.

1.1.9 Trusts, health boards and any other relevant healthcare providers should consider conducting annual satisfaction surveys of people with RCC – developed by their urology multidisciplinary team and people with RCC – and use the results to guide quality improvement programmes.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on general information.

Full details of the evidence and the committee's discussion are in evidence review D: information needs.

Diagnosis

1.2 Imaging

1.2.1 For people who are suspected to have renal cell carcinoma (RCC), offer:

- triple-phase contrast-enhanced CT (CECT) of the abdomen **or**
- MRI of the abdomen, ideally with contrast, if they cannot have triple-phase CECT.

See also NICE's diagnostics guidance on point-of-care creatinine devices to assess kidney function before CT imaging with intravenous contrast. Also see recommendations on assessing risk factors and preventing acute kidney injury in adults having iodine-based contrast media in NICE's guideline on acute kidney injury.

1.2.2 Offer MRI of the abdomen, ideally with contrast, if there is not enough information about the renal lesion after triple-phase CECT to inform next steps.

1.2.3 If a suspected RCC is detected on a triple-phase CECT or MRI of the abdomen, to complete staging also offer:

- CECT of the chest and pelvis **or**
- MRI of the pelvis and CT (without contrast) of the chest if the person cannot have CECT.

1.2.4 If imaging is uncertain or suggests the renal lesion is malignant, discuss the results in a multidisciplinary team meeting to determine:

- whether further investigations are needed, including other imaging or biopsy (see the section on biopsy) **and**
- possible management options (see the sections on managing localised and locally advanced renal cell carcinoma and managing advanced renal cell carcinoma).

1.2.5 Consider contrast-enhanced ultrasound if:

- the person cannot have triple-phase CECT (for example, because of poor renal function or an allergy to the contrast agents used for CECT) and cannot have MRI (for example, because of metal in the body) **or**
- there is uncertainty about the nature of the renal lesion after triple-phase CECT, MRI (with or without contrast) or both.

1.2.6 Consider 99mTc-sestamibi single-photon emission computed tomography CT (SPECT/CT) after triple-phase CECT or MRI (with or without contrast) if:

- knowing whether the person has an oncocytic renal lesion (including oncocytoma or chromophobe RCC) would change management **and**
- biopsy is not an option or the person declines it.

1.2.7 Discharge the person if:

- imaging suggests the renal lesion is benign (for example, a Bosniak 1 or 2 cyst or an angiomyolipoma) **and**
- the person is not at high risk of complications.

1.2.8 Refer the person for monitoring outside of the cancer pathway if imaging suggests the renal lesion is benign but the person is at risk of complications (for example, people with a Bosniak 1 or 2 cyst that is causing pain).

See the section on active surveillance for oncocytomas and Bosniak 2F cysts for information on doing active surveillance if imaging suggests the renal lesion is a Bosniak 2F cyst.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on imaging.

Full details of the evidence and the committee's discussion are in evidence review I1: CT and MRI for diagnosing renal lesions in adults with suspected renal

cell carcinoma and evidence review I2: additional imaging tests for differentiating types of renal lesions.

1.3 Biopsy

Biopsy for suspected localised or locally advanced RCC

1.3.1 Offer biopsy to help confirm a diagnosis and inform management options for people with suspected localised or locally advanced RCC who:

- do not meet any of the criteria in recommendation 1.3.3 **and**
- have a renal lesion that:
  - is 4 cm in diameter or smaller **and**
  - has a solid component that is large enough to get a tissue sample from.

1.3.2 Consider biopsy to help confirm a diagnosis and inform management options for people with a renal lesion that is larger than 4 cm in diameter and has a solid component large enough to get a tissue sample from when the person does not meet any of the criteria in recommendation 1.3.3 and any of the following apply:

- imaging suggests the lesion is benign
- the person will have thermal ablation or stereotactic ablative radiotherapy (SABR), which will damage the tissue, making interpretation of a biopsy result difficult if it is done later
- the person requests it (for example, because they would prefer to avoid surgery if the lesion is benign).

1.3.3 Do not offer biopsy if any of the following apply:

- the renal lesion has grown into the renal vein or inferior vena cava and the person is a candidate for surgical treatment
- the renal lesion is in a location that is not accessible for biopsy
- getting a tissue sample is not possible
- the person cannot have any treatment

- it is not going to change management.

If biopsy is not offered, explain why to the person.

1.3.4 If a biopsy sample does not give enough information to help confirm a diagnosis, consider repeating the biopsy if a radiologist thinks that:

- a second biopsy will be successful **or**
- a different image-guided approach might be needed for successful tissue sampling.

1.3.5 Offer additional opportunities to have a biopsy to people who meet the criteria in recommendations 1.3.1 and 1.3.2 and who have previously declined it, if biopsy is still possible and provides useful information.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on biopsy for suspected localised or locally advanced renal cell carcinoma.

Full details of the evidence and the committee's discussion are in evidence review J: renal biopsy.

Biopsy for suspected metastatic RCC

1.3.6 Offer biopsy to help confirm a diagnosis and inform management options for people with suspected metastatic RCC if the person:

- has not been previously diagnosed with RCC **and**
- is not planning to have surgery as the first treatment.

See also NICE's guideline on metastatic malignant disease of unknown primary origin in adults: diagnosis and management.

1.3.7 When deciding whether to biopsy the renal lesion or metastases for people who have not been previously diagnosed with RCC, factor in the size and location of the renal lesion and metastases.

See also the sections on investigation of suspected brain metastases in NICE's guideline on brain tumours (primary) and brain metastases in over 16s and on timing of invasive interventions (where biopsy is mentioned) in NICE's guideline on spinal metastases and metastatic spinal cord compression.

1.3.8 Consider biopsy of the metastases to inform management options if:

- the person has previously had treatment for RCC with no metastases **and**
- there is clinical uncertainty about whether the metastases come from RCC.

1.3.9 Do not biopsy the renal lesion or metastases if it is not going to change management.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on biopsy for suspected metastatic RCC.

Full details of the evidence and the committee's discussion are in evidence review J: renal biopsy.

Biopsy for people with RCC who have a heritable RCC predisposition syndrome

1.3.10 Do not routinely do a renal biopsy for people with von Hippel–Lindau (VHL) syndrome with a suspicious renal lesion, as the lesion is almost always clear cell RCC.

1.3.11 Do not do a renal biopsy for people with known hereditary leiomyomatosis and renal cell carcinoma (HLRCC) syndrome with a suspicious renal lesion because of the aggressive nature of the lesion.

1.3.12 Consider renal biopsy for people with Birt–Hogg–Dubé (BHD) syndrome or tuberous sclerosis complex (TSC) and a suspicious renal lesion to determine the type of lesion before deciding which management options

are suitable.

See also recommendations 1.3.8 and 1.3.9 in the section on biopsy for suspected metastatic RCC if the person has suspected metastatic RCC.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on biopsy for people with RCC who have a heritable RCC predisposition syndrome.

Full details of the evidence and the committee's discussion are in evidence review J: renal biopsy.

Biopsy information

1.3.13 When discussing possible biopsy with a person with suspected RCC, support them in making an informed decision by explaining:

- that having a biopsy is recommended when it is possible and can provide clinically useful information about the type of renal lesion, because:
  - partial nephrectomy or total nephrectomy can lead to reduced kidney function and surgical complications, and these procedures can be avoided if the lesion is known to be benign
  - it might support active surveillance as a suitable option if the lesion is known to be at low risk of progression based on lesion type, grade or both
- the expected wait time at their centre to have the biopsy and get their results
- that although it is normal to feel anxious when waiting for results, it would be very unlikely for the renal lesion to progress in a way that would change treatment options and outcomes during the waiting period
- that complications from a biopsy are generally minor (for example, mild pain or some limited bleeding), and the number of people who experience severe complications is low

- that seeding of the tumour (cancer cells spreading) along the path where the biopsy needle went in is extremely rare
- that biopsy results may not be conclusive, and the test may need repeating
- that if a biopsy is not done before treatment, it may be an option later for people who go on to have active surveillance.

For a short explanation of why the committee made this recommendation and how it might affect practice, see the rationale and impact section on biopsy information.

Full details of the evidence and the committee's discussion are in evidence review J: renal biopsy.

Managing oncocytomas and Bosniak 2F cysts

1.4 Active surveillance for oncocytomas and Bosniak 2F cysts

Active surveillance for oncocytomas

1.4.1 Offer active surveillance to people whose renal lesion is likely to be an oncocytoma (based on imaging, biopsy results, or both) if they have no symptoms. Discuss treating the oncocytoma with the person if they decline this.

See the section on active surveillance information, imaging types and scheduling.

1.4.2 For people with a renal lesion suspected to be an oncocytoma with symptoms such as haematuria (blood in urine), discuss treating the lesion with them.

1.4.3 For people under active surveillance for a renal lesion suspected to be an oncocytoma that has a growth rate greater than 5 mm in diameter per year, discuss with the person:

- having a biopsy, or a repeat biopsy, to help confirm the diagnosis (see the section on biopsy) **or**
- staying on active surveillance or treating the lesion if the person chooses not to have a biopsy or a biopsy is not possible.

1.4.4 For people who choose to have a biopsy during active surveillance for a renal lesion originally suspected to be an oncocytoma that has a growth rate greater than 5 mm in diameter per year, if the lesion is found to be:

- malignant, then move to treatment for renal cell carcinoma (RCC; see the section on managing localised and locally advanced RCC or managing advanced RCC)
- benign, then consider:
  - staying on active surveillance **or**
  - treating the oncocytoma.

Active surveillance for Bosniak 2F cysts

1.4.5 Offer active surveillance to people with Bosniak 2F cysts.

See the section on active surveillance information, imaging types scheduling.

1.4.6 If the Bosniak 2F cyst progresses during active surveillance, follow the relevant recommendations for:

- suspected or confirmed localised or locally advanced RCC (see the section on managing localised and locally advanced RCC) **or**
- advanced RCC (see the section on managing advanced RCC).

Discharging people with oncocytomas or Bosniak 2F cysts from active surveillance

1.4.7 Stop active surveillance and discharge the person with an oncocytoma or Bosniak 2F cyst back to primary care if treatment for RCC, if they were to develop it, is no longer an option.

1.4.8 Consider stopping active surveillance and discharging the person with an oncocytoma or Bosniak 2F cyst back to primary care if the renal lesion remains stable for 5 years.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rational and impact section on managing oncocytomas and Bosniak 2F cysts.

Full details of the evidence and the committee's discussion are in evidence review E: monitoring of untreated renal lesions using active surveillance.

Managing localised and locally advanced renal cell carcinoma

1.5 Non-pharmacological options for suspected or confirmed localised renal cell carcinoma and Bosniak 3 and 4 cysts

Shared decision making

1.5.1 When deciding between non-pharmacological options for suspected or confirmed localised renal cell carcinoma (RCC) and Bosniak 3 and 4 cysts, discuss with the person:

- the benefits and risks of each option that is suitable for them, including that:
  - surgery is associated with a lower risk of recurrence than thermal ablation and stereotactic ablative radiotherapy (SABR) but there may be a greater risk of short-term complications, and if the whole kidney is removed, then a greater reduction in kidney function is expected
  - thermal ablation may have a lower risk of short-term complications than surgery, but a higher risk of recurrence
  - there is a lack of evidence for SABR compared with surgery or thermal ablation, so its relative effectiveness and chance of complications are uncertain, but there may be a higher risk of recurrence

  - active surveillance has a higher risk of renal lesion growth and spread than interventions to treat the lesion
- that people under active surveillance may be able to have treatment later if they wish to.

For a short explanation of why the committee made this recommendation and how it might affect practice, see the rationale and impact section on shared decision making about non-pharmacological options for suspected or confirmed localised RCC and Bosniak 3 and 4 cysts.

Full details of the evidence and the committee's discussion are in evidence review B: management of localised renal cell carcinoma using non-surgical interventions or active surveillance.

Surgery, thermal ablation, active surveillance or SABR

1.5.2 When deciding which management options are suitable for suspected or confirmed localised RCC and Bosniak 3 and 4 cysts, take into account:

- renal lesion factors (such as location, size of the solid mass or solid nodule in a Bosniak 3 or 4 cyst, and type) and the person's clinical characteristics
- that surgery is the preferred option for renal lesions 2 cm in diameter and larger when it is suitable
- that thermal ablation and SABR should not be used without biopsy confirmation of malignancy
- that for solid renal masses larger than 4 cm in diameter, thermal ablation may need multiple sessions
- that SABR should only be used if thermal ablation and surgery are not suitable and treating the renal lesion is thought to be in the person's best interest
- that SABR is not suitable for renal lesions that are larger than 7 cm in diameter

- whether reducing the risk of complications from surgery is important enough to justify the higher risks from non-surgical options; compared with surgery:
  - thermal ablation and SABR have a higher risk of recurrence
  - active surveillance has a higher risk of renal lesion growth and spread
- the person's preferences.

See table 1 and the section on information for people before and after kidney surgery if surgery is the chosen option. See the section on active surveillance information, imaging types and scheduling if active surveillance is the chosen option.

Renal lesions 2 cm in diameter and larger

1.5.3 Offer surgery for people with localised solid renal masses, or Bosniak 3 or 4 cysts, that are 2 cm in diameter and larger after:

- imaging for diagnosis and staging **and**
- discussion with a multidisciplinary team.

1.5.4 When deciding between partial nephrectomy (preferably robot-assisted) or total nephrectomy (preferably minimally invasive), take into account:

- the factors in table 1 **and**
- that 4 cm in diameter is often the cut-off used for partial nephrectomy, but there is little evidence to support this and the decision should be driven by the renal lesion's complexity.

Table 1 Factors to take into account when deciding between partial and total nephrectomy for suspected or confirmed localised RCC and Bosniak 3 and 4 cysts

Partial nephrectomy is preferred when both factors apply	Total nephrectomy is preferred when either factor applies
The renal lesion can be entirely removed through this approach while preserving the remaining kidney tissue (based on lesion	The renal lesion cannot be entirely removed with partial nephrectomy (based on lesion

location, size and the person's clinical characteristics).	location, size and the person's clinical characteristics).
Preserving renal function is important enough to justify the greater risk of complications with partial nephrectomy compared with total nephrectomy, for example, people with: • only 1 functioning kidney **or** • lesions on both kidneys **or** • reduced kidney function.	Reducing the risk of complications is more important than preserving kidney function.

See also the section on information for people before and after kidney surgery.

1.5.5 For people with Bosniak 3 or 4 cysts 2 cm in diameter and larger who cannot have surgery or decline it, consider:

- active surveillance or thermal ablation **or**
- SABR, if thermal ablation is not suitable and active surveillance is declined.

1.5.6 For people with solid renal masses between 2 and 4 cm in diameter who cannot have surgery or decline it, consider:

- active surveillance or thermal ablation **or**
- SABR, if thermal ablation is not suitable and active surveillance is declined.

1.5.7 For people with solid renal masses larger than 4 cm in diameter who cannot have surgery or decline it, consider:

- thermal ablation **or**
- SABR, if thermal ablation is not suitable.

Renal lesions less than 2 cm in diameter

1.5.8 Consider active surveillance for people with localised solid renal masses, or Bosniak 3 or 4 cysts, that are less than 2 cm in diameter after:

- imaging for diagnosis and staging **and**
- discussion with a multidisciplinary team.

1.5.9 For people with localised solid renal masses, or Bosniak 3 or 4 cysts, that are less than 2 cm in diameter who decline active surveillance, consider:

- surgery or thermal ablation **or**
- SABR, if thermal ablation is not suitable.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on surgery, thermal ablation, active surveillance or SABR.

Full details of the evidence and the committee's discussion are in evidence review A: management of localised renal cell carcinoma using partial versus radical nephrectomy and evidence review B: management of localised renal cell carcinoma using non-surgical interventions or active surveillance.

Active surveillance information, imaging types and scheduling

1.5.10 Ensure all people who are undergoing active surveillance have agreed a personalised care plan with their healthcare professional, which is given to them and their GP, and documented in their health record. The plan should include:

- the person's active surveillance imaging schedule
- for people with a diagnosis of RCC, details of when their primary care cancer care reviews will happen and what these will involve
- a named healthcare professional and examples of when the person should contact them (such as if they have persistent symptoms).

1.5.11 As part of active surveillance, offer imaging (CT, MRI or ultrasound) at regular intervals, basing the choice of imaging on the renal lesion's and the person's clinical characteristics (such as kidney function).

1.5.12 Consider alternating CT with ultrasound or MRI to reduce radiation exposure.

See also the sections on assessing risk factors and preventing acute

kidney injury in adults having iodine-based contrast media in NICE's guideline on acute kidney injury.

1.5.13 Consider using the following imaging schedule, making changes if more frequent or additional types of imaging are needed based on the renal lesion's and the person's clinical characteristics and wishes:

- year 1: imaging between 3 and 6 months, and again at 12 months, after the start of active surveillance
- years 2 to 5: imaging at least annually
- after year 5: discuss with the person the benefits and risks of continuing active surveillance or being discharged if there are no triggers for moving to treatment (see the section on managing oncocytomas and Bosniak 2F cysts and the section on moving from active surveillance to treatment or discharge for renal lesions 4 cm in diameter or smaller).

1.5.14 Compare current imaging findings to the most recent previous and baseline imaging findings to see if there are changes in the size of the renal lesion and other characteristics.

1.5.15 Consider more frequent or additional types of imaging if there are changes in the size of the renal lesion or other characteristics that need enhanced monitoring but are not triggers for a discussion about moving to treatment based on recommendation 1.5.16 in the section on moving from active surveillance to treatment or discharge for renal lesions 4 cm in diameter or smaller.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on active surveillance information, imaging types and scheduling.

Full details of the evidence and the committee's discussion are in evidence review E: monitoring of untreated renal lesions using active surveillance.

Moving from active surveillance to treatment or discharge for renal lesions 4 cm in diameter or smaller

1.5.16 For people with solid renal masses, or Bosniak 3 or 4 cysts, 4 cm in diameter or smaller, discuss moving from active surveillance to treatment if:

- the renal lesion's growth rate (or the growth rate of the solid component for Bosniak 3 or 4 cysts) is greater than 5 mm in diameter per year **or**
- the renal lesion is likely to be larger than 4 cm in diameter by the time of the next scan **or**
- there is stage progression **or**
- the Bosniak 3 or 4 cyst progresses or changes characteristics **or**
- the person's clinical circumstances (for example, pregnancy or comorbidities) which made treatment unsuitable previously have since changed to decrease the risk of treatment, and treatment is indicated **or**
- the person wants to move to treatment, and this is still suitable for them.

1.5.17 Stop active surveillance and discharge the person with a solid renal mass, or Bosniak 3 or 4 cysts, 4 cm in diameter or smaller from active surveillance back to primary care if treatment is no longer an option.

1.5.18 Consider stopping active surveillance and discharging the person with a solid renal mass, or Bosniak 3 or 4 cysts, 4 cm in diameter or smaller from active surveillance back to primary care if the renal lesion remains stable for 5 years.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on moving from active surveillance to treatment or discharge for renal lesions 4 cm in diameter or smaller.

Full details of the evidence and the committee's discussion are in evidence review E: monitoring of untreated renal lesions using active surveillance.

1.6 Surgery for suspected or confirmed locally advanced RCC

1.6.1 Offer total nephrectomy for people with suspected or confirmed locally advanced RCC after:

- comprehensive imaging for diagnosis and staging **and**
- discussion with a multidisciplinary team (which may include cardiothoracic, vascular and hepatobiliary surgeons).

1.6.2 Consider the following approaches for total nephrectomy:

- minimally invasive total nephrectomy, when suitable based on the renal lesion's and the person's clinical characteristics **or**
- open total nephrectomy, if minimally invasive approaches are not suitable because, for example:
  - lesion size limits the creation of a pneumoperitoneum (inflation of gas into the abdomen to create enough space to do a minimally invasive surgery)
  - the lesion is at risk of rupture
  - control of the inferior vena cava, needed for resection of the tumour thrombus (the blood clot containing tumour cells that has extended into a vein near the lesion), cannot be achieved adequately by minimally invasive approaches.

  See also the section on information for people before and after kidney surgery.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on surgery for suspected or confirmed locally advanced RCC.

Full details of the evidence and the committee's discussion are in evidence review C: management of locally advanced renal cell carcinoma using nephrectomy or stereotactic ablative radiotherapy.

1.7 Information for people before and after kidney surgery

1.7.1 Before surgery for RCC, discuss with the person:

- the approach being used (minimally invasive or open surgery)
- that the removal of part or all of a kidney will reduce kidney function, but for many people, this is unlikely to impact overall health
- that if there are changes to their medical record after surgery – for example, new mention of chronic kidney disease (CKD) – and this concerns them, then they should discuss this with their healthcare provider
- that they may need to take additional measures to help protect remaining kidney function, for example, blood pressure control and lifestyle changes.

See also section 7.4 (example patient information) in the Getting It Right First Time (GIRFT) guide Urology: Towards better care for patients with kidney cancer and the Kidney Cancer UK and GIRFT Kidney cancer fact sheet: consent consultation general information – planning for surgery and beyond.

After surgery, see information and education for people with CKD in NICE's guideline on chronic kidney disease, if relevant, and the Kidney Cancer UK and GIRFT Kidney cancer fact sheet: post nephrectomy and follow up.

For a short explanation of why the committee made this recommendation and how it might affect practice, see the rationale and impact section on information for people before and after kidney surgery.

Full details of the evidence and the committee's discussion are in evidence review D: information needs.

1.8 Risk prediction tools for localised or locally advanced RCC

1.8.1 Consider using 1 of the following risk prediction tools to calculate the 5-year risk of recurrence of clear cell RCC:

- Karakiewicz
- Kattan
- Leibovich 2003
- Sorbellini
- SSIGN
- UISS.

1.8.2 Consider using the VENUSS tool to calculate the 5-year risk of recurrence of papillary RCC.

1.8.3 Do not rely on risk prediction tools alone, and always use them with clinical judgement (including whether pathology information is available from surgical samples or biopsy), when deciding:

- follow-up schedules (see the section on types of follow-up imaging and scheduling)
- future treatment options.

1.8.4 If the person has had treatment for more than 1 lesion, use the highest risk of recurrence to determine the follow-up schedule.

1.8.5 If a relevant NICE technology appraisal guidance or NHS clinical commissioning criterion for RCC uses a particular risk prediction tool to determine eligibility for systemic anticancer therapy (SACT), use that tool in addition to any other tools in recommendations 1.8.1 and 1.8.2 if SACT is indicated.

1.8.6 Ensure that pathology reports contain the disease stage (using the TNM staging system) and all the other pathology information needed to

calculate a risk score for each type of RCC, using tools selected by the local multidisciplinary team from recommendations 1.8.1 and 1.8.2.

1.8.7 Consider reporting a risk score in the pathology report for each type of RCC, using tools selected by the local multidisciplinary team from recommendations 1.8.1 and 1.8.2.

1.8.8 Ensure that the risk score is recorded clearly in the person's clinical records before any decisions about follow-up schedules or future treatment options are made.

1.8.9 When using risk prediction tools for people with localised or locally advanced RCC, ensure that they know:

- the name of the tool
- what the tool has been used for
- what the results mean for their follow-up care or future treatment options.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on risk prediction tools for localised or locally advanced RCC.

Full details of the evidence and the committee's discussion are in evidence review K: risk prediction tools for localised and locally advanced renal cell carcinoma.

1.9 Adjuvant SACT

1.9.1 Pembrolizumab is recommended as an option in NICE technology appraisal guidance for adjuvant treatment of RCC at increased risk of recurrence after nephrectomy, with or without metastatic lesion resection. For full details, see the guidance on pembrolizumab (TA830, 2022).

1.10 Follow-up for localised and locally advanced RCC

1.10.1 Offer follow-up to people who have completed treatment (including any adjuvant treatment) for localised or locally advanced RCC.

1.10.2 During follow-up, ensure all people who have had treatment for localised or locally advanced RCC have agreed a personalised care plan with their healthcare professional, which is given to them and their GP, and documented in their health record. The plan should include:

- the person's risk of recurrence, follow-up imaging schedule and the expected duration of follow-up if there remains no sign of recurrence
- details of when their primary care cancer care reviews will happen and what these will involve
- a named healthcare professional and examples of when the person should contact them (such as if they have persistent symptoms).

For an example follow-up letter, see section 7.2 in the GIRFT guide Urology: Towards better care for patients with kidney cancer. See also section 3.9 on post-surgery follow-up in the GIRFT guide, particularly the information on patient support during follow-up, principles for good communication with patients, and information to communicate to patients.

Testing before follow-up

1.10.3 After completing treatment and before starting follow-up, offer estimated glomerular filtration rate (eGFR) creatinine and albumin–creatinine ratio (ACR) testing to detect any renal insufficiency that might need separate management.

See also NICE's guideline on chronic kidney disease.

Types of follow-up imaging and scheduling

1.10.4 Offer contrast-enhanced CT (CECT) of the chest, abdomen and pelvis at regular intervals to detect recurrence (see recommendation 1.10.7 for a

suggested follow-up imaging schedule).

See also NICE's diagnostics guidance on point-of-care creatinine devices to assess kidney function before CT imaging with intravenous contrast. Also see recommendations on assessing risk factors and preventing acute kidney injury in adults having iodine-based contrast media in NICE's guideline on acute kidney injury.

1.10.5 If CECT should be avoided to reduce radiation exposure, offer:

- MRI (with or without contrast) of the abdomen and pelvis **and**
- CT (without contrast) of the chest, unless the person cannot have CT.

1.10.6 If CECT should be avoided because the contrast agent is contraindicated, offer:

- CT (without contrast) of the chest and MRI (with or without contrast) of the abdomen and pelvis **or**
- CT (without contrast) of the chest, abdomen and pelvis.

1.10.7 Consider using the follow-up imaging schedule in table 2 based on the person's calculated risk of recurrence (see the section on risk prediction tools for localised or locally advanced RCC), making changes if more frequent or additional types of imaging are needed based on clinical and pathological characteristics.

Table 2 Minimum recommended follow-up imaging schedule

Time after completing treatment	Low risk of recurrence	Intermediate risk of recurrence	High risk of recurrence
Month 3	–	–	CT
Month 6	–	CT	CT
Year 1	CT	CT	CT
Year 1.5	–	–	CT
Year 2	–	CT	CT
Year 3	CT	CT	CT
Year 4	–	CT	CT
Year 5	CT	CT	CT

More than 5 years (see the section on discharge)	Discharge	CT every 2 years or discharge	CT every 2 years or discharge

This table is adapted from GIRFT's guide Urology: Towards better care for patients with kidney cancer.

1.10.8 Consider using the intermediate-risk status follow-up schedule when accurate risk assessment is not possible (for example, for people who have had thermal ablation or SABR), making changes if more frequent or additional types of imaging are needed based on clinical and pathological characteristics.

1.10.9 Consider using the low-risk status follow-up schedule for people with chromophobe RCC, making changes if more frequent or additional types of imaging are needed based on clinical and pathological characteristics.

Recurrence or development of metastases

1.10.10 If recurrence or metastases are suspected during follow-up, do further imaging, a biopsy or both, to confirm recurrence or metastases and to determine their type and extent (see the sections on imaging, biopsy for suspected localised or locally advanced RCC and biopsy for suspected metastatic RCC).

1.10.11 If metastasis is confirmed, follow the recommendations for managing advanced RCC (see the sections on non-pharmacological management and SACT for advanced RCC).

Discharge

1.10.12 Consider discharging the person from follow-up if treatment for RCC recurrence or metastases, if developed, is no longer an option.

1.10.13 Consider discharging people who are at low risk of recurrence from follow-up if there is no sign of recurrence after the scan at 5 years.

1.10.14 Discuss with people who are at intermediate or high risk whether to continue follow-up or discharge if there is no sign of recurrence after the scan at 5 years, taking their fitness into account.

1.10.15 If follow-up is continued for longer than 5 years for people at intermediate or high risk, consider:

- doing a CT every 2 years **and**
- discussing possible discharge each time scan results are reviewed and there is no sign of recurrence.

1.10.16 When discharging the person from follow-up, advise them that primary care is their main point of contact and give them examples of when the person should contact them (such as if they have persistent symptoms).

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on follow-up for localised and locally advanced RCC.

Full details of the evidence and the committee's discussion are in evidence review F: follow-up of previously treated renal cell carcinoma.

Managing advanced renal cell carcinoma

The following recommendations apply to people with advanced renal cell carcinoma (RCC), unless metastatic RCC is specified.

1.11 Referring people with advanced RCC

1.11.1 Refer people with advanced RCC to a specialist uro-oncology multidisciplinary team with relevant expertise in managing kidney cancer (for example, a radiologist, pathologist, oncologist and urologist with speciality in cancer surgery).

1.11.2 Refer people with metastatic RCC to a specialist multidisciplinary team, based on where the disease has metastasised to in the body (such as the brain, spine or lung) when additional specialist input or skill is needed.

See also the section on recognising spinal metastases or metastatic spinal cord compression (MSCC) in NICE's guideline on spinal metastases and MSCC and the section on investigation of suspected brain metastases in NICE's guideline on brain tumours (primary) and brain metastases in over 16s.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on referring people with advanced RCC.

Full details of the evidence and the committee's discussion are in evidence review H: management of advanced renal cell carcinoma using non-pharmacological interventions.

1.12 Information for people with advanced RCC

See also the section on general information for people with suspected or confirmed RCC.

1.12.1 Discuss with the person what supportive and palliative care is and when it may be needed, such as to control pain and other symptoms. See also:

- NICE's guideline on end of life care for adults
  - assessing holistic needs
  - supporting carers
  - providing information
- NICE's guideline on care of dying adults in the last days of life
  - communication
  - shared decision making
- NICE's cancer service guidance on improving supportive and palliative care for adults with cancer.

For a short explanation of why the committee made this recommendation and how it might affect practice, see the rationale and impact section on information for people with advanced RCC.

Full details of the evidence and the committee's discussion are in evidence review D: information needs.

1.13 Risk prediction tools for metastatic RCC

1.13.1 Consider using the International Metastatic Renal Cell Carcinoma Database Consortium (IMDC version 1) to predict overall survival when deciding about treatment options for people with metastatic RCC.

1.13.2 Do not rely on the IMDC alone, and always use it with clinical judgement, when deciding about future treatment options, taking into account that the usefulness and accuracy of the tool is more uncertain:

- in rarer RCC subtypes
- in people with a heritable RCC predisposition syndrome
- when making decisions about second- or subsequent-line therapy.

1.13.3 If a relevant NICE technology appraisal guidance or NHS clinical commissioning criterion for RCC uses a particular risk prediction tool to determine eligibility for systemic anticancer therapy (SACT) for people with metastatic RCC, use that tool in addition to IMDC if SACT is indicated.

1.13.4 Ensure that the results of the risk score are recorded clearly in the clinical records of the person with metastatic RCC before any decisions about future treatment options are made.

1.13.5 When using the IMDC risk prediction tool for people with metastatic RCC, ensure that they know:

- the name of the tool
- what the tool has been used for

- that most of the data supporting the tool comes from clear cell RCC, and so the usefulness and accuracy of the tool in rarer RCC subtypes is more uncertain
- what the results mean for their potential treatment options.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on risk prediction tools for metastatic RCC.

Full details of the evidence and the committee's discussion are in evidence review L: risk prediction tools for metastatic renal cell carcinoma.

1.14 Non-pharmacological management of metastatic RCC

1.14.1 Consider regular imaging using CT (or MRI, if CT is unsuitable) to monitor the disease before SACT for people with low-volume, slow-growing metastases who do not have symptoms.

1.14.2 Offer any non-pharmacological interventions after treatment with SACT has been started for people with high-volume metastases (see recommendation 1.14.4 for a possible exception if the person has persistent symptoms that could be controlled by surgery).

Treating the primary renal lesion in people with metastatic RCC

See also the section on information for people before and after kidney surgery.

1.14.3 Consider cytoreductive nephrectomy (CN) before SACT for oncological control when:

- immediate SACT is not indicated (for example, because of low-volume metastatic disease) **and**
- surgery is suitable based on the renal lesion's and person's clinical characteristics.

1.14.4 Consider CN (before or after SACT has been started) to manage persistent symptoms that could be controlled by surgery (for example, bleeding or pain).

1.14.5 Consider CN after SACT has been started if:

- the person has had a durable partial response or better to SACT in the metastatic sites **and**
- most of the disease that is left after SACT is in the primary site **and**
- surgery is suitable based on the renal lesion's and person's clinical characteristics.

Treating metastases

1.14.6 Consider non-pharmacological interventions to treat metastases, such as external beam radiotherapy (including stereotactic ablative radiotherapy [SABR]), metastasectomy or thermal ablation.

See the sections on radiotherapy and invasive interventions in NICE's guideline on spinal metastases and metastatic spinal cord compression, and the section on management of confirmed brain metastases in NICE's guideline brain tumours (primary) and brain metastases in over 16s. See also the NHS England commissioning criteria for SABR for patients with metachronous extracranial oligometastatic cancer.

See also recommendation 1.11.2 in the section on referring people with advanced RCC, on using a specialist multidisciplinary team when additional input on treating metastases is needed.

1.14.7 Consider metastasectomy after SACT has been started when:

- no new metastatic lesions have occurred for at least 6 months **and**
- treatment could result in the person having no visible evidence of disease on imaging.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on non-pharmacological management of metastatic RCC.

Full details of the evidence and the committee's discussion are in evidence review H: management of advanced renal cell carcinoma using non-pharmacological interventions.

1.15 SACT for advanced RCC

See the section on risk prediction tools for people with metastatic RCC to support SACT decision making.

See also NICE's visual summaries on RCC:

- favourable risk International Metastatic Renal Cell Carcinoma Database Consortium criteria (IMDC)
- intermediate or poor risk IMDC.

First-line SACT

1.15.1 For medicines recommended as options in NICE technology appraisal guidance for first-line treatment of advanced RCC irrespective of IMDC risk in some people, see the guidance on:

- avelumab with axitinib (TA645, 2020) through the Cancer Drugs Fund
- tivozanib (TA512, 2018)
- pazopanib (TA215, 2013)
- sunitinib (TA169, 2009).

1.15.2 For medicines recommended as options in NICE technology appraisal guidance for first-line treatment of advanced RCC with an intermediate or poor risk as defined in the IMDC, see the guidance on:

- cabozantinib with nivolumab (TA964, 2024)
- lenvatinib with pembrolizumab (TA858, 2023)
- nivolumab with ipilimumab (TA780, 2022)
- cabozantinib (TA542, 2018).

Subsequent treatment

1.15.3 For medicines recommended as options in NICE technology appraisal guidance for previously treated advanced RCC, irrespective of IMDC risk, in some people, see the guidance on:

- lenvatinib with everolimus (TA498, 2018)
- cabozantinib (TA463, August 2017)
- everolimus (TA432, February 2017)
- nivolumab (TA417, 2016)
- axitinib (TA333, 2015).

Other subsequent treatment options, including first-line treatment options in recommendations 1.15.1 and 1.15.2, may also be available in the NHS England Cancer Drugs Fund list via clinical commissioning policy.

Neurotrophic tyrosine receptor kinase (NTRK) fusion-positive solid tumours

1.15.4 For NTRK inhibitors recommended as options in NICE technology appraisal guidance through the Cancer Drugs Fund for treating locally advanced and metastatic NTRK fusion-positive solid tumours when there are no other satisfactory treatment options, see the guidance on:

- entrectinib (TA644, August 2020)
- larotrectinib (TA630, May 2020).

Treatments not recommended

1.15.5 For medicines not recommended in NICE technology appraisal guidance for treating advanced RCC, see the guidance on:

- pembrolizumab with axitinib (TA650, 2020)
- bevacizumab, sorafenib, sunitinib and temsirolimus (TA178, 2009).

Renal cell carcinoma in people with a heritable renal cell carcinoma predisposition syndrome

1.16 Genetic assessment to diagnose heritable renal cell carcinoma predisposition syndromes

1.16.1 Assess people with renal cell carcinoma (RCC) to determine whether they meet any of the following criteria associated with having a heritable RCC predisposition syndrome:

- up to age 46 inclusive (or an age eligible for inherited renal cancer genetic testing based on the rare and inherited disease eligibility criteria in the National Genomic Test Directory [NGTD], if different)
- multiple renal tumours
- family history of renal cancer (first- or second-degree relative)
- signs or symptoms associated with a hereditable RCC predisposition syndrome (for example, cerebellar or spinal haemangioblastoma, or spontaneous pneumothorax [collapsed lung])
- tumour type commonly associated with heritable RCC predisposition syndromes, for example, fumarate hydratase (FH)-deficient RCC or succinate dehydrogenase (SDH)-deficient RCC.

1.16.2 If a person with RCC meets any of the criteria in recommendation 1.16.1, healthcare professionals who can directly request genetic testing for heritable RCC predisposition syndromes, according to local policies and procedures, should do the following:

- check the rare and inherited disease eligibility criteria for inherited renal cancer in the NGTD to determine:
  - who should be tested for mutations that are associated with an inherited predisposition for kidney cancer **and**
  - which gene panel or panels they should be tested for
- request any relevant tests following local policies and procedures.

1.16.3 Healthcare professionals who cannot directly request genetic testing for a heritable RCC predisposition syndrome should consult local policies and procedures and refer people who meet any of the criteria in recommendation 1.16.1 to a relevant healthcare professional who can do a detailed assessment and request testing if needed (see recommendation 1.16.2).

1.16.4 Before testing a person with RCC for a heritable RCC predisposition syndrome, discuss the following with them:

- most people will have a negative test result unless there are additional indicators of a heritable RCC predisposition syndrome
- a positive result can influence treatment options and follow-up for RCC, indicate a risk of developing non-RCC conditions related to the syndrome and have implications for family members
- access to specialist genetic services for ongoing support and advice will be available
- it may be possible to have the test in future if they decline it and then change their mind.

1.16.5 Refer people with RCC who are then diagnosed with a heritable RCC predisposition syndrome to a specialist multidisciplinary team with expertise in managing renal lesions in this population.

1.16.6 When a person with RCC is diagnosed with a heritable RCC predisposition syndrome, discuss the following with the person:

- what the results could mean for them and their family members
- that there are other non-RCC conditions related to the syndrome that they have an increased chance of developing, and how and where these would be managed
- how to access genetic counselling and support services for their condition.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on genetic assessment to diagnose heritable RCC predisposition syndromes.

Full details of the evidence and the committee's discussion are in evidence review G: genetic assessment and management of RCC associated with heritable renal cell carcinoma syndromes and evidence review D: information needs.

1.17 Active surveillance for suspected or confirmed localised RCC in people with a heritable RCC predisposition syndrome

1.17.1 For people with a renal lesion and a heritable RCC predisposition syndrome associated with more aggressive RCC, such as hereditary leiomyomatosis and renal cell carcinoma (HLRCC) syndrome, consider:

- prompt surgery (see the section on surgery for people with suspected or confirmed RCC who have a heritable RCC predisposition syndrome) **or**
- active surveillance (using MRI or ultrasound) only if immediate surgery is not an option, and move to surgery as soon as this is possible.

1.17.2 For people with a renal lesion and a heritable RCC predisposition syndrome that is not associated with more aggressive RCC, consider active surveillance using MRI or ultrasound for any renal lesions that are less than 3 cm in diameter.

1.17.3 Consider coordinating imaging:

- within the urology multidisciplinary team, when the person has multiple renal lesions that are at different stages of management (including active surveillance) or having follow-up after treatment **and**
- with other specialities involved in managing the syndrome, such as clinical genetics, endocrinology for von Hippel–Lindau (VHL) syndrome and respiratory for Birt–Hogg–Dubé (BHD) syndrome.

1.17.4 For people with a renal lesion and a heritable RCC predisposition syndrome that is not associated with more aggressive RCC, consider using the following imaging schedule unless renal lesion characteristics or changes in the lesion indicate more frequent or additional types of imaging are needed:

- year 1: imaging between 3 and 6 months and then at 12 months after the start of active surveillance
- year 2 onward: imaging at least annually or as decided by the specialist multidisciplinary team.

1.17.5 For people with a renal lesion and a heritable RCC predisposition syndrome associated with more aggressive RCC who are undergoing active surveillance, determine a more frequent imaging schedule than the one in recommendation 1.17.4, based on the person's clinical needs.

1.17.6 Ensure all people with a heritable RCC predisposition syndrome who are undergoing active surveillance have agreed a personalised care plan with their healthcare professional, which is given to them and their GP, and documented in their health record. The plan should include:

- the person's active surveillance imaging schedule and, when possible, their coordinated imaging schedule
- details of when their primary care cancer care reviews will happen and what these will involve
- a named healthcare professional and examples of when the person should contact them (such as if they have persistent symptoms).

1.17.7 For people with a renal lesion and a heritable RCC predisposition syndrome that is not associated with more aggressive RCC, discuss moving from active surveillance to treatment if:

- the renal lesion is 3 cm in diameter or larger on the most recent scan **or**
- the growth rate of the renal lesion suggests that it might be 3 cm in diameter or larger before the next scan **or**

- the person wants to move to treatment for 1 or more renal lesions and this is still suitable for them, taking into account competing clinical priorities.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on active surveillance for suspected or confirmed localised RCC in people with a heritable RCC predisposition syndrome RCC.

Full details of the evidence and the committee's discussion are in evidence review G: genetic assessment and management of RCC associated with heritable renal cell carcinoma syndromes.

1.18 Surgery for suspected or confirmed localised RCC in people with a heritable RCC predisposition syndrome

1.18.1 Consider partial nephrectomy when this can completely remove the renal lesion based on the lesion's location and size, and the person's clinical characteristics.

1.18.2 Consider other nephron-sparing treatments, such as thermal ablation or stereotactic ablative radiotherapy (SABR), if:

- these can completely destroy the renal lesion **and**
- partial nephrectomy is not possible or is likely to be very challenging because of previous partial nephrectomy.

1.18.3 Consider total nephrectomy or surgically removing more tissue around the lesion during partial nephrectomy for people with syndromes associated with more aggressive RCC.

See also recommendations in the section on managing advanced RCC.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on surgery for

suspected or confirmed localised RCC in people with a heritable RCC predisposition syndrome.

Full details of the evidence and the committee's discussion are in evidence review G: genetic assessment and management of RCC associated with heritable renal cell carcinoma syndromes.

1.19 Systemic anticancer therapy

1.19.1 Belzutifan is recommended with managed access through the Cancer Drugs Fund as an option for treating von Hippel–Lindau (VHL) syndrome in adults who need treatment for VHL associated RCCs, central nervous system hemangioblastomas or pancreatic neuroendocrine tumours, when localised procedures are unsuitable or undesirable. For full details, see the guidance on belzutifan (TA1011, 2024).

1.20 Follow-up of localised or locally advanced RCC after treatment in people with a heritable RCC predisposition syndrome

1.20.1 Offer follow-up to people who have completed treatment for localised or locally advanced RCC.

1.20.2 Ensure all people with a heritable RCC predisposition syndrome who have had treatment for RCC have agreed a personalised care plan with their healthcare professional, which is given to them and their GP, and documented in their health record. The plan should include:

- the person's risk of recurrence, follow-up imaging schedule and, when possible, their coordinated imaging schedule
- details of when their primary care cancer care reviews will happen and what these will involve
- a named healthcare professional and examples of when the person should contact them (such as if they have persistent symptoms).

For an example follow-up letter, see section 7.2 in the GIRFT guide

Urology: Towards better care for patients with kidney cancer. See also section 3.9 on post-surgery follow-up in the GIRFT guide, particularly the information on patient support during follow-up, principles for good communication with patients and information to communicate to patients.

1.20.3 Consider an MRI of the abdomen and CT of the chest for follow-up after RCC treatment for people with a heritable RCC predisposition syndrome.

See also NICE's diagnostics guidance on point-of-care creatinine devices to assess kidney function before CT imaging with intravenous contrast. Also see recommendations on assessing risk factors and preventing acute kidney injury in adults having iodine-based contrast media in NICE's guideline on acute kidney injury.

1.20.4 Within the urology multidisciplinary team, use the intermediate-risk status minimum recommended follow-up imaging schedule (see table 2 in the section on types of follow-up imaging and scheduling) to determine imaging frequency to be used for at least 5 years, making changes if more frequent or additional types of imaging are needed based on clinical and pathological characteristics.

1.20.5 After 5 years, discuss with the clinical team that oversees standard surveillance for heritable RCC predisposition syndromes when to stop follow-up and return solely to standard surveillance.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on follow-up of localised or locally advanced RCC after treatment in people with a heritable RCC predisposition syndrome.

Full details of the evidence and the committee's discussion are in evidence review G: genetic assessment and management of RCC in people with heritable renal cell carcinoma syndromes.

Terms used in this guideline

This section defines terms that have been used in a particular way for this guideline.

Active surveillance

Monitoring of localised renal cell carcinoma (RCC), Bosniak cysts and oncocytomas before treatment. Monitoring usually involves a set schedule of imaging to observe the renal lesion or lesions over a period of time.

Advanced RCC

RCC that is locally advanced and inoperable, or metastatic.

Cancer care navigator

Non-clinical staff who support people throughout the cancer care journey and act as a liaison with clinical nurse specialist and other clinical services. Their responsibilities often include coordinating appointments and providing information and emotional support.

Durable partial response

A decrease in renal lesion size of at least 30% of the sum of diameters of target measurable lesions compared with pre-treatment, which is observed at least 6 months after the start of treatment with systemic anticancer therapy and after at least 1 follow-up imaging scan. See the RECIST guidelines.

First- or second-degree relative

Mother, father, daughter, son, sister, brother, aunt, uncle, aunt, niece, nephew, grandmother, grandfather, granddaughter, grandson, and half-sibling.

Follow-up

Monitoring in secondary care involving a set schedule of imaging to detect recurrence or metastases of RCC in people who have had treatment with curative intent for localised or locally advanced RCC.

Heritable RCC predisposition syndrome

A heritable genetic condition associated with significantly increased risk of developing RCC. This is also known as hereditary renal cancer syndrome.

High-volume metastases

Three or more metastatic deposits in different organs.

Lesion

This encompasses both renal masses (solid) and cysts.

Locally advanced RCC

RCC that has grown into the surrounding tissue or blood vessels. It may have spread to nearby lymph nodes but has not spread to distant parts of the body. In the context of this guideline, this refers to locally advanced RCC that is operable. Inoperable locally advanced RCC is covered under the term ‘advanced RCC’.

Low-volume metastases

One or 2 metastatic deposits that can be treated directly.

Metastatic RCC

RCC that has spread from the kidney to other parts of the body, for example, the lungs, lymph nodes or bones. This is also called stage 4 cancer.

Oncological control

In the context of advanced RCC, this is an approach that aims to increase life expectancy, reduce disease burden and prevent the cancer from growing further and causing symptoms.

Partial nephrectomy

Surgery to remove the primary renal lesion and part of the kidney.

Standard surveillance

In the context of heritable RCC predisposition syndromes, this refers to regular surveillance protocols for people with a known heritable RCC predisposition

syndrome to ensure early diagnosis and timely treatment of renal cancer or other signs and symptoms associated with the syndrome.

TNM staging system

A system to describe the amount and spread of RCC in the body. T describes the size of the tumour and any spread of cancer into nearby tissue. N describes spread of cancer to nearby lymph nodes. M describes metastasis, which is the spread of cancer to other parts of the body.

Total nephrectomy

Surgery to remove the primary renal lesion and the whole kidney. This is also called radical nephrectomy.

Recommendations for research

The guideline committee has made the following recommendations for research.

Key recommendations for research

1 Combinations and sequences of diagnostic approaches to differentiate between benign and malignant renal lesions

What are the most accurate and cost-effective combinations and sequences of diagnostic approaches (imaging and biopsy) for differentiating between benign and malignant renal lesions in people with suspected renal cell carcinoma (RCC)?

For a short explanation of why the committee made this recommendation for research, see the rationale section on imaging.

Full details of the evidence and the committee's discussion are in evidence review I1: CT and MRI for diagnosing renal lesions in adults with suspected renal cell carcinoma and evidence review I2: additional imaging tests for differentiating types of renal lesions.

2 Risk prediction tools for people with localised RCC undergoing active surveillance

Which risk prediction tools, biomarkers or factors can most accurately predict the risk of progression, metastasis, or both of localised RCC in people who are undergoing active surveillance across a broad population with different characteristics (for example, ethnicity and gender), including all subtypes of RCC?

For a short explanation of why the committee made this recommendation for research, see the rationale section on risk prediction tools for localised and locally advanced RCC.

Full details of the evidence and the committee's discussion are in evidence review K: risk prediction tools for localised and locally advanced renal cell carcinoma.

3 Stereotactic ablative radiotherapy for treating localised RCC

What is the clinical and cost effectiveness of stereotactic ablative radiotherapy (SABR) compared with surgical interventions, non-surgical interventions and active surveillance, for localised RCC?

For a short explanation of why the committee made this recommendation for research, see the rationale section on surgery, thermal ablation, active surveillance or SABR.

Full details of the evidence and the committee's discussion are in evidence review B: management of localised renal cell carcinoma using non-surgical interventions or active surveillance.

4 Active surveillance approaches for early detection of disease progression

For people with small renal lesions (whether benign, malignant or unknown) that have not been treated, what are the most clinically and cost-effective approaches to active surveillance (including method, duration, appropriate frequency of imaging

and when to discharge), based on the type of renal lesion, for the early detection of disease progression in people with localised RCC?

For a short explanation of why the committee made this recommendation for research, see the rationale section on active surveillance information, imaging types and scheduling.

Full details of the evidence and the committee's discussion are in evidence review E: monitoring of untreated renal lesions using active surveillance.

5 Follow-up strategies for localised and locally advanced RCC

For people who have had treatment for localised or locally advanced RCC, what are the most clinically and cost-effective risk of recurrence stratified follow-up strategies (based on method, duration, and frequency)?

For a short explanation of why the committee made this recommendation for research, see the rationale section on follow-up for localised and locally advanced RCC.

Full details of the evidence and the committee's discussion are in evidence review F: follow-up of previously treated renal cell carcinoma.

Other recommendations for research

6 Risk prediction tools for people with localised or locally advanced RCC having thermal ablation or SABR

Which risk prediction tools, biomarkers or clinical factors can most accurately predict the risk of recurrence in people with localised or locally advanced RCC who have not had surgery of the primary renal lesion (that is, they are having thermal ablation or SABR) across a broad population with different characteristics (for example, ethnicity and sex), including all subtypes of RCC?

For a short explanation of why the committee made this recommendation for research, see the rationale section on risk prediction tools for localised and locally advanced RCC.

Full details of the evidence and the committee's discussion are in evidence review L: risk prediction tools for localised and locally advanced renal cell carcinoma.

7 Risk prediction tools for people with localised or locally advanced chromophobe RCC

Which risk prediction tools, biomarkers or clinical factors can most accurately predict the risk of recurrence in people with localised or locally advanced chromophobe RCC across a broad population with different characteristics (for example, ethnicity and sex)?

For a short explanation of why the committee made this recommendation for research, see the rationale section on risk prediction tools for localised and locally advanced RCC.

Full details of the evidence and the committee's discussion are in evidence review L: risk prediction tools for localised and locally advanced renal cell carcinoma.

8 Risk prediction tools for metastatic RCC

Which risk prediction tools, biomarkers or clinical factors can most accurately predict survival, risk of disease progression, or response to treatment across a broad population with different characteristics (for example, ethnicity and sex) who have metastatic RCC?

For a short explanation of why the committee made this recommendation for research, see the rationale section on risk prediction tools for metastatic RCC.

Full details of the evidence and the committee's discussion are in evidence review L: risk prediction tools for metastatic renal cell carcinoma.

9 Metastasectomy for metastatic RCC

What is the clinical and cost effectiveness of metastasectomy before systemic anticancer therapy (SACT) or after SACT has been started compared with SACT alone for people with metastatic RCC who have had their primary mass removed?

For a short explanation of why the committee made this recommendation for research, see the rationale section on non-pharmacological treatments for advanced RCC.

Full details of the evidence and the committee's discussion are in evidence review H: management of advanced renal cell carcinoma using non-pharmacological interventions.

10 Thermal ablation and external beam radiotherapy after SACT has been started for managing metastatic RCC

What is the clinical and cost effectiveness of thermal ablation or external beam radiotherapy (excluding SABR) after SACT has been started compared with SACT alone for treating metastases in people with metastatic RCC?

For a short explanation of why the committee made this recommendation for research, see the rationale section on non-pharmacological treatments for advanced RCC.

Full details of the evidence and the committee's discussion are in evidence review H: management of advanced renal cell carcinoma using non-pharmacological interventions.

11 Different types of minimally invasive radical nephrectomy techniques compared to each other

What is the clinical effectiveness, cost effectiveness and impact on quality of life of different types of minimally invasive radical nephrectomy techniques compared to each other in people with locally advanced RCC?

For a short explanation of why the committee made this recommendation for research, see the rationale section on surgery for suspected or confirmed locally advanced RCC.

Full details of the evidence and the committee's discussion are in evidence review C: management of locally advanced renal cell carcinoma using nephrectomy or stereotactic ablative radiotherapy.

12 SABR for treating the primary mass in locally advanced inoperable RCC

What is the clinical and cost effectiveness of SABR for treating the primary mass after SACT has been started in people with locally advanced inoperable RCC?

For a short explanation of why the committee made this recommendation for research, see the rationale section on non-pharmacological treatments for advanced RCC.

Full details of the evidence and the committee's discussion are in evidence review H: management of advanced renal cell carcinoma using non-pharmacological interventions.

Rationale and impact

These sections briefly explain why the committee made the recommendations and how they might affect practice.

General information

Recommendations 1.1.1 to 1.1.9

Why the committee made the recommendations

Evidence on information needs for people with suspected or confirmed renal cell carcinoma (RCC) was limited. The committee used themes from the evidence and their experiences to draft recommendations.

The committee cross referred to other NICE guidelines that cover aspects of care that aligned with the committee's experiences and the evidence on shared decision making, communicating information, taking patient views and preferences into account, and supporting people in social care to make decisions. They also cross referred to NICE content on depression in adults with a chronic physical health problem, because they agreed that having a cancer diagnosis and undergoing treatments are likely to lead to stress and anxiety, and possibly depression, and that people will need support in dealing with these issues.

Based on their expertise and experience, the committee agreed that it was important for people to have access to a clinical nurse specialist with training and experience in kidney cancer to provide this support and information. They noted that, in some places, cancer care navigators are available and can take on some of the work of signposting people to support services and coordinating appointments. But they should not replace clinical nurse specialists.

The committee agreed that it is important that people with RCC have opportunities to be involved in research, including clinical and non-clinical studies, to access new treatments before they are widely available, help improve the evidence base for treatments that will benefit others, and share their views and experiences of treatments. Opportunities for people should not be limited to their own centres, but

the committee acknowledged that taking part in research in other centres may cause issues, for example, having to travel further.

The committee noted the importance of improving the experiences of people with RCC. They suggested that quality improvement programmes could be informed by a patient satisfaction survey developed with input from people with lived experience to ensure that they capture what matters.

How the recommendations might affect practice

The availability of clinical nurse specialists varies across the country, and they may not all have training in kidney cancer. To consistently achieve this support for everyone with RCC, more clinical nurse specialists may need to be recruited, and specialist training will probably be needed.

The recommendation promoting research involvement could lead to an increase in people being involved in clinical and non-clinical studies.

Return to recommendations

Imaging

Recommendations 1.2.1 to 1.2.8

Why the committee made the recommendations

The committee recommended using triple-phase contrast-enhanced CT (CECT) first because it can successfully identify renal cell carcinoma (RCC) in most people, like contrast-enhanced MRI, but is less expensive. It is also less time consuming per scan than an MRI, and so more appointments are available, and more people can get scans more quickly. CECT is also preferred over MRI for people with claustrophobia, because they are less enclosed, and people with metal implants meaning MRI scanners cannot be used.

The committee agreed that there are situations when MRI, ideally with contrast, should be used in addition to or instead of CECT. One situation is when CECT is not suitable, for example, in people with very reduced renal function or with allergies to the contrast agent being used. Another is when the renal lesion type, and therefore potential next steps, are still unclear after a CECT. The committee agreed that CECT

or MRI of the abdomen would usually be enough to detect if a mass is present. CECT of the chest and pelvis should then be offered to complete staging. But the committee recognised that for people who cannot have CECT, MRI of the pelvis is needed with non-contrast CT of the chest. This is because MRI imaging has much poorer resolution for the chest than CT.

There are several potential results from initial imaging. When there is high confidence of a benign renal lesion, for example, a Bosniak 1 or 2 (not a Bosniak 2F) cyst or an angiomyolipoma, the committee agreed that most people can be discharged. Some people may still benefit from continued monitoring outside of the cancer pathway though, for example people with a Bosniak 1 or 2 cyst that is causing pain, or women, trans men and non-binary people registered female at birth who are of childbearing age and have an angiomyolipoma. They also noted that there is no standard monitoring approach, and this would need to be tailored to the individual. But, if imaging is uncertain or suggests a malignant renal lesion, the committee highlighted the importance of multidisciplinary team discussions to determine possible options and next steps. These might include additional imaging, a biopsy or treatment.

Based on limited evidence and their expertise and experience, the committee agreed that contrast-enhanced ultrasound can guide next steps if needed. Contrast-enhanced ultrasound can help differentiate solid and cystic renal lesions and provide information about lesion characteristics and complexity. The ‘inert’ microbubble contrast agent used in contrast-enhanced ultrasound can be used for people who cannot have the contrast agents used for CT and MRI because of an allergy or poor renal function.

The evidence showed that 99mTc-sestamibi single-photon emission computed tomography CT (SPECT/CT) may provide useful information about whether a renal lesion is likely to be malignant or benign. But the committee agreed that this test is only useful when a person does not wish to or cannot have a biopsy (for example, because of the lesion’s position or because they are taking anticoagulant medication) and their initial imaging could not show whether the lesion was oncocytic. To try to improve the efficiency and effectiveness of the diagnostic process, the committee drafted a recommendation for research on combinations and

sequences of diagnostic approaches to most accurately differentiate between benign and malignant renal lesions.

How the recommendations might affect practice

CECT is commonly used in current practice to help diagnose RCC. MRI is also commonly used, but availability may be more limited because of the longer scanning duration per person and competing demands on the machines from other disease specialities. The recommendations for CECT and MRI are not expected to change current practice.

The committee acknowledged that contrast-enhanced ultrasound is a test that must be carried out by a specialist who may not be available at all centres. However, the machines used for contrast-enhanced ultrasound are readily available in most places. The recommendations for contrast-enhanced ultrasound may lead to an increase in its use, and therefore more demand for specialists. They also noted that 99mTc-sestamibi SPECT/CT is not commonly used for diagnosing kidney cancer in the NHS, but as it is used for imaging the parathyroid and the heart, there is likely to be some availability and expertise already in place. The recommendations for 99mTc-sestamibi SPECT/CT may lead to an increase in its use, although this is expected to be limited as it is only recommended in very specific circumstances.

Return to recommendations

Biopsy for suspected localised or locally advanced renal cell carcinoma

Recommendations 1.3.1. to 1.3.5

Why the committee made the recommendations

Evidence supported biopsy as a diagnostic tool for suspected renal cell carcinoma (RCC) for people with renal lesions 4 cm in diameter or smaller to guide management decisions and, in particular, prevent an unnecessary nephrectomy in people with benign or low-risk malignant lesions. The committee agreed that although biopsy is not routinely offered to people with renal lesions larger than 4 cm in diameter, there are some situations when biopsy could be used to support particular management options or to reassure the person.

The committee agreed that there are situations when biopsy may not be suitable, such as when a person has renal lesion growth in the renal vein or inferior vena cava, because surgery is the only treatment option and delaying treatment for a biopsy is undesirable. Biopsy is also not suitable if the person cannot have any treatment because of the presence of comorbidities or if they are too frail. If a biopsy cannot obtain enough tissue (for example, because there is not a substantial solid component or the lesion is smaller than 2 cm in diameter), or if accessing the renal lesion would be difficult (for example, if the lesion's position makes it inaccessible to a biopsy needle), the committee agreed a biopsy should not be done. They also agreed that a biopsy should not be done when management will not change, such as when the patient has decided to have surgery regardless of the biopsy results. If a person cannot have a biopsy, the committee agreed that it is essential to explain the reason for this. Otherwise, the person may feel confused or anxious if they learn about biopsy from other people with suspected RCC.

The committee agreed a repeat biopsy could be an option if the first one fails. They also agreed that ensuring people are given the opportunity to have a biopsy even if they have previously declined one is important. This is particularly relevant for people under active surveillance who want to move to treatment, because a biopsy would help determine the most suitable options.

How the recommendations might affect practice

Biopsy is not used consistently across the country. Many local centres are not currently able to offer biopsy or can only offer biopsy on a limited basis. This is because of historical service configurations where surgery was mainly carried out without biopsy. So, the infrastructure and staff needed to collect and analyse the biopsy samples were not established. The recommendations would lead to an increased numbers of biopsies taking place in some places and a corresponding resource impact. The committee advised that interventional radiology provision would need to increase in some places, including more staff, and ways of working would change as people would need to be monitored for several hours after a biopsy. To offer biopsy to more people, referrals to specialist centres may increase, or some local centres that do not currently offer biopsy may need additional training to be able to do so. There would also be implications for histopathology services in

terms of staff and diagnostic resources after an increase in the numbers of biopsies. But an increase in the number of biopsies that are carried out is expected to lead to reduction in unnecessary surgeries, with associated cost savings.

Return to recommendations

Biopsy for suspected metastatic RCC

Recommendations 1.3.6 to 1.3.9

Why the committee made the recommendations

Biopsy results could guide systemic anticancer therapy (SACT) decisions for people with suspected metastatic renal cell carcinoma (RCC) who do not have a previous diagnosis of RCC, but this is not necessary if the person has surgery as their first treatment. This is because the same information can be obtained from pathological assessment of the removed renal lesion.

The decision whether to biopsy the renal lesion or the metastases is complex and depends on many factors, such as the location of the renal lesion. The committee agreed that biopsy of metastatic lesions may not be necessary if the person has previously had treatment for RCC with no metastatic disease and now has suspected metastases, as the metastatic lesions are likely to be the same RCC. But if there is suspicion that the metastases could be from another malignancy (for example, if the metastases are seen several years after the initial treatment or diagnosis, or if the person currently has or has had another type of cancer) then clinical judgement should be used to determine whether to do a biopsy.

The committee agreed that biopsy of the renal lesion or metastases would not be suitable when the results would not provide any information to guide treatment decisions (for example, when people cannot have SACT or other treatments) as the risks would outweigh any potential benefits.

How the recommendations might affect practice

The use of biopsy for people with suspected metastatic RCC varies, but it is current practice to do a biopsy in this population if it would guide treatment. The recommendations should standardise practice, leading to a small uptake in biopsy,

but this would have limited resource implications as the group of people who would have a biopsy is very small.

Return to recommendations

Biopsy for people with RCC who have a heritable RCC predisposition syndrome

Recommendations 1.3.10 to 1.3.12

Why the committee made the recommendations

Biopsy results could guide treatment decisions for people with suspicious renal lesions and a heritable renal cell carcinoma (RCC) predisposition syndrome. The committee agreed that the decision to biopsy a suspicious renal lesion would depend on the type of syndrome. Renal lesions in people with von Hippel–Lindau (VHL) syndrome are almost always clear cell RCC, but there could be cases when the diagnosis is uncertain and a biopsy would be a useful tool to determine the type of lesion. Biopsy should not be done for people with hereditary leiomyomatosis and renal cell carcinoma (HLRCC) syndrome because of the aggressive nature of the renal lesions associated with this syndrome and the risk of spread. But biopsy may be useful for people with Birt–Hogg–Dubé (BHD) syndrome and tuberous sclerosis complex (TSC).

How the recommendations might affect practice

Biopsy practice for people with suspected RCC and a heritable RCC predisposition syndrome varies but it is current practice to do a biopsy for some population subgroups to determine lesion type. The recommendations should standardise practice, leading to a small uptake in biopsy, but this would have limited resource implications as the group of people who would have a biopsy is very small.

Return to recommendations

Biopsy information

Recommendation 1.3.13

Why the committee made the recommendation

Based on evidence supporting people's information needs about biopsy and the diagnostic accuracy of biopsy, the committee agreed that biopsy should be used when it is possible and can provide clinically useful information. They noted that people are often concerned about the risks of biopsy and this can put them off having one. They agreed that it is important to reassure people about the rarity of severe complications. People are also often anxious about cancer cells spreading along the path where the biopsy needle goes in. The committee emphasised that the likelihood of this happening is extremely low, and the only available evidence for this hypothesis comes from reports of case series studies with very small numbers of participants.

The committee agreed that another reason people may decide not to have a biopsy is because it could take several weeks, from waiting for an appointment to getting the results. This can cause anxiety because people worry that the lesion could progress during the waiting period. They agreed that it is important to reassure people that the lesion is unlikely to progress in a way that would negatively impact their treatment options or outcomes. Finally, the committee noted that people who choose not to have a biopsy may be able to have one later, for example, to help guide treatment options if they have been under active surveillance and are moving to treatment.

How the recommendation might affect practice

The committee noted that information sharing about biopsy varies, and that people with suspected RCC are often more aware of the potential risks of having a biopsy than the benefits. Improving the quality of the information given to people about biopsy and focusing on the benefits could increase uptake and this would have resource implications (see the rationale sections on biopsy for suspected localised or locally advanced RCC, biopsy for suspected metastatic RCC and biopsy for people with RCC who have a heritable RCC predisposition syndrome for more information). But an increase in the number of biopsies that are done is expected to reduce unnecessary surgeries, with associated cost savings.

Return to recommendation

Managing oncocytomas and Bosniak 2F cysts

Recommendations 1.4.1 to 1.4.8

Why the committee made the recommendations

There was no evidence on active surveillance for oncocytomas or Bosniak 2F cysts of any size. The committee therefore used their expertise and experience to make consensus recommendations that reflect best current practice.

Active surveillance for oncocytomas

Oncocytomas are benign, but the committee agreed that active surveillance should be offered to people whose renal lesion is likely to be an oncocytoma if they have no symptoms, because of uncertainty around the potential harms of immediate discharge. When people have symptoms such as haematuria, treating the lesion should be discussed regardless of its size or growth rate when it is deemed to be the source of the symptoms.

The committee agreed that a suspected oncocytoma with a growth rate greater than 5 mm in diameter per year should trigger a discussion about having a biopsy because the suspected oncocytoma may be malignant or have become malignant. Even if biopsy results indicate a benign renal lesion, removing the oncocytoma may be appropriate to address symptoms or prevent symptoms from developing. The committee recognised that not everyone would want, or be able to have, a biopsy. Some of these people may prefer to stay on active surveillance or have the oncocytoma removed.

Active surveillance for Bosniak 2F cysts

Based on their experience and expertise, the committee agreed that active surveillance should be offered to people with Bosniak 2F cysts. This is because there is a low chance that these cysts are malignant, and malignancy would usually be detected during active surveillance. Therefore treatment, for example surgery, is not routine. Discussing moving to treatment would only happen if there was progression to a Bosniak 3 or 4 cyst, or to a localised, locally advanced or advanced renal cell carcinoma (RCC).

Discharging people with oncocytomas or Bosniak 2F cysts from active surveillance

There was no evidence to inform recommendations about the duration of active surveillance. The committee, based on their experience and expertise, agreed that stopping active surveillance should be discussed if no substantial changes have been recorded after 5 years. If the suspected oncocytoma is actually a malignant mass, it is unlikely it would be undetected during that time. It is also unlikely that a Bosniak 2F cyst would develop into an RCC after this time. They noted that the lack of evidence for duration of active surveillance should be discussed with the person. In addition, when there are no treatment options for RCC for the person, for example because of comorbidities, then active surveillance becomes unnecessary and the person can be discharged back to primary care.

How the recommendations might affect practice

The recommendations reflect current practice in some centres, but there may be some variation across England.

Return to recommendations

Shared decision making about non-pharmacological options for suspected or confirmed localised RCC and Bosniak 3 and 4 cysts

Recommendation 1.5.1

Why the committee made the recommendation

The recommendation on factors to discuss when choosing non-pharmacological treatments for suspected or confirmed localised renal cell carcinoma (RCC), and Bosniak 3 and 4 cysts, is based on the evidence and the committee's experience. By highlighting these points, the committee hope to improve the ability of people with RCC to choose a suitable treatment option for themselves with support from their healthcare provider.

How the recommendation might affect practice

This recommendation should reflect current good practice but may help standardise this where practice varies.

Return to recommendation

Surgery, thermal ablation, active surveillance or SABR

Recommendations 1.5.2 to 1.5.9

Why the committee made the recommendations

The evidence on non-pharmacological interventions for people with localised renal cell carcinoma (RCC) was for people with RCC that was proven or suspected on imaging. Studies did not specify whether the participants had renal lesions that were solid or cystic, and much of the evidence could not be split by the size of the person's lesion. The committee agreed that people with Bosniak 3 and 4 cysts have an increased chance of malignancy compared with Bosniak 1 and 2 cysts, and that in many cases, management should be similar to management of solid masses. Therefore, they chose to include people with Bosniak 3 and 4 cysts in these recommendations along with people with solid renal masses. The committee used their expertise and experience to extrapolate from the evidence to draft recommendations based on size and type of renal lesion.

The committee agreed that many factors need to be taken into account when choosing between non-pharmacological management options for people with localised solid renal masses or Bosniak 3 or 4 cysts. They made a recommendation covering some key points to help with decision making.

Renal lesions 2 cm in diameter and larger

The committee agreed that, when surgery is possible, it is the gold-standard treatment for localised RCC, and Bosniak 3 and 4 cysts, 2 cm in diameter and larger. They noted that although the total diameter of the cyst is usually used to measure size, the size of the solid component should be taken into account as well, as a large cyst with small solid component may be less concerning than a large cyst with large solid component.

The evidence comparing total and partial nephrectomy was very low certainty. The studies were not randomised controlled trials, and it was difficult to assess the true relationship between choice of procedure and clinical outcomes. The evidence showed that partial and total nephrectomy are similar in terms of disease recurrence

and survival, and that there were more post-operative complications with partial nephrectomy. This aligned with the committee's experience. The committee also thought that the complexity of the partial nephrectomy procedure could lead to more intra-operative complications (such as bleeding). They emphasised that partial nephrectomy is a nephron-sparing procedure, which means that renal function can be better preserved compared with total nephrectomy. This would make partial nephrectomy done with robotic assistance the preferred surgical option for people who already have conditions affecting their kidney function, to avoid kidney failure or the need for dialysis. Robotic assistance allows the surgeon to be sufficiently dexterous to complete the partial nephrectomy. When total nephrectomy is used, the committee agreed that minimally invasive techniques were preferable because they allow for less blood loss and more rapid recovery. The committee were unable to specify a minimum renal lesion size for partial nephrectomy, because the evidence was too uncertain.

The evidence suggested that thermal ablation has a higher risk of recurrence than partial nephrectomy. The committee agreed that in their experience, risk of recurrence is higher for thermal ablation than total nephrectomy, too. The committee also noted that for renal masses larger than 4 cm in diameter, thermal ablation may need to be repeated.

There was only limited evidence on stereotactic ablative radiotherapy (SABR). The committee agreed that SABR likely has a higher risk of recurrence than surgery. The evidence comparing thermal ablation and SABR was very limited, but the committee noted that thermal ablation is more established in practice. Therefore, the committee recommended that SABR is only used when thermal ablation is not an option for solid renal masses or Bosniak 3 or 4 cysts that are 2 cm or larger in diameter. The committee drafted a recommendation for research to address the gap in the evidence base around the effectiveness of SABR in comparison to other non-pharmacological interventions, including surgery.

Based on the evidence, the committee agreed that surgery should be the first treatment option but may not be preferred over non-surgical options in all cases. Surgery may be unsuitable (for example, because of the renal lesion characteristics, or because the person has multiple comorbidities or is at high risk of surgical

complications). Alternatively, surgery may be possible but have risks that are considered too high, or the person may not want it. In these situations, non-surgical interventions such as thermal ablation or SABR may be suitable alternatives to surgery for people with solid renal masses or Bosniak 3 or 4 cysts that are 2 cm or larger in diameter.

There was limited evidence for active surveillance and the results were very uncertain. In many cases, there was no clear difference in outcomes between the treatments being compared. When there was a statistically significant difference, active surveillance was associated with a shorter survival than other management options. But the committee recognised that some people choose active surveillance over treatment. This can be because they want to delay treatment so they can, for example, attend a key life event, or because the renal lesion is small and growing slowly. In these situations, active surveillance may be a suitable alternative to surgery. Active surveillance is not recommended for solid renal masses larger than 4 cm in diameter because they are more likely to grow and spread, so need to be treated to prevent greater harm. Active surveillance is still an option for Bosniak 3 and 4 cysts of this size.

Renal lesions less than 2 cm in diameter

For people with renal lesions less than 2 cm in diameter, surgery or non-surgical treatment is often unnecessary and may not be possible if the lesion is very small or, in the case of Bosniak 3 or 4 cysts, lacks a large enough solid nodule. In contrast to larger renal lesions, active surveillance may be the best management option for people with lesions this small.

How the recommendations might affect practice

Partial and total nephrectomy are the most common treatments for localised RCC in the UK. Partial nephrectomy is becoming more common, and the recommendations support this. The number of partial nephrectomies being offered varies, but this is because of differences in availability in local areas. The recommendations are expected to standardise practice, and a higher rate of partial nephrectomies may lead to increased referrals to specialist multidisciplinary team centres. This would

increase short-term costs, but some of these may be offset by long-term savings as more people benefit from preserved kidney function.

The recommendations may result in increased use of thermal ablation, SABR and active surveillance, but mainly in a population who cannot have surgery and would otherwise not have received treatment. The recommendations are not expected to replace many partial nephrectomies with non-surgical treatments. Practice varies, as these non-surgical treatments are not available everywhere.

Return to recommendations

Active surveillance information, imaging types and scheduling

Recommendations 1.5.10 to 1.5.15

Why the committee made the recommendations

No evidence on active surveillance approaches (method, duration, appropriate frequency of imaging, and when to discharge) was identified. The committee relied on their expertise and experiences to draft consensus recommendations. They made a recommendation for research on active surveillance approaches for early detection of disease progression to try to address the evidence gap.

The committee agreed that it is important that people who are undergoing active surveillance are aware of the lack of evidence underlying active surveillance regimens and duration. They should be provided with a personalised care plan to help them understand their imaging schedule and how to seek help should they experience symptoms that concern them.

The committee agreed that although CT and MRI produce more detailed images of a lesion than ultrasound, reducing radiation exposure may justify using ultrasound as part of active surveillance. Also, some people may be unable to tolerate specific contrast agents, which may limit the imaging options available to them.

The committee suggested an active surveillance imaging schedule that could be tailored to individual needs. They agreed that the first scan should be 3 to 6 months after starting active surveillance, to detect early changes and reassure people who may feel anxious. Scan frequency could then be reduced unless there were changes

to the renal lesion indicating the need for more frequent imaging or moving to treatment.

How the recommendations might affect practice

The recommendations reflect current practice in some centres, but there is likely to be substantial variation. The types of imaging recommended reflect the imaging currently used, but when they are used may vary in practice. There is no single, established schedule or duration of active surveillance, and when people are discharged varies. The recommendations are expected to make it clearer when active surveillance may be suitable and increase people's confidence to select this option. It could therefore increase imaging, but this may be balanced by a reduction in the number of people undergoing other treatments such as surgery.

Return to recommendations

Moving from active surveillance to treatment or discharge for renal lesions 4 cm in diameter or smaller

Recommendations 1.5.16 to 1.5.18

Why the committee made the recommendations

No evidence on when to move from active surveillance to treatment or discharge was identified. The committee relied on their expertise and experiences to draft consensus recommendations. They highlighted the key factors that could lead to a discussion about moving from active surveillance to treatment. Bosniak 3 and 4 cysts are much more likely to be malignant than Bosniak 2F cysts, and so the committee agreed that deciding factors for moving from active surveillance to treatment should be similar to those for solid renal masses. They noted that it may be helpful to explain the lack of evidence underlying the duration of active surveillance to people with renal lesions 4 cm in diameter or smaller.

The committee agreed that stopping active surveillance should be discussed if no substantial changes have been recorded after 5 years because it is unlikely that a renal mass less than 4 cm in diameter will progress after this time. When people have no treatment options available, then active surveillance also becomes unnecessary.

How the recommendations might affect practice

These recommendations reflect current good practice but may help standardise practice where it varies.

Return to recommendations

Surgery for suspected or confirmed locally advanced RCC

Recommendations 1.6.1 and 1.6.2

Why the committee made the recommendations

Most of the evidence evaluated surgical techniques for total nephrectomy for people with locally advanced disease. The committee agreed that this reflected current practice and their experience, as it is very unlikely that a partial nephrectomy would be done in this population. They agreed that minimally invasive procedures for total nephrectomy are preferred in practice, as they are expected to minimise surgical complications and reduce length of hospital stay compared with open procedures. Although this was not clearly shown in the evidence, the committee noted the poor quality of the evidence (because of small studies with high risk of bias) and that the studies were done when minimally invasive techniques were being introduced. To address this uncertainty, the committee made a recommendation for research on different types of minimally invasive radical nephrectomy techniques compared to each other.

Based on the evidence and their expertise and experience, the committee agreed that minimally invasive procedures for total nephrectomy should be done when technically and clinically possible. They noted that minimally invasive techniques would not be possible or adequate in more complex cases, and that open total nephrectomy should be used instead.

The committee also highlighted that people with locally advanced renal cell carcinoma (RCC) and inferior vena cava thrombus should have an abdominal MRI to show the extent of tumour thrombus before the type of surgery can be decided. Minimally invasive procedures may sometimes be possible in this population, but they agreed that open total nephrectomy should be used otherwise. In all cases, they agreed that the surgical approach should be decided by a multidisciplinary team,

which may include expertise from specialties such as cardiothoracic, vascular and hepatobiliary surgeons.

There was no evidence identified for using SABR in this population.

How the recommendations might affect practice

Minimally invasive techniques for total nephrectomy, including robot-assisted and laparoscopy-assisted techniques, are the preferred method for total nephrectomy in people with locally advanced RCC. It is not anticipated that these recommendations will result in changes in practice. Additional expertise may be needed to use these techniques in people who have locally advanced RCC and inferior vena cava thrombus, and this may not currently be readily available in all centres.

Return to recommendations

Information for people before and after kidney surgery

Recommendation 1.7.1

Why the committee made the recommendation

Based on the evidence and their expertise, the committee agreed that people need as much information as possible about their treatment options to be able to make an informed decision. This led the committee to recommend some key points for healthcare professionals to discuss with people before surgery. These are in addition to information about the benefits and risks of surgery, and the short-term side effects (such as pain), which should be covered routinely as part of any discussion about treatment options, and are covered within the cross-referenced NICE guidelines in the general information section of this guideline.

How the recommendation might affect practice

The committee noted that it is standard practice to provide people with information before surgery but that what information is given to people varies. The recommendations are expected to standardise practice as they reinforce best practice and highlight what is important to people.

Return to recommendation

Risk prediction tools for localised or locally advanced RCC

Recommendations 1.8.1 to 1.8.9

Why the committee made the recommendations

The evidence supported the usefulness of some risk prediction tools in classifying people with non-metastatic renal cell carcinoma (RCC) into different risk groups for recurrence and that this could be used to help decide follow-up schedules and future treatment options. The evidence was limited to the most common RCC subtypes, namely clear cell RCC, papillary RCC, and chromophobe RCC. Clear cell RCC had the most evidence. The committee therefore limited their recommendations and research recommendations on risk prediction tools to these subtypes.

The evidence for risk tools that predict a 5-year risk of recurrence of clear cell RCC showed that the Leibovich 2003, SSIGN, UISS, Karakiewicz, Kattan and Sorbellini models demonstrated a poor to good ability at discriminating between those at high and low risk of recurrence. The evidence supported the use of any of these tools, so the committee decided not to recommend a single specific tool. The evidence showed that the VENUSS tool had a fair discriminative ability and was superior to other risk prediction tools at predicting papillary RCC recurrence.

The evidence for predicting chromophobe RCC recurrence was limited to the Leibovich 2003 tool and showed a poor discriminative ability. But the committee noted that tumour grading, which is included in the Leibovich 2003 risk model, is not strictly applicable to this tumour subtype and this limits the usefulness of this tool for people with chromophobe RCC. The committee were therefore not able to recommend using this tool and instead made a recommendation for research on the development of a tool appropriate for this subtype.

The committee agreed that a risk prediction tool should not be used in isolation because they are not completely accurate. Clinical judgement should also be used, taking into account the person's clinical characteristics, which can also affect the risk of recurrence and are not included in the recommended risk tools. They noted that the risk prediction tools have not been validated in people with rarer forms of kidney cancer or heritable RCC predisposition syndromes (for example, Von Hippel–Lindau

syndrome), so there is more uncertainty about the accuracy of these tools in these populations.

People included in the studies had undergone nephrectomy to remove the primary renal lesion, and pathology information from a surgical specimen was used to calculate risk of recurrence. The committee recognised that it may also be possible for the tools to use pathology data from biopsy samples, but the results may be less accurate and reliable.

Since no risk prediction tools were identified that were designed to estimate the risk of recurrence in people who have had stereotactic ablative radiotherapy (SABR) or thermal ablation rather than nephrectomy, the committee drafted a recommendation for research on risk prediction tools for people with localised or locally advanced RCC having thermal ablation or SABR to address this gap in the evidence. They also drafted a recommendation for research to develop a risk prediction tool to estimate the risk of progression in people who are under active surveillance for a localised RCC.

Adjuvant treatment is now available for people at increased risk of recurrence after surgery for non-metastatic RCC. The committee acknowledged that, in the future, eligibility for systemic anticancer therapy (SACT) may depend on risk stratification using a specific risk prediction tool stated in a NICE technology appraisal guidance or NHS commissioning criteria. They therefore agreed that these risk prediction tools should be used in addition to any other tool mentioned in the recommendations when SACT is indicated for people with localised or locally advanced RCC.

The recommended risk prediction tools rely on information provided in pathology reports and other clinical characteristics in some cases. The committee noted that whether pathology reports contain all the pathology information needed to calculate the risk of recurrence using the recommended risk prediction tools varies in practice. Making this information available and including the calculated risk score in pathology reports, when possible, would save time during the multidisciplinary team meetings.

To reduce variation in practice and promote the use of risk prediction tools, the committee noted the importance of recording the risk score on the person's clinical record before deciding about follow-up schedules or future treatment options.

The committee agreed that it is important that people understand their risk of recurrence and how it is calculated using the risk prediction tools so that they can be fully involved in decision making about their follow-up schedules and treatment options.

How the recommendations might affect practice

Risk prediction tools for localised and locally advanced RCC are currently used in the UK, but the specific tools used vary. Leibovich 2003 is commonly used for clear cell and other types of RCC. Additional tools are recommended for clear cell RCC, although there is scope in the recommendations to choose from multiple tools. This may impact on practice less if centres decide to continue using Leibovich 2003. VENUSS may not be used currently for calculating the risk of recurrence of papillary RCC in all centres. The recommendations may reflect a change in practice and lead to standardisation of the use of tools for papillary RCC.

The recommendation to provide all the relevant pathology information and to report calculated risk scores on pathology reports is expected to change practice in some areas but is already happening in others.

Return to recommendations

Follow-up for localised and locally advanced RCC

Recommendations 1.10.1 to 1.10.16

Why the committee made the recommendations

Very limited evidence was identified on follow-up approaches (methods, duration and appropriate frequency of imaging, and when to discharge) for localised and locally advanced renal cell carcinoma (RCC). The committee relied on their expertise and experiences, to draft consensus recommendations. They also drafted a recommendation for research on follow-up strategies to fill this gap in the evidence base.

Information to provide during follow-up

The committee agreed that people should be told to seek help if they have symptoms that could indicate recurrence of the RCC or metastasis. These would

likely be persistent, rather than acute, symptoms lasting for several weeks. Telling people who have had treatment for RCC in advance about their expected duration of follow-up if there is no sign of recurrence may help to manage their expectations and any anxiety.

Testing before follow-up

The committee agreed on the importance of testing for renal insufficiency after treatment has been completed but before follow-up begins because this could need separate management, for example, if the person has developed chronic kidney disease. It could also affect whether contrast agents could be used during follow-up imaging.

Types of follow-up imaging and scheduling

A very small amount of uncertain evidence (because of high risk of bias and partially indirect to the area of interest) indicated that cross-sectional imaging (as opposed to X-rays or ultrasounds) may be better at detecting recurrences as part of regular follow-up. The committee agreed that, in their experience, contrast-enhanced CT (CECT) was the best imaging type to detect recurrence. But they acknowledged that there are circumstances when CECT is not suitable because radiation exposure should be reduced or avoided (for example, if the person is pregnant). They agreed that, in these cases, MRI of the abdomen and pelvis could be used with non-contrast chest CT, which uses a lower dose of radiation than CECT, unless CT is contraindicated. They also noted that some people cannot have CT contrast agents (for example, people with contrast allergies or at a higher risk of kidney injury). In these cases, a combination of MRI of the abdomen and pelvis and non-contrast CT of the chest, or non-contrast CT of the chest, abdomen and pelvis, would be appropriate.

The committee noted that there was no evidence about the most effective frequency or duration of imaging during follow-up. They used their clinical expertise, experience and awareness of other NHS England guidance (GIRFT's guide Urology: Towards better care for patients with kidney cancer) to suggest a minimum follow-up imaging schedule that could be used as a starting point and then tailored to individual needs. There was evidence supporting the use of some risk prediction tools to classify

people into different risk groups to help decide future follow-up schedules (see the rationale section on risk prediction tools for localised or locally advanced renal cell carcinoma). The recommended schedule therefore has 3 levels of risk of recurrence and the person's level of risk should be assessed using the recommended risk prediction tools.

The evidence supporting the use of risk prediction tools came from studies that included prognostic factors based on pathology data from surgical samples. People who have stereotactic ablative radiotherapy (SABR) or thermal ablation do not have this level of pathology information but may instead have pathology information from biopsy. The committee agreed that their risk of recurrence could be estimated from biopsy samples using the same tools but it may be less accurate for these people and so they recommended using the moderate risk of recurrence schedule as a minimum starting point. No risk prediction tools were recommended for people with chromophobe RCC. But the committee agreed that chromophobe RCC is generally considered to have a lower risk of recurrence than other types of RCC. They therefore recommended the low-risk follow-up schedule for people with this type of RCC.

Recurrence or development of metastases

The committee agreed that when recurrence or metastases are suspected, then more imaging (for example, contrast-enhanced ultrasound or bone scans) and tests (for example, biopsy of the lesion or metastases) may be needed to confirm this diagnosis.

Discharge

There was no evidence on follow-up duration or when to discharge people. So, the committee were unable to give a precise duration of follow-up for each recurrence risk group. But they agreed that follow-up is only worth doing while any recurrence or metastases can be treated. The committee agreed that clinicians sometimes think that keeping people on follow-up regimens for long periods of time is simpler than discharging them. But identifying when discharge is appropriate for the person is important for people having follow-up and for efficient resource use. The committee were aware that being under follow-up was stressful for some people while others

find continued scans reassuring. They therefore agreed that it is important to discuss the lack of evidence for follow-up duration with the person when considering discharging them.

The committee agreed that people at low risk of recurrence, with no sign of recurrence on their 5-year scan, were unlikely to have a recurrence after this time and could safely be discharged. In contrast, people at intermediate or high risk may benefit from a longer follow-up period, as their absolute risk of recurrence is likely to be higher. Also, although their absolute risk of recurrence decreases over time, it is likely to remain higher than people classified as being at lower risk of recurrence at the start of follow-up. The duration of this extended follow-up is unclear, so the committee recommended revisiting the decision to discharge these people from follow-up after every subsequent scan if there is no sign of recurrence.

How the recommendations might affect practice

The recommendations reflect current practice in some areas but the duration and timing of follow-up imaging varies across the UK. Most of the follow-up imaging is cross sectional, mainly contrast-enhanced CT. The recommendations are expected to standardise follow-up schedules and duration. Imaging frequency may increase in some centres and decrease in others. The recommendations will also make it clearer to people that they have a named contact for any information needs. This is standard practice and should not have any implications on how often services are accessed.

Return to recommendations

Referring people with advanced RCC

Recommendations 1.11.1 and 1.11.2

Why the committee made the recommendations

Based on their expertise and experience, the committee recommended that multidisciplinary teams be involved in discussions about the potential integration of pharmacological and non-pharmacological treatments because deciding suitable treatment options can be very complex as they are based on many factors. These include the person’s performance status, number and location of metastases, baseline risk group, general health and comorbidities. They recognised that in some

situations, additional specialist input may be needed based on the site of metastases, as the site could affect what treatments are suitable (for example, the potential for surgical resection).

How the recommendations might affect practice

The recommendations reflect current good practice but may result in a slight increase in referrals to specialist uro-oncology multidisciplinary teams in places where this is not happening.

Return to recommendations

Information for people with advanced RCC

Recommendation 1.12.1

Why the committee made the recommendation

The committee agreed that most of the information and principles underlying what information to share, communication and shared decision making in the general information section also applied for people with advanced RCC. However, the particulars of the treatments being discussed would be specific for people with advanced RCC. In addition, these people would need to be made aware of supportive and palliative care options. They therefore cross referred to other guidance that cover end of life care and care of dying adults in the last days of life.

How the recommendation might affect practice

It is standard practice to ensure that there is a discussion with the person about palliative care, and that the relevant information and sources of support are given to them. There is currently some variation in practice with what information is provided and the recommendations are expected to standardise practice by signposting to all the relevant existing NICE guidance.

Return to recommendation

Risk prediction tools for metastatic RCC

Recommendations 1.13.1 to 1.13.5

Why the committee made the recommendations

Most of the available evidence focused on the International Metastatic Renal Cell Carcinoma Database Consortium (IMDC) and Memorial Sloan Kettering Cancer Center (MSKCC) risk prediction tools applied before first-line systemic anticancer therapy (SACT) for adults with clear cell metastatic renal cell carcinoma (RCC). The committee agreed that using risk prediction tools for these people aligned with current clinical practice. The discriminative ability for predicting overall survival was similar and poor for both IMDC and MSKCC. Despite this, the committee agreed that using a prediction tool alongside clinical judgement might be helpful. They preferred the IMDC because it:

- provides information about risk stratification
- was developed when the new anti-angiogenic drug treatments became available
- is embedded in current practice
- is used as part of the eligibility criteria for systemic treatments in some technology appraisal guidance
- does not need measurement of lactate dehydrogenase (LDH) to calculate the score (unlike MKSCC), which makes it easier to use as this information is not always readily available.

So although the IMDC alone is not very accurate at classifying people into risk groups, the committee agreed to consider using the IMDC tool to guide decisions around management options. They emphasised that this risk prediction tool should be used with clinical judgement, including consideration of individual clinical characteristics such as fitness and comorbidities, because it is not very accurate on its own. This is particularly important for certain groups of people with rarer RCC subtypes, when there is less or no evidence about the accuracy of the tool in predicting overall survival, and when making decisions about second- or subsequent-line therapy, as prior interventions may potentially bias predictive results. The committee also made a recommendation for research on developing and testing new risk prediction tools for different RCC subtypes (including clear cell RCC) to predict outcomes for metastatic RCC.

The committee acknowledged that eligibility for SACT may depend on risk stratification using a specific risk prediction tool stated in relevant NICE technology appraisal guidance or NHS commissioning criteria. They therefore agreed that these risk prediction tools should be used in addition to the IMDC when SACT is indicated.

To reduce variation in practice and promote the use of risk prediction tools the committee noted the importance of recording the risk scores on the person's clinical record before deciding on future treatment. To support shared decision making and reduce confusion, the committee included a recommendation to ensure that people with metastatic RCC are provided with certain information about the IMDC tool. They emphasised the importance of people understanding predictions about their life expectancy and the impact of potential treatment options on this so they can make fully informed decisions.

How the recommendations might affect practice

The IMDC prognostic tool is currently the preferred tool to predict survival and guide treatment decisions in people with metastatic RCC so it is not anticipated that these recommendations will change practice.

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Non-pharmacological management of metastatic RCC

Recommendations 1.14.1 to 1.14.7

Why the committee made the recommendations

There was limited low to very low-certainty evidence comparing non-pharmacological interventions before systemic anticancer therapy (SACT) with non-pharmacological interventions after SACT has started. Evidence was also limited comparing non-pharmacological interventions before or after SACT with SACT alone. The only non-pharmacological intervention covered by this evidence was cytoreductive nephrectomy (CN), a type of surgery. Therefore, although this section of the guideline covers advanced renal cell carcinoma (RCC), most of the recommendations do not apply to people with locally advanced inoperable RCC as CN would not be a suitable option for them.

It was difficult to assess from the included studies (1 randomised controlled trial and a number of observational studies) whether CN before SACT was better than SACT alone. The committee agreed, based on their expertise and experience, that people with metastatic RCC may benefit from surveillance before SACT if they have low-volume, slow-growing metastases, and therefore have a very low risk of progression. Using surveillance in these cases will delay starting treatments, which may have side effects that negatively affect people's quality of life, until SACT is clinically indicated. They also agreed that people with advanced RCC with 3 or more deposits in different organs are likely to benefit most from immediate treatment when SACT is indicated and therefore any non-pharmacological interventions should be used after SACT has been started.

Treating the primary renal lesion in people with metastatic disease

The committee agreed that people are likely to benefit more from immediate SACT when SACT is indicated. But they identified 2 scenarios when CN may be useful before SACT. First, when immediate SACT is not indicated and surgery is suitable. Second, although there was no evidence about the impact of CN on quality of life, and evidence on CN for symptomatic control was not assessed, the committee agreed that CN could be used when the primary mass is causing severe symptoms that could be controlled by surgery. They noted that this might happen before SACT, or alternatively after SACT has been started.

There was some low-certainty evidence (2 randomised controlled trials with some risk of bias and imprecise results) that survival may be improved for people having CN after SACT has been started compared with CN before SACT. The committee agreed that the specific characteristics of the person and their lesion or lesions would determine whether CN would be effective and noted that this level of information could not be determined from the evidence identified. They identified some factors to help the clinician decide whether someone would benefit from CN after SACT had started.

There was no evidence about other non-pharmacological interventions for treating the primary mass in people with metastatic RCC, so the committee chose not to recommend other specific treatments. There was also no evidence about non-pharmacological interventions for treating the primary mass in people with locally

advanced inoperable RCC, so the committee made a recommendation for research on stereotactic ablative radiotherapy (SABR) after SACT has been started in this population.

Treating metastases

There was no evidence identified about non-pharmacological interventions for treating metastases in RCC, so the recommendation on possible non-pharmacological treatment options is based on the committee's clinical expertise and experience. The committee noted that SABR is already commissioned for patients with metachronous extracranial oligometastatic cancer.

Taking the lack of evidence into account, the committee drafted a recommendation for research on promoting research into the clinical and cost effectiveness of metastasectomy in people with metastatic RCC who have had their primary mass removed. They also drafted a recommendation for research on promoting more research into thermal ablation and external beam radiotherapy (EBRT) of metastases after SACT has been started for people with metastatic RCC.

How the recommendations might affect practice

Most people with metastatic RCC currently receive SACT before a non-pharmacological intervention, and these recommendations support that. Small proportions of people have non-pharmacological interventions before or after SACT, and these recommendations are not expected to change that, but they could provide some standardisation across settings.

Return to recommendations

Genetic assessment to diagnose heritable RCC predisposition syndromes

Recommendations 1.16.1 to 1.16.6

Why the committee made the recommendations

Genetic testing criteria for heritable renal cell carcinoma (RCC) predisposition syndromes are described in the National Genomic Test Directory's (NGTD) rare and inherited disease eligibility criteria document. These criteria are regularly updated,

and new criteria are added as new genetic variants are identified. The committee decided to cross refer to this, and so an evidence review to determine factors associated with these syndromes was not carried out. As the NGTD includes many testing criteria covering multiple syndromes, the committee recommended key features for healthcare professionals to assess in people with a suspected heritable RCC syndrome (based on the testing criteria for R224 inherited renal cancer) that would then prompt consultation of the NGTD.

Most genetic testing is requested by clinical genetics teams, but other specialities can request genetic testing with the move towards ‘mainstreaming’, where genetic testing is requested by treating teams. The committee recommended following local policies and procedures to determine whether the healthcare professional who does the initial assessment should also do the detailed assessment and request testing following the NGTD, or if they should refer the person on to another team to do this.

Based on their experience and the evidence, the committee agreed before testing a person with RCC for a heritable RCC predisposition syndrome that it is important to explain the likelihood of having a positive test and what this could mean for the person and the family. They recognised that this is likely to be a very stressful time for the person with RCC and that they will need access to specialist genetic services for ongoing support and advice to help them understand and process the information they are given. The committee were aware that some people decline the test initially and wanted people with RCC to know that the test could be done later if they change their mind.

The committee agreed that it is important for people who have suspected or confirmed RCC who are then diagnosed with a heritable RCC predisposition syndrome to be managed by a specialist multidisciplinary team because they have complex conditions that need input from multiple specialties. The committee also recognised the importance of ensuring that these newly diagnosed people are provided with information and support at this stage and on an ongoing basis.

How the recommendations might affect practice

Local pathways for accessing genetic assessment of heritable predisposition syndromes for RCC vary across the UK. These recommendations have been written

to accommodate this and any changes that may occur in the future, and are therefore not expected to change local pathways. The recommendation listing the factors to assess before doing a detailed assessment following the NGTD may help standardise the early stage of the genetic assessment process but is not expected to have a large resource impact, as the numbers of people being assessed is likely to be relatively small.

The committee noted that the information provided to people with RCC and a suspected or confirmed heritable RCC predisposition syndrome varies. The recommendations are expected to help standardise practice by providing people with some key points to cover before and after diagnosis, including the correct information on how to access specialist genetic services. This could mean that more people access these services, but providing this information is standard practice in many places and the number of people affected are small, so any resource impact would be minimal.

Return to recommendations

Active surveillance for suspected or confirmed localised RCC in people with a heritable RCC predisposition syndrome

Recommendations 1.17.1 to 1.17.7

Why the committee made the recommendations

Very little evidence was identified for this review, and it was of poor quality as only non-comparative studies were found, so the committee used their expertise and experience to draft consensus recommendations.

As people with heritable renal cell carcinoma (RCC) predisposition syndromes are likely to have multiple renal lesions in their life, treating RCC in this population aims to balance the risk of metastases with preserving renal function for as long as possible. Some syndromes associated with aggressive disease, such as hereditary leiomyomatosis and renal cell carcinoma (HLRCC; where the RCC is typically a fumarate hydratase [FH]-deficient RCC), would ideally have the RCC treated promptly, without active surveillance. But this population may have competing clinical needs related to comorbidities, and so immediate treatment may not always be

possible. The committee agreed that active surveillance may be suitable in these cases until it is possible to move to treatment. In contrast, people with syndromes associated with less aggressive disease, such as von Hippel–Lindau syndrome (VHL), Birt–Hogg–Dubé syndrome (BHD), hereditary papillary renal cell carcinoma (HPRCC) and tuberous sclerosis complex (TSC), could have active surveillance until the lesion is 3 cm in diameter before moving to treatment.

People with a heritable RCC predisposition syndrome receive imaging throughout their life as part of standard surveillance to identify renal and non-renal lesions and to monitor other complications associated with their syndrome. They may have some RCCs that are being monitored using active surveillance before any treatment, and other RCC sites that are being monitored as part of follow-up after treatment. The committee agreed that active surveillance for RCC in this population should use MRI or ultrasound imaging, instead of CT, to limit long-term radiation exposure. They also emphasised the importance of clinicians coordinating imaging to prevent duplication and to minimise the person's hospital appointments.

The committee recommended the same active surveillance imaging schedule as for sporadic RCC (RCC occurring in people who do not have a heritable RCC predisposition syndrome) for the first year. From year 2 onwards, the specialist multidisciplinary team should tailor the schedule to ensure that the active surveillance imaging is not less frequent than renal imaging in the active surveillance protocol for sporadic RCC, which is usually every year. They agreed that people who have a renal lesion and a heritable RCC predisposition syndrome associated with more aggressive RCC who are undergoing active surveillance should have a more intensive schedule of imaging than people with less aggressive forms, but were unable to specify exactly what this should be.

The information to be provided during active surveillance, and criteria to trigger a discussion about moving from active surveillance to treatment, were also adapted from those for sporadic RCC, but using 3 cm as the lesion size cut off to reflect the threshold in recommendation 1.17.2.

How the recommendations might affect practice

Managing heritable predisposition syndromes for RCC does not vary widely across the UK. It is standard practice to use active surveillance in people with a heritable RCC predisposition syndrome unless they have a syndrome associated with aggressive RCC. Therefore, it is unlikely that the recommendations will have a large impact on practice, but they are expected to encourage standardisation where variation exists.

People with heritable predisposition syndromes for RCC often have other indications that need monitoring. If recommendations for coordinating imaging for active surveillance and follow-up of RCC and non-RCC related imaging are considered alongside other appointments for other conditions, this could be an opportunity to create efficiencies and avoid duplication of appointments.

Return to recommendations

Surgery for suspected or confirmed localised RCC in people with a heritable RCC predisposition syndrome

Recommendations 1.8.1 to 1.8.3

Very little evidence was identified for this review, and it was of poor quality as only non-comparative studies were found, so the committee used their expertise and experience to draft consensus recommendations.

The committee agreed that when treatment is indicated, people with syndromes associated with less aggressive disease should be offered nephron-sparing treatment instead of total nephrectomy if possible, as the importance of preserving renal function outweighs the risk of recurrence or other complications. This is because people with these syndromes are likely to have multiple lesions over their lifetime. They noted that lesion location and size and the person's clinical characteristics, such as comorbidities and previous abdominal surgery, would determine which, if any, of these treatments are suitable.

The committee recommended partial nephrectomy before other nephron-sparing treatments because it can be difficult to perform partial nephrectomy on a kidney that

has already undergone thermal ablation or stereotactic ablative radiotherapy (SABR) because of the renal tissue inflammation that these procedures can cause. For people with syndromes associated with more aggressive disease, such as hereditary leiomyomatosis and renal cell carcinoma (HLRCC), it is more important to fully remove the lesion, and so total nephrectomy or removing more tissue around the lesion is recommended.

How the recommendations might affect practice

Managing heritable predisposition syndromes for RCC does not vary widely across the UK. It is standard practice to use nephron-sparing treatments in people with a heritable RCC predisposition syndrome unless they have a syndrome associated with aggressive RCC. Therefore, it is unlikely that the recommendations will have a large impact on practice, but they are expected to encourage standardisation where variation exists.

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Follow-up of localised or locally advanced RCC after treatment in people with a heritable RCC predisposition syndrome

Recommendations 1.20.1 to 1.20.5

Why the committee made the recommendations

No evidence on follow-up strategies for people with a hereditary renal cell carcinoma (RCC) predisposition syndrome after treatment of an RCC was identified. The committee therefore used their expertise and experience to make consensus recommendations. The information to be provided is similar to that provided for people with sporadic RCC during follow-up.

The committee recommended abdominal MRI to reduce radiation exposure because people with RCC who have a heritable RCC predisposition syndrome will have long-term imaging to monitoring these renal lesions as well as more imaging during standard surveillance for their non-RCC related conditions associated with the syndrome. But CT is needed for chest imaging because of the low resolution of chest MRI.

The committee agreed that the intermediate-risk status minimum follow-up imaging schedule that is recommended for people who have had treatment for sporadic RCC should be used as a starting point for these people too, and should be continued for at least 5 years. But the committee were aware that people with RCC who have hereditable RCC predisposition syndromes are also under the care of other healthcare professionals who monitor the person's syndrome using standard surveillance imaging. There was no evidence on when to stop follow-up for a treated RCC and return solely to standard surveillance. The committee agreed that this should be decided based on the person's clinical needs, in discussion with the other healthcare professionals, and not based on a set follow-up duration. They noted that standard surveillance and follow-up schedules may overlap, but in practice it would be unlikely for a person to have a scan for surveillance if they just had a scan for follow-up. But the committee highlighted that the situation may be more complex than this, because people with hereditable RCC predisposition syndromes may have several renal lesions at different stages of treatment, active surveillance or follow-up.

How the recommendations might affect practice

Recommended follow-up schedules using MRI or CT imaging reflect current practice for treating RCC in people with a heritable RCC predisposition syndrome.

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Context

According to Cancer Research UK, kidney cancer is the 6th most common cancer in adults in the UK, with approximately 13,800 new cases each year. Kidney cancer incidence rates have almost doubled since the 1990s, have increased by about 25% between 2007 and 2019, and are projected to rise further by 2040. Kidney cancer is the 13th most common cause of cancer death in the UK, accounting for around 3% of all cancer deaths. Kidney cancer can be cured if found early, but early diagnosis is challenging as most people at this stage do not have symptoms. Many people are diagnosed incidentally based on investigations for other reasons. After diagnosis, the most common treatment options include surgery to remove part or all of the kidney, ablation of the mass or active surveillance. Systemic anticancer therapies are options for advanced (metastatic and locally advanced inoperable) disease.

The Kidney Cancer UK Quality Performance Audit (2022) identified substantial variation across all quality performance indicators throughout the entire kidney cancer care pathway, which demonstrated the need for a national guideline for kidney cancer.

This guideline covers adults (18 years and older) with suspected or confirmed renal cell carcinoma, including all subtypes. It covers areas of uncertainty or variation in practice related to diagnosis (imaging and biopsy), management of different stages of disease (localised, locally advanced and advanced) and risk-stratified follow-up after nephrectomy or non-surgical treatment. The guidance also covers information and support needs for people affected by kidney cancer throughout all stages of the care pathway, and recommendations for the diagnosis of heritable kidney cancer predisposition syndromes and management of renal cell carcinoma in this population.

This guideline aims to help standardise the management of kidney cancer.

Finding more information and committee details

To find NICE guidance on related topics, including guidance in development, see the NICE topic page on renal cancer.

For details of the guideline committee, see the committee member list.