



Kidney cancer: diagnosis and management

NICE guideline

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Your responsibility

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

All problems (adverse events) related to a medicine or medical device used for treatment or in a procedure should be reported to the Medicines and Healthcare products Regulatory Agency using the [Yellow Card Scheme](#).

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should [assess and reduce the environmental impact of implementing NICE recommendations](#) wherever possible.

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This guideline is the basis of QS215.

Overview

This guideline covers diagnosing and managing renal cell carcinoma in people aged 18 and over. 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 suspected or confirmed renal cell carcinoma, their families and carers.

Information and support

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.

Healthcare professionals should follow our general guidelines for people delivering care:

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

These recommendations are to help healthcare professionals provide information and support to people with suspected or confirmed renal cell carcinoma.

We have also written [information for people with suspected or confirmed renal cell carcinoma, their families and the general public](#).

1.1 Information for healthcare professionals to support people with suspected or confirmed renal cell carcinoma

- 1.1.1 When referring someone with suspected renal cell carcinoma (RCC) for initial investigations, 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 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 suspected or confirmed RCC during diagnosis, management and [follow-up](#) or palliative care.

1.1.4 The clinical nurse specialist supporting the person with suspected or confirmed RCC should:

- act as the key worker to address the person's information and care needs and
- give their contact details to the person and
- have training and experience in kidney cancer care and
- attend multidisciplinary team meetings and
- act as a link between the urology and oncology teams and
- liaise between secondary and primary care, supporting communication and care coordination.

1.1.5 Give the person with suspected or confirmed RCC the contact details for a [cancer care navigator](#), if available.

1.1.6 Throughout their care, 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 the person to voluntary or community emotional support services, or refer the person to NHS psychological health support services, if and when 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](#), [Kidney Cancer UK](#) 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 [uro-oncology 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 information for healthcare professionals to support people with suspected or confirmed renal cell carcinoma](#).

Full details of the evidence and the committee's discussion are in [evidence review D: information needs](#).

Diagnosis

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](#).

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See also the [section on renal cancer in NICE's guideline on suspected cancer](#).

1.2 Imaging

- 1.2.1 When a person has suspected renal cell carcinoma (RCC) and there is not enough information from any previous imaging to inform next steps, offer either:

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

See also [NICE's HealthTech guidance on point-of-care creatinine devices to assess kidney function before CT imaging with intravenous contrast](#), and [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 multiphasic CECT to inform next steps.

1.2.3 If a possible RCC is detected on abdominal imaging, offer CT of the chest and pelvis (ideally with contrast) to complete staging.

1.2.4 If imaging is inconclusive or suggests the renal lesion may be malignant, discuss the results in a [uro-oncology 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 RCC](#) and [managing advanced RCC](#)).

If brain or spinal metastases are suspected, see the [sections on investigation of suspected brain metastases in NICE's guideline on brain tumours \(primary\) and brain metastases in over 16s](#) and [imaging investigations in NICE's guideline on spinal metastases and metastatic spinal cord compression](#).

1.2.5 Consider contrast-enhanced ultrasound if either:

- the person cannot have multiphasic 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 multiphasic CECT, MRI (with or without contrast) or both.

- 1.2.6 Consider 99mTc-sestamibi single-photon emission computed tomography CT (SPECT/CT) after multiphasic CECT or MRI (with or without contrast) if:
- increasing confidence in whether the person has an oncocytic renal lesion (including an oncocytoma or chromophobe RCC) would change management and
 - biopsy is not an option or the person declines it.
- 1.2.7 Refer the person for monitoring or treatment of local symptoms outside of the cancer pathway if imaging suggests the renal lesion is benign (for example, a Bosniak 1 or 2 cyst or an angiomyolipoma) but the person is at risk of complications (such as bleeding) or has symptoms that need management (such as pain).
- See the [section on active surveillance for oncocytomas and Bosniak 2F cysts](#) for information on offering [active surveillance](#) if imaging suggests the renal lesion is a Bosniak 2F cyst.
- 1.2.8 Discharge the person if:
- imaging suggests the renal lesion is benign and
 - the person is not at higher risk of complications and does not have symptoms that need 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 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 renal 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 renal 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 renal biopsy, and explain why to the person, if any of the following apply:

- it is not going to change management
- the renal lesion has grown into the renal vein or inferior vena cava and the person is a candidate for surgical treatment
- getting a tissue sample is not possible (for example, the renal lesion is in a

location that is not accessible for biopsy).

- 1.3.4 If a renal biopsy sample does not give enough information to help confirm a diagnosis, consider repeating the biopsy if a radiologist thinks that either:
- a second biopsy will be successful
 - a different image-guided approach might be needed for successful tissue sampling.
- 1.3.5 Offer additional opportunities to have a renal biopsy to people who have previously declined it if:
- they meet the criteria in recommendations 1.3.1 and 1.3.2 and
 - biopsy is still possible and could provide 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 RCC](#).

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](#) who:
- have not been previously diagnosed with RCC and
 - are not going 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 either the renal lesion or the 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 [timing of invasive interventions 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 was previously treated 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 suspected RCC who have a heritable RCC predisposition syndrome

- 1.3.10 Do not routinely offer a renal biopsy to 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 offer a renal biopsy to people with known hereditary leiomyomatosis and RCC (HLRCC) syndrome with a suspicious renal lesion and instead expedite treatment (see the [section on managing RCC in people with a heritable RCC predisposition syndrome](#)).

- 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 the [section on biopsy for suspected metastatic RCC](#) if metastases are suspected.

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 for healthcare professionals to discuss with people with suspected RCC

- 1.3.13 When discussing possible diagnostic 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 confirmed to be benign through a biopsy
 - active surveillance may be a suitable option if the lesion is confirmed to be at low risk of progression through a biopsy 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 if you have an RCC, 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 for healthcare professionals to discuss with people with suspected RCC](#).

Full details of the evidence and the committee's discussion are in [evidence review J: renal biopsy](#).

Managing oncocytomas and Bosniak 2F cysts

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- [Service user experience in adult mental health](#)
- [Shared decision making](#).

1.4 Active surveillance for oncocytomas and Bosniak 2F cysts

Active surveillance for oncocytomas

1.4.1 For people with a renal [lesion](#) that is likely to be an oncocytoma (based on imaging, biopsy results or both), who have:

- no symptoms, then:
 - offer [active surveillance](#)
 - offer to treat the oncocytoma if they decline active surveillance
- symptoms, such as haematuria (blood in their urine), then:
 - offer to treat the oncocytoma
 - offer active surveillance if they decline treatment.

See the [section on active surveillance information, imaging types and scheduling](#).

1.4.2 For people undergoing active surveillance for a renal lesion that is likely to be an oncocytoma that has a growth rate greater than 5 mm in diameter in a year, discuss with the person the following options:

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

1.4.3 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 in a year, if the lesion is found to be:

- malignant, then move to treatment for renal cell carcinoma (RCC), following the recommendations in the [section on managing localised and locally](#)

advanced RCC or managing advanced RCC

- benign, then consider:
 - continuing active surveillance or
 - treating the benign lesion.

1.4.4 Consider managing oncocytic renal neoplasms of low malignant potential, not otherwise specified, in the same way as an 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 to a Bosniak 3 or 4 cyst during active surveillance, follow the relevant recommendations in the section on managing localised and locally advanced RCC or managing advanced RCC.

Stopping active surveillance

1.4.7 Stop active surveillance and discharge the person with an oncocytoma or Bosniak 2F cyst if treatment for local symptoms, or treatment for RCC if developed in the future, is no longer an option. Explain to the person why they are being discharged from the active surveillance pathway.

1.4.8 Consider stopping active surveillance of an oncocytoma or Bosniak 2F cysts after 5 years and discharging the person, taking into account their preferences and clinical characteristics (such as age and fitness), if the:

- oncocytoma does not have a growth rate greater than 5 mm in diameter in any 12-month period
- Bosniak 2F cyst has not progressed to stage 3 or 4.

- 1.4.9 When discharging a person from active surveillance because their lesion has remained stable for 5 years:
- explain why they are being discharged
 - explain that if they had a malignancy, it is likely that it would be detected by this time
 - provide examples of symptoms that the person should contact primary care about (such as if they have blood in their urine or persistent abdominal pain).

For a short explanation of why the committee made these recommendations and how they might affect practice, see the [rationale 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

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- [Service user experience in adult mental health](#)
- [Shared decision making](#).

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

See also [NICE's visual summary on management of localised renal cell carcinoma \(RCC\)](#).

Shared decision making

1.5.1 When deciding between non-pharmacological options for suspected or confirmed localised 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 may be associated with a lower risk of local recurrence than [thermal ablation](#) and stereotactic ablative radiotherapy (SABR), but there may be a greater risk of short-term complications
 - a greater reduction in kidney function is expected from surgically removing the whole kidney compared with thermal ablation and SABR
 - 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, and there may also 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 undergoing 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 management of 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 component in a Bosniak 4 cyst), complexity and histological subtype
- that surgery is the preferred option for solid renal masses, and Bosniak 4 cysts, 2 cm in diameter or larger when it is suitable
- that SABR is not suitable for renal lesions that are larger than 7 cm in diameter
- that for solid renal masses larger than 4 cm in diameter, only certain types of thermal ablation may be suitable, multiple sessions may be needed and this may need to be done in a specialist centre
- that thermal ablation and SABR should not be used without prior biopsy confirmation of malignancy before treatment
- whether reducing the risk of surgical complications is important enough to justify the higher risks associated with non-surgical options compared with surgery, including that:
 - thermal ablation and SABR may have a higher risk of local recurrence
 - active surveillance has a higher risk of renal lesion growth and spread
- the person's clinical characteristics, including comorbidities and frailty

- the person's preferences.

See [table 1](#) and the [section on information for healthcare professionals to discuss with 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 or larger

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

- imaging for diagnosis and staging and
- discussion with a [uro-oncology multidisciplinary team](#).

See also the [section on biopsy for suspected localised or locally advanced RCC](#) for information on when to offer biopsy before surgery.

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](#)
- that 4 cm in diameter is often the maximum renal lesion size for partial nephrectomy, but there is little evidence to support this.

Table 1 Factors to take into account when deciding between partial and total nephrectomy for suspected or confirmed localised RCC and Bosniak 3 or 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 location, size and complexity, and the person's clinical characteristics).	The renal lesion cannot be entirely removed with partial nephrectomy (based on lesion location, size and complexity, and the person's clinical characteristics).

Partial nephrectomy is preferred when both factors apply	Total nephrectomy is preferred when either factor applies
<p>Preserving renal function is important enough to justify the greater risk of complications from partial nephrectomy compared with total nephrectomy, for example, people with any of the following:</p> <ul style="list-style-type: none"> • only 1 functioning kidney • lesions on both kidneys • reduced kidney function. 	<p>Reducing the risk of complications is more important than preserving kidney function.</p>

See also the [section on information for healthcare professionals to discuss with people before and after kidney surgery](#).

1.5.5 Liaise with local renal services if there is any expectation that renal replacement therapy might be needed.

See [NICE's guideline on perioperative care in adults](#) for considerations around perioperative care and enhanced recovery programmes.

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

- active surveillance or thermal ablation
- 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.

1.5.8 For people with Bosniak 4 cysts 2 cm in diameter or larger who cannot have surgery or decline it, consider 1 of the following, taking into account the size of the cyst and its solid component:

- thermal ablation

- SABR
- active surveillance.

1.5.9 For people with Bosniak 3 cysts 2 cm in diameter or larger, consider either:

- active surveillance
- surgery if the person declines active surveillance.

Renal lesions less than 2 cm in diameter

1.5.10 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 uro-oncology multidisciplinary team.

1.5.11 For people with localised solid renal masses, or Bosniak 4 cysts, that are less than 2 cm in diameter who decline active surveillance, consider surgery or thermal ablation.

1.5.12 For people with Bosniak 3 cysts less than 2 cm in diameter who decline active surveillance, consider 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, 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

1.5.13 Offer all people who are undergoing active surveillance the opportunity to discuss and agree 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
- clarity that active surveillance is managed in secondary care
- a named healthcare professional and examples of symptoms that the person should contact them about (such as if they have blood in their urine or persistent abdominal pain).

1.5.14 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).

1.5.15 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](#).

1.5.16 Consider using the following imaging schedule, making changes if more frequent imaging is needed based on the renal lesion's and person's clinical characteristics, and the person's preferences:

- 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 have been no triggers for moving to treatment (see the [sections on managing oncocytomas and Bosniak 2F cysts](#) and on [moving from active surveillance to treatment or discharge for renal lesions 4 cm in diameter or smaller](#)).

- 1.5.17 Compare current imaging findings to the most recent previous and baseline imaging findings to see if there are changes in the renal lesion's size and other characteristics.
- 1.5.18 Consider more frequent imaging if there are changes in the renal lesion's size or other characteristics that need enhanced monitoring but are not triggers for a discussion about moving to treatment.

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

- 1.5.19 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 any of the following apply:
- the renal lesion's growth rate (or the growth rate of the solid component for Bosniak 4 cysts) is greater than 5 mm in diameter in a year
 - the renal lesion is likely to be larger than 4 cm in diameter by the time of the next scan
 - there is stage progression (based on the clinical [TNM staging system](#)) in the solid renal mass
 - the Bosniak 3 or 4 cyst progresses or changes characteristics
 - the person's clinical circumstances (for example, pregnancy or comorbidities) which made treatment unsuitable previously have since changed
 - the person wants to move to treatment, and this is still suitable for them.

- 1.5.20 Stop active surveillance and discharge the person with a solid renal mass, or Bosniak 3 or 4 cyst, 4 cm in diameter or smaller from active surveillance if treatment for RCC is no longer an option.
- 1.5.21 Consider stopping active surveillance and discharging the person with a solid renal mass, or Bosniak 3 or 4 cyst, 4 cm in diameter or smaller from active surveillance if the renal lesion remains stable for 5 years (that is, it does not meet any of the criteria in recommendation 1.5.19), taking into account the person's preferences and clinical characteristics (such as age and fitness).
- 1.5.22 When discharging a person from active surveillance because their lesion has remained stable for 5 years or treatment for RCC is no longer an option:
- explain why they are being discharged
 - explain the lack of evidence on how long active surveillance should last
 - provide examples of symptoms that the person should contact primary care about (such as if they have blood in their urine or persistent abdominal pain).

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 Referring people with complex locally advanced RCC to specialist centres

- 1.6.1 Refer people with complex [locally advanced RCC](#) (for example, people with inferior vena cava tumour thrombus) to a uro-oncology multidisciplinary team with relevant expertise in managing kidney cancer and extensive retroperitoneal surgery (for example, a urologist with speciality in kidney cancer surgery, oncologist, radiologist, and pathologist).

For a short explanation of why the committee made this recommendation and how it might affect practice, see the rationale and impact section on [referring people with complex locally advanced RCC to specialist centres](#).

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 Surgery for suspected or confirmed locally advanced RCC

1.7.1 Offer total nephrectomy to people with suspected or confirmed locally advanced RCC after:

- comprehensive imaging for diagnosis and staging and
- discussion with a uro-oncology multidisciplinary team (which may also include cardiothoracic, vascular and hepatobiliary surgeons) and
- liaising with local renal services if there is any expectation that renal replacement therapy might be needed.

See [NICE's guideline on perioperative care in adults](#) for additional considerations around perioperative care and enhanced recovery programmes.

1.7.2 Consider either of the following approaches for total nephrectomy:

- minimally invasive, when suitable based on the renal lesion's location, size and complexity, and the person's clinical characteristics
- open, if minimally invasive approaches are not suitable because, for example:
 - the lesion's 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, cannot be achieved adequately by minimally invasive approaches.

See also the [section on information for healthcare professionals to discuss with 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](#).

1.8 Information for healthcare professionals to discuss with people before and after kidney surgery

1.8.1 Before surgery for RCC, share the following information with the person:

- the approach being used (minimally invasive or open surgery)
- that adjuvant systemic anticancer therapy (SACT) might be recommended after surgery when appropriate
- 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 and does not necessarily lead to progressive chronic kidney disease (CKD)
- that if there is new mention of CKD on their medical record and this concerns them, then they should discuss this with their healthcare professional
- the kidney's role in the body and 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 [Kidney Cancer UK and GIRFT Kidney cancer fact sheet: post nephrectomy and follow up](#) and if relevant, the [section on information and education for people with CKD in NICE's guideline on chronic kidney disease](#).

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 healthcare professionals to discuss with people before and after kidney surgery](#).

Full details of the evidence and the committee's discussion are in [evidence review D: information needs](#).

1.9 Risk prediction tools for localised and locally advanced RCC

1.9.1 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](#).

1.9.2 Consider using the [VENUSS](#) tool to calculate the 5-year risk of recurrence of

papillary RCC.

- 1.9.3 Do not rely on risk prediction tools alone, and always use them with clinical judgement (including whether pathology information is available from surgical samples after nephrectomy or biopsy), when deciding:
- follow-up imaging schedules (see the [section on types of follow-up imaging and scheduling](#))
 - future treatment options (including adjuvant SACT).
- 1.9.4 If the person has had treatment for more than 1 renal lesion, use the highest calculated risk of recurrence to determine the follow-up schedule.
- 1.9.5 If relevant NICE technology appraisal guidance or NHS clinical commissioning criteria for RCC use a particular risk prediction tool to determine eligibility for systemic anticancer therapy (SACT) for people with localised or locally advanced RCC, use that tool instead of the tools in recommendations 1.9.1 and 1.9.2 if SACT is indicated.
- 1.9.6 Pathologists should include in the pathology reports:
- the tumour stage (using the TNM staging system)
 - other pathology information needed to calculate a risk score for each type of RCC, using tools selected by the local uro-oncology multidisciplinary team from recommendations 1.9.1 and 1.9.2.
- 1.9.7 Consider reporting a risk score in the pathology report using a tool selected by the local uro-oncology multidisciplinary team from recommendation 1.9.1 or 1.9.2, depending on the person's type of RCC.
- 1.9.8 Record the risk score clearly in the person's clinical records before any decisions about follow-up schedules or future treatment options are made.
- 1.9.9 When using risk prediction tools for people with localised or locally advanced RCC, share with them:
- 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 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](#).

1.10 Adjuvant SACT

1.10.1 When adjuvant SACT is an option, discuss with the person:

- the benefits and risks
- whether it might impact any future treatment decisions
- whether there are opportunities to take part in clinical trials of adjuvant SACT that are still in the research stage of development (see [recommendation 1.1.8 in the section on information for healthcare professionals to support people with suspected or confirmed RCC](#)).

For a short explanation of why the committee made this recommendation and how it might affect practice, see the [rationale and impact section on adjuvant SACT](#).

Full details of the evidence and the committee's discussion are in [evidence review D: information needs](#).

1.10.2 Pembrolizumab is recommended as an option for adjuvant treatment of RCC at increased risk of recurrence after nephrectomy, with or without metastatic lesion resection. For full details, see [NICE's technology appraisal guidance on pembrolizumab \(TA830, 2022\)](#).

1.11 Follow-up for localised and locally advanced RCC

See also [NICE's visual summary on management of localised RCC](#).

- 1.11.1 Offer follow-up to people who have completed treatment (including any adjuvant treatment) for localised or locally advanced RCC.
- 1.11.2 Offer all people who are undergoing follow-up the opportunity to discuss and agree 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 is no sign of recurrence
 - clarity that follow-up is managed in secondary care
 - a named healthcare professional
 - examples of symptoms that could indicate recurrence or metastases that the person should contact their healthcare professional about (such as if they have blood in their urine or persistent abdominal pain).

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

- 1.11.3 After completing treatment and before starting follow-up, offer estimated glomerular filtration rate (eGFR) creatinine testing.
- 1.11.4 If eGFR is less than 60 ml/minute/1.73 m², inform the person's primary care provider.

- 1.11.5 Primary care healthcare professionals should offer people with a GFR less than 60 ml/minute/1.73 m² albumin–creatinine ratio testing.

See also [NICE's guideline on chronic kidney disease](#), including the [section on referral criteria for specialist assessment when relevant](#).

Types of follow-up imaging and scheduling

- 1.11.6 Offer contrast-enhanced CT (CECT) of the chest, abdomen and pelvis at regular intervals to detect recurrence (see recommendation 1.11.9 for a suggested follow-up imaging schedule).

See also [NICE's HealthTech guidance on point-of-care creatinine devices to assess kidney function before CT imaging with intravenous contrast](#). Also see 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](#).

- 1.11.7 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.

- 1.11.8 If CECT should be avoided because the contrast agent is contraindicated, offer either:

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

- 1.11.9 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 and locally advanced RCC](#)), making changes if more frequent imaging is needed based on clinical and pathological characteristics.

Table 2 Minimum recommended follow-up imaging schedules based on risk of recurrence

Time after completing treatment	Low risk of recurrence	Intermediate risk of recurrence	High risk of recurrence
Month 3	–	–	scan
Month 6	–	scan	scan
Year 1	scan	scan	scan
Year 1.5	–	–	scan
Year 2	–	scan	scan
Year 3	scan	scan	scan
Year 4	–	scan	scan
Year 5	scan	scan	scan
More than 5 years (see the section on discharge)	discharge	scan every 2 years or discharge	scan every 2 years or discharge

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

- 1.11.10 Consider using the intermediate-risk follow-up imaging schedule in table 2 when accurate risk assessment is not possible (for example, for people who have had thermal ablation or SABR), making changes if more frequent imaging is needed based on clinical and pathological characteristics.
- 1.11.11 For people with chromophobe RCC, consider using the follow-up imaging schedules from table 2, making changes if more frequent imaging is needed based on the following clinical and pathological characteristics:
- low risk, when there is none of the following:
 - fat invasion
 - sarcomatoid differentiation
 - nodal involvement.

- intermediate risk, when there is both:
 - fat invasion
 - no sarcomatoid differentiation or nodal involvement.
- high risk, when there is either or both:
 - sarcomatoid differentiation
 - nodal involvement.

1.11.12 For people with a positive surgical margin after partial nephrectomy, consider increasing the frequency of follow-up imaging by changing to the next highest risk schedule, making changes if more frequent imaging is needed based on clinical and pathological characteristics.

Recurrence or development of metastases

1.11.13 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](#)).

1.11.14 If metastasis is confirmed, follow the recommendations for managing [advanced RCC](#) in the [sections on non-pharmacological management of metastatic RCC](#) and [SACT for advanced RCC](#).

Discharge

1.11.15 Consider discharging people from follow-up if treatment for potential future RCC recurrence or metastases is no longer an option.

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

- 1.11.17 Discuss with people who are at intermediate or high risk of recurrence whether to continue follow-up or be discharged if there is no sign of recurrence or metastases after the scan at 5 years, taking into account the person's preferences and clinical characteristics (such as age, fitness and comorbidities).
- 1.11.18 If follow-up is continued for longer than 5 years for people who are at intermediate or high risk of recurrence, consider:
- doing a scan every 2 years
 - discussing possible discharge each time there is no sign of recurrence or metastases on the scan taking into account the person's preferences and clinical characteristics (such as age, fitness and comorbidities)
 - stopping follow up and discharging the person after 10 years unless there is a reason not to.
- 1.11.19 When discharging a person from follow-up:
- explain why they are being discharged
 - provide examples of symptoms that could indicate recurrence or metastases that the person should contact primary care about (such as if they have blood in their urine or persistent abdominal pain).

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

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.

Healthcare professionals should follow our general guidelines for people delivering care:

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

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

1.12 Referring people with advanced RCC

1.12.1 Refer people with advanced RCC to a [uro-oncology multidisciplinary team](#) with

relevant expertise in managing kidney cancer (for example, a radiologist, pathologist, oncologist and urologist with speciality in kidney cancer surgery).

- 1.12.2 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](#).

1.13 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 treatment.

- 1.13.3 If relevant NICE technology appraisal guidance or NHS clinical commissioning criteria for RCC use a particular risk prediction tool that is not the IMDC to determine eligibility for systemic anticancer therapy (SACT) for people with metastatic RCC, use that tool instead of the IMDC if SACT is indicated.
- 1.13.4 Record the risk score clearly in the person's clinical records before any decisions about future treatment options are made.
- 1.13.5 When using the IMDC risk prediction tool for people with metastatic RCC, share with them:
- 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 For people with [oligometastatic cancer](#) who do not have symptoms, consider regular imaging using CT (or MRI, if CT is unsuitable) to monitor the disease before starting treatment with SACT.
- 1.14.2 For people with [widespread metastases](#), offer any non-pharmacological

interventions after, not before, starting treatment with SACT unless the person either:

- has persistent symptoms that could be controlled by kidney surgery (see recommendation 1.14.4) or
- urgently needs treatment of symptoms related to metastases (for example, in the brain, bone or spinal cord).

Treating the primary renal lesion in people with metastatic RCC

See also the [section on information for healthcare professionals to discuss with people before and after kidney surgery](#), and [NICE's guideline on perioperative care in adults](#) for considerations around perioperative care and enhanced recovery programmes.

- 1.14.3 Consider cytoreductive nephrectomy (CN) before SACT for [oncological control](#) when:
- immediate SACT is not indicated (for example, because of oligometastatic disease) and
 - surgery is suitable based on the renal [lesion's](#) and person's clinical characteristics.
- 1.14.4 Consider CN (before or after starting treatment with SACT) to manage persistent symptoms that could be controlled by surgery (for example, bleeding or pain).
- 1.14.5 Consider CN after starting treatment with SACT if:
- the disease 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.
- 1.14.6 Discuss with the person why CN is or is not an option for them at this time and

explain that in some cases this could change in the future.

Treating metastases

- 1.14.7 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 1.12.2 in the section on referring people with advanced RCC](#), on using a specialist multidisciplinary team when additional input on treating metastases is needed.

- 1.14.8 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.

See [NICE's guideline on perioperative care in adults](#) for considerations around perioperative care and enhanced recovery 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 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](#).

- 1.14.9 Denosumab is recommended as an option for preventing skeletal-related events in adults with bone metastases from solid tumours other than prostate cancer. For full details, see [NICE's technology appraisal guidance on denosumab \(TA265, 2012\)](#).

1.15 SACT for advanced RCC

See the [section on risk prediction tools for people with metastatic RCC](#) to support SACT decision making, and [recommendation 1.1.8 in the section on information for healthcare professionals to support people with suspected or confirmed RCC](#).

See also NICE's visual summaries on SACT for advanced RCC:

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

First-line treatment

- 1.15.1 For medicines recommended as options for first-line treatment of advanced RCC irrespective of IMDC risk, see NICE's technology appraisal guidance on:
- [tivozanib \(TA512, 2018\)](#)
 - [pazopanib \(TA215, 2013\)](#)
 - [sunitinib \(TA169, 2009\)](#).

1.15.2 Avelumab with axitinib is recommended as an option for untreated advanced RCC with a favourable risk as defined in the IMDC. For full details, see [NICE's technology appraisal guidance on avelumab with axitinib \(TA1120, 2026\)](#).

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

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

Subsequent treatment

1.15.4 For medicines recommended as options for previously treated advanced RCC, irrespective of IMDC risk, in some people, see NICE's technology appraisal 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 1.15.3, may also be available through the [NHS England Cancer Drugs Fund](#) via clinical commissioning policy.

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

- 1.15.5 Larotrectinib is recommended as an option through the Cancer Drugs Fund for treating locally advanced or metastatic NTRK fusion-positive solid tumours when there are no other satisfactory treatment options. For full details, see [NICE's technology appraisal guidance on larotrectinib \(TA630, May 2020\)](#).

Treatments not recommended

- 1.15.6 For medicines not recommended for treating advanced RCC, see NICE's technology appraisal guidance on:
- [pembrolizumab with axitinib \(TA650, 2020\)](#)
 - [bevacizumab, sorafenib, sunitinib and temsirolimus \(TA178, 2009\)](#).

1.16 Palliative and end of life care for people with advanced RCC

See also the [section on information for healthcare professionals to support people with suspected or confirmed RCC](#).

- 1.16.1 Discuss with people with advanced RCC what supportive and palliative care is and when it may be needed, such as to control pain and other symptoms, in line with:
- [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](#).

1.16.2 When providing palliative and end of life care to people with advanced RCC, follow the recommendations in [NICE's guidelines on end of life care for adults and care of dying adults in the last days of life](#).

For a short explanation of why the committee made these recommendations and how they might affect practice, see the [rationale and impact section on palliative and end of life care for people with advanced RCC](#).

Full details of the evidence and the committee's discussion are in [evidence review D: information needs](#).

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

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](#).

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Healthcare professionals should follow our general guidelines for people delivering care:

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

1.17 Genetic assessment to diagnose heritable renal cell carcinoma predisposition syndromes

See also [NICE's visual summary on diagnosis and management of renal cell carcinoma \(RCC\) in people with a heritable RCC predisposition syndrome](#).

- 1.17.1 Assess people with RCC to determine whether they meet any of the following criteria associated with having a [heritable RCC predisposition syndrome](#):
- aged 46 or younger (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 heritable RCC predisposition syndrome (for example, cerebellar or spinal haemangioblastoma, or spontaneous pneumothorax)
 - tumour type commonly associated with heritable RCC predisposition syndromes, for example, fumarate hydratase (FH)-deficient RCC or succinate dehydrogenase (SDH)-deficient RCC.
- 1.17.2 If a person with RCC meets any of the criteria in recommendation 1.17.1, healthcare professionals who:
- can directly request genetic testing for heritable RCC predisposition syndromes, according to local policies and procedures, should:
 - check the rare and inherited disease eligibility criteria in the [NGTD](#) to determine who should be tested for conditions that are associated with an inherited predisposition for RCC and which gene panel or panels they should be tested for, and
 - request any relevant tests following local policies and procedures, and after discussing with the person.
 - cannot directly request genetic testing for a heritable RCC predisposition

syndrome should:

- consult local policies and procedures and
- refer the person to a relevant healthcare professional who can do a detailed assessment and request testing, if needed.

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

- the expected waiting time at their centre to have the genetic test and get their results
- most people will have a negative 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
 - have implications for family members
- access to specialist genetic services for ongoing support and advice will be available if the result is positive
- it may be possible to have the test in the future if they decline it and then change their mind.

1.17.4 Refer people with RCC who are then diagnosed with a heritable RCC predisposition syndrome to a uro-oncology multidisciplinary team with expertise in managing renal lesions in this population.

1.17.5 When a person with RCC is diagnosed with a heritable RCC predisposition syndrome, discuss with them:

- 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 renal cell carcinoma \(RCC\) associated with heritable RCC syndromes](#) and [evidence review D: information needs](#).

1.18 Managing localised and locally advanced RCC in people with a heritable RCC predisposition syndrome

Localised RCC in people with a heritable RCC predisposition syndrome

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

- 1.18.1 For people with a renal lesion and a heritable RCC predisposition syndrome associated with more aggressive RCC, such as hereditary leiomyomatosis and RCC (HLRCC) syndrome which is associated with FH-deficient RCC, consider either:
- prompt surgery (see the [section on surgery for suspected or confirmed localised RCC in people with a heritable RCC predisposition syndrome](#))
 - [active surveillance](#) (using MRI or ultrasound), only if immediate surgery is not an option, followed by surgery as soon as possible.
- 1.18.2 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.

1.18.3 Consider coordinating imaging:

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

1.18.4 For people with a renal lesion and a heritable RCC predisposition syndrome that is not associated with more aggressive RCC who are undergoing active surveillance, consider using the following imaging schedule, making changes if more frequent imaging is needed based on the renal lesion's and person's clinical characteristics, and the person's preferences:

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

1.18.5 For people with a renal lesion and a heritable RCC predisposition syndrome associated with more aggressive RCC who are undergoing active surveillance, agree a more frequent imaging schedule than in recommendation 1.18.4, based on the person's clinical needs and preferences.

1.18.6 Offer all people with a heritable RCC predisposition syndrome who are undergoing active surveillance the opportunity to discuss and agree 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
- clarity that active surveillance is managed in secondary care

- a named healthcare professional and examples of symptoms that the person should contact them (such as if they have blood in their urine or persistent abdominal pain).
- 1.18.7 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 any of the following apply:
- the renal lesion is 3 cm in diameter or larger on the most recent scan
 - the renal lesion's growth rate suggests that it might be 3 cm in diameter or larger before the next scan
 - 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](#).

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

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

See [NICE's guideline on perioperative care in adults](#) for considerations around perioperative care and enhanced recovery programmes.

- 1.18.8 Consider [partial nephrectomy](#) when this can completely remove the renal lesion or lesions based on location and size, and the person's clinical characteristics.
- 1.18.9 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.

1.18.10 Consider total nephrectomy or surgically removing more tissue around the lesion during partial nephrectomy for people with syndromes associated with more aggressive 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 renal cell carcinoma \(RCC\) associated with heritable RCC syndromes](#).

Systemic anticancer therapy for localised RCC in people with a heritable RCC predisposition syndrome

See also [recommendation 1.1.8 in the section on information for healthcare professionals to support people with suspected or confirmed RCC](#).

1.18.11 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 [NICE's technology appraisal guidance on belzutifan \(TA1011, 2024\)](#).

Locally advanced RCC in people with a heritable RCC predisposition syndrome

See the section on [surgery for suspected or confirmed locally advanced RCC](#).

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

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

1.18.13 Offer all people with a heritable RCC predisposition syndrome who are undergoing follow-up the opportunity to discuss and agree 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
- that follow-up is managed in secondary care
- a named healthcare professional
- examples of symptoms that could indicate recurrence or metastases that the person should contact their healthcare professional about (such as if they have blood in their urine or persistent abdominal pain).

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.

1.18.14 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 HealthTech 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](#).

1.18.15 Within the uro-oncology multidisciplinary team, use the intermediate-risk follow-up imaging schedule (see [table 2 in the section on types of follow-up](#)

[imaging and scheduling](#)) for at least 5 years, making changes if more frequent imaging is needed based on clinical and pathological characteristics.

- 1.18.16 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 renal cell carcinoma \(RCC\) in people with heritable RCC syndromes](#).

1.19 Managing advanced RCC in people with a heritable RCC predisposition syndrome

See the [section on managing advanced RCC](#).

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 in people for whom treatment is an option. Monitoring usually involves a set schedule of imaging to observe the renal lesion or lesions, and detect any changes, over 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 specialists and other clinical services. Their responsibilities often include coordinating appointments and providing information and emotional support.

Durable partial response

A decrease of at least 30% of the sum of diameters of target measurable lesions compared with pre-treatment, observed at least 6 months after starting treatment with systemic anticancer therapy and after at least 1 follow-up imaging scan. See the [RECIST guidelines](#).

First- or second-degree relative

First- degree relative refers to a mother, father, daughter, son, sister, or brother. Second-degree relative refers to an aunt, uncle, niece, nephew, grandmother, grandfather, granddaughter, grandson, or half-sibling.

Follow-up

Monitoring in secondary care involving a set schedule of imaging to detect RCC recurrence or metastases 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 or other renal lesions. This is also known as hereditary renal cancer syndrome.

Lesion

This refers to 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'.

Metastatic RCC

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

Oligometastatic cancer

Cancer that has metastasised to a maximum of 3 sites, with a total of 5 or fewer metastatic lesions.

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

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 symptoms associated with the syndrome.

Thermal ablation

The use of heat (microwave or radiofrequency ablation) or cold (cryoablation) to treat a renal lesion.

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.

Uro-oncology multidisciplinary team

A urology- oncology multidisciplinary team consists of a group of healthcare professionals with expertise in managing kidney cancer (for example, a radiologist, pathologist, oncologist and urologist with speciality in kidney cancer surgery).

Widespread metastases

Cancer that has metastasised to more than 3 sites (that is, it has spread more widely than oligometastatic cancer).

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 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 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, thermal ablation 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), 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 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 RCC who are having thermal ablation or SABR, and have not had surgery?

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](#).

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 K: 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 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](#).

10 Thermal ablation after SACT has been started for managing metastatic RCC

What is the clinical and cost effectiveness of thermal ablation 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 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](#).

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 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](#).

Rationale and impact

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

Information for healthcare professionals to support people with suspected or confirmed renal cell carcinoma

[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 experience to make recommendations.

The committee cross referred to other NICE guidelines that cover aspects of care that aligned with the committee's experience 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.

Based on their expertise and experience, the committee agreed that it was important for people with suspected or confirmed RCC to have access to a clinical nurse specialist with training and experience in kidney cancer to provide this support and information. They agreed that it is important that the clinical nurse specialist attends multidisciplinary team meetings and acts as a link between the urology and oncology teams to ensure continuity of care. 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 acknowledged 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. In addition, people who are diagnosed with kidney cancer because of an incidental finding on a scan for a completely unrelated condition may

experience high levels of stress and anxiety because their diagnosis was unexpected. The committee noted that people will need different levels of support and that this could be provided by voluntary, community and NHS services.

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 should not be limited to their own centres, but the committee acknowledged that taking part in research in other centres may cause issues, such as 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. Existing surveys for people with kidney cancer, such as Kidney Cancer UK's patient survey, could be used or adapted.

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 suspected or confirmed RCC, more clinical nurse specialists with training in kidney cancer may need to be recruited, and some of the existing staff may need specialist training.

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

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Imaging

[Recommendations 1.2.1 to 1.2.8](#)

Why the committee made the recommendations

The committee noted that many people are referred for investigations for RCC based on incidental findings on imaging done for other reasons. In these cases, it may not be

necessary to repeat the imaging if the existing results provide sufficient information to inform the next steps.

The committee recommended using multiphase contrast-enhanced CT (CECT) first because it can successfully identify 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 some metal implants who cannot safely use MRI scanners.

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, for people with very reduced renal function or with allergies to the contrast agent being used. Another is when the renal lesion type, and so 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. CT of the chest and pelvis should then be offered to complete staging.

There are several potential results from initial imaging. When there is high confidence of a benign renal lesion, such as 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 or treatment of local symptoms outside of the cancer pathway though, such as 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. People with an angiomyolipoma made up of mostly blood vessels may also be at higher risk of complications. They also noted that there is no standard monitoring approach, and this would need to be tailored to the individual. But, if imaging is inconclusive 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.

The committee did not review evidence for the diagnosis of metastases and so were unable to make any specific recommendations on this topic. But they cross referred to other NICE guidelines that cover diagnosing brain and spinal cord metastases.

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 ^{99m}Tc-sestamibi single-photon emission computed tomography CT (SPECT/CT) may provide useful information about whether a renal lesion is more 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 made 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 done by a specialist who may not be available at all centres. But 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 so more demand for specialists. They also noted that ^{99m}Tc-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 ^{99m}Tc-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.

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Biopsy for suspected localised or locally advanced RCC

Recommendations 1.3.1. to 1.3.5

Why the committee made the recommendations

Evidence supported biopsy as a diagnostic tool for suspected RCC for people with renal lesions 4 cm in diameter or smaller to guide management decisions and, in particular, prevent an unnecessary nephrectomy for 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 renal lesion has grown into 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 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 person 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 that 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 undergoing 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 done without biopsy. So, the infrastructure and staff needed to collect and analyse the biopsy samples were not established. The recommendations would lead to more 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 because 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 is expected to lead to fewer unnecessary surgeries, with associated cost savings.

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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 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 diagnosis or treatment, or if the person 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.

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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 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 useful to determine the type of lesion. Biopsy should not be done for people with hereditary leiomyomatosis and RCC (HLRCC) syndrome. Instead, treatment of renal lesions should be expedited because of the risk of spread and the aggressive nature of lesions associated with this syndrome. But biopsy may be useful for people with Birt–Hogg–Dubé (BHD) syndrome and tuberous sclerosis complex (TSC).

How the recommendations might affect practice

The use of biopsy 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.

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Biopsy information for healthcare professionals to discuss with people with suspected RCC

[Recommendation 1.3.13](#)

Why the committee made the recommendation

Based on evidence supporting people's information needs about biopsy and its diagnostic accuracy, 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. They also noted that biopsy results sometimes differed from pathology results obtained from samples taken during or after surgery. But they stressed that this should not be seen as a reason not to have a biopsy because the situation is rare, and that if there was concern about the changing characteristics of a lesion believed to be benign then a biopsy can be repeated. 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 undergoing 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 is expected to reduce unnecessary surgeries, with associated cost savings.

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Managing oncocytomas and Bosniak 2F cysts

[Recommendations 1.4.1 to 1.4.9](#)

Why the committee made the recommendations

There was no evidence on active surveillance for oncocytomas or Bosniak 2F cysts of any size. So, the committee 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 should the suspected oncocytoma turn out to be a malignant lesion instead. When people have symptoms, such as haematuria (blood in urine), that are deemed to be caused by the renal lesion, treating the lesion should be discussed regardless of its size or growth rate.

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 to re-confirm the diagnosis. Even if biopsy results indicate that the lesion is likely to be an oncocytoma, removing it 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 people may prefer to stay on active surveillance or have the oncocytoma removed or otherwise treated. The committee agreed that oncocytic renal neoplasms of low malignant potential, not otherwise specified, should be offered the same management options as oncocytomas because they are generally low risk and can be monitored using

active surveillance.

The committee did not review evidence about treatment options for oncocytomas and so were unable to make recommendations on this. But in their experience these would likely involve surgery to remove the oncocytoma or thermal ablation to destroy it.

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. So, treatment, such as 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 RCC.

Stopping 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. They agreed that if the person's lesion was malignant, it is likely that it would be detected 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, active surveillance becomes unnecessary and the person can be discharged when there are no suitable treatment options (for example, because the person is too frail) for local symptoms, or RCC if developed in the future.

How the recommendations might affect practice

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

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Shared decision making about non-

pharmacological management of 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 between non-pharmacological options for suspected or confirmed localised RCC and Bosniak 3 and 4 cysts is based on the evidence and the committee's experience. The committee noted that healthcare professionals should explain to people that there may be a lower risk of local recurrence with surgery compared to thermal ablation and stereotactic ablative radiotherapy (SABR). They were aware that risk of recurrence can also vary depending on the type of surgery or ablation, and lesion characteristics. But the evidence review was not designed to look at this specifically. By highlighting these points, the committee hope to improve the ability of people with RCC to choose a treatment option for themselves with support from their healthcare professional.

How the recommendation might affect practice

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

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Surgery, thermal ablation, active surveillance or SABR

Recommendations 1.5.2 to 1.5.12

Why the committee made the recommendations

The evidence on non-pharmacological interventions for people with localised 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 Bosniak 4 cysts are more likely to be malignant than Bosniak 3 cysts. They agreed that, in many cases, management of Bosniak 4 cysts should be similar to management of solid masses. But they noted the lack of specific evidence about how to manage them. The committee used their expertise and experience to extrapolate from the evidence to make recommendations based on size and type of renal lesion, and included people with Bosniak 3 and 4 cysts in some recommendations along with people with solid renal masses.

The committee agreed that many factors need to be taken into account when choosing between non-pharmacological management options for localised solid renal masses and Bosniak 3 or 4 cysts. They made a recommendation covering some key points to help with decision making. The committee agreed that there should be biopsy confirmation of malignancy before using thermal ablation or SABR. But they noted that there may be rare situations when thermal ablation or SABR are used when biopsy has been attempted multiple times without confirmation of malignancy, and malignancy is strongly suspected by the multidisciplinary team.

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 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 too. This is because 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 are more post-operative complications with partial nephrectomy than total nephrectomy. This aligned with the committee's experience. Because partial nephrectomy is more complex than total nephrectomy, the committee also thought that it could lead to more intra-operative complications, such as bleeding. They noted that robotic assistance is preferable for partial nephrectomy because it allows the surgeon to be sufficiently dexterous. When total nephrectomy is used, the committee agreed that minimally invasive techniques are preferable because they result in less blood loss and a quicker recovery.

The committee 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 using 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. The committee noted that, in addition to blood tests, there are several imaging modalities to assess renal function depending on the circumstances and agreed that it would not be possible to specify which method to use.

The committee were unable to specify a maximum renal lesion size for partial nephrectomy, because the evidence was too uncertain. But they agreed that factors such as the lesion's size, location and complexity, and the person's clinical characteristics, should be considered. The committee were aware of tools usually used in research settings for measuring renal lesion complexity (such as R.E.N.A.L and PADUA) that might be help decision making, but they did not review the evidence for these tools.

The committee also noted the importance of liaising with local renal services when there are any expectations that a person with RCC may need dialysis after treatment so they can access this treatment quickly.

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 also higher for thermal ablation than total nephrectomy. They also noted that thermal ablation may need to be repeated for renal masses larger than 4 cm in diameter.

Evidence on SABR was limited. 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. So, the committee recommended that SABR should only be used when thermal ablation is not an option for solid renal masses that are 2 to 4 cm in diameter. They did not include this ranking of treatments for solid renal masses larger than 4 cm in diameter to align with the draft NHS England commissioning policy for SABR for localised RCC. The committee also noted that the effectiveness of SABR is uncertain for lesions larger than 7 cm in diameter, so specified that it should only be used for lesions smaller than 7 cm. The committee made a recommendation for research to address the gap in the evidence base around the effectiveness of SABR in comparison to surgical interventions, thermal ablation and active surveillance.

Based on the evidence, the committee agreed that surgery should be the first treatment

option for people with localised solid renal masses, or Bosniak 4 cysts, that are 2 cm in diameter or larger 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). Or 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 4 cysts that are 2 cm or larger in diameter. But for people with Bosniak 4 cysts, the committee emphasised that the size of the solid component is key for determining treatment options. For people with Bosniak 3 cysts 2 cm in diameter or larger the committee did not recommend thermal ablation or SABR because these lesions lack the solid tissue component needed for biopsy and these treatments.

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 treatment options compared with active surveillance. 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. Without biopsy confirmation of malignancy, active surveillance is still an option for Bosniak 4 cysts of this size. But the committee noted that Bosniak 4 cysts with biopsy confirmation of malignancy should be managed based on the size of their solid component and so, in addition to surgery, other management options such as SABR and thermal ablation may also be suitable.

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 4 cysts, lacks a large enough solid component. In contrast to larger renal lesions, active surveillance may be the best management option for people with lesions this small. For people with Bosniak 3 cysts less than 2 cm in diameter, thermal ablation is not an option because they lack the solid component needed for this treatment.

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 centres with more expertise in these types of procedures. 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 had 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. In particular, the use of SABR will require sign off in a uro-oncology multidisciplinary team meeting with the necessary expertise.

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Active surveillance information, imaging types and scheduling

[Recommendations 1.5.13 to 1.5.18](#)

Why the committee made the recommendations

No evidence on active surveillance approaches (methods, duration, imaging frequency, and when to discharge) was identified. The committee relied on their expertise and experience to make 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 agree a personalised care plan with their healthcare professional to help them understand their imaging schedule and how to seek help if 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 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. So, it could increase imaging, but this may be balanced by fewer people having other treatments such as surgery.

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

[Recommendations 1.5.19 to 1.5.22](#)

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 experience to make 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.

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. They noted that it may be helpful to explain the lack of evidence underlying the duration of active surveillance and to let them know when and how to seek help if needed. 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.

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Referring people with complex locally advanced RCC to specialist centres

[Recommendation 1.6.1](#)

Why the committee made the recommendation

The committee agreed that it is important that people with complex locally advanced RCC have their cases discussed and managed by a uro-oncology multidisciplinary team with specialist expertise to ensure that they have access to the expertise needed to provide their treatment. This team may take over the person's care completely, or alternatively, manage their surgery with oncology treatment carried out locally.

How the recommendation might affect practice

This recommendation reflects current good practice but may help standardise practice where it varies.

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Surgery for suspected or confirmed locally advanced RCC

[Recommendations 1.7.1 and 1.7.2](#)

Why the committee made the recommendations

Most of the evidence evaluated surgical techniques for total nephrectomy for people with locally advanced RCC. 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 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 uro-oncology multidisciplinary team, which may also include expertise from specialities such as cardiothoracic, vascular and hepatobiliary surgeons. In addition, the committee noted the importance of liaising with local renal services when there any expectations that a person with RCC may need dialysis after surgery so they can access this treatment quickly.

The committee agreed that it is very important that people with locally advanced RCC have surgery in a timely manner to reduce the risk of progression to metastatic disease. 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 for 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 for people who have locally advanced RCC and inferior vena cava thrombus, and this may not currently be readily available in all centres.

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Information for healthcare professionals to discuss with people before and after kidney surgery

[Recommendation 1.8.1](#)

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. So, they recommended some key points for healthcare professionals to discuss, or share in another format, 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.

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.

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Risk prediction tools for localised and locally advanced RCC

Recommendations 1.9.1 to 1.9.9

Why the committee made the recommendations

The evidence supported the usefulness of some risk prediction tools in classifying people with non-metastatic RCC into different risk groups for recurrence and that this could be used to help decide follow-up schedules and future treatment options. There was only evidence for the most common RCC subtypes, namely clear cell RCC, papillary RCC, and chromophobe RCC. Clear cell RCC had the most evidence.

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 people 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. So, the committee were not able to recommend this tool and instead made a recommendation for research on the development of a tool appropriate for this subtype. The committee did not recommend using the Leibovich 2018 tool because it predicted progression-free survival rather than recurrence.

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

People included in the studies had a 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 SABR or thermal ablation rather than nephrectomy, the committee drafted a recommendation for research on risk prediction tools for people with localised 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 undergoing 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 SACT may depend on risk stratification using a specific risk prediction tool stated in NICE technology appraisal guidance or NHS commissioning criteria. So, they 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 pathology reports containing all the pathology information needed to calculate risk of recurrence using the recommended 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 follow-up schedules or future treatment options. They 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 these decisions.

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 a standardisation of tools used 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.

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Adjuvant SACT

[Recommendation 1.10.1](#)

Why the committee made the recommendation

The committee highlighted that healthcare professionals should tell people with RCC that although adjuvant SACT may be an option for them, its use after surgery for localised or locally advanced RCC may affect which treatments they can have in the future. This is because prior immunotherapy use may affect eligibility for future immunotherapy if they developed metastatic disease. People with RCC may also be able to take part in clinical trials of adjuvant SACT that are still in development, although if it is a randomised trial then they may not be assigned to the group receiving the new treatment.

How the recommendation might affect practice

This recommendation reflects current good practice but may help standardise practice where it varies.

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Follow-up for localised and locally advanced RCC

[Recommendations 1.11.1 to 1.11.19](#)

Why the committee made the recommendations

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

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 completing treatment but before starting follow-up 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 for follow-up imaging.

Types of follow-up imaging and scheduling

A very small amount of uncertain evidence (because studies were at 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, 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 follow-up imaging. They used their clinical expertise, experience and awareness of other NHS England guidance (such as the [Getting it Right the First Time \(GIRFT\) 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). So, the recommended schedule 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 after removing the tumour. People who have 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. So, they recommended using the intermediate risk of recurrence schedule for these people as a minimum starting point.

No risk prediction tools were recommended for people with chromophobe RCC. But the committee agreed that chromophobe RCC generally has a lower risk of recurrence than other types of RCC. So, the low risk of recurrence follow-up schedule is usually appropriate for people with this type of RCC. But the committee noted that the risk of recurrence may be increased by several factors. When these are present, the intermediate- or high-risk schedules may be more appropriate.

The committee also noted that a positive surgical margin after partial nephrectomy increases a person's risk of recurrence compared to not having a positive surgical margin. So, they recommended that these people should have their risk level increased by one risk category. So, for example, if the person was assigned to the low-risk category for clear cell RCC recurrence using a risk tool, but had a positive surgical margin, they would move to the intermediate-risk category for follow-up.

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 for confirmation.

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 if any recurrence or metastases can be treated. The committee agreed that healthcare professionals 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 follow-up was stressful for some people while others find continued scans reassuring. So, they 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 or develop metastases after this time and could safely be discharged. In contrast, people at intermediate or high risk may benefit from a longer follow-up period. This is because even though their absolute risk of recurrence decreases over time, it is likely to remain higher than those classified as low risk 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, and discharging the person at 10 years unless there is a reason not to. This could be because the person is still very young, or they want to continue having follow-up despite counselling about how they are now at low risk of recurrence or metastases.

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 follow-up imaging is cross sectional, mainly CECT. 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 during follow up. This is standard practice and should not have any implications on how often services are accessed.

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Referring people with advanced RCC

[Recommendations 1.12.1 and 1.12.2](#)

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. Identifying suitable treatment options can be very complex because these decisions are based on many factors. Factors include the person's performance status, number and location of metastases, baseline risk group, general health and comorbidities. The committee 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 multidisciplinary teams in places where this is not happening.

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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 SACT for adults with clear cell metastatic 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, because 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 treatment, 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. So, they 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 future treatment options. To support shared decision making and reduce confusion, the committee included a recommendation that people with metastatic RCC are given 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 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 1.14.8](#)

Why the committee made the recommendations

There was limited low to very low-certainty evidence comparing non-pharmacological interventions before 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. So, although this section of the guideline covers advanced 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 multiple observational studies) whether CN before SACT was better than SACT alone. The committee agreed, based on their expertise and experience, that people with oligometastatic RCC who do not have symptoms may benefit from surveillance before SACT when there is a low risk of progression and the disease is judged to be stable. Using surveillance in these cases will delay starting treatments that may have side effects that negatively affect people's quality of life until SACT is clinically indicated. They also agreed that people with widespread metastases are likely to benefit most from immediate treatment when SACT is indicated. So, any non-pharmacological interventions should be used after, not before, SACT has been started. But urgent treatment for symptoms, such as metastatic spinal cord compression, should not be delayed to start SACT.

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 or 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 characteristics of the lesion (or lesions), and of the person, would determine whether CN would be effective, and that this level of information could not be determined from the evidence. They identified some factors to help healthcare professionals decide whether someone would benefit from CN after SACT had started. They also agreed that if CN is not an option, and so not offered, this should be explained to the person. This is because not removing the primary tumour may be difficult for some people to cope with, and understanding the reasons for this may help them come to terms with the situation.

There was no evidence about other non-pharmacological interventions for treating the primary mass for 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 for 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 RCC metastases, 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.

Because of the lack of evidence, the committee made a recommendation for research on the clinical and cost effectiveness of metastasectomy in people with metastatic RCC who have had their primary mass removed. They also made a recommendation for research on

thermal ablation of metastases after SACT has been started for people with metastatic RCC.

How the recommendations might affect practice

Most people with metastatic RCC currently have SACT before a non-pharmacological intervention, and these recommendations support that. Small proportions of people have no non-pharmacological interventions at all, and these recommendations are not expected to change that. But they could provide some standardisation across settings.

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Palliative and end of life care for people with advanced RCC

[Recommendations 1.16.1 and 1.16.2](#)

Why the committee made the recommendation

The committee agreed that most of the principles underlying information sharing, communication and shared decision making in the section on information for healthcare professionals to support people with suspected or confirmed RCC also applied for people with advanced RCC. But these people and their healthcare professionals would also need to be aware of supportive and palliative care options when these become relevant. So, they cross referred to other NICE guidance on these topics.

How the recommendation might affect practice

It is standard practice to ensure that palliative care is discussed with people when appropriate, and that the relevant information and sources of support are given to them. There is currently some variation in what information is provided. The recommendations are expected to standardise practice by signposting to all the relevant existing NICE guidance.

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Genetic assessment to diagnose heritable RCC predisposition syndromes

Recommendations 1.17.1 to 1.17.5

Why the committee made the recommendations

Genetic testing criteria for heritable 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 there was no evidence review to determine factors associated with these syndromes. 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', which is when 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 that, before testing a person with RCC for a heritable RCC predisposition syndrome, 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 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 specialities. The committee also recognised the importance of ensuring that these newly

diagnosed people are given 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 RCC predisposition syndromes vary across the UK. These recommendations have been written to accommodate this and any changes that may occur in the future. So, they are 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.

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

[Recommendations 1.18.1 to 1.18.7](#)

Why the committee made the recommendations

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

Because people with heritable 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 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 VHL syndrome, BHD syndrome and TSC, could have active surveillance until the lesion is 3 cm in diameter before moving to treatment.

People with a heritable RCC predisposition syndrome have 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 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 for these people as for people with sporadic RCC (RCC occurring without 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 imaging schedule than people with syndromes associated with less aggressive RCC. But were unable to specify exactly what this should be.

The information to give people 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 in diameter as the lesion size cut off to reflect the threshold in recommendation 1.18.2.

How the recommendations might affect practice

Managing heritable RCC predisposition syndromes does not vary widely across the UK. It

is standard practice to use active surveillance for people with a heritable RCC predisposition syndrome unless they have a syndrome associated with aggressive RCC. So, 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 RCC predisposition syndromes 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 appointment duplication.

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

[Recommendations 1.18.8 to 1.18.10](#)

Very little evidence was identified for this review, and it was of poor quality because only non-comparative studies were found. So, the committee used their expertise and experience to make 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, to preserve renal function. The importance of preserving renal function outweighs the risk of recurrence or other complications 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 had thermal ablation or SABR. This is because of the renal tissue inflammation that these procedures can cause. For people with syndromes associated with more aggressive disease, such as HLRCC, it is more important to fully remove the lesion. So, total

nephrectomy or removing more tissue around the lesion is recommended.

How the recommendations might affect practice

Managing heritable RCC predisposition syndromes does not vary widely across the UK. It is standard practice to use nephron-sparing treatments for people with a heritable RCC predisposition syndrome unless they have a syndrome associated with aggressive RCC. So, 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 1.18.12 to 1.18.16](#)

Why the committee made the recommendations

No evidence on follow-up strategies for people with a heritable RCC predisposition syndrome after treatment of an RCC was identified. So, the committee used their expertise and experience to make consensus recommendations. The information given is similar to what is given to people with sporadic RCC during follow-up.

The committee recommended abdominal MRI to reduce radiation exposure. This is because people with RCC who have a heritable RCC predisposition syndrome will have long-term imaging to monitor these renal lesions, and 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 of recurrence follow-up imaging schedule for people who have had treatment for sporadic RCC should be used as a starting point for these people too and continued for at least 5 years. But the committee were aware that people with RCC who have a heritable RCC predisposition syndrome are also under the care of other healthcare professionals who monitor their 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. The committee highlighted, though, that the situation may be more complex than this, because people with hereditary 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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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 full details of the evidence and the guideline committee's discussions, see the [evidence reviews](#). You can also find information about how the guideline was developed, including [details of the committee](#).

NICE has produced [tools and resources to help you put this guideline into practice](#). For general help and advice on putting our guidelines into practice, see [resources to help you put NICE guidance into practice](#).

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