

## Kidney Cancer

### Consultation on draft guideline - Stakeholder comments table 17/09/2025 – 28/10/2025

Stakeholder	Document	Page No	Line No	Comments	Developer's response
Action Kidney Cancer	Guideline	General	General	Refer to patient/s, not person/people with kidney cancer throughout.	Thank you for your comment. Throughout all NICE guidance we aim to use person-centred language and avoid labelling people. Therefore, NICE prefer to use the terms 'person' and 'people' over 'patient(s)'. Please see the <a href="#">NICE style guide on Talking about people</a> for more information.
Action Kidney Cancer	Guideline	General	General	Quality of life issues and supportive care are not fully addressed throughout the guidelines.	Thank you for your comment. We included quality of life outcomes in the outcomes of interest in many of our evidence review protocols but found no or very limited evidence on this. However, the committee discussed quality of life impact extensively, with the lay members of the committee providing their expertise on this. The committee made a recommendation for clinical nurse specialist support for all people with suspected or confirmed kidney cancer, throughout the duration of the care pathway. This should ensure a point of contact for supportive care and concerns around quality of life. The committee also recommended that people should be provided with ongoing information and support based on a personalised assessment of what the person needs at different points throughout their care. We have also cross-referred to other useful NICE guidance to support these recommendations.
Action Kidney Cancer	Guideline	General	General	Healthcare professionals should tailor treatment plans to each patient's needs and lifestyle for a more personalised service.	Thank you for your comment. This principle is covered by a section of the NICE guideline on <a href="#">Patient experience in adult NHS services</a> on <a href="#">Tailoring healthcare services for each patient</a> . We cross refer to this guideline in the general information section in a recommendation that talks about providing information and support based on a personalised assessment.
Action Kidney Cancer	Guideline	004	007	Healthcare professionals and Trusts should signpost patients to kidney cancer patient support	Thank you for your comment. In the overview and in the information and support sections of the guideline, we cross refer to NICE's <a href="#">Patient experience in adult NHS services</a>

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				organisations for information and support throughout their cancer journey.	<p><a href="#">guideline</a> (CG138), and explicitly signpost to the sections on providing information. This section includes a recommendation clearly stating that all people receiving care through NHS services should be informed about where they can find additional information and support through national and local groups (see recommendation 1.5.18 in CG138).</p> <p>We agree that informing people with kidney cancer about where they can find additional information and support through charities is very important, which is why we think it is best to refer people to the full-length guidelines focused on patient experience and written by experts rather than just having a small amount of advice in this guideline.</p> <p>We do not routinely signpost to individual organisations for information and support within guidelines (with the exception of specific documents that have been developed in partnership with the NHS). However, we have listed some specific charities that provide information and support for people with kidney cancer in the 'information for the public' tab on NICE's webpage for the guideline. We have added a cross reference to this section to the start of the Information and support section of the guideline.</p>
Action Kidney Cancer	Guideline	008	006	Futureproofing: Consider mentioning PET/CT scan using <sup>89</sup> Zr-DFO-girentuximab to diagnose ccRCC.	Thank you for your comment. The use of PET-CT scans for the detection and diagnosis of renal lesions was not evaluated as part of this guideline and is out of scope of this current piece of work. Therefore, no changes were made to the recommendations. However, if you have evidence to support its inclusion in future work, please can you share it with us by submitting a topic suggestion through our topic

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					<p>prioritisation process. See here for information on the prioritisation process and the submission form:</p> <ul style="list-style-type: none"> <li>• <a href="#">Prioritising our guidance topics</a></li> <li>• <a href="#">Topic suggestion</a>.</li> </ul>
Action Kidney Cancer	Guideline	008	006	<p>What is SPECT/CT and how frequently is it used for the diagnosis of RCC? How many hospitals have this facility/capability in England? Is SPECT/CT needed in the guidelines? SPECT/CT is not in routine use and it has not been validated for the diagnosis of RCC:</p> <p><a href="https://www.urotoday.com/index.php?option=com_content&amp;view=article&amp;id=163351:99mtc-tc-sestamibi-spect-ct-for-the-diagnosis-of-kidney-tumours-a-multi-centre-feasibility-study-multi-mibi-study&amp;catid=1161&amp;utm_source=newsletter_14654&amp;utm_medium=email&amp;utm_campaign=uroalerts-oncology-weekly&amp;aid=12421112">https://www.urotoday.com/index.php?option=com_content&amp;view=article&amp;id=163351:99mtc-tc-sestamibi-spect-ct-for-the-diagnosis-of-kidney-tumours-a-multi-centre-feasibility-study-multi-mibi-study&amp;catid=1161&amp;utm_source=newsletter_14654&amp;utm_medium=email&amp;utm_campaign=uroalerts-oncology-weekly&amp;aid=12421112</a></p>	<p>Thank you for your comment. The committee confirmed that 99mTc-sestamibi SPECT/CT is widely available in the UK and will usually be available in hospitals that have a nuclear medicine department. It is commonly used in current practice for the identification and localisation of parathyroid adenomas, and to detect perfusion abnormality in the heart. Research has been carried out on the use of this imaging technique for the diagnosis of RCC and this was examined as part of evidence review I2. The committee are also aware of the MULTI-MIBI clinical trial that you refer to in your comment.</p> <p>The committee stressed that the recommendation for use of 99mTc-sestamibi SPECT/CT in diagnosis will only be relevant to a small population of people who have already had CT or MRI where more information on whether the lesion is an oncocytic renal lesion or are unable to have a biopsy is needed.</p>
Action Kidney Cancer	Guideline	008	023	<p>Delays in diagnostic waiting times and staffing issues can impact the patient pathway, potentially affecting compliance with the 28-day faster diagnosis standard.</p>	<p>Thank you for your comment. The committee acknowledge that there may be diagnostic waiting times and staffing issues impacting on the patient pathway, but they do not expect that the recommendations on imaging would cause any extra delays. Most of the recommendations are routine practice and priority has been given to imaging modalities that are more readily available. Therefore, no changes have been made to the recommendation.</p>
Action Kidney Cancer	Guideline	009	001	<p>Consider factors such as cost, local expertise, staff availability, infrastructure, and waiting times when</p>	<p>Thank you for your comment. The committee discussed how the recommendations for biopsy might affect practice</p>

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					types. However, there is currently a gap in care for people with renal cell carcinoma (RCC), as biopsies are routinely available and used to inform diagnosis and treatment decisions in many other tumour types, but this is not established practice for RCC.
Action Kidney Cancer	Guideline	009	003	We assume these will be CT image-guided biopsies? Is this feasible in all hospitals?	Thank you for your comment. The committee did not specify in the recommendations which imaging modality would be used to guide the biopsy. They agreed that, in their experience, biopsies are not limited to CT-guided but are more frequently guided by ultrasound in practice. They agreed that CT only-guided biopsies would not be feasible in all hospitals and agreed to keep the recommendations inclusive of all appropriate imaging modalities.
Action Kidney Cancer	Guideline	014	026	We are uncomfortable with this recommendation. Surely, active surveillance should continue to give the patient peace of mind that they are being cared for, even if treatment is not an option? Patients are likely to feel abandoned by the health care system if they do not receive regular follow-up visits. Bosniak cysts could also become malignant over time, and these need to be monitored.	<p>Thank you for your comment. The committee agreed that active surveillance refers to monitoring when treatment is possible but declined or delayed. When treatment for RCC, if the person were to develop it, is no longer an option, active surveillance is no longer possible based on this definition, and the person should be discharged from this form of monitoring.</p> <p>The person with an oncocytoma or Bosniak 2F cyst will still be able to seek help through other routes, for example, via their GP if they develop symptoms, but they will no longer be eligible for monitoring under the active surveillance pathway. They would also be able to access palliative care.</p> <p>The committee retained the recommendation to discharge the person with an oncocytoma or Bosniak 2F cyst if treatment for RCC, should they develop it, is no longer possible but expanded this to include mention of local symptoms. Also, additional clarification was included in the</p>

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					definition of active surveillance in the 'terms used in this guideline' section to explain that active surveillance is only an option when treatment is still possible.
Action Kidney Cancer	Guideline	016	011	Is surgery the preferred option for renal lesions 2 cm in diameter and larger? Lesions less than 4 cm and indolent/slow growing should undergo active surveillance, unless a biopsy proves the lesion is an aggressive high-grade cancer.	<p>Thank you for your comment. The committee saw evidence (reviews A and B) about the effectiveness of surgery compared with thermal ablation, stereotactic ablative radiotherapy (SABR) and active surveillance. The evidence suggested that surgery may result in improved recurrence and survival outcomes compared with the non-surgical interventions, and the committee agreed that surgery would usually be the preferred intervention to think about for people with localised solid renal masses that are 2 cm in diameter or larger. They included factors that should be taken into account when deciding between suitable management options for localised RCC (see the first recommendation under the heading 'Surgery, thermal ablation, active surveillance or SABR') for a particular individual. The committee noted that type of renal lesion, which would encompass histological type and grade, is included as a consideration in this recommendation.</p> <p>The committee have recommended active surveillance as an option for people with renal masses between 2 and 4 cm in diameter who cannot have surgery or decline it. In addition, for people with localised solid renal masses that are less than 2 cm in diameter active surveillance is recommended as the first option over surgery and thermal ablation.</p>
Action Kidney Cancer	Guideline	017	017	Should malignancy and grade be confirmed with a biopsy prior to surgery (see above comment)?	Thank you for your comment. The biopsy section of the guideline covers when biopsy should be conducted before treatment, which includes surgery. This varies depending on the size of the lesion and whether having biopsy will

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Action Kidney Cancer	Guideline	019	006	The sharing of health records between primary and secondary care is essential to ensure that follow-up appointments and scans are not overlooked. Consistency in record-keeping is particularly important when a second opinion is required. Additionally, it is important to address how patients can access their medical records in the context of the 10-year health plan.	<p>Thank you for your comment. The committee agreed that the sharing of health records between primary and secondary care is essential, but they noted that this is covered by an existing recommendation in <a href="#">NICE's guideline on patient experience in adult NHS services</a> (CG138).</p> <p>The kidney cancer guideline cross refers to CG138 in the information and support section of the guideline and explicitly signpost to the section on <a href="#">continuity of care and relationships</a>. This includes a recommendation clearly stating that all healthcare professionals should ensure clear and timely exchange of patient information to other healthcare professionals and social care professionals particularly at the point of any transitions in care (see recommendation 1.4.3 in CG138). To avoid duplication with other NICE guidelines, which can lead to inconsistencies in care for patients when guidelines are updated at different points in time, the committee were unable to add the requested recommendation.</p> <p>How patients can access their medical records in the context of the 10-year health plan is a general issue across the NHS and is not within the scope of this guideline or NICE to address.</p>

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Action Kidney Cancer	Guideline	025	015	The potential risks (AEs) and benefits of adjuvant treatment need to be discussed with the patient to enable them to make an informed decision about whether to proceed. In addition, prior use of immunotherapy may affect a patient's eligibility for future immunotherapy treatment, as physicians generally do not prescribe it more than once. Patients considering adjuvant immunotherapy should be informed if this choice would prevent them from receiving further immunotherapy should their disease progress.	Thank you for your comments. The committee agree that it is important to discuss the impact on future treatments when considering adjuvant SACT. Therefore, they made a new recommendation in the Adjuvant SACT section to encourage this discussion and included the benefits and harms and impact on future treatment options.
Action Kidney Cancer	Guideline	026	004	The sharing of health records between primary and secondary care is essential to ensure that follow-up appointments and scans are not overlooked. Consistency in record-keeping is particularly important when a second opinion is required. Additionally, it is important to address how patients can access their medical records in the context of the 10-year health plan.	<p>Thank you for your comment. The committee agreed that the sharing of health records between primary and secondary care is essential, but they noted that this is covered by an existing recommendation in <a href="#">NICE's guideline on patient experience in adult NHS services</a> (CG138).</p> <p>The kidney cancer guideline cross refers to CG138 in the information and support section of the guideline and explicitly signpost to the section on <a href="#">continuity of care and relationships</a>. This includes a recommendation clearly stating that all healthcare professionals should ensure clear and timely exchange of patient information to other healthcare professionals and social care professionals</p>

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					<p>particularly at the point of any transitions in care (see recommendation 1.4.3 in CG138). To avoid duplication with other NICE guidelines, which can lead to inconsistencies in care for patients when guidelines are updated at different points in time, the committee were unable to add the requested recommendation.</p> <p>NICE is unable to address how patients will access their medical records in the context of the 10-year health plan as this is beyond our remit.</p>
Action Kidney Cancer	Guideline	026	021	Mention here whether it is primary or secondary care that monitors eGFR following nephrectomy.	Thank you for your comment. The committee highlighted that assessment of eGFR is carried out after treatment in secondary care prior to beginning follow up imaging. However, they agreed that if eGFR is low (less than 60 ml/min/1.73m <sup>2</sup> ), primary care should be informed and ACR testing should thereafter be carried out in primary care. The recommendations have been amended to reflect these points.
Action Kidney Cancer	Guideline	028	022	Further clarification is needed regarding the rationale for discharging patients who experience recurrence or metastases. For example: 'Consider discussing discharge from follow-up after RCC recurrence or development of metastases with the patient if treatment is not feasible due to comorbidities or at the patient's request.' It is important to outline what safeguards exist for vulnerable individuals and to clarify why these patients may not be monitored through active surveillance. Patients should be given the choice for active surveillance, so they do not feel abandoned by the health service.	Thank you for your comment. These recommendations refer to follow up imaging after treatment with curative intent with the aim of detecting recurrence or metastases to allow for early treatment. When treatment for RCC recurrence or metastases is no longer possible then monitoring in this way no longer has a purpose and patients should be discharged. However, the committee noted that symptoms management may be possible even when treatment for the RCC or metastases is no longer an option. They agreed that patients should be informed about why they are being discharged and to contact their GP if they have symptoms. Therefore, an additional recommendation has been added to the section on follow-up for localised and locally advanced RCC to state that healthcare professionals

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					<p>should explain to the patient why they are being discharged and inform them to contact primary care if they have any problematic symptoms. They would also be able to access palliative care.</p> <p>The committee noted that active surveillance refers to monitoring when treatment is possible but declined or delayed. Active surveillance is no longer possible, based on this definition if the person is unable to have any treatment. It is not used for monitoring people who have reached the follow up stage of the treatment pathway and can no longer have any treatments. The committee included additional clarification in the definition of active surveillance in the 'terms used in this guideline' section to explain that active surveillance is only an option when treatment is still possible.</p>
Action Kidney Cancer	Guideline	029	019	'(..... and urologist with speciality in <b>kidney</b> cancer surgery).'	Thank you for your comment. The committee discussed this and agreed to make the amendment suggested.
Action Kidney Cancer	Guideline	030	010	Refer patient to a specialist kidney cancer patient organisation for information, support and advice.	Thank you for your comment. The committee agreed that informing people with kidney cancer about where they can find additional information and support is very important and noted that this is covered by <a href="#">NICE's guideline on patient experience in adult NHS services</a> (CG138) that is cross referred to from the Information and support sections of the kidney cancer guideline. The <a href="#">information</a> section of CG138 includes a recommendation clearly stating that all people receiving care through NHS services should be informed about where they can find additional information and support through national and local groups (see recommendation 1.5.18 in CG138).

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Action Kidney Cancer	Guideline	034	001	Guideline needed for sequencing of SACT for advanced/metastatic RCC: <a href="https://www.esmo.org/guidelines/living-guidelines/esmo-living-guideline-renal-cell-carcinoma/renal-cell-carcinoma-esmo-guidelines-slide-set">https://www.esmo.org/guidelines/living-guidelines/esmo-living-guideline-renal-cell-carcinoma/renal-cell-carcinoma-esmo-guidelines-slide-set</a>	Thank you for your comment. Sequencing is outside the scope of technology appraisal (TA) incorporation. Please see the <a href="#">Interim process and methods statement for bringing together NICE guidance</a> for more information about NICE's approach to including NICE technology appraisal recommendations in guideline topic areas. However, the visual summaries of the TAs will provide clinicians with all possible treatment options at each stage without sequencing the SACT options.
Action Kidney Cancer	Guideline	034	001	Guideline needed for SACT for rare subtypes of RCC, e.g. papillary, chromophobe, collecting duct, RMC etc. There is evidence of different treatment schedules for papillary, chromophobe, collecting duct and RMC: <a href="https://www.esmo.org/guidelines/living-guidelines/esmo-living-guideline-renal-cell-carcinoma/renal-cell-carcinoma-esmo-guidelines-slide-set">https://www.esmo.org/guidelines/living-guidelines/esmo-living-guideline-renal-cell-carcinoma/renal-cell-carcinoma-esmo-guidelines-slide-set</a>	Thank you for your comment. We have not looked at how or when to use SACT as part of this work. We have incorporated existing TAs into the guideline. Please see the <a href="#">Interim process and methods statement for bringing together NICE guidance</a> for more information about NICE's approach to including NICE technology appraisal recommendations in guideline topic areas.
Action Kidney Cancer	Guideline	034	001	Guideline needed for the use of TKI treatment breaks (ref. STAR trial <a href="https://www.annalsofoncology.org/article/S0923-7534(21)04408-2/fulltext">https://www.annalsofoncology.org/article/S0923-7534(21)04408-2/fulltext</a> ). Also consider treatment breaks and personalised treatment schedules for immunotherapy (ref. REFINE trial <a href="https://refine.mrcctu.ucl.ac.uk/">https://refine.mrcctu.ucl.ac.uk/</a> when data become available).	Thank you for your comment. We have not looked at drug treatment schedules or breaks as part of this work. We have incorporated existing TAs into the guideline. Please see the <a href="#">Interim process and methods statement for bringing together NICE guidance</a> for more information about NICE's approach to including NICE technology appraisal recommendations in guideline topic areas.
Action Kidney Cancer	Guideline	036	019	Assess whether the NHS can afford and has the expertise for genomic testing on patients and	Thank you for your comment. It is beyond the scope of this guideline to assess whether the NHS can afford genetic testing for heritable kidney cancer predisposition

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Action Kidney Cancer	Guideline	041	013	The sharing of health records between primary and secondary care is essential to ensure that follow-up appointments and scans are not overlooked. Consistency in record-keeping is particularly important when a second opinion is required. Additionally, it is important to address how patients can access their medical records in the context of the 10-year health plan.	<p>Thank you for your comment. In the overview and in a recommendation in the information and support section of guideline we cross refer to <a href="#">NICE's patient experience in adult NHS services guideline</a> (CG138) and explicitly signpost to the section on <a href="#">continuity of care and relationships</a>. This section includes a recommendation clearly stating that all healthcare professionals should ensure clear and timely exchange of patient information to other healthcare professionals and social care professionals particularly at the point of any transitions in care (see recommendation 1.4.3 in CG138). To avoid duplication with other NICE guidelines, which can lead to inconsistencies in care for patients when guidelines are updated at different points in time, the committee were unable to add the requested recommendation.</p> <p>How patients can access their medical records in the context of the 10-year health plan is a general issue across the NHS and is not within the scope of this guideline or NICE to address.</p>
Action Kidney Cancer	Guideline	047	007	Recommendation for research: what is the optimal treatment duration for immunotherapy (currently set	Thank you for your comment. We can only make research recommendations in areas where we have carried out a

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Action Kidney Cancer	Guideline	060	010	<p>We are uncomfortable with this recommendation. Surely, active surveillance should continue to give the patient peace of mind that they are being cared for, even if treatment is not an option? Patients are likely to feel abandoned by the health care system if they do not receive regular follow-up visits.</p>	<p>Thank you for your comment. The committee agreed that active surveillance refers to monitoring when treatment is possible but declined or delayed. When treatment for RCC, if the person were to develop it, is no longer an option, active surveillance is no longer possible based on this definition, and the person should be discharged from this form of monitoring.</p> <p>The person with an oncocytoma or Bosniak 2F cyst will still be able to seek help through other routes, for example, via their GP if they develop symptoms, but they will no longer be eligible for monitoring under the active surveillance pathway. They would also be able to access palliative care.</p> <p>The committee retained the recommendation to discharge the person with an oncocytoma or Bosniak 2F cyst if treatment for RCC, should they develop it, is no longer possible but expanded this to include mention of local symptoms. Also, additional clarification was included in the definition of active surveillance in the 'terms used in this</p>

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					guideline' section to explain that active surveillance is only an option when treatment is still possible.
Action Kidney Cancer	Visual summaries, accessible versions	General	General	Are these documents meant for patients and the public? If so, they are unsuitable and need to be written in lay language and with clear explanation. A list of links within a document is not acceptable to most patients and will not be useful. Infographics and videos should be used wherever possible. Documents should be translated into different languages for people whose first language is not English.	Thank you for your comments. The visual summaries are a visual representation of the guideline section on SACT for advanced RCC. They are intended to support understanding of where the TAs are placed in the treatment pathway and facilitate shared decision making. The accessible versions of the visual summaries are for screen readers.
Association of Clinical Psychologists UK	Guideline	General	General	<p>ACP-UK points out that the diagnosis and treatment of kidney cancer involves many psychological stressors, such as uncertainty, anxiety, fear of recurrence, body image issues (especially post-surgery), coping with side-effects, potential loss of function and adjusting to long-term active surveillance among others. Patients often need help adjusting to life after treatment (including comorbidities like chronic kidney disease) and dealing with survivorship issues.</p> <p>There is evidence that early psychological intervention in cancer improves outcomes (both quality of life and mental health), reduces distress and helps with decisional regret and many other factors. Psychological wellbeing affects treatment adherence, quality of life and clinical outcomes vs possible outcomes. Clinical psychologists provide specialist, evidence-based interventions to support decision making, enable adaptive coping, facilitate and oversee behavioural change interventions pre-</p>	<p>Thank you for your comment. The committee agreed that a cancer diagnosis and its associated treatments can be traumatic experiences for the patient. They noted that many of these issues are not specific to kidney cancer but apply to people with other types of cancer as well.</p> <p>The guideline section on general information includes a recommendation about discussing emotions with people with renal cell carcinoma and signposting or referring them to psychological services if appropriate.</p> <p>This guideline has not reviewed the evidence around the provision of psychological support for people with kidney cancer, and we are unable to make more detailed recommendations on this topic. However, if you have evidence to support the inclusion of this topic in future work for kidney cancer, or at a wider level for people with cancer in general, please can you share it with us by submitting a topic suggestion through our topic prioritisation process. See here for information on the prioritisation process and the submission form:</p>

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				and during treatment, and in complex psychosocial and ethical presentations in palliative care contexts. ACP-UK firmly believes that psychology (assessment, screening, referral and interventions) should be woven in throughout the guideline – from diagnosis through active treatment, surveillance, follow-up and end-of-life.	<ul style="list-style-type: none"> <li>• <a href="#">Prioritising our guidance topics</a></li> <li>• <a href="#">Topic suggestion</a>.</li> </ul>
Association of Clinical Psychologists UK	Guideline	General	General	<p><b>Communication</b></p> <p>ACP-UK believes that clinical psychologists should contribute to designing information materials, decision aids, etc. In line with NICE (2004) guidance, there should be training for those delivering information/support to recognise psychological distress, and that referrals must be made appropriately. ACP-UK would also like to see psychological literacy incorporated into MDTs – ensuring all team members are alert to psychosocial issues.</p>	<p>Thank you for your comment. The details of training for healthcare professionals are outside of the remit of NICE guidance, so the committee is unable to make recommendations on this area. Psychological and psychosocial support are topics that have not been reviewed as part of this current piece of work. However, the committee agree that it is important to identify psychological distress and ensure patients receive clear information and appropriate referrals to services that could support them. The guideline section on general information includes a recommendation about discussing emotions with people with renal cell carcinoma and signposting or referring them to psychological services if appropriate. In addition, the committee have made recommendations offering clinical nurse specialist support to people with renal cell carcinoma. The committee anticipates that together these recommendations will strengthen patient access to services that provide appropriate emotional, psychological and psychosocial care.</p>
Association of Clinical Psychologists UK	Guideline	General	General	<p>ACP-UK would like a recommendation included that shared decision making be supported by psychosocial support, including contributions/interventions from embedded specialist psychological support for people with decisional conflict; access to embedded specialist psychological</p>	<p>Thank you for your comment. Psychological support for people with kidney cancer during decision making has not been reviewed as part of this current piece of work and therefore the committee are unable to make any detailed recommendations about this. However, if you have evidence to support its inclusion in future work specifically</p>

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				support helps patients understand trade-offs, manage uncertainty, reduce decisional regret and ultimately impacts outcomes and costs.	<p>for people with kidney cancer or more widely across cancers, please can you share it with us by submitting a topic suggestion through our topic prioritisation process. See here for information on the prioritisation process and the submission form:</p> <ul style="list-style-type: none"> <li>• <a href="#">Prioritising our guidance topics</a></li> <li>• <a href="#">Topic suggestion</a></li> </ul>
Association of Clinical Psychologists UK	Guideline	006	004	<p>Information and support, Section 1 ACP-UK points out that the draft says discuss coping, etc but only gives nurse or navigator roles and there is limited advice and guidance here for a significant clinical concern. The guidance should be explicitly recommending embedded specialist psychological support access aligned to the evidence base in terms of positive impact on outcomes. ACP-UK is concerned that reports of high distress need to be appropriately managed and risk managed, that screening for distress should be routine and that thresholds for onward referral to specialist embedded psycho-oncology services, should be included.</p> <p>ACP-UK feels that it is erroneous and misleading to have emotional support as only referenced in the cancer navigator's role. This does not fit with the ACCEND framework (<a href="https://www.hee.nhs.uk/our-work/cancer-diagnostics/aspirant-cancer-career-education-development-programme/accend-framework">https://www.hee.nhs.uk/our-work/cancer-diagnostics/aspirant-cancer-career-education-development-programme/accend-framework</a>). The cancer navigator's role is assistive, thus typically limited to the detection of needs and some delegated tasks/signposting, not in the focal offer of emotional support, which is primarily undertaken by clinical nurse specialists. We would</p>	<p>Thank you for your comment. Psychological support, and when to provide it, for people with kidney cancer has not been reviewed as part of this current piece of work and therefore the committee are unable to make any detailed recommendations about this. However, if you have evidence to support its inclusion in future work specifically for people with kidney cancer, or more widely across cancers, please can you share it with us by submitting a topic suggestion through our topic prioritisation process. See here for information on the prioritisation process and the submission form:</p> <ul style="list-style-type: none"> <li>• <a href="#">Prioritising our guidance topics</a></li> <li>• <a href="#">Topic suggestion</a></li> </ul> <p>The committee noted that the recommendation about asking the person about their emotions was not intended to only be carried out by a clinical nurse specialist or cancer care navigator, but that they expected that these discussions would be carried out by a range of healthcare specialists to different levels. For example, a cancer care navigator could provide support by signposting to voluntary support services or suggesting that the person raises these issues with the clinical nurse specialist in their next meeting.</p>

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				<p>like to see more reference made to existing models of care, eg, the Transforming care pathway of psychosocial care, level 2 (targeted) assessment and interventions and psycho-oncology services for the provision of a stratified approach for the oversight of (and supervision/training of) targeted and specialist psychological interventions, also consistent with prehabilitative recommendations.</p> <p>Principles of care would be the early detection of needs, particularly those psychosocial factors that affect engagement with, and adherence to, treatment, the escalation of concerns to psycho-oncology services for specialist interventions and the provision of embedded psychological care.</p>	
Association of Clinical Psychologists UK	Guideline	006	009	<p>ACP-UK is concerned that in section 1.1.6 there is the statement (and link), See also NICE's guideline on depression in adults with a chronic physical health problem. ACP-UK points out that it is a fundamental misunderstanding to equate psychological support for people living with kidney cancer with the treatment of mental ill-health. The current NICE reference to mental health and depression guidance as the primary source of support for distress related to kidney cancer is clinically and conceptually flawed. Distress in the context of cancer is not, in most cases, a mental disorder; it is a natural and adaptive response to serious illness that requires specialist psychological understanding and intervention within oncology pathways. Evidence shows that integrated psychological care improves clinical outcomes,</p>	<p>Thank you for your comment. The committee intended to signpost adults with kidney cancer who have depression to NICE guidance that can support their needs. This was not intended to equate psychological support for people living with kidney cancer with the treatment of mental ill-health.</p> <p>The committee agree that this is an important topic, however the management of psychological distress and provision of psychological support is outside the scope of current piece of work. If you have evidence to support its inclusion in future work specifically for people with kidney cancer, or more widely across cancers, please can you share it with us by submitting a topic suggestion through our topic prioritisation process. See here for information on the prioritisation process and the submission form:</p> <ul style="list-style-type: none"> <li>• <a href="#">Prioritising our guidance topics</a></li> </ul>

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				treatment adherence, and quality of life. What people with kidney cancer need is a coherent, embedded psychology offer within their cancer care – focused on optimising wellbeing, adjustment, and recovery – not a referral pathway predicated on the presence of a diagnosable mental health condition.	<ul style="list-style-type: none"> <li><a href="#">Topic suggestion</a></li> </ul>
Association of Clinical Psychologists UK	Guideline	005-006	027 – 030	<p><b>Information and support, Section 1</b> ACP-UK would like an additional bullet under point 1.1.4 that the clinical nurse specialist has training and experience in order to provide specialist psychological support that meets the NICE (2004) criteria for level 2, with specific training and experience of cancer-related psychological distress.</p> <p><a href="https://www.nice.org.uk/guidance/csg4">https://www.nice.org.uk/guidance/csg4</a> <a href="https://www.transformationpartners.nhs.uk/wp-content/uploads/2017/11/Psychological-support-for-people-affected-by-cancer.pdf">https://www.transformationpartners.nhs.uk/wp-content/uploads/2017/11/Psychological-support-for-people-affected-by-cancer.pdf</a></p>	<p>Thank you for your comment. The Cancer service guideline (CSG4) on Improving supportive and palliative care for adults with cancer is from 2004 and the recommendations within it are expected to be out of date. The details of training for healthcare professional and service configuration are outside of the remit of NICE guidance, so the committee is unable to make recommendations on this area now.</p> <p>The committee discussed the role of the clinical nurse specialist and agreed that it centres on providing advice and support, as well as guiding patients towards the most appropriate services. They are not expected to be trained in delivering psychological interventions. Instead, their responsibility is to recognise when specialist psychological support may be needed and to ensure patients are directed to the appropriate services.</p>
Association of Clinical Psychologists UK	Guideline	023	001 – 012	<p><b>Information for people before and after kidney surgery, Section 1.7</b> ACP-UK would like to see the inclusion of psychological preparation for surgery / non-surgical management in order to help with expectations and coping. We would like to see the addition of a recommendation for preoperative psychological assessment of patients' coping, fears and mental state and that psychological preparation should be</p>	<p>Thank you for your comments. Please note that the recommendation under "Information and Support" about the clinical nurse specialist does apply during management, follow-up and palliative care, therefore including before and after surgery. The committee already recommend that discussions about how the person is coping should happen</p>

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				<p>offered. We would also like to see a recommendation that follow-up psychological support is offered after surgery, to help patients adjust to functional changes, body image, adaptation to CKD and/or reduced renal function.</p> <p>ACP-UK also points out that embedded specialist psychological support is integral to optimising rehabilitation/survivorship planning.</p>	<p>(this could be carried out by the clinical nurse specialist, or other clinician responsible for the person's care). The committee also noted that in their experience, psychological assessment is not routinely carried out prior to or after surgery.</p> <p>If you would like to suggest future work looking at when psychological support should be provided specifically for people with kidney cancer, or more widely across cancers, please can you share it with us by submitting a topic suggestion through our topic prioritisation process. See here for information on the prioritisation process and the submission form:</p> <ul style="list-style-type: none"> <li>• <a href="#">Prioritising our guidance topics</a></li> <li>• <a href="#">Topic suggestion</a></li> </ul>
Association of Clinical Psychologists UK	Guideline	029	012 – 022	<p><b>Advanced disease, Section 1.11</b></p> <p>ACP-UK would like to see an explicit recommendation that embedded specialist psychological support is included as part of the palliative/supportive care team and that psychological interventions for distress, existential anxiety, grief, family/carer support are offered. Screening for depression, anxiety, quality of life etc in advanced disease, and timely referral should be routine.</p>	<p>Thank you for your comment. Please note that the recommendation under "Information and Support" about the clinical nurse specialist applies during palliative care, therefore including advanced disease. The committee already recommend that discussions about how the person is coping should happen (this could be done by the clinical nurse specialist, or other clinician responsible for the person's care). The committee did not look at psychological care of people with advanced RCC as part of this current piece of work and are therefore unable to be more specific.</p> <p>Palliative and end of life care is out of the scope of this guideline because it is covered by <a href="#">NICE's guidelines on end of life care for adults</a> and <a href="#">care of dying adults in the last days of life</a>, and <a href="#">NICE's cancer service guideline on improving supportive and palliative care for adults with cancer</a>. The committee are therefore unable to make</p>

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					<p>specific recommendations on this for people with advanced RCC. However, if you have evidence to support its inclusion in future work on the palliative care or end of life guidelines, please can you share it with us by submitting a topic suggestion through our topic prioritisation process. See here for information on the prioritisation process and the submission form:</p> <ul style="list-style-type: none"> <li>• <a href="#">Prioritising our guidance topics</a></li> <li>• <a href="#">Topic suggestion</a>.</li> </ul>
Association of Clinical Psychologists UK	Guideline	030	007 – 020	<p><b>Section 1.12</b> ACP-UK feels it is important that patients (and carers) are prepared and counselled for end-of-life decision making, with counselling around loss, sense of control, etc, also offered.</p>	<p>Thank you for your comment. Counselling for end-of-life decision making is out of scope for this guideline. This would be covered by the <a href="#">NICE guideline on end of life care for adults</a> (NG142). However, if you would like to suggest that NG142 is updated and have evidence to support this please can you share it with us by submitting a topic suggestion through our topic prioritisation process. See here for information on the prioritisation process and the submission form:</p> <ul style="list-style-type: none"> <li>• <a href="#">Prioritising our guidance topics</a></li> <li>• <a href="#">Topic suggestion</a></li> </ul>
Association of Clinical Psychologists UK	Guideline	037	007 – 028	<p><b>Genetics Section 1.16.4–1.16.6</b> ACP-UK would like to see the inclusion of psychological assessment/support for coping with the implications of positive tests, family implications and emotional impact. Ensure access to specialist psychological support for people dealing with risk and surveillance burden.</p>	<p>Thank you for your comments. We have not reviewed the evidence for psychological assessment and support around genetic testing results as part of this current work. However, if you have evidence to support its inclusion in future work specifically for people with kidney cancer, or more widely across cancers, please can you share it with us by submitting a topic suggestion through our topic prioritisation process. See here for information on the prioritisation process and the submission form:</p> <ul style="list-style-type: none"> <li>• <a href="#">Prioritising our guidance topics</a></li> <li>• <a href="#">Topic suggestion</a>.</li> </ul>

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Association of Clinical Psychologists UK	Guideline	039	014	<b>Surveillance section 1.17.6</b> ACP-UK would like to see the inclusion of psychological monitoring/support during active surveillance and as part of a patient's personalised care plan, including regular check-ins for anxiety and uncertainty, structured and evidence-based psychosocial interventions, and support for anxiety about recurrence and transition of care when considering discharge.	Thank you for your comment. Please note that the recommendation under "Information and Support" about the clinical nurse specialist apply during management, which includes during active surveillance and when considering discharge. The committee already recommend that discussions about how the person is coping should happen (this could be done by the clinical nurse specialist, or other clinician responsible for the person's care). We did not review evidence for psychosocial support during active surveillance, so the committee are unable to make recommendations on this topic.
Association of Clinical Psychologists UK	Guideline	039	022	ACP-UK would like assurances that the named healthcare professional includes someone (or a clear pathway) for psychological care.	Thank you for your comment. The intention of this recommendation is that people with a heritable predisposition undergoing active surveillance have a personalised care plan. The committee decided not to specify who the named healthcare professional should be. However, the recommendation under "Information and Support" about the clinical nurse specialist does apply during management, which includes during active surveillance. The committee already recommend that discussions about how the person is coping should happen throughout their care (this could be done by the clinical nurse specialist, or other clinician responsible for the person's care).
Boston Scientific	Guideline	015	014	The guideline's blanket statement that "thermal ablation has a higher risk of recurrence than surgery" ( <b>Page 15, Lines 14-15; Page 62, Lines 15-17</b> ) is potentially misleading when applied to cryoablation without qualification. A growing body of evidence suggests that cryoablation may have superior	Thank you for your comments. The committee discussed the risk of recurrence between different treatment methods. The related evidence review (review B) compared thermal ablation (as a single intervention with subgroups to investigate the different effects of the types of thermal ablation, where possible), partial nephrectomy, total nephrectomy, stereotactic ablative radiotherapy (SABR) and active surveillance. The review did not include studies

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				<p>oncological outcomes compared to radiofrequency ablation.</p> <p>The rationale section states: "The evidence suggested that thermal ablation has a higher risk of recurrence than partial nephrectomy" (<b>Page 62, Lines 15-16</b>). However, much of the older evidence underpinning this conclusion is dominated by studies on RFA. More recent meta-analyses and comparative studies indicate that while both are effective, cryoablation may be associated with a lower local tumour progression (LTP) rate. A 2022 meta-analysis directly comparing cryoablation and RFA for small renal masses found that cryoablation was associated with a significantly lower local recurrence rate (OR: 2.25; 95% CI: 1.38 to 3.67; p = 0.001) [6].</p> <p>The proposed mechanism for this difference relates back to the ablation physics. Cryoablation creates a sharper, more predictable ablation margin that is easily visible on imaging, allowing the operator to confidently ensure a complete "negative margin." The cytotoxic effect is also more uniform throughout the ice ball [2]. RFA, conversely, can be susceptible to heat sink effects from adjacent blood vessels, leading to uneven heating and potential skip areas where viable tumour cells can persist at the periphery [1].</p> <p>While the committee correctly notes a general "lack of evidence for SABR" (<b>Page 15, Line 20</b>), there is a parallel need to disaggregate the evidence for the</p>	<p>which compared one type of thermal ablation with another. Evidence on all three types of thermal ablation included in the protocol (cryoablation, microwave ablation and radiofrequency ablation) was identified, with 25 studies examining solely cryoablation.</p> <p>Although in the committee's experience, cryoablation is commonly used in RCC, they decided not to specifically mention cryoablation in the recommendations because it was not the aim of the evidence review to differentiate between types of thermal ablation. They were also aware of variation in availability across the country. The committee agreed that a statement about recurrence in the recommendation would be useful to clinicians and people with RCC.</p> <p>However, they decided to amend the statements about risk of recurrence to make them less definite in recognition of the variation within intervention types. They also added text to the related rationale and impact to clarify this.</p>

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				<p>various percutaneous ablation technologies. To state that "thermal ablation" has a higher recurrence rate without acknowledging the potential superiority of cryoablation within this group does a disservice to this technology and may lead clinicians and patients to undervalue a potentially more effective minimally invasive option. This is especially true for tumours between 2-4 cm, where recommendation <b>1.5.6 (Page 18, Lines 9-11)</b> suggests active surveillance or thermal ablation as alternatives to surgery.</p> <p>References</p> <ol style="list-style-type: none"> <li>1. Ahmed, M., Brace, C. L., Lee, F. T., &amp; Goldberg, S. N. (2011). Principles of and advances in percutaneous ablation. <i>Radiology</i>, 258(2), 351-369.</li> <li>2. Erinjeri, J. P., &amp; Clark, T. W. (2010). Cryoablation: mechanism of action and devices. <i>Journal of Vascular and Interventional Radiology</i>, 21(8 Suppl), S187-S191.</li> <li>3. Georgiades, C., &amp; Rodriguez, R. (2014). Efficacy and safety of percutaneous cryoablation for stage 1A kidney cancer: a systematic review and meta-analysis. <i>Journal of Vascular and Interventional Radiology</i>, 25(8), 1141-1149.</li> </ol>	

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				<p>4. Breen DJ, Bryant TJ, Abbas A, Shepherd B, McGill N, Anderson JA, Lockyer RC, Hayes MC, George SL. Percutaneous cryoablation of renal tumours: outcomes from 171 tumours in 147 patients. <i>BJU Int.</i> 2013 Oct;112(6):758-65.</p> <p>5. Hinshaw, J. L., Lubner, M. G., Ziemlewicz, T. J., Lee, F. T., &amp; Brace, C. L. (2014). Percutaneous tumor ablation tools: microwave, radiofrequency, or cryoablation—what should you use and why? <i>Radiographics</i>, 34(5), 1344-1362.</p> <p>6. Shi H, Li J, Fan Z, Yang J, Fu S, Wang H, Wang J, Zhang J. Comparison of Radiofrequency Ablation Versus Cryoablation For T1 Renal Tumors: An Evidence-Based Analysis of Comparative Outcomes. <i>Front Oncol.</i> 2022 Apr 22;12:802437.</p> <p>7. Katsanos, K., Mailli, L., Krokidis, M., McGrath, A., Sabharwal, T., &amp; Adam, A. (2014). Systematic review and meta-analysis of thermal ablation versus surgical nephrectomy for small renal tumours. <i>Cardiovascular and Interventional Radiology</i>, 37(2), 427-437. (This study often shows heterogeneity based on ablation type). A more direct comparison can be found in single-center cohort studies, but large-scale renal-specific meta-analyses directly comparing RFA and cryoablation are</p>	

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				still needed, which itself is an argument for not grouping them together.*	
Boston Scientific	Guideline	016	General	<p>The guideline repeatedly uses the term "thermal ablation" without explicitly defining its constituent technologies. Cryoablation is not a "Thermal" Ablation in the conventional sense.</p> <p><b>Thermal Ablation (Radiofrequency Ablation, Microwave Ablation):</b> These technologies operate on the principle of frictional heating. They use high-frequency electrical currents or microwaves to agitate water molecules within tissue, generating temperatures often exceeding 60°C. This intense heat causes instantaneous protein denaturation and coagulative necrosis, effectively "cooking" the tumour cells. The process is rapid and relies on conductive heating from the probe tip.</p> <p><b>Cryoablation:</b> In stark contrast, cryoablation is a freezing process. It utilises the Joule-Thomson effect, circulating argon gas to rapidly cool probes to temperatures as low as -40°C. This creates an ice ball that engulfs the target lesion. The mechanism of cell death is multifactorial and sequential:</p> <ul style="list-style-type: none"> <li>• Intracellular ice formation: Directly ruptures organelles and cell membranes.</li> <li>• Vascular disruption: Freezing causes endothelial damage, leading to microvascular thrombosis and ischaemia hours to days after the procedure.</li> </ul>	<p>Thank you for your comment and providing information about the cryoablation procedure and supporting references. The committee discussed this and agreed not to use the term ablation to avoid implying that non-thermal ablation types had also been considered in the evidence review. They also decided that it was not necessary to use separate terms for the three types of thermal ablation considered (cryoablation, microwave ablation and radiofrequency ablation) as all mentions of thermal ablation refer to all 3 types.</p> <p>The related evidence review (review B) looked at thermal ablation as a single intervention rather than investigating the relative effects of each type separately. Subgroup analysis was conducted to investigate the different effects of the types of thermal ablation where possible, but this could only be done within the thermal ablation versus partial nephrectomy comparison. The review did not include studies which compared one type of thermal ablation with another.</p> <p>The committee acknowledges the different mechanisms of action of the types of thermal ablation but agreed that the term 'thermal ablation' was widely used and understood by clinicians. To reduce any confusion, they agreed to add the term 'thermal ablation' to the terms used section of the guideline to clarify what types of ablation are included (cryoablation, microwave ablation and radiofrequency ablation).</p>

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				<ul style="list-style-type: none"> <li>• Apoptosis: Induction of programmed cell death.</li> </ul> <p>The resultant necrotic tissue is then gradually reabsorbed by the body. To classify this complex, freeze-induced cytotoxic process under the same umbrella as hyperthermic "thermal ablation" is a fundamental mischaracterisation. It is akin to classifying both freezing and burning as "thermal injury" without acknowledging the profound biological differences in tissue response and healing. This mechanistic distinction is not a semantic quibble; it has direct clinical ramifications.</p> <p>The conflation of these technologies in the guideline prevents a nuanced appreciation of cryoablation's unique advantages, which are critical for shared decision-making as emphasised in section 1.5.1 (Page 15, Lines 9-23).</p> <p><b>From the Patient Perspective:</b></p> <p><b>Reduced Procedural Pain:</b> Heat-based ablation is often reported as significantly more painful than cryoablation. The burning sensation and associated muscle contractions can require higher levels of sedation or analgesia. Cryoablation, however, has an inherent anaesthetic effect; the freezing process numbs the treated area, leading to better patient tolerance, often under moderate sedation rather than general anaesthesia [3]. This aligns with the</p>	

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				<p>guideline's focus on patient experience and minimising treatment burden.</p> <p><b>Enhanced Visualisation and Safety:</b> This is a critical point for the interventional radiologist. The evolving ice ball formed during cryoablation is clearly visible under real-time ultrasound, CT, or MRI guidance. This allows for precise monitoring of the ablation zone and its relationship to critical adjacent structures like the renal collecting system, bowel, or ureter [4]. As noted in the rationale (<b>Page 62, Lines 1-4</b>), the committee highlighted the risk of complications with partial nephrectomy; this concern for precision is equally relevant to ablation. In contrast, the "bubble" of gas formed during RFA can obscure the target lesion on ultrasound, and MWA can create unpredictable heat sinks near vessels, increasing the risk of non-target injury [1]. The superior visualisation of cryoablation directly supports the guideline's aim to improve safety.</p> <p><b>From the NHS and System Perspective:</b></p> <p><b>Potential for Outpatient or Short-Stay Management:</b> The improved patient tolerance and reduced pain profile of cryoablation make it a stronger candidate for outpatient or 23-hour stay procedures compared to some heat-based techniques. This can increase theatre efficiency, reduce inpatient bed</p>	

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				<p>occupancy, and lower overall treatment costs—a key consideration for the NHS [5].</p> <p><b>Treating Complex Tumours:</b> The ability to precisely visualise the ablation margin makes cryoablation particularly suitable for treating central or hilar tumours, which are closer to vital structures. The guideline acknowledges the importance of lesion location in decision-making (e.g., <b>Page 16, Line 8:</b> "renal lesion factors (such as location...)"). By not distinguishing cryoablation, the guideline fails to highlight its specific utility in these challenging cases where other thermal techniques might be riskier [4].</p> <p>The draft NICE guideline represents a critical step towards standardising kidney cancer care in the UK. However, its classification of cryoablation under the umbrella term "thermal ablation" is a significant oversight. It is:</p> <ol style="list-style-type: none"> <li>1. <b>Scientifically Inaccurate:</b> It ignores the fundamental difference between cell death induced by freezing versus heating.</li> <li>2. <b>Clinically Unhelpful:</b> It prevents clinicians from appreciating the distinct advantages of cryoablation, particularly in terms of patient comfort, procedural safety, and applicability to complex tumour locations.</li> <li>3. <b>Potentially Misleading:</b> It risks perpetuating an outdated view of recurrence rates by lumping a potentially more effective modality</li> </ol>	

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				<p>(cryoablation) with less effective ones under a single label.</p> <p>We strongly urge the committee to revise the guideline to explicitly distinguish cryoablation from heat-based thermal ablation techniques. The terms "cryoablation" and "thermal ablation" (or preferably "heat-based ablation") should be used separately throughout the document. This would allow for more precise recommendations, facilitate truly informed shared decision-making as championed by the guideline itself, and ensure that the UK's clinical practice reflects the most nuanced and accurate understanding of available technologies.</p> <p>References:</p> <ol style="list-style-type: none"> <li>1. Ahmed, M., Brace, C. L., Lee, F. T., &amp; Goldberg, S. N. (2011). Principles of and advances in percutaneous ablation. <i>Radiology</i>, 258(2), 351-369.</li> <li>2. Erinjeri, J. P., &amp; Clark, T. W. (2010). Cryoablation: mechanism of action and devices. <i>Journal of Vascular and Interventional Radiology</i>, 21(8 Suppl), S187-S191.</li> <li>3. Georgiades, C., &amp; Rodriguez, R. (2014). Efficacy and safety of percutaneous cryoablation for stage 1A kidney cancer: a systematic review and meta-analysis. <i>Journal</i></li> </ol>	

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				<p>of Vascular and Interventional Radiology, 25(8), 1141-1149.</p> <p>4. Breen DJ, Bryant TJ, Abbas A, Shepherd B, McGill N, Anderson JA, Lockyer RC, Hayes MC, George SL. Percutaneous cryoablation of renal tumours: outcomes from 171 tumours in 147 patients. <i>BJU Int.</i> 2013 Oct;112(6):758-65.</p> <p>5. Hinshaw, J. L., Lubner, M. G., Ziemlewicz, T. J., Lee, F. T., &amp; Brace, C. L. (2014). Percutaneous tumor ablation tools: microwave, radiofrequency, or cryoablation—what should you use and why? <i>Radiographics</i>, 34(5), 1344-1362.</p> <p>6. Shi H, Li J, Fan Z, Yang J, Fu S, Wang H, Wang J, Zhang J. Comparison of Radiofrequency Ablation Versus Cryoablation For T1 Renal Tumors: An Evidence-Based Analysis of Comparative Outcomes. <i>Front Oncol.</i> 2022 Apr 22;12:802437.</p> <p>7. Katsanos, K., Mailli, L., Krokidis, M., McGrath, A., Sabharwal, T., &amp; Adam, A. (2014). Systematic review and meta-analysis of thermal ablation versus surgical nephrectomy for small renal tumours. <i>Cardiovascular and Interventional Radiology</i>, 37(2), 427-437. (This study often shows heterogeneity based on ablation type). A more direct comparison can be found in single-center cohort studies, but large-scale renal-specific meta-analyses</p>	

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				directly comparing RFA and cryoablation are still needed, which itself is an argument for not grouping them together.*	
Boston Scientific	Guideline	016	005	<p>Within the thermal ablation section for localised and locally advanced RCC we urge the committee to consider the findings of the recent publication titled "Comparison of health economics in robot-assisted partial nephrectomy and CT-guided cryoablation for the management of T1 renal cell carcinoma: an analysis of a prospective Danish cohort" (Junker et al., 2025).</p> <p>This study provides robust real-world evidence comparing robot-assisted partial nephrectomy (RAPN) and percutaneous cryoablation (PCA) in patients with T1 RCC. The analysis found no significant differences in oncological outcomes between the two modalities, while PCA demonstrated a shorter hospital stay and a net monetary benefit of €9,045 at a willingness-to-pay threshold of €40,000/QALY. These findings support the inclusion of PCA as a cost-effective, clinically viable alternative to RAPN in the management of small renal masses and this evidence should be incorporated and considered when providing treatment recommendations to ensure optimal resource allocation and patient outcomes.</p> <p>Link to the paper: <a href="#">Comparison of health economics in robot-assisted partial nephrectomy and CT-guided cryoablation for the management of T1 renal cell</a></p>	<p>Thank you for your comment. The study you have referenced was published after our search cut-off. We have assessed the study and confirmed that it meets our protocol criteria otherwise.</p> <p>We investigated whether the results of this study would make any difference in the conclusions of our effectiveness analyses. On reanalysis, we could see that the direction of effect for local recurrence and metastases for thermal ablation vs partial nephrectomy was unchanged by the addition of this study: partial nephrectomy still showed improved recurrence compared with thermal ablation, and metastases were still not statistically significantly different. Due to the unchanged conclusions about effectiveness, which indicate that the recommendations would not change, the committee agreed not to add this study to the review at this time. They also noted that selectively adding new studies to a review is not systematic and that additional searches would need to be carried out if this reference was added at this time. When the review is updated in the future, the study will be reassessed at that point for inclusion.</p>

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				<a href="#">carcinoma: an analysis of a prospective Danish cohort   CardioVascular and Interventional Radiology</a>	
British Association of Urological Surgeons (BAUS) - Section of Oncology	Guideline	007	004	Suggest defining which phases are required for a 'triple-phase CT' explicitly or consider using the term 'multiphase CT' if a more general term is desirable to allow flexibility.	Thank you for your comment. We discussed this with the committee, and they agreed that the term 'multiphase CT' is a more general term that captures triple-phase CT and other CT imaging that could include more than 3 phases. They decided against defining which phases are required for triple phase CT and to allow for more flexibility changed the term to 'multiphase CT' in the recommendation as you suggested.
British Association of Urological Surgeons (BAUS) - Section of Oncology	Guideline	008	009	This section overstates the value of 99mTc-sestamibi SPECT CT in differentiating oncocytic renal neoplasms from other types of renal cell carcinoma. The sensitivity and specificity of 99mTc-sestamibi SPECT CT in this context is not 100% as implied by the current wording ('knowing').	Thank you for your comment. The committee discussed this and agreed to change to the word 'knowing' to 'increasing confidence in', to reflect that 99mTc-sestamibi SPECT-CT does not have 100% sensitivity and specificity in diagnosing renal lesions.
British Association of Urological Surgeons (BAUS) - Section of Oncology	Guideline	016	005	<p>The role of SABR in the management of primary and oligometastatic renal cancer is evolving, and we believe further consideration is warranted regarding its integration into treatment pathways and this NICE guideline.</p> <p>SABR is currently under consideration by NHS England as a commissioned treatment for localised renal cancer and it is important that the NICE guideline aligns with this recommendation.</p> <p>We agree that SABR should only be used if thermal ablation and surgery are not suitable and treating the renal lesion is thought to be in the person's best interest (1.5.2). We agree that SABR is not suitable</p>	<p>Thank you for these comments. The committee are aware of the draft commissioning policy for SABR for localised RCC, which was released for consultation after this guideline, and revised their recommendations with it in mind.</p> <p>For Bosniak 4 cysts larger than 2 cm, the committee agreed that both stereotactic ablative therapy (SABR) and thermal ablation would only be conducted where there was a solid component to target, and only after biopsy confirmation of malignancy, as specified in an earlier recommendation. They discussed further that for people with Bosniak 4 cysts who cannot have surgery or decline it, the treatment options depend on many factors including the size of the cyst and its solid component, as well as patient factors. They</p>

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				<p>for renal lesions that are larger than 7 cm in diameter (1.5.2).</p> <p>The prominence of SABR as a treatment for patients with small renal masses in this guideline should be reconsidered. For example, we suggest that SABR is removed as a treatment option from sections 1.5.5 (Bosniak 3 or 4 cysts larger than 2cm and unsuitable for surgery), 1.5.6 (solid renal masses between 2 and 4 cm in diameter who cannot have surgery or decline it), and 1.5.9 (for people with localised solid renal masses, or Bosniak 3 or 4 cysts, that are less than 2 cm in diameter who decline active surveillance).</p> <p>We note that the NICE guideline committee has drafted a recommendation to address deficiencies in the evidence base regarding the effectiveness of SABR compared to other treatment options.</p>	<p>therefore rewrote the recommendation to allow for thermal ablation, SABR and active surveillance to be equal options for this group.</p> <p>For solid renal masses 2-4cm, the committee were aware of the NHSE draft commissioning paper. The committee agreed that if SABR was recommended for use in people with solid renal masses over 4cm, it should not be withheld from people with renal masses 2-4cm when, in the committee's experience, there is no reason for the effectiveness to be reduced in this group. Therefore, they decided not to remove SABR as an option from this recommendation.</p> <p>For solid renal masses 4cm or larger, the committee discussed the positioning of thermal ablation and SABR in this recommendation and agreed that they should both be options for people who cannot have surgery or decline it, rather than SABR only being an option when thermal ablation was not suitable. This is due to uncertainty about the performance of thermal ablation for larger lesions, and the draft NHSE commissioning policy recommendation for SABR to be provided for people with T1b renal lesions.</p> <p>For Bosniak 3 or 4 cysts and sold renal masses less than 2cm, the committee agreed that inclusion of SABR in this recommendation does not reflect clinical practice. While SABR may be technically possible in solid renal masses under 2cm, it is not standard practice outside of exceptional circumstances. Therefore, SABR has been removed from this recommendation.</p>

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British Association of Urological Surgeons (BAUS) - Section of Oncology	Guideline	022	001	Surgical Approach. Recommendations around the extent of surgery, particularly lymph node dissection and ipsilateral adrenalectomy, could benefit from description within this NICE guideline if within its remit. Clarity on when these procedures are indicated would help standardise surgical practice and ensure optimal outcomes.	<p>Thank you for your comment. The committee reviewed the evidence for nephrectomy, which can be carried out with extensions to surgery such as lymph node dissection and adrenalectomy. However, the focus of the question was for different surgical approaches (e.g. minimally invasive vs open techniques), rather than when extensions to surgery, such as adrenalectomy, are indicated and are therefore unable to make recommendations on this. However, if you have evidence to support the inclusion of this topic in future work, please can you share it with us by submitting a topic suggestion through our topic prioritisation process. See here for information on the prioritisation process and the submission form:</p> <ul style="list-style-type: none"> <li>• <a href="#">Prioritising our guidance topics</a></li> <li>• <a href="#">Topic suggestion.</a></li> </ul>
British Association of Urological Surgeons (BAUS) - Section of Oncology	Guideline	022	001	We recommend stronger emphasis on the importance of timely referral of patients with complex or locally advanced kidney cancers to high-volume, specialist centres with access to multidisciplinary expertise. This reflects best practice and ensures patients receive optimal care.	<p>Thank you for your comment. The committee agreed that a recommendation was needed for the referral of people with complex locally advanced kidney cancers to a specialist multidisciplinary team to ensure that they have access to expertise in managing this type of kidney cancer. A new recommendation was added to reflect this before the section on surgery for suspected or confirmed locally advanced RCC.</p>
British Association of Urological Surgeons (BAUS) - Section of Oncology	Guideline	025	015	We note that the guideline references the use of adjuvant therapy and acknowledges that pembrolizumab, as evaluated in the KEYNOTE-564 trial, remains the pivotal study to have demonstrated a positive result in this setting. Given the potential toxicities and impact on quality of life associated with immune checkpoint inhibitors, and that benefits of adjuvant SACT may be modest, we suggest that the	<p>Thank you for your comments. We did not search for evidence on who might benefit from adjuvant treatment as drug treatment was out of scope of the current work because this area was already covered by technology appraisals (TAs). We have incorporated existing TAs into the guideline. Please see the <a href="#">Interim process and methods statement for bringing together NICE guidance</a> for more information about NICE's approach to including NICE</p>

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				<p>guideline provide a more balanced discussion including the alternative is surveillance. There should be focus on patient selection, risk stratification, and shared decision-making.</p> <p>The NICE guideline committee may wish to consider this as a research recommendation, i.e. defining the cohort of patients who are likely to derive greatest benefit from adjuvant SACT and identify those at greatest risk of side effects such that treatment can be individualised.</p>	<p>technology appraisal recommendations in guideline topic areas.</p> <p>Taking your comment and other stakeholder feedback into account, we have included adjuvant therapy in the discussion recommendation before surgery for RCC and added a new recommendation to discuss the benefits and risks of adjuvant SACT in the section on adjuvant SACT. However, we are unable to be more specific because we have not reviewed the evidence relating to this treatment. We are also unable to make a research recommendation on this topic for the same reason.</p>
British Association of Urological Surgeons (BAUS) - Section of Oncology	Guideline	028	004	Consider including a specific recommendation for adhering to an intermediate-risk status follow-up following partial nephrectomy where there is a positive surgical margin.	Thank you for your comment. The committee agreed that having a positive surgical margin after a partial nephrectomy does increase the risk of recurrence. They decided to align with the <a href="#">GIRFT kidney cancer guideline</a> that suggests using the next level risk status follow-up when there is a positive surgical margin after partial nephrectomy. They also agreed that further changes to increase the imaging frequency may be required where appropriate based on clinical and pathological characteristics. Therefore, a new recommendation was added to the section on follow up for localised and locally advanced RCC to reflect this.
British Association of Urological Surgeons (BAUS) - Section of Oncology	Guideline	016 & 018	015 & 015	While ablation is increasingly used in selected patients, typically for tumours <3cm in size, its role in tumours larger than 4 cm is more controversial. In some specialist centres it may be feasible to effectively treat these patients with multiple sessions, but we would recommend discouraging this as standard practice.	Thank you for this comment. The committee discussed the recommendation about thermal ablation and SABR for solid renal masses 4 cm or larger. They agreed that thermal ablation should be retained as an option for this group, because there are some centres that are able to offer ablation for these larger lesions, although they acknowledged that only certain types of ablation may be suitable and multiple sessions may be needed. These

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					<p>points are highlighted in the recommendation on factors to take into account when deciding which management options are suitable for suspected or confirmed localised RCC and Bosniak 3 and 4 cysts.</p> <p>The committee also agreed that thermal ablation and SABR should both be options for people with solid renal masses larger than 4 cm who cannot have surgery or decline it, rather than SABR only being an option when thermal ablation was not suitable. This is due to uncertainty about the performance of thermal ablation for larger lesions, and the draft NHSE commissioning policy recommendation for SABR to be provided for people with T1b renal lesions. They made changes to the recommendations to reflect these discussions.</p>
British Nuclear Medicine Society (BNMS)	Guideline	General	General	The BNMS welcomes the introduction of 99mTc-sestamibi SPECT-CT in selected circumstances. This examination is already widely available across NHS nuclear medicine departments, with existing expertise meaning only minimal additional training is required. We therefore support its inclusion in the guidance.	Thank you for your comment and support for this recommendation.
British Society of Interventional Radiology (BSIR)	Evidence	General	General	The studies comparing thermal ablation and partial nephrectomies are less than certain about the superiority of one over the other. Therefore other factors such as functional status and patient preference should be included. This can be made clear in the guideline.	Thank you for your comment. There was a large amount of evidence comparing thermal ablation and partial nephrectomy (more than for other comparisons in the evidence review), however the committee agreed that the certainty of the evidence is generally very low. The evidence suggests that partial nephrectomy may have improved outcomes compared with thermal ablation for various outcomes, except adverse events. The committee

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					<p>agreed that surgery should generally be the preferred option over thermal ablation.</p> <p>In the section on non-pharmacological options for suspected or confirmed localised renal cell carcinoma and Bosniak 3 and 4 cysts, there is already a recommendation that includes things to discuss with the person when deciding between these options, and a separate recommendation on things the clinician should take into account. These recommendations include the person's clinical characteristics and the person's preferences.</p>
British Society of Interventional Radiology (BSIR)	Evidence	General	General	The volume of evidence is good.	Thank you for your comment.
British Society of Interventional Radiology (BSIR)	Guideline	General	General	The diagnostic pathway and the biopsy pathways are robust. There is no ambiguity around the guidance.	Thank you for your comment and support for this section of the guideline.
British Society of Interventional Radiology (BSIR)	Guideline	General	General	There should be more clarity around the complications associated with the individual treatment options as this will be a significant factor in the available options and the patient choice.	Thank you for your comment. The committee discussed complications at various points during the development of the guideline. The guideline mentions taking into account complications of biopsy, surgery (including in table 1), thermal ablation, SABR (in terms of complications being uncertain). Please see also the recommendation on shared decision making in the section on non-pharmacological management. There was very limited evidence about the complications of the individual treatment options, and these were included in the review if they were reported according to an accepted classification, for example Clavien Dindo,

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					<p>rather than as individual complications. Therefore, we are unable to make specific recommendations about complications and would expect that this is a standard part of the discussion between the clinician and the person with RCC.</p> <p>The committee agreed that the addition of a link to <a href="#">NICE's guideline on perioperative care in adults</a> (NG180) would support clinicians in management of complications specifically related to surgery.</p>
British Society of Interventional Radiology (BSIR)	Guideline	General	General	The lack of evidence to support SABR is clear and the guideline supports the same.	Thank you for your comment and support of the SABR recommendations.
British Society of Interventional Radiology (BSIR)	Guideline	General	General	Secondary ablation plays a very important role in the ongoing management of renal cancers and has an effect on the overall outcomes. Please consider discussing this in the guidelines.	<p>Thank you for your comment. The use of secondary ablation was not evaluated as part of this current piece of work. The committee are therefore unable to make recommendations on this topic.</p> <p>However, if you have evidence to support its inclusion in future work, please can you share it with us by submitting a topic suggestion through our topic prioritisation process. See here for information on the prioritisation process and the submission form:</p> <ul style="list-style-type: none"> <li>• <a href="#">Prioritising our guidance topics</a></li> <li>• <a href="#">Topic suggestion</a>.</li> </ul>
British Society of Interventional Radiology (BSIR)	Guideline	1.10	Table 2	The table suggest a robust follow up protocol and standardisation of this is supported.	Thank you for your comment and support for this section of the guideline.

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British Society of Interventional Radiology (BSIR)	Guideline	1.10	General	The guidance does not clearly discuss the treatment options of local recurrence following thermal ablation or partial nephrectomies.	<p>Thank you for your comment. Treatment for local recurrence after thermal ablation or partial nephrectomy was not evaluated as part of this current piece of work. The committee are therefore unable to make recommendations on this topic.</p> <p>However, if you have evidence to support its inclusion in future work, please can you share it with us by submitting a topic suggestion through our topic prioritisation process. See here for information on the prioritisation process and the submission form:</p> <ul style="list-style-type: none"> <li>• <a href="#">Prioritising our guidance topics</a></li> <li>• <a href="#">Topic suggestion</a>.</li> </ul>
British Society of Interventional Radiology (BSIR)	Guideline	1.5.1	014	The document quotes surgery as having a lower risk of recurrence, but there is a significant difference in outcomes between partial vs robotic vs total nephrectomies. It is therefore inaccurate to refer to "surgery" as a single procedure. This should be clarified.	<p>Thank you for your comment. The committee discussed the risk of recurrence between different treatment methods. The related evidence review (review A) compared partial and total nephrectomy. The committee acknowledged that the evidence could not differentiate between partial and total nephrectomy for most recurrence outcomes, but they noted that local recurrence would not be expected in total nephrectomy. Overall, they agreed that a statement about recurrence in the recommendation would be useful to clinicians and people with RCC.</p> <p>The committee agreed to amend the statements about risk of recurrence to make them less definite in recognition of the variation within intervention types and specific that they were referring to local recurrence. They also added text to the related rationale and impact to clarify this.</p>
British Uro-Oncology Group (BUG)	Guideline	General	General	<b>Sestamibi SPECT/CT Non-invasive functional characterisation</b> It gives metabolic/functional information rather than	Thank you for your comment and support for this recommendation.

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				<p>just structural detail. That's valuable when CT/MRI morphology is indeterminate.</p> <p><b>Useful in biopsy-ineligible patients</b> The draft explicitly links it to scenarios where biopsy is "not an option or the person declines it." That is important for equity:</p> <ul style="list-style-type: none"> <li>• Some lesions are hard to biopsy safely (deep location, near vessels).</li> <li>• Some patients are anticoagulated/high bleeding risk.</li> <li>• Some patients simply do not want an invasive procedure.</li> </ul> <p><b>Shared decision-making</b> The language "if ... would change management" is good governance. It prevents ordering sestamibi scans as routine, and instead anchors it to: "Will this result alter what we do next?"</p>	
British Uro-Oncology Group (BUG)	Guideline	General	General	<p>Local treatment of metastases The recommendation could distinguish more clearly between: Symptom control (palliative radiotherapy to a painful bone lesion, decompression of spinal cord compression, control of bleeding), versus Consolidative/curative-intent metastatectomy or SABR after appropriate SACT response.</p>	<p>Thank you for your comment. The committee discussed whether to specify that the recommendations on treating metastases were for oncological control or symptom control. They decided not to specify which because the interventions can be used for either purpose, and may sometimes be used for both purposes. They also noted that there was no evidence for treatments for metastases identified as part of review H, and therefore they agreed to keep the recommendations at a high level. Therefore, no changes have been made to these recommendations as a result of this comment.</p>
British Uro-Oncology Group (BUG)	Guideline	004	002	<p>1.1 We welcome the recommendations regarding the information for people with suspected or confirmed</p>	<p>Thank you for your comment and support for this recommendation.</p>

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				renal cell carcinoma notably the need for a named clinical nurse specialist.	
British Uro-Oncology Group (BUG)	Guideline	004	002	1.1 We propose that clinical nurse specialist should be able to attend the multi-disciplinary team (MDT) team meetings.	Thank you for your comment. The committee acknowledged the central role of the clinical nurse specialist within the multi-disciplinary team (MDT). Although this was implied, the committee agreed that the significance of clinical nurse specialist involvement in the MDT should be clearly stated to reduce variation in practice and made it explicit within the recommendation about the role of the clinical nurse specialist.
British Uro-Oncology Group (BUG)	Guideline	005	023	1.1.3 We agree that people with renal cell carcinoma (RCC) should be provided the clinical nurse specialist's contact details. We suggest that the clinical nurse specialist be present at the point of diagnosis in the urology clinics and be present in oncology clinics to provide vital link between urology and oncology department.	Thank you for your comment. The committee agreed that it was important that the clinical nurse specialist acts as a link between urology and oncology and have added text in the recommendation to reflect this.
British Uro-Oncology Group (BUG)	Guideline	005	023	1.1.3 Presence of clinical nurse specialists in both urology and oncology clinics will provide the continuity of care to persons when they are referred from urology to oncology services both in locally advanced/metastatic setting and in post-nephrectomy setting.	Thank you for your comment. As mentioned in a previous response, we have added text to the recommendation to support the clinical nurse specialist acting as a link between urology and oncology. We have also added explanatory text to the rationale for the recommendation to describe that this would help to ensure continuity of care.
British Uro-Oncology Group (BUG)	Guideline	006	013	1.1.8 We agree that adults with RCC need to be provided with information regarding clinical trials. There are significant challenges to the delivery of clinical trials within NHS to people with RCC. We suggest that people with RCC have appropriate access to research nurses (RN) who can discuss clinical trials with patients.	Thank you for your comment and support for this recommendation. The committee agreed that treating clinicians would typically have the necessary information about clinical trials to share with patients and would be aware of trials available both within their centre and beyond. While the committee acknowledged that research nurses also play a role in this process, they agreed not to specify a particular healthcare professional in the recommendation, as doing so could limit opportunities for

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					discussion about trial participation to the specific trials the nurses are involved in. The committee concluded that the existing recommendation sufficiently addresses the need to discuss clinical trials with patients.
British Uro-Oncology Group (BUG)	Guideline	007	002	1.2 Imaging: We agree with the proposal for adults who are suspected to have renal cell carcinoma (RCC) to undergo triple-phase contrast-enhanced CT (CECT) of the abdomen or MRI of the abdomen, ideally with contrast, if they cannot have triple phase CECT.	Thank you for your comment and support for this recommendation. In response to another stakeholder comment, the committee discussed the use of the term triple-phase CT and whether the phases need to be defined. They noted that the term 'multiphasic CT' is a more general term that captures triple-phase CT and other CT imaging that could include more than 3 phases. They decided against defining which phases are required for triple phase CT and to allow for more flexibility changed the term to 'multiphasic CT' in the recommendations.
British Uro-Oncology Group (BUG)	Guideline	007	002	<b>1.2: General Brain imaging:</b> We propose that contrast enhanced CT of brain be considered as a baseline investigation of all patients with metastatic renal cell carcinoma who are deemed suitable for systemic anti-cancer therapy (SACT).	<p>Thank you for your comment. This section of the guideline refers to imaging in the context of diagnosis only. The evidence review on CT imaging (review I1) aimed to assess the diagnostic accuracy of CT scan or MRI for diagnosing renal lesions. We have not reviewed the evidence for the use of CT, or other imaging, in detecting brain metastases or imaging them before systemic anti-cancer therapy and are therefore unable to make specific recommendation about this.</p> <p>However, if you have evidence to support the assessment of CT imaging as a baseline investigation of all patients with metastatic renal cell carcinoma who are deemed suitable for systemic anti-cancer therapy in future work, please can you share it with us by submitting a topic suggestion through our topic prioritisation process. See here for information on the prioritisation process and the submission form:</p>

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					<ul style="list-style-type: none"> <li>• <a href="#">Prioritising our guidance topics</a></li> <li>• <a href="#">Topic suggestion.</a></li> </ul>
British Uro-Oncology Group (BUG)	Guideline	009	001	<p><b>1.3 Biopsy</b></p> <p>The draft uses “4 cm” as a decision threshold, which matches the common T1a definition. That’s pragmatic. In practice, the decision is not just based on size — it also incorporates <b>growth rate, comorbidity, solitary kidney, baseline renal function, and patient preference</b>. It may help to make explicit that “≤4 cm” is a priority group for biopsy, not the only group that benefits.</p> <p>The draft is right to name the situations where biopsy is inappropriate (renal vein/IVC thrombus, etc.), but it could expand In those cases, urgent surgical planning should proceed through the specialist MDT without delay.</p> <p><b>Capacity and equity:</b> the draft acknowledges that many centres historically went straight to surgery and do not yet have robust percutaneous biopsy pathways. This is an important aspect for accessibility and equity: people in areas without good interventional radiology access are at higher risk of immediate nephrectomy, even for lesions that might be benign. We would suggest: Access to biopsy should not depend on postcode; there should be referral routes into regional centres for renal mass biopsy and histopathology review.</p>	<p>Thank you for your comments. The committee, agree that people with a renal lesion measuring 4 cm or smaller are a priority group for biopsy. To emphasise this, they made a strong recommendation for this group and put this recommendation at the start of the section.</p> <p>The committee also recognised that, in some cases, biopsy may be appropriate for people with lesions larger than 4 cm to support management decisions, and therefore included an additional weaker ‘consider’ recommendation for biopsy in this group that includes some information about when this may be useful. With these recommendations, the committee believes they have adequately addressed situations where biopsy could usefully be performed outside the 4 cm threshold.</p> <p>The committee decided against expanding the recommendation for when biopsy should not be used to add text that ‘urgent surgical planning should proceed through the specialist MDT without delay’ in relation to situations where the person has a renal vein/IVC thrombus. This is because the recommendation applies specifically to biopsy decisions and does not extend to guidance on patient management in each of the listed scenarios. However, the rationale that accompanies this recommendation already explains that in this situation biopsy is not suitable because surgery is the only treatment option and delaying treatment for a biopsy is undesirable.</p>

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				<p>Hereditary disease Should highlight cross-reference to sestamibi imaging as a non-invasive alternative where appropriate (especially for BHD). To optimise safety and equity, add links to hereditary RCC MDT review, expert pathology, and non-invasive imaging options.</p>	<p>For an explanation of the rationale behind these decisions, please refer to the biopsy sections within the rationale and impact part of the guideline and for more details, see the discussion section of evidence review J on biopsy.</p> <p>The section on how the biopsy recommendations might affect practice reflects the committee's discussion on the issues you raised regarding capacity and equity. While the committee acknowledges variations in biopsy availability, they anticipate that the recommendations will help reduce these disparities over time. It is also important to note that making recommendations on service delivery falls outside the scope of this guideline.</p> <p>The guideline includes sestamibi imaging when biopsy is not an option under specific conditions within the imaging section. However, we cannot specify using this as a non-invasive alternative to biopsy in people with BHD in this context as the evidence base for this area was not reviewed. The section of the guideline that covers genetic assessment to diagnose a renal cell carcinoma (RCC) predisposition syndrome in people with RCC has a recommendation about referring these people to a specialist multidisciplinary team with expertise in managing renal lesions in this population.</p>
British Uro-Oncology Group (BUG)	Guideline	009	003	<p>1.3.1 We agree that biopsy be considered for suspected localised or locally advanced RCC. We also propose that the biopsy results to be reported as per the International Society of Urological Pathology (ISUP) and World Health Organization (WHO) renal tumour classification 2016 in a timely manner. <a href="https://doi.org/10.1016/j.eururo.2016.02.029">https://doi.org/10.1016/j.eururo.2016.02.029</a></p>	<p>Thank you for your comment. The evidence review on biopsy assessed how accurate a biopsy is for diagnosing renal cell carcinoma. It focused on whether a biopsy can correctly identify malignancy or non-malignancy, but it did not evaluate the ability of a biopsy to classify tumours according to the International Society of Urological Pathology (ISUP) or the World Health Organization (WHO)</p>

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					renal tumour classification 2016. The committee were therefore unable to make recommendations pertaining to this, but they noted that histopathology reports are issued in accordance with the Royal College of Pathologists Dataset for histopathological reporting of adult renal parenchyma neoplasms, which is in also line with the recently updated ICCR renal epithelial neoplasms dataset. Both recommend reporting tumour type in accordance with the World Health Organization (WHO) Classification of Urinary and Male Genital Tumours. The committee also noted that the Royal College of Pathologists dataset is under review currently.
British Uro-Oncology Group (BUG)	Guideline	010	013	1.3.6 We welcome the recommendation for biopsy for suspected RCC. With the different histological subtypes of RCC, it is vital to understand the exact subtype for therapeutic and prognostic purposes. We also propose that the biopsy results to be reported as per the International Society of Urological Pathology (ISUP) and World Health Organization (WHO) renal tumour classification 2016 in a timely manner. <a href="https://doi.org/10.1016/j.eururo.2016.02.029">https://doi.org/10.1016/j.eururo.2016.02.029</a>	Thank you for your comment. The committee did not evaluate the ability of a biopsy to classify tumours according to the International Society of Urological Pathology (ISUP) or the World Health Organization (WHO) renal tumour classification 2016. The committee were therefore unable to make recommendations pertaining to this, but they noted that histopathology reports are issued in accordance with the Royal College of Pathologists Dataset for histopathological reporting of adult renal parenchyma neoplasms, which is also in line with the recently updated ICCR renal epithelial neoplasms dataset. Both recommend reporting tumour type in accordance with the World Health Organization (WHO) Classification of Urinary and Male Genital Tumours. The committee also noted that the Royal College of Pathologists dataset is under review currently.
British Uro-Oncology Group (BUG)	Guideline	015	006	1.5 We welcome the recommendation people with localised solid renal masses be provided with information regarding all modalities of treatment including Surgery, thermal ablation, active surveillance or stereotactic ablative radiotherapy (SABR). We urge the Commissioners ensure that	Thank you for your comment and support for this recommendation.

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				they commission services for SABR to provide options and informed choice for patients.	
British Uro-Oncology Group (BUG)	Guideline	016	005	<p><b>Surgery, thermal ablation, active surveillance or SABR</b></p> <p>Surgery is the preferred option for renal lesions 2 cm in diameter and larger when it is suitable” is clinically consistent with the committee’s earlier rationale, but it risks being interpreted as “we always operate at 2 cm.” In practice, there are 2–3 cm lesions in frail people where active surveillance may be appropriate and therefore clarifying this would be helpful.</p> <p>The line “thermal ablation and SABR should not be used without biopsy confirmation of malignancy” is correct though there should be the option in selected cases where biopsy is not feasible due to lesion being technically inaccessible. Hence, the wording here should reflect that non-surgical treatment without biopsy should only proceed after MDT agreement that malignant behaviour is highly likely and the confirmation of technical inaccessibility for biopsy.</p>	<p>Thank you for your comments. Regarding 2-3cm lesions: The committee saw evidence (in reviews A and B) about the effectiveness of surgery compared with thermal ablation, stereotactic ablative radiotherapy (SABR) and active surveillance. The evidence suggested that surgery may result in improved recurrence and survival outcomes compared with the non-surgical interventions, and the committee agreed that surgery would usually be the preferred option for lesions of this size. However, they discussed factors that should be taken into account when deciding on management options for localised RCC and made a recommendation listing factors to take into account when deciding which management options are suitable for localised renal cell carcinoma and Bosniak 3 or 4 cysts, all of which may impact on which interventions are most suitable for the person.</p> <p>The committee noted that this recommendation already specifies taking into account the person's clinical characteristics. The committee decided to expand on this to include comorbidities and frailty as well. The same recommendation talks about balancing the risk of complications from surgery (which may be increased with frailty) with the risks of non-surgical options. They also note in the rationale and impact section that some people choose active surveillance over treatment, and that active surveillance may be a suitable alternative to surgery.</p> <p>Regarding biopsy confirmation of malignancy: The committee discussed scenarios where biopsy is not feasible</p>

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					due to the lesion being technically inaccessible. They agreed that while this does sometimes happen, it is very rare that these lesions would be able to be ablated. They discussed that after multiple failed biopsy attempts, thermal ablation or SABR may still be carried out in practice, but that it was important not to imply that this should be done routinely, and that there should be a high threshold of effort before proceeding without biopsy. They added text to the rationale and impact section to acknowledge this. The committee also noted that the commissioning policy on SABR may specify more detail about biopsy prior to SABR. The committee decided to retain the recommendation as it is without making any change.
British Uro-Oncology Group (BUG)	Guideline	016	020	<p><b>1.5.2 SABR not for lesions &gt;7 cm)</b>            Would be helpful to explain that larger targets increase motion management complexity, raise normal tissue dose, and reduce certainty of full ablative coverage.            It is important to specify that SABR requires MDT sign-off and access to regional expertise, so that potential for SABR is not limited.            SABR-treated patients should have the same structured imaging follow-up / personalised care planning pathway.</p>	<p>Thank you for your comments. The committee discussed reasons for not using SABR above 7cm and decided that this level of technical detail was too great to include in the guideline. However, they added text to the rationale section to highlight the uncertainty about the effectiveness of SABR above 7cm.</p> <p>The committee agreed to add text to the section on how the recommendations might affect practice noting that sign off for SABR would require the multidisciplinary team (MDT) to include the relevant expertise.</p> <p>The committee agreed that SABR-treated patients should have the same structured imaging follow-up / personalised care planning pathway as other patients and they are specifically mentioned in the section on follow up imaging and schedules.</p>

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British Uro-Oncology Group (BUG)	Guideline	023	002	1.7.1 Information for people before and after kidney surgery: Adults undergoing surgery would need to be made aware of the potential need for adjuvant therapy after review of the pathology results. This will aid the people to be well prepared when they are being discussed the results of pathology and when the referral is made to oncologists for adjuvant therapy.	Thank you for your comment. The committee agreed that people should be aware before surgery that adjuvant systemic anticancer treatment may be recommended after surgery. Therefore, we have added this to the section on information given to people before and after surgery.
British Uro-Oncology Group (BUG)	Guideline	025	015	1.9 Adjuvant SACT: As pembrolizumab is recommended as an option in NICE technology appraisal guidance for adjuvant treatment of RCC at increased risk of recurrence after nephrectomy	Thank you for your comment. This TA (TA830) has been incorporated into the guideline
British Uro-Oncology Group (BUG)	Guideline	025	016	1.9.1 We propose that all post nephrectomy pathology results are discussed in MDT to ensure that the option of adjuvant therapy is considered. This is relevant since pembrolizumab is recommended as an option in NICE technology appraisal guidance for adjuvant treatment of RCC at increased risk of recurrence after nephrectomy.	Thank you for your comment. The committee noted that all post-nephrectomy pathology results are routinely discussed at MDT along with risk prediction scores for recurrence to determine appropriate follow-up schedules and further treatment options. We currently have a recommendation in the section on Risk prediction tools for localised or locally advanced RCC which suggests that pathology information from surgical samples post nephrectomy or biopsy are included as part of clinical judgment when deciding future treatment options. However, to clarify, the committee agreed to add "adjuvant SACT" to the recommendation as an example of a future treatment option after surgery.
British Uro-Oncology Group (BUG)	Guideline	026	001	1.10 We propose that people who have completed treatment (including any adjuvant treatment) for localised or locally advanced RCC, be provided with written information and schedule of their follow-up.  <b>1.10 Follow-up for localised and locally advanced RCC</b>	Thank you for your comments. Please note that the recommendation in the follow-up for localised and locally advanced RCC section of the guideline for a personalised care plan to be agreed between the health care professional and the person who has had treatment includes information and schedule of their follow-up, which is given to them and their GP and documented in their

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				<p>It is better to mention that the secondary care team (urology / uro-oncology / specialist renal mass clinic) is responsible for coordinating surveillance until formal discharge, not the GP by default. Availability for CNS for questions, anxiety, and escalation between scans. It will also help to determine when cases need to be rediscussed e.g. accelerated growth, new enhancing nodule, new consistent symptoms) and align &gt;5 mm/year" language to reduce site-to-site variation.</p> <p>Important to specify that lack of local surveillance clinic should not force a patient into surgery.</p>	<p>health record. Therefore, no new addition has been made to this effect.</p> <p>The team responsible for coordinating follow-up was discussed with the committee and they agreed that this is managed by the secondary care team and should be reflected in the guideline. Therefore, an additional bullet has been added to the recommendation on agreeing a personalised care plan to inform the person that follow-up will be managed by the secondary care team. This recommendation also includes mention of a named healthcare professional and examples of when the person should contact them. This could be the clinical nurse specialist as the recommendation under "Information and Support" about clinical nurse specialist support applies during follow-up. Therefore, no additional mention of the clinical nurse specialist has been made.</p> <p>Imaging during follow up occurs after treatment, which could be surgery or another treatment. Active surveillance, which could be used instead of, or before, surgery then this is covered within section 1.5 of the guideline. The recommendations in this section provide guidance about who should have surgery or active surveillance taking into account the person's clinical characteristics and preferences. The committee do not expect that active surveillance will be unavailable and as a result, force a person into having surgery. However, they are unable to make recommendations about service organisation and delivery as this is out of scope of the guideline.</p>

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British Uro-Oncology Group (BUG)	Guideline	032	013	<p><b>Treating the primary renal lesion in people with metastatic RCC</b></p> <p>We agree with the selective, staged approach. It is important to highlight that CN decisions should be based with full assessment of prognostic risk, biological tempo, and MDT discussion.</p>	<p>Thank you for your comment. The guideline includes a section 1.12 on referring people with advanced RCC to a multidisciplinary team (MDT) to manage their cases. In addition, the section on risk prediction tools for metastatic RCC contains recommendations about assessing risk when deciding on treatment options for people with metastatic RCC. It is therefore implied that discussions about treatment options will be discussed in the MDT and no new changes have been made as a result of this comment.</p>
British Uro-Oncology Group (BUG)	Guideline	059	001	<p><b>Managing oncocytomas and Bosniak 2F cysts</b></p> <p>This should include following: Define typical follow-up imaging intervals and modalities. Emphasise shared decision-making at discharge. Link surveillance pathways to CNS support and regional oversight. Encourage consistent practise across the country</p>	<p>Thank you for your comments. The guideline has suggested imaging schedule and modalities for all people undergoing active surveillance in section 1.5 of the guideline, which is applicable to oncocytomas and Bosniak 2F cysts.</p> <p>The committee acknowledged the importance of a personalised decision between the patient and the clinician when discharging people with an oncocytoma or Bosniak 2F cyst from active surveillance after 5 years. They agreed that people's individual preferences and clinical characteristics should be considered and the recommendation was changed to reflect this point. If, however, the person is being discharged from active surveillance because they are unable to have treatment for local symptoms or RCC if they were to develop it, then these factors are not relevant because active surveillance is, by definition, only for people who are able to have</p>

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					<p>treatment. (Active surveillance is defined in the terms used section of the guideline.)</p> <p>The committee discussed the role of clinical nurse specialists (CNS) in caring for people with oncocytoma or Bosniak 2F cysts. They agreed that CNS involvement may be beneficial in providing education, symptom management and coordination of care and noted that in their experience, care of people with these renal lesions is often nurse led. However, they agreed that practice varies across the country and that where CNS availability is limited it would be important to prioritise support for people with renal cell carcinoma over people with an oncocytoma or Bosniak 2F cyst. Therefore, they decided not to include CNS support in the recommendations for people with oncocytomas and Bosniak 2F cysts or link this to surveillance pathways. However, they amended the wording of the recommendations for CNS to include support for those with suspected RCC, which would cover people with oncocytoma or Bosniak 2F cysts before their diagnosis.</p> <p>The committee acknowledged variation in the management of oncocytomas and Bosniak 2F cysts nationally and believe that the recommendations set out in this guideline should promote uniform practice across the country.</p>
Centre for Perioperative Care	Guideline	022-023	Sections 1.6 & 1.7	<p><b>1. Lack of Reference to Perioperative Pathway Principles</b> Sections 1.6 and 1.7 focus on surgical decision-making and pre/post-operative information but do not reflect the broader perioperative pathway. There is no mention of:</p>	<p>Thank you for your comments. We have cross-referred to the <a href="#">NICE guideline on Shared decision making</a> under the recommendation for healthcare professionals in all settings to provide ongoing information and support at different times throughout the person's care. This would also include</p>

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				<ul style="list-style-type: none"> <li>• Shared decision making (SDM)- despite NICE's own guidance (NG197), SDM is not explicitly integrated into the surgical planning or recovery process in these sections.</li> <li>• Prehabilitation- no reference is made to preparing patients physically and psychologically for surgery, which is vital for reducing post-op complications and improving outcomes</li> <li>• Medicines optimisation- particularly relevant for patients with multimorbidity or polypharmacy, yet absent from the surgical context.</li> <li>• Comprehensive assessment and optimisation- including frailty, nutrition, and comorbidities, which are critical in surgical risk stratification and recovery planning.</li> </ul> <p>These omissions risk undermining the holistic, patient centred approach that perioperative care promotes.</p> <p><b>2. Missed Opportunity to Link with Existing NICE Guidance</b> There is no cross-reference to NICE's own guidance on:</p> <ul style="list-style-type: none"> <li>• Perioperative care of adults (NG180)- which outlines best practice for assessment, optimisation, and recovery.</li> <li>• Quality standards for perioperative care (QS195)- which provide measurable indicators for safe and effective surgical pathways.</li> </ul>	<p>during discussions around surgery and the recovery process.</p> <p>The committee discussed your comments and agreed that whilst important, prehabilitation, medicines optimisation and comprehensive perioperative assessment and optimisation are best practice; these apply to all surgical procedures and are not specific to renal surgery. So they decided not to add these as specific considerations in the recommendations. However, they agreed that the <a href="#">NICE guideline for Perioperative care in adults</a> would cover many of these aspects and agreed that it would be useful to add a cross-reference to this within the section on information for people before and after surgery.</p> <p>The quality standard you reference, QS195, is for renal and ureteric stones and therefore not specific to kidney cancer so we have not linked explicitly to this. However, for information, there is a quality standard for <a href="#">perioperative care in adults</a> currently in development.</p>

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				<p>Incorporating these would strengthen the guideline's alignment with national standards and improve consistency across surgical specialties to ensure there is continuity of guidance.</p> <p><b>3. Recommendations for Improvement</b> CPOC recommends that sections 1.6 and 1.7 be revised to:</p> <ul style="list-style-type: none"> <li>• Include references to SDM, prehabilitation, preoperative optimisation, medicines optimisation, and post-operative recovery planning.</li> <li>• Link explicitly to NICE NG180 and QS195.</li> <li>• Emphasise the importance of multidisciplinary perioperative assessment, especially for patients with complex needs.</li> </ul> <p>These additions would ensure the guideline reflects current best practice and supports improved outcomes for patients undergoing kidney cancer surgery.</p>	
East of England Cancer Alliance	Guideline	014	011 – 013	<p>Current practice to discharge all Oncocytomas if they are asymptomatic – this document says to follow up for 5 years. Will require a change in practice – Can the evidence be shared / incorporated</p>	<p>Thank you for your comment. There was no evidence that met the inclusion criteria for this review (review E on active surveillance), so the committee used their expertise to draft consensus recommendations. The committee noted that oncocytic renal neoplasms cover a spectrum of pathological features from benign renal oncocytomas to chromophobe renal cell carcinoma and that it can be hard to distinguish between the two by imaging. The committee therefore agreed that it is important to monitor suspected</p>

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					oncocytomas for a period of time. The committee agreed that 5 years was a reasonable amount of time for this monitoring because if the suspected oncocytoma is a malignant mass, it is unlikely it would be undetected during that time. The committee noted that this reflected current practice in their centres but might be a change in practice elsewhere. Therefore, no changes were made to this recommendation.
East of England Cancer Alliance	Guideline	016	011 - 012	To offer surgery for renal lesions more than 2 cm and active surveillance for lesions less than 2 cm (1.5.8) - (EAU advice <b>active surveillance</b> up to 4 cm) – clarification with the draft committee	Thank you for your comment. The committee clarified that surgery would usually be the preferred option for people with a lesion 2cm in diameter or larger where it is suitable (after taking into account the factors outlined in the guideline recommendations). Active surveillance would usually be the preferred management option for people with lesions less than 2cm (this is supported by weaker evidence and is therefore a weak recommendation, denoted by the word 'consider'). The committee noted that not everyone would want active surveillance and that this might be declined, in which case other options could be considered.
East of England Cancer Alliance	Guideline	018	018	To offer surgery for renal lesions more than 2 cm and active surveillance for lesions less than 2 cm (1.5.8) - (EAU advice <b>active surveillance</b> up to 4 cm) – clarify with the draft committee	Thank you for your comment. The committee clarified that surgery would usually be the preferred option for people with a lesion 2cm in diameter or larger where it is suitable (after taking into account the factors outlined in the guideline recommendations). Active surveillance would usually be the preferred management option for people with lesions less than 2cm (this is supported by weaker evidence and is therefore a weak recommendation, denoted by the word 'consider'). The committee noted that not everyone would want active surveillance and that this might be declined, in which case other options could be considered.

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East of England Cancer Alliance	Guideline	024	010	We have to use VENUSS for <b>papillary RCC</b> in our histology report	Thank you for your comment and support of our recommendation to use the VENUSS tool for this population.
East of England Cancer Alliance	Guideline	036	003	Request for <b>Genetic testing</b> – Useful to ensure links with regional genomic teams	Thank you for your comment. We agree that this is useful but this point would be expected to be covered by local processes and is too general to add to the recommendations.
Kidney Cancer UK	Evidence review D	General	General	The Guideline Committee appears not to have considered the Kidney Cancer UK report published on our website in August 2024 called 'Navigating the psychological impact of kidney cancer.' This may be due the fact that it was not published in a peer review journal, and consequently not picked up in literature searches. The report is based on ten years of data from the Charity's annual patient survey and may provide some additional information as well as helping support some points already made It can be accessed here <a href="https://www.kcuk.org.uk/wp-content/uploads/2024/09/patient-support-and-mental-health.pdf">https://www.kcuk.org.uk/wp-content/uploads/2024/09/patient-support-and-mental-health.pdf</a>	Thank you for your comment. The report you have referenced was not identified in our search. However, we have looked at the paper, and it does not meet the criteria listed in the protocol for the review on information needs as it is not a published peer-reviewed qualitative research study carried out using the methods listed in our protocol. However, we have highlighted this report to the committee, mentioned it in the evidence review, and noted there that it reflects some of the evidence found in the evidence review.
Kidney Cancer UK	Guideline	General	General	Sometimes people who have had partial or full nephrectomy are misdiagnosed with Chronic Kidney Disease, mistaking this for the reduced kidney function following surgery. It may be useful to include a recommendation in 1.7 Information for people before and after kidney surgery to clarify this with the person with RCC. (Or alternatively 1.10.3)	Thank you for your comment. The committee decided to add your suggested text specifically because some people will go onto have chronic kidney disease (CKD). However, they added text to say that reduced kidney function after surgery does not necessarily lead to progressive chronic kidney disease (CKD). The recommendation already has a bullet to prompt people to discuss a new mention of CKD on their medical record with their healthcare provider if this concerns them.
Kidney Cancer UK	Guideline	General	General	The section on patient information and support:	Thank you for your comment. Recommending greater collaboration between NHS trust and hospitals with

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				<ul style="list-style-type: none"> <li>• Needs a stronger recommendation for NHS trusts and hospitals to collaborate more closely with reputable patient charities to provide information and support.</li> <li>• Would benefit from a clear emphasis on providing patients with information on all clinically relevant treatment options to ensure they make fully informed decisions.</li> <li>• Whilst using links to other pieces of NICE guidance to avoid duplication is useful, this section of the guideline has done so to too great an extent. Whilst still employing the links, there needs to be more commentary to emphasise particular needs of people with kidney cancer. All patients with a serious disease are anxious, and all cancer patients particularly so. Many kidney cancer patients are even more anxious because their diagnosis is an incidental finding from a scan for a completely unrelated condition. Their high level of shock comes from the impact of a cancer diagnosis for which they have had no opportunity to prepare. In kidney cancer this happens in around 50% of all patients.</li> </ul>	<p>charities is beyond NICE's remit. However, we do cross refer to the <a href="#">NICE guideline on patient experience in adult NHS services</a>, which explicitly recommends signposting people to where to find information and support from local and national organisations, and offering people information on relevant treatment options so they can make informed decisions. There is also a separate tab on the guideline webpage for information for the public that contains links to charities that can provide information and support.</p> <p>Although the information and support section of the guideline makes extensive use of cross referrals to other NICE content where the same overarching principles apply, we worked with the committee to highlight the information needs that are specific to people with kidney cancer and included these as explicit recommendations in appropriate places throughout this guideline. These are discussed in detail in evidence review D on information needs and commentary is provided in the rationales that accompany these recommendations. In addition, in response to your comment we have added text to the rationale of the general information section of the guideline, and the committee discussion of the information needs evidence review, to highlight the specific experiences of anxiety related to people with a kidney cancer diagnosis that is made based on incidental findings.</p>
Kidney Cancer UK	Guideline	General	General	The section on diagnosis does not comment on imaging to detect brain metastases that are secondaries to kidney cancer. This is an area of current debate, and a national audit is ongoing. Whilst not delaying progress of this guideline, it may	Thank you for your comment. The evidence reviews on imaging for diagnosis (reviews I1 and I2) did not aim to assess imaging for the detection of metastases. They aimed to assess the diagnostic accuracy of CT, MRI, contrast-enhanced ultrasound and 99mTc-sestamibi single-photon emission computed tomography CT for diagnosing

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				be an area to watch as additional guidance may be needed at a later stage.	and characterising renal lesions. Therefore, we are unable to make a specific recommendation about the use of any of these types of imaging for detecting brain metastasis. However, we discussed this with the committee and agreed to provide links to the NICE guidelines on <a href="#">brain tumours and brain metastases (NG99)</a> and <a href="#">spinal metastases and metastatic spinal cord compression (NG234)</a> , where imaging for suspected brain or spinal metastases are discussed in more depth. Therefore, text was added to refer to these guidelines if brain, bone or spinal metastases are suspected.
Kidney Cancer UK	Guideline	General	General	<p>In places, the guideline uses a lot of links to other pieces of NICE guidance. We understand the reasons for doing so, but we would suggest that these parts of the document be reviewed to ensure:</p> <ul style="list-style-type: none"> <li>• There is sufficient narrative to place the links (and the information they provide) in context relating to kidney cancer</li> <li>• The significance of the any specific points in relation to kidney cancer is pointed out.</li> </ul>	<p>Thank you for your comments. We have cross referred to other NICE guidelines that focus on issues that apply across patient populations, and it is the responsibility of the clinician who is providing this information to the person with kidney cancer to discuss relevant points with them. This section of the guideline is written with the clinician in mind and is not intended to provide a detailed source of information for patients. We have added a cross reference to the guidelines website tab that covers information for the public at the top of this section now. This will be published at the same time as the guideline.</p> <p>The format of NICE guidelines does not allow for the inclusion of large amounts of narrative text as part of the recommendations. However, we have tried to provide some context within the recommendations by highlighting specific sections that are particularly relevant within the <a href="#">NICE guideline on patient experience in adult NHS services</a> and <a href="#">NICE guideline on shared decision making</a> for example. We also recommend discussing with the person with kidney cancer how they are coping with their emotions and</p>

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					<p>suggest signposting to psychological support services if appropriate before cross referring to the <a href="#">NICE guideline on depression in adults with a chronic physical health problem</a>, which is applicable to a wider population.</p> <p>The rationale that accompanies the information section of the guideline provides a narrative to support the recommendations.</p> <p>Although the information and support section of the guideline makes extensive use of cross referrals to other NICE content where the same overarching principles apply, we worked with the committee to highlight the information needs that are specific to people with kidney cancer and included these as explicit recommendations in appropriate places throughout this guideline. These are discussed in detail in evidence review D on information needs and commentary is provided in the rationales that accompany these recommendations.</p>
Kidney Cancer UK	Guideline	005	001	<p>There is a lot of useful guidance available through the various links. However, there is no clear statement to say that patients with kidney cancer should be offered information on their diagnosis and treatment at every point on the pathway. This should include information on all clinically relevant diagnostic procedures, including biopsy, and all clinically relevant treatment options, include specialised treatment available at another hospital that may be a long distance away. An informed choice can only be made when a patient has been offered and has considered this information.</p>	<p>Thank you for your comment. The committee agreed that it is essential that people with kidney cancer are supported to make informed decisions by having access to the right information at the right time.</p> <p>In the Overview, and in the second recommendation in the Information and support sections of the guideline, there is content about providing ongoing information and support based on what is needed at different times. We then cross refer to the <a href="#">NICE guideline on patient experience in adult NHS services</a> (CG138), and explicitly signpost to the sections on <a href="#">information</a> and <a href="#">an individualised approach to care</a>. These sections include recommendations clearly</p>

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				Ensuring the patient has access to information on biopsy is particularly important because it may be carried out as an additional part of the original diagnostic plan, e.g. to confirm findings from imaging. This can worry patients. Providing information about the procedure is therefore important.	<p>stating that all people receiving care through NHS services should be offered information on their diagnosis and treatment at every point in the pathway (see, in particular, recommendation 1.5.14 in CG138), including treatment available at non-local centres (see recommendation 1.3.3 in CG138).</p> <p>It is NICE policy to refer readers to guidelines such as this one and the <a href="#">NICE guideline on shared decision making</a> that apply across topics because they are full length guidelines that have been developed by experts over a long period of time, rather than just having a small amount of advice developed by a disease specific committee like the one for the kidney cancer guideline. In addition, this ensures consistency in messaging around these topics across guidelines.</p> <p>On biopsy specifically, the biopsy section of the guideline includes a recommendation on what to discuss with people about biopsy to help them make an informed decision.</p>
Kidney Cancer UK	Guideline	005	025	Suggest adding two words 'designated' and 'name' to strengthen the need for each person to have their own CNS. '...and give them the designated clinical nurse specialist's name and contact details'	Thank you for your comment. The committee carefully considered the suggestion to include the words 'designated' and 'name' but decided against adding these words to the recommendation. They agree that these terms imply that CNS support must be delivered by a single, individually identified nurse, and this would restrict flexibility and create unnecessary burdens or operational pressures for some centres. The committee were aware that in many trusts CNS responsibilities are shared across a team. This ensures that patients always have access to CNS

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					<p>expertise, and across the pathway, rather than being dependent on the availability of one individual.</p> <p>The committee agreed that retaining the current wording reflects the diversity of CNS provision across centres and is not restrictive to one model of CNS provision.</p>
Kidney Cancer UK	Guideline	006	004	At start of sentence insert 'At regular points throughout the pathway,'	Thank you for your comment. The committee considered this and agreed that discussions with the person with renal cell carcinoma regarding emotions and coping should take place at regular points throughout the pathway. To reflect this, they have amended the wording of the recommendation as requested.
Kidney Cancer UK	Guideline	006	General	Add a point stating that people with RCC should be informed about patient charities that can provide additional information and support when needed. Website and support line details should be made available to them. (This is because NHS services are not able to generate all the necessary information and cannot make it available at any time 24/7. If the NHS tried to do this it would put too much strain on services and divert resources, when the information already exists; it simply needs to be signposted).	<p>Thank you for your comment. In the Overview and in the Information and support sections of the guideline, we cross refer to the <a href="#">NICE guideline on patient experience in adult NHS services</a> (CG138) and explicitly signpost to the sections on information. This section includes a recommendation clearly stating that all people receiving care through NHS services should be informed about where they can find additional information and support through national and local groups (see recommendation 1.5.18 in CG138).</p> <p>We agree that informing people with kidney cancer about where they can find additional information and support through charities is very important, which is why we think it is best to refer people to the full-length guidelines focused on patient experience and written by experts rather than just having a small amount of advice in this guideline.</p> <p>We are unable to cross refer to individual charities that offer information and support from within the guideline. However,</p>

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					contact details for relevant charities will be included on the 'information for the public' tab on NICE's webpage for the guideline. We have included a cross reference to this tab at the start of the guideline section on information and support.
Kidney Cancer UK	Guideline	006	015	Include Kidney Cancer UK link to information on clinical trials <a href="http://kcuk.org.uk/research/clinical-trials/">kcuk.org.uk/research/clinical-trials/</a> In addition, this and line 018 appear to be the only mention of clinical trials in the guidelines. Given the latest results reported in the National Kidney Cancer Audit's State of the Nation report (2025) shows that only 1% of patients in England had consented for a clinical trial, we believe a recommendation that more patients should be informed about and offered access to a relevant clinical trial should be included.	Thank you for your comment. The committee already made a recommendation to discuss involvement in clinical trials, and believe this is sufficient to support informing patients about relevant clinical trials. However, following your suggestion, they have added a link to the Kidney Cancer UK clinical trial webpage in the recommendation.
Kidney Cancer UK	Guideline	011	011	This statement needs some revision. It assumes the treating physician has the experience and expertise to be considering all possible treatment options that are clinically relevant. For example, if they are considering only carrying out a nephrectomy and not a partial nephrectomy, when a partial nephrectomy would be viable and clinically relevant, a biopsy could be said to be unnecessary on the grounds that it would not change the patient's management. Suggest changing to: 'Do not biopsy the renal lesion or metastases if after considering all relevant treatment options, it is not going to change management.'	Thank you for your comment. The committee discussed decided against making the suggested change because it is expected as part of general good clinical practice that clinicians will think about all potential treatment options before making decisions even if they need to seek additional expertise to provide them.
Kidney Cancer UK	Guideline	011	015	At this point, the guideline does not recommend routine biopsy for people with von Hippel-Lindau	Thank you for your comment. This section of the guideline is focused on when to carry out or not carry out a biopsy. Surgery for renal cell carcinoma in people with a heritable

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				syndrome, but there is no guidance on the size at which they should be considered for surgery.	renal cell carcinoma predisposition syndrome is covered in sections 1.18 and 1.19.  The scope of this guideline covers people with heritable predisposition to renal cell carcinoma which is a broader category than just people with von Hippel-Lindau (VHL) syndrome. Therefore, the committee did not make specific recommendations for managing renal lesions associated with VHL. However, in the section on active surveillance for suspected or confirmed localised RCC in people with heritable RCC predisposition, we already have a recommendation that suggests that treatment (including surgery) should be considered for renal lesions 3cm in diameter or larger for people with heritable RCC predisposition syndrome that is not associated with more aggressive RCC. This would include people with renal lesions associated with VHL.
Kidney Cancer UK	Guideline	015	014	We understand the term 'thermal ablation' is a general term used in European guidelines. However, we believe this should be changed to RF ablation and cryoablation to recognise the two different techniques. In the eyes of patients 'thermal' is often perceived as heat. For some patients this may influence their decision on treatment, some people would not like the idea of heat being used but would be more comfortable with cold.	Thank you for your comment. The committee agreed to add the term "thermal ablation" to the terms used section of the guideline to clarify what types of ablation are included (cryoablation, microwave ablation and radiofrequency ablation) and to highlight that thermal refers to both heating and cooling.
Kidney Cancer UK	Guideline	023	014	We agree with the reference to sources of patient information, but we feel this point should be preceded by a sentence reinforcing the importance of providing patients with information and ensuring they have been able to consider all applicable options.	Thank you for your comment. In the Overview and the Information and support sections of the guideline we cross refer to <a href="#">NICE guideline on patient experience in adult NHS services</a> (CG138), and explicitly signpost to the section on information, and also refer to the <a href="#">NICE guideline on Shared Decision making</a> . These guidelines include

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					<p>recommendations clearly stating that all people receiving care through NHS services should be offered information so that they are able to consider all possible options.</p> <p>The guideline also includes a recommendation to support shared decision making around treatment options for people with localised renal cell carcinoma in section 1.5 that specifically says that they should have the benefits and risks of all suitable options discussed with them.</p>
Kidney Cancer UK	Guideline	023	020	The link to 'information and education for people with CKD in the NICE guideline on chronic kidney disease' risks confusion between reduced kidney function due to surgery versus reduced kidney function due to CKD (see comment 8).	Thank you for your comment. The committee agreed that not everyone who has kidney surgery will develop chronic kidney disease (CKD). However, some people will and they therefore decided to retain the reference to the <a href="#">section on information and education for people with CKD in NICE's guideline on chronic kidney disease</a> . The information to discuss before surgery recommendation is intended to be used by the healthcare professional as part of a conversation with the person undergoing surgery and the healthcare professional is only expected to discuss the contents of the CKD guidelines information section if it is relevant for the patient. This recommendation also has bullets to stress that kidney surgery does not necessarily lead to progressive CKD and that the person should ask their healthcare professional about any new mention of CKD on their medical record if this concerns them.
Kidney Cancer UK	Guideline	025	006	We agree with this point. From speaking to patients and health care professionals, our impression is that this does not always happen.	Thank you for your comment and support for this recommendation.
Kidney Cancer UK	Guideline	025	015	The possibility of adjuvant SACT as a treatment option should be discussed with patients before surgery as this might affect their decision to undergo	Thank you for your comment. The committee agreed that people should be aware before surgery that adjuvant systemic anticancer treatment may be recommended after

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				surgery. We suggest a point to this effect be added here and also in 1.7 'Information for people before and after kidney surgery (page 023).	surgery. Therefore, this has been added to the section on information given to people before and after surgery. However, the committee decided that this information would be less useful if given at the time of deciding between surgery and other non-pharmacological treatments. This is because treatments that would exclude subsequent treatment with adjuvant SACT such as thermal ablation and SABR are mainly considered for those people with smaller, low risk renal lesions or who are too frail to have surgery. Adjuvant SACT is suitable for people who are at higher risk of recurrence after surgery and who are well or fit enough to receive the treatment. The committee therefore decided against adding mention of adjuvant SACT to the non-pharmacological options shared decision making recommendation.
Kidney Cancer UK	Guideline	025	019	Based on reports we have had from patients, our impression is that often the recommendations in TA830, 2022 are not being followed.	Thank you for your comment. By placing the technology appraisals (TAs) in the guideline and by providing visual summaries of the TA options, we hope that this will make it clearer for clinicians where individual TAs, including TA830, are relevant and increase their use where appropriate.
Kidney Cancer UK	Guideline	028	024	Discharging people for whom recurrence is considered low risk should be done in discussion with, and agreement of, the patient. This point is made regarding intermediate or high-risk patients (page 029, line 001) but is not reflected here for low-risk patients. We believe that a further Holistic Needs Assessment would be valuable at this time to identify any support needs that should be addressed once scans and hospital follow-up are ended.	Thank you for your comment. The committee agreed that people with low risk of recurrence do not need to be followed up for longer than 5 years if there hasn't been a recurrence or metastases at that time. Patient committee members also highlighted that remaining on monitoring beyond 5 years when the risk of recurrence is low creates further unnecessary anxiety. The committee therefore agreed that as the intention of this recommendation is to discharge the person who has been treated for RCC after 5 years of follow-up, no changes were required to this recommendation. In contrast, for people at intermediate and high risk it is expected that follow up is continued after 5

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					years and continued discussions are needed to determine when this ceases.
Kidney Cancer UK	Guideline	029	009	May be worth including a recommendation to remind people being discharged from follow up, of the contact details of patient charities.	<p>Thank you for your comment. In the Overview and in the second recommendation in the information and support section of the guideline we cross refer to <a href="#">NICE guideline on patient experience in adult NHS services</a> (CG138) and explicitly signpost to the section on information. This section includes a recommendation clearly stating that all people receiving care through NHS services should be informed about where they can find additional information and support through national and local groups (see recommendation 1.5.18 in CG138).</p> <p>These recommendations apply throughout patient's diagnosis and treatment pathway and have therefore not been repeated at this point in the guideline.</p>
Kidney Cancer UK	Guideline	030	010	Although palliative care is mentioned here and a link to separate guidance is provided at line 019, this does not reflect the importance of the role played by palliative care in treating advanced kidney cancer. A short paragraph on its role and how it should be integrated into the person's overall care would be helpful here.	<p>Thank you for your comment. We have not looked at any evidence relating to palliative care because this is out of scope of the guideline and are therefore limited to cross referring to other NICE guidelines on this topic. However, the committee agreed to add a specific section to the guideline for palliative and end of life care. They brought the cross references for information to discuss with the person with advanced RCC and added a recommendation to highlight that palliative and end of life care should be provided in line with the recommendations in the <a href="#">NICE's guidelines on end of life care for adults</a> and <a href="#">care of dying adults in the last days of life</a>, and <a href="#">NICE's cancer service guideline on improving supportive and palliative care for adults with cancer</a>.</p>
Kidney Cancer UK	Guideline	030	013	The Holistic Needs Assessment is mentioned only once in the document; here on line 13, which is a link	<p>Thank you for your comment. The committee agreed that assessing holistic needs is very important, which is why we</p>

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				to another piece of NICE guidance. Although this is preceded by a short sentence on supportive care, this is not sufficient to reflect the importance of ensuring the person's holistic needs are known and appropriately supported. At least one further sentence is needed to emphasise its importance would be useful at this point.	have signposted people to <a href="#">NICE's guideline on end of life care for adults</a> , a full-length guideline that has a full section focused on this topic written by experts rather than just having a small amount of advice in this guideline.
Kidney Cancer UK	Guideline	031	016	(See comment 12)	Thank you for your comment and support for this recommendation.
Kidney Cancer UK	Guideline	034	General	Although clinical nurse specialists are mentioned earlier in the guideline, the role of the CNS is not mentioned here in relation to treating advanced/metastatic kidney cancer. These are long-term patients. and the CNS role is particularly valuable here. We suggest adding a point here to emphasise this and a link back to page 005 line 023.	Thank you for your comment. Please note that the recommendation under "Information and Support" about the clinical nurse specialist applies during management, follow-up or palliative care, and includes advanced disease. To prevent repetition, we have not added the requested recommendation.
Kidney Cancer UK	Guideline	036	017	Fumarate hydratase-deficient tumours are mentioned here, but there is no specific guidance regarding follow up or imaging.	Thank you for your comment. Fumarate hydratase-deficient lesions are associated with Hereditary Leiomyomatosis and Renal Cell Cancer syndrome (HLRCC). We currently give HLRCC as an example of a syndrome associated with aggressive RCC in recommendations on imaging and follow up for heritable RCC. We have added some text to clarify this within the recommendations.
Kidney Cancer UK	Guideline	052	011	Kidney Cancer UK provides an online training course on kidney cancer for nurses, which carries three CPD hours. It is available free of charge <a href="https://healthpro.kcuk.org.uk/courses/kidney-cancer-training-program-2024/">https://healthpro.kcuk.org.uk/courses/kidney-cancer-training-program-2024/</a>	Thank you for your comment. We are unable to specifically signpost to the Kidney Cancer UK training, but we have included text in the committee discussion section of evidence review D to mention that there may be some existing training provided by Kidney cancer UK.

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Kidney Cancer UK	Guideline	055	021	We agree with this point. Waiting times for biopsies are already excessive in many places (see comment 24). Such delays cause a great deal of fear amongst patients.	Thank you for your comment.
Kidney Cancer UK	Guideline	058	013	We strongly agree with this point. Patients tell us biopsy results frequently take months, not weeks. We are currently measuring in our latest patient survey the length of time it takes for biopsy results to be received.	Thank you for your comment.
Kidney Cancer UK	Guideline	062	015	It may be worthwhile to separate the different ablative therapy methods to see if there is any difference between them regarding risk of recurrence.	<p>Thank you for your comment. The relevant evidence review (review B) did not aim to compare the different types of thermal ablation against each other and did not include studies with this aim. It aimed to compare effectiveness of thermal ablation with other non-pharmacological treatments. Where possible, subgroup analysis by type of thermal ablation was conducted although this was only possible in a minority of cases and did not show a difference between types of thermal ablation (for thermal ablation compared with partial nephrectomy; the outcomes of recurrence at up to 5 years, local recurrence at up to five years and metastasis at up to 5 years).</p> <p>However, if you have evidence to support including the comparison of types of ablation with each other in future work please can you share it with us by submitting a topic suggestion through our topic prioritisation process. See here for information on the prioritisation process and the submission form:</p> <ul style="list-style-type: none"> <li>• <a href="#">Prioritising our guidance topics</a></li> <li>• <a href="#">Topic suggestion</a>.</li> </ul>

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Kidney Cancer UK	Guideline	067	017	We agree with this point, but it appears to focus mainly on verbal information during discussions with health care professionals. People often become overloaded with information, and some will absorb it much more effectively from written booklets. The need is for as much information as possible to be provided, not only through discussions with health care professionals, but also from other sources in different formats to suit the needs of all patients. Discussions with health care professionals are vital and patients may need to have further discussions once they have had time to consider – hence the importance of named clinical nurse specialists. This also needs to be supported by information online that can be accessed whenever needed and as often as required, and for some patients written information in hardcopy printed booklets. Reputable patient charities can support patients and NHS staff by providing these.	<p>Thank you for your comment. We agree that providing information in different formats to suit people's unique needs is very important, which is why we cross refer to NICE's <a href="#">Patient experience in adult NHS services guideline</a>, and the section on information and support includes multiple recommendations about this.</p> <p>We agree that the way we have worded recommendations in the information for healthcare professionals to support people before and after kidney surgery section of the guideline, and its associated rationale, puts greater emphasis on verbal information. We have therefore changed this to state that information should be shared, without specifying in which format, to avoid preferencing only verbal information.</p>
Kidney Research UK	Guideline	005	030	We strongly support the provision of kidney cancer clinical nurse specialists but query where the funding for these positions and relevant training for them will come from.	<p>Thank you for your comment. The committee's role is to develop guidance based on best practice and the evidence available, with the aim of improving patient care and outcomes. Our recommendations are therefore focused on what constitutes high-quality effective care, rather than on the mechanisms by which resources are allocated. Although a resource impact assessment is carried out to accompany the guideline, decisions about how recommendations are implemented fall outside the remit of guideline development. However, the committee agreed that the positive recommendation for clinical nurse specialist support could be used as the basis for the</p>

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					development of a business case to obtain funding for them at a more local level.
Kidney Research UK	Guideline	006	04	Suggest amendment 'Discuss with the person with RCC <b>and their carers</b> ' as we know that the burden on the patient support system is also high. There is a need to ensure that the carers are themselves supported so that they can, in turn, best provide support for the patient.	Thank you for your comment. Family members and carers of people with renal cell carcinoma are not within the defined population for this guideline, and therefore we are unable to make recommendations specifically for their support. Involvement of family members and/or carers is already addressed in the NICE guideline on <a href="#">Patient experience in adult NHS services</a> (recommendation 1.3.10). We cross refer to this recommendation from second recommendation in the section on information and support. In addition, it is important to note that sharing information with carers or family members requires the individual's consent.
Kidney Research UK	Guideline	006	013	There is evidence to show that current involvement of kidney cancer patients in clinical trials is very low, and we query whether there is sufficient training in place for healthcare professionals (HCPs) who wish to carry out this type of research. We believe that greater involvement of clinical staff (including nurses and pharmacists) working in kidney cancer is key to ensuring that patients benefit fully from the opportunities these present.	Thank you for your comment. Training healthcare professionals to carry out research in a clinical trial setting is outside of the scope of this guideline and beyond NICE's remit.
Kidney Research UK	Guideline	006	020	Kidney Cancer UK carries out an annual patient survey. We suggest that this could be disseminated locally and developed further to collect both national and local feedback to help address patient concerns in a joined-up and co-ordinated manner.	Thank you for your comment. We have added text to the rationale of the information and support section of the guideline to highlight the Kidney Cancer UK patient survey.
Kidney Research UK	Guideline	017	009-012	This lacks information about those patients on the radiotherapy / ablation options.	Thank you for your comment. The committee agreed it was important that people are provided with information about all relevant treatment options. They decided against making recommendations about what information to provide for

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					<p>people having thermal ablation or SABR because some of this information would be too detailed and specific to the type of treatment for this guideline, while other information was judged to be covered by general good clinical practice. However, they noted that the recommendation for providing CNS support for all people with suspected or confirmed renal cell carcinoma should provide them with a point of contact for their support needs, including information on treatment options. There is also a section of the guideline on shared decision making for people with localised renal cell carcinoma (RCC) and Bosniak 3 and 4 cysts when choosing between treatment options that should encourage healthcare professionals to provide information on the treatments. In addition, we cross refer to the <a href="#">NICE guideline on patient experience in adult NHS services</a>, which explicitly recommends giving people information on relevant treatment options so they can make informed decisions.</p>
Kidney Research UK	Guideline	023	003	<p>There is a lack of information available to patients receiving newer treatment options such as cryotherapy and other types of ablations. One patient fed back to us that they were unable to contact their consultant to talk through what their proposed treatment would involve and had, instead, to turn to various charity support options to finally gain access to a consultant who could talk them through the treatment being proposed.</p>	<p>Thank you for your comment. The committee agreed it was important that people are provided with information about all relevant treatment options. They decided against making recommendations about what information to provide for people having thermal ablation or SABR because some of this information would be too detailed and specific to the type of treatment for this guideline, while other information was judged to be covered by general good clinical practice. However, they noted that the recommendation for providing CNS support for all people with suspected or confirmed renal cell carcinoma should provide them with a point of contact for their support needs, including information on treatment options. There is also a section of the guideline on shared decision making for people with localised renal cell carcinoma (RCC) and Bosniak 3 and 4 cysts when</p>

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					choosing between treatment options that should encourage healthcare professionals to provide information on the treatments. In addition, we cross refer to the <a href="#">NICE guideline on patient experience in adult NHS services</a> , which explicitly recommends giving people information on relevant treatment options so they can make informed decisions.
Kidney Research UK	Guideline	023	007	Clear information on Chronic Kidney Disease (CKD) should be provided at this point in the patient journey, not after a diagnosis has been made. Patients should be clearly told about the expectation for monitoring of their kidney function going forward; this should include information about the timings of tests as well as the importance of both eGFR and uACR tests for accurate prediction and detection of CKD. Patients should receive a clear explanation about CKD and staging before it arises in order to enable them to make informed choices for themselves about how best to protect their remaining kidney function. We have evidence that many people do not receive this information and find it extremely distressing.	Thank you for your comment. The committee, including expertise from lay members, discussed this and agreed that this level of information about chronic kidney disease (CKD) prior to surgery might be too overwhelming to consider alongside all the information being provided around surgery and that the details of CKD diagnosis and management are not within the scope of this guideline. They also noted that not everyone would develop CKD and that people may worry unnecessarily if everyone is told in detail about it at this time. Therefore, they decided not to add this information for people who are about to have renal surgery. However, in this section on information before and after surgery, we have a cross-reference to the <a href="#">NICE guideline on Chronic kidney disease</a> , which has a section on <a href="#">information and education</a> , where this is relevant for the person. This guideline also covers investigations for and management of CKD.
Kidney Research UK	Guideline	023	010	As commented on above, if patients are to understand the need to protect their remaining kidney function, they need to have a clear grasp of what the kidney 'does' and what CKD means.	Thank you for your comment. The committee, including expertise from lay members, discussed this and agreed that providing detailed information about CKD prior to surgery might be too overwhelming to consider alongside all the information being provided around surgery. They also noted that not everyone would develop CKD and that people may worry unnecessarily if everyone is told in detail about it at this time. Therefore, they decided not to add this information for people who are about to have renal surgery.

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					<p>However, in this section on information before and after surgery, we have a cross-reference to the <a href="#">NICE guideline on Chronic kidney disease</a>, which has a section on <a href="#">information and education</a>, where this is relevant for the person. This guideline also covers investigations for and management of CKD.</p> <p>The committee agreed that it is important for people to understand the role of the kidneys in the body and added some text to reflect this in the section on information before and after surgery.</p>
Kidney Research UK	Guideline	037	07-017	Clinicians referring patients for genetic testing should provide realistic expectations of when test results can be expected as well as waiting times involved when accessing specialist genetic services for support and advice.	Thank you for your comment. The committee agreed it would be useful to add some text to the recommendations to cover waiting time for genetic test results and access to specialist genetic services. However, because the times can vary across different centres, they decided not to specify the approximate waiting time in the recommendation. Instead, they expect that this conversation would be guided by the average waiting time for each individual centre.
Kidney Research UK	Guideline	037	018-020	Again, clear expectations about timelines need to be communicated with the patient if they are to be referred to a multidisciplinary specialist team.	<p>Thank you for your comment. The committee clarified that the clinical management of the person with RCC who has a heritable RCC predisposition syndrome (i.e. their case) will be referred to the specialist multidisciplinary team and that the individual patient does not attend these in person. The patient will have consultations with a member of that team to discuss management options.</p> <p>Information on expected waiting times for consultations should always be provided when a person is referred. This is covered in <a href="#">NICE's guideline on Patient experience in adult NHS services</a> (see recommendation 1.5.14) as a</p>

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					basic part of good clinical practice. Therefore, the committee did not make a specific recommendation on timelines here.
Kidney Research UK	Guideline	046	008	We support this research recommendation as patients living with multiple long-term conditions are not always suitable for surgical approaches and would benefit from more treatment options that have been evaluated for their effectiveness.	Thank you for your comment and support for this recommendation.
Kidney Research UK	Guideline	048	008	Again, we support this recommendation. We know that patients diagnosed with later stage disease have worse mortality rates. Stratifying patients and personalising their treatment approaches is essential if we are to progress our understanding of biomarkers and clinical factors.	Thank you for your comment and support for this recommendation.
Kidney Research UK	Guideline	050	001	Yes, we support this research recommendation. It is important to find which approach will best support a patient's quality of life and provide patients with clear information about what a treatment involves. We know that information can be lacking for patients receiving new types of treatment.	Thank you for your comment and support for this recommendation.
Merck, Sharp and Dohme UK	Guideline	General	General	The guideline provides an opportunity to draw attention to the role of clinical trials in the management of renal cell carcinoma. Currently, clinical trials are only mentioned twice, under 'general information'. We ask that NICE consider including trial participation as a potential management option in relevant sections of the guidelines (e.g. following the list of subsequent therapy options or treatments not recommended section p35 and/or in the recommendations for research section. The guideline	Thank you for your comment. As you note, there is already a recommendation in the general information section that covers discussing involvement in clinical trials with people with RCC. The committee agreed that this recommendation covered the key points they wanted to make to encourage people with renal cell carcinoma to take part in clinical trials, and that any decision to take part would be made as part of shared decision with the person. To highlight this recommendation, they have added cross references at the start of the adjuvant SACT and SACT for advanced RCC sections.

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				<p>should recommend that clinicians discuss trial opportunities with patients as part of shared decision-making, and that referral pathways to recruiting clinical trials should be considered where appropriate:</p> <p>Recent national audits show that recruitment into trials in kidney cancer is frequently below expected standards and that there is significant variability across the country. Audit data supports the need for guideline encouragement to consider clinical trial participation.</p> <ul style="list-style-type: none"> <li>• Kidney Cancer UK. Quality Practice Indicators for Renal Cancer: National Audit Report 2023. Kidney Cancer UK; 2023. Report and supporting documents available from: <a href="https://www.kcuk.org.uk/quality-practice-indicators">https://www.kcuk.org.uk/quality-practice-indicators</a></li> <li>• ACCORD Renal Cancer Audit 2022–2023: National audit of systemic therapy pathways and clinical trial recruitment. (ACCORD programme; 2023). <a href="https://accordproject.org.uk/renal-audit">https://accordproject.org.uk/renal-audit</a></li> <li>• NIHR Clinical Research Network portfolio statistics — recruitment to cancer studies, including renal cancer trials.</li> </ul>	

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				<p><a href="https://www.nihr.ac.uk/health-and-care-professionals/clinical-research-network.htm">https://www.nihr.ac.uk/health-and-care-professionals/clinical-research-network.htm</a></p> <ul style="list-style-type: none"> <li>NCRAS have also commented under recruitment across the UK.</li> </ul>	
Merck, Sharp and Dohme UK	Guideline	004	004	With regard to NICE's guideline on suspected cancer, we request that NICE guideline NG12 to be explicitly referenced in this guideline.	Thank you for your comment. The guideline already provides a cross reference to the <a href="#">NICE guideline on suspected cancer</a> (NG12) in the section on information and support. We have now also added it to the start of the section on diagnosis.
Merck, Sharp and Dohme UK	Guideline	007	General	<p>The guideline should be updated for RCC symptoms to reflect latest evidence and to support primary care HCP's with regard to identifying symptoms in both new &amp; recurrent suspected renal cancer (in the current NICE guideline NG12, <a href="#">visible haematuria is the only stated symptom</a>). We request a section be added into the guideline on the symptoms for both early diagnosis and for recurrent disease.</p> <p>Symptoms may include blood in the urine, a lump in the abdomen, or back pain.[1][2][3] Fever, weight loss, and tiredness may also occur.[1][2][3] Complications can include spread to the lungs or brain.[5] Usual onset after the age of 45 [4]:</p> <ol style="list-style-type: none"> <li><a href="#">"Renal Cell Cancer Treatment"</a>. National Cancer Institute. 2019. <a href="#">Archived</a> from the original on 10 April 2019. Retrieved 8 June 2019.</li> </ol>	<p>Thank you for your comment. The assessment of symptoms for the diagnosis recurrent disease was not within the scope of the reviews conducted as part of this current guideline work, and so recommendations in this area have not been made. However, if you have evidence to support its inclusion in future work, please can you share it with us by submitting a topic suggestion through our topic prioritisation process. See here for information on the prioritisation process and the submission form:</p> <ul style="list-style-type: none"> <li><a href="#">Prioritising our guidance topics</a></li> <li><a href="#">Topic suggestion</a></li> </ul> <p>The assessment of symptoms for early diagnosis comes under the scope of the <a href="#">NICE guideline on Suspected cancer: recognition and referral</a> and is out of scope for the kidney cancer guideline. If you would like to suggest an update to the renal cancer recommendations in that guideline then please submit a topic suggestion using the links above.</p>

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				<p>2. <a href="#">"Transitional Cell Cancer (Kidney/Ureter) Treatment"</a>. National Cancer Institute. 2019. <a href="#">Archived</a> from the original on 8 June 2019. Retrieved 8 June 2019.</p> <p>3. <a href="#">"Wilms Tumour and Other Childhood Kidney Tumours Treatment"</a>. National Cancer Institute. 2019. <a href="#">Archived</a> from the original on 10 April 2019. Retrieved 8 June 2019.</p> <p>4. <a href="#">"Cancer of the Kidney and Renal Pelvis - Cancer Stat Facts"</a>. SEER. <a href="#">Archived</a> from the original on 11 June 2019. Retrieved 30 May 2019.</p> <p>5. Sommers MS, Fannin E (2014). <a href="#">Diseases and Disorders: A Nursing Therapeutics Manual</a>. F.A. Davis. p. 657. <a href="#">ISBN 978-0-8036-4487-8</a>.</p> <p>Other symptoms that are consistent with advanced disease include weight loss, fever, night sweats, palpable swollen lymph nodes in the neck, non-reducing varicocele, bone pain, continuous cough, and bilateral lower leg swelling.[15][16][17]:</p> <p>15. Campbell SC, Lane BR (2012). "Malignant Renal Tumours". In Wein AJ, Kavoussi LR (eds.). <i>Campbell-Walsh Urology</i>. Elsevier. <a href="#">ISBN 978-1-4557-7567-5</a>.</p>	

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				<p>16. Hidayat K, Du X, Zou SY, Shi BM (July 2017). "Blood pressure and kidney cancer risk: meta-analysis of prospective studies". <i>Journal of Hypertension</i>. <b>35</b> (7): 1333–1344. <a href="https://doi.org/10.1097/HJH.0000000000001286">doi:10.1097/HJH.0000000000001286</a>. <a href="https://pubmed.ncbi.nlm.nih.gov/28157813/">PMID 28157813</a>. <a href="https://pubmed.ncbi.nlm.nih.gov/3454741/">S2CID 3454741</a>.</p> <p>17. Professionals SO. "<a href="#">EAU Guidelines: Renal Cell Carcinoma</a>". Uroweb. <a href="#">Archived</a> from the original on 2019-08-13. Retrieved 2019-12-03.</p>	
Merck, Sharp and Dohme UK	Guideline	0023	02	Add recommendation for adjuvant to be discussed with patients before and after surgery. E.g. the following is from the Getting It Right First Time (GIRFT) programme: Potential adjuvant therapy should be mentioned by the urologist in the pre-surgical consultation. This will be confirmed following risk' stratification from the patient's pathology and discussed further in the follow-up visit ( <a href="#">Page 14 Section 3.4</a> ).	Thank you for your comment. The committee agreed that people should be aware before surgery that adjuvant systemic anticancer treatment may be recommended after surgery. Therefore, we have added this to the recommendation on information given to people before and after surgery.
Merck, Sharp and Dohme UK	Guideline	023	010	We agree with the importance for discussion pre/post surgery. Opportunity to expand on additional measure not only to protect remaining kidney function but also to reduce the risk of recurrence (depending on surgical outcomes and other clinical and pathological characteristics).	<p>Thank you for your comment and support for this section of the guideline. The committee did not review the evidence about how to protect remaining kidney function so were unable to provide more detail about this. They also didn't look at measures to reduce the risk of recurrence as part of the current piece of work and so were unable to provide any guidance on this.</p> <p>If you have evidence to support the inclusion of either topic in future work, please can you share it with us by submitting</p>

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					<p>a topic suggestion through our topic prioritisation process. See here for information on the prioritisation process and the submission form:</p> <ul style="list-style-type: none"> <li>• <a href="#">Prioritising our guidance topics</a></li> <li>• <a href="#">Topic suggestion.</a></li> </ul>
Merck, Sharp and Dohme UK	Guideline	024	020	<p>Suggest moving or repeating 1.8.5 to/in 1.8.1's1 list of risk prediction tools to avoid this being missed when making management decisions.</p>	<p>Thank you for your comment. To avoid duplication of recommendations, and to retain the clarity of the individual recommendations, we have not repeated the wording of the recommendation you suggested, nor merged them. It is expected that the clinician will read more than just the first recommendation when using these tools.</p>
Merck, Sharp and Dohme UK	Guideline	025	015	<p>Highlight need for adjuvant treatment to start within 12 weeks of surgery as per the KN-564 study and Blueteq approval criteria relating to NICE TA830:</p> <p style="text-align: center;"><i>'8. No more than 12 weeks have elapsed since the date of nephrectomy or metastasectomy'</i></p> <p><a href="https://www.england.nhs.uk/wp-content/uploads/2017/04/national-cdf-list-v1.375.pdf">https://www.england.nhs.uk/wp-content/uploads/2017/04/national-cdf-list-v1.375.pdf</a>.</p> <p>In addition, this was a topic addressed in a recent Delphi consensus publication where 86% agreed that treatment should commence within this 12 week window, <a href="https://www.ejancer.com/article/S0959-8049(25)00351-X/fulltext#fig0010">https://www.ejancer.com/article/S0959-8049(25)00351-X/fulltext#fig0010</a> (see Supplementary Table 1 in: <a href="https://www.ejancer.com/cms/10.1016/j.ejca.2025.115569/attachment/4dd3bb5c-9733-4dfa-b25a-f658b3164b51/mmc1.docx">https://www.ejancer.com/cms/10.1016/j.ejca.2025.115569/attachment/4dd3bb5c-9733-4dfa-b25a-f658b3164b51/mmc1.docx</a>):</p>	<p>Thank you for your comment. This information is available on the NHS England Cancer Drugs fund and the Blueteq approval form and not within the TA recommendation. We are therefore unable to refer to it in the guideline.</p>

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				<i>"5. Per protocol, patients eligible for the KEYNOTE-564 trial had to be screened and randomized within 90 days of surgery. This time frame should be adhered to for eligible patients, now that pembrolizumab has been approved for adjuvant therapy use."</i> : "Agree: 86%, Disagree: 14%"	
Merck, Sharp and Dohme UK	Guideline	033	General	<p>No direction on 1<sup>st</sup> line treatment availability in those who have progressed after adjuvant immunotherapy (i.e. immuno-oncology therapy [IO]+IO or IO+ tyrosine kinase inhibitor [TKI] only available if no prior IO or if progression &gt;12 months after last dose of adjuvant IO). As per Blueteq approval criteria from the cancer drugs fund (CDF) list <a href="https://www.england.nhs.uk/wp-content/uploads/2017/04/national-cdf-list-v1.375.pdf">https://www.england.nhs.uk/wp-content/uploads/2017/04/national-cdf-list-v1.375.pdf</a> for IO containing treatments in advanced RCC. Lenvatinib + Pembrolizumab (TA858), Nivolumab + Ipilimumab (TA780), Cabozantinib + Nivolumab (TA964), Avelumab + Axitinib (TA645)</p> <p><i>'...- no previous adjuvant/neoadjuvant systemic immune-modulatory therapy of any kind and the patient is treatment naïve for the locally advanced/metastatic RCC indication or - prior adjuvant/neoadjuvant therapy with immune-modulatory therapies for RCC anti-Programmed Death receptor-1 (PD-1), anti-Programmed Death-1 ligand-1 (PD-L1), anti-PD L2, anti-CD137 or anti-cytotoxic T lymphocyte associated antigen-4 (anti-CTLA-4) antibodies and last dose received by the</i></p>	<p>The guideline and visual summaries outline all available treatment options in advanced RCC, which include first line treatments that do not contain an immunotherapy, as part of TA incorporation. Please see the <a href="#">Interim process and methods statement for bringing together NICE guidance</a> for more information about NICE's approach to including NICE technology appraisal recommendations in guideline topic areas.</p> <p>Treatment choice should be based on shared decision making, consideration of previous treatments and NHSE commissioning criteria.</p>

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				<i>patient was 12 or more months prior to this application and the patient is treatment-naïve for the locally advanced/metastatic RCC indication.'</i>	
Merck, Sharp and Dohme UK	Guideline	040	014	More clarity needed as to when total nephrectomy should be considered for suspected or confirmed localised RCC in people with a heritable RCC predisposition syndrome.	Thank you for your comment. We currently have a recommendation that states that total nephrectomy should be considered for people with syndromes associated with more aggressive RCC. Due to the limited evidence on heritable RCC, the committee were unable to provide more detail about when total nephrectomy should be considered. They agreed this would be determined on a case-by-case basis.
Merck, Sharp and Dohme UK	Guideline	041	002	We welcome the inclusion of heritable RCC predisposition syndrome management in the draft guideline. However, for VHL disease, the current draft does not direct clinicians to refer people with suspected or confirmed VHL to a centralised specialist VHL MDT service. This omission is important, clinicians and experts repeatedly highlight centralised VHL MDT care as best practice to improve outcomes for people with this rare, multisystem disorder. Given the rarity, lack of a nationally commissioned service and nature of VHL, this guideline is likely the most appropriate opportunity to provide robust national guidance on management. We therefore request that NICE add an explicit recommendation that patients with suspected or confirmed VHL are referred to a specialist VHL MDT and that the guideline signposts	<p>Thank you for your comment. The committee agreed that specialist VHL specific MDT services are not widely available. However, it is beyond the remit of this guideline to make recommendations about how the services for people with VHL should be provided by commissioners. In addition, the care of people with VHL is only covered in this guideline in relation to the management of their renal cell carcinoma. Wider management of their syndrome and other symptoms relating to it are out of scope.</p> <p>In the guideline there is a recommendation for referring people with RCC who are diagnosed with a heritable RCC predisposition syndrome to a specialist multidisciplinary team with expertise in managing renal lesions in this population. This would include VHL MDT services with expertise in managing renal lesions where they are available.</p>

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				<p>clinicians to MDTMs for referral pathways and surveillance protocols.</p> <ul style="list-style-type: none"> <li>• Shepherd STC, Drake WM, Turajlic S. The road to systemic therapy in von Hippel-Lindau (VHL) disease: Are we there yet? Eur J Cancer. 2023 Mar;182:15-22. doi: 10.1016/j.ejca.2022.12.011. Epub 2022 Dec 20. PMID: 36708612.</li> <li>• Wolters WPG. et al. Multidisciplinary integrated care pathway for von Hippel-Lindau disease. Cancer. 2022 Aug 1;128(15):2871-2879. doi: 10.1002/cncr.34265. Epub 2022 May 17. PMID: 35579632; PMCID: PMC9542729.</li> <li>• Maher, E.R., Adlard, J., Barwell, J. et al. Evaluation of tumour surveillance protocols and outcomes in von Hippel-Lindau disease in a national health service. Br J Cancer 126, 1339–1345 (2022). <a href="https://doi.org/10.1038/s41416-022-01724-7">https://doi.org/10.1038/s41416-022-01724-7</a></li> <li>• VHL White Paper: Opportunities for Improving Long-term Care in von Hippel-Lindau (VHL) Specialist Services. A call to action for NHS decision-makers. 2023. (Fully funded and organised by MSD UK)</li> </ul>	

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Merck, Sharp and Dohme UK	Guideline	045	General	<p>Evidence for post-adjuvant IO therapies are currently limited to case reports and retrospective analyses <a href="https://www.sciencedirect.com/science/article/pii/S0302283824024990">https://www.sciencedirect.com/science/article/pii/S0302283824024990</a>. Variability on clinical opinion on this subject can be highlighted in a recent Delphi consensus study <a href="https://www.ejancer.com/article/S0959-8049(25)00351-X/fulltext#fig0010">https://www.ejancer.com/article/S0959-8049(25)00351-X/fulltext#fig0010</a> (see supplementary Table 2 in: <a href="https://www.ejancer.com/cms/10.1016/j.ejca.2025.115569/attachment/4dd3bb5c-9733-4dfa-b25a-f658b3164b51/mmc1.docx">https://www.ejancer.com/cms/10.1016/j.ejca.2025.115569/attachment/4dd3bb5c-9733-4dfa-b25a-f658b3164b51/mmc1.docx</a>) with specific emphasis on those relapsing between 6-12 months after their last dose of adjuvant immunotherapy:</p> <p><i>“13a. Patients who relapse during or within 6 months of completion of their adjuvant therapy with an immune checkpoint inhibitor (ICI) are considered ICI-refractory. Agree: 80% Disagree: 20%”</i></p> <p><i>“13b. Patients who relapse during or within 9 months of completion of their adjuvant therapy with an ICI are considered ICI-refractory. Agree: 47% Disagree: 53%”</i></p> <p><i>“13c. Patients who relapse during or within 12 months of completion of their adjuvant therapy with an ICI are considered ICI-refractory. Agree: 20% Disagree: 80%”</i></p> <p>Ongoing randomised phase 3 studies in 1<sup>st</sup> line advanced RCC are likely to have only a small</p>	Thank you for your comment. It was out of scope of the current piece of work to look at evidence on post adjuvant immunotherapies. Therefore, the committee were unable to make a research recommendation this.

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				number of patients in the post adjuvant IO group and will not be powered to draw any statistical conclusions in this subgroup. Hence a significant area for future research which would impact clinical outcomes and cost-effectiveness.	
Merck, Sharp and Dohme UK	Guideline	047	General	<p>Highlight use of biomarkers to identify patients as most appropriate for adjuvant therapy as an 'Other recommendation for future research.'</p> <p>There are currently no biomarkers available to guide treatment in the adjuvant setting. A better understanding of individualised RCC biology could lead to more precise patient selection, identification of patients who may benefit from adjuvant therapy and improved clinical outcomes. Data suggests that biomarkers such as Kidney Injury Molecule-1 (KIM-1) have a prognostic and predictive role in patients with resected high-risk RCC. Further prospective research in this space is required to validate these biomarkers in this setting. (Rin <i>et al.</i> Annals of Oncology. <a href="https://doi.org/10.1016/j.annonc.2025.08.007">https://doi.org/10.1016/j.annonc.2025.08.007</a>).</p>	<p>Thank you for your comment. We did not search for evidence on who might benefit from adjuvant treatment as this was out of scope of the current piece of work. Therefore, the committee were unable to make a research recommendation this. However, if you have evidence to support its inclusion in future work, please can you share it with us by submitting a topic suggestion through our topic prioritisation process. See here for information on the prioritisation process and the submission form:</p> <ul style="list-style-type: none"> <li>• <a href="#">Prioritising our guidance topics</a></li> <li>• <a href="#">Topic suggestion</a>.</li> </ul>
Merck, Sharp and Dohme UK	Guideline	033, 045	General	<p>No differentiation between regimens that may be most effective for those with non-clear cell (ncc) RCC (i.e. Papillary, chromophobe, undefined) for 1<sup>st</sup> line advanced disease.</p> <p>There is a distinct lack of phase 3 evidence in the ncc-RCC population but as these are rare disease subtypes, we may never see this level of evidence for this patient group. There are various phase 2 studies</p>	<p>Thank you for your comment. It was not within the scope of this piece of work to review evidence on the pharmacological treatment of advanced RCC as the TAs were incorporated unchanged into the guideline. The committee were therefore unable to make research recommendations as well. However, if you have evidence to support the inclusion of this topic in future work, please can you share it with us by submitting a topic suggestion through our topic prioritisation process. See here for</p>

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				<p>which provide evidence for effectiveness in various subtypes of ncc-RCC.</p> <p>For papillary RCC see SWOG PAPMET with efficacy for Cabozantinib monotherapy in these patients <a href="https://ascopubs.org/doi/10.1200/JCO.24.00767">https://ascopubs.org/doi/10.1200/JCO.24.00767</a>.</p> <p>Keynote B61 provides phase 2 evidence for Pembrolizumab and Lenvatinib in combination to treat various subtypes of nccRCC <a href="https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(23)00276-0/fulltext#fig1">https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(23)00276-0/fulltext#fig1</a>.</p> <p>If there are to be no specific recommendations for the nccRCC subgroup in the guidelines then there is justification for this to be highlighted as an area for further research. Although not a large population there is significant variability in practice across the UK and nccRCC patients have been excluded from many of the larger phase 3 studies in advanced RCC.</p>	<p>information on the prioritisation process and the submission form:</p> <ul style="list-style-type: none"> <li>• <a href="#">Prioritising our guidance topics</a></li> <li>• <a href="#">Topic suggestion</a>.</li> </ul>
Merck, Sharp and Dohme UK	Guideline	001, 084	General	<p>It would be more helpful to readers if the 3-paragraph summary right at the back of the guideline (on page 84 out of 85) was on page 1 as it talks to the 'Why' of the 1st NICE RCC guideline including:</p> <p style="text-align: center;"><i>"...Kidney cancer can be cured if found early, but early diagnosis is challenging as most people at this stage do not have symptoms. Many people are diagnosed incidentally</i></p>	<p>Thank you for your comment. This text is part of the context section of the guideline. It has now been removed from the guideline template and therefore will not be part of the final version of this guideline when published.</p> <p>The symptoms associated with the recurrence or metastases of RCC were not included in the current piece of work. Where appropriate the committee have added blood in urine or persistent abdominal pain to the recommendations as symptoms to be aware of, but they</p>

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				<p><i>based on investigations for other reasons. After diagnosis..."</i></p> <p>We propose that these 3 paragraphs should go on page 1 before the 'Who is it for?' and 'What does it include?' sections.</p> <p>Symptoms are mentioned 24 times in the document but bearing in mind the above stated challenge, the current document does not spend any time detailing the 'symptoms' for healthcare professional's (HCP's) to consider. NG12 was last updated in May 2025, however there were however no updates in the urological cancers section for Renal Cancer (the last change to this was in 2015).</p>	<p>were unable to be more specific or widen this list of symptoms. However, if you have evidence to support the inclusion of this topic in future work, please can you share it with us by submitting a topic suggestion through our topic prioritisation process. See here for information on the prioritisation process and the submission form:</p> <ul style="list-style-type: none"> <li>• <a href="#">Prioritising our guidance topics</a></li> <li>• <a href="#">Topic suggestion</a>.</li> </ul> <p>The assessment of symptoms for early diagnosis comes under the scope of the <a href="#">NICE guideline on Suspected cancer: recognition and referral</a> and is out of scope for the kidney cancer guideline. If you would like to suggest an update to the renal cancer recommendations in that guideline then please submit a topic suggestion using the links above, providing evidence to support your request.</p>
Merck, Sharp and Dohme UK	Visual Summaries	N/A	N/A	<p>The visual summaries focus specifically on advanced kidney cancer and there is no mention of treatment choice in 1st line advanced RCC is different for those who have previously received IO in the adjuvant phase (see comment 1).</p> <p>We suggest the addition of a visual summary specifically for adjuvant SACT treatment. This could include appropriate patient identification criteria as per pathway recommended in the GIRFT document <a href="https://gettingitrightfirsttime.co.uk/wp-content/uploads/2023/06/20230616_Urology_Guidance_Kidney-cancer-Outline-FINAL-V1.pdf">https://gettingitrightfirsttime.co.uk/wp-content/uploads/2023/06/20230616_Urology_Guidance_Kidney-cancer-Outline-FINAL-V1.pdf</a>. Alternatively, we would suggest amending the current visual summaries for SACT in advanced RCC to</p>	<p>The guideline and visual summaries outline all available treatment options in advanced RCC, which include first line treatments that do not contain an immunotherapy, as part of TA incorporation. Please see the <a href="#">Interim process and methods statement for bringing together NICE guidance</a> for more information about NICE's approach to including NICE technology appraisal recommendations in guideline topic areas.</p> <p>Treatment choice should be based on shared decision making, consideration of previous treatments and NHSE commissioning criteria.</p>

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				account for those who have previously received adjuvant IO treatment.	
Merck, Sharp and Dohme UK	Visual summary for intermediate/ poor risk IMDC	General	General	Include key confirming meaning of dotted vs solid lines within flow chart on all diagram pages.	Thank you for your comment. A key will be included on each page.
National Cancer Audit Collaborating Centre	Guideline	017	018	Rec 1.1.3 – Whether the guideline should include documentation that clinical nurse specialist support has been offered to patients.	Thank you for your comment. The committee decided that the decision whether to record this should be made at a local level and so declined to add this to the recommendation.
National Cancer Audit Collaborating Centre	Guideline	017	018	Rec 1.5.4 – Whether the guideline should include reference to the use of a tumour complexity score (RENAL or PADUA) to guide decisions between partial and total nephrectomy.	Thank you for your comment. We discussed these scoring systems with the committee. They agreed that these tools are more commonly used in research rather than clinical practice. Therefore, they decided not to specify them in the recommendations. However, they agreed to add some text in the related rationale to acknowledge that they may help to understand the complexity of renal lesions.
National Cancer Audit Collaborating Centre	Guideline	022	001	Rec 1.6 – Whether the recommendation for surgery for locally advanced renal cell carcinoma should include reference to an Enhanced Recovery After Surgery (ERAS) protocol.	Thank you for your comment. The committee agreed that it would be helpful to include more information about perioperative care and decided to cross refer to the <a href="#">NICE guideline on perioperative care in adults</a> , which includes recommendations about <a href="#">enhanced recovery programmes</a> . This has been added to all the sections of the guideline where we refer to surgery. The committee were unable to refer to any specific protocol because they had not looked

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					<p>at the evidence, and it falls under the scope of the perioperative care guideline.</p> <p>However, if you think that the recommendations in the perioperative care guideline need updating, please can you share this with us by submitting a topic suggestion through our topic prioritisation process. See here for information on the prioritisation process and the submission form:</p> <ul style="list-style-type: none"> <li>• <a href="#">Prioritising our guidance topics</a></li> <li>• <a href="#">Topic suggestion</a>.</li> </ul>
National Cancer Audit Collaborating Centre	Guideline	022	001	Rec 1.6 – Whether the recommendation for surgery for locally advanced renal cell carcinoma should include consideration of timeliness of surgery following MDT discussion.	<p>Thank you for your comment. The committee agreed that it is important that people with locally advanced RCC are able to access surgery in a timely manner because these lesions are at great risk of progressing to metastatic disease. However, the decision for when surgery should take place would be considered on a case-by-case basis in the urology-oncology MDT also factoring in the resources available. Therefore, the committee did not make a recommendation about this.</p>
NHS Cancer Programme for England	Guideline	General	General	We support the development of this clinical guideline as it addresses an area of unmet need. We encourage NICE to progress with its development and publication without further delay.	<p>Thank you for your comment and support for the guideline.</p>
NHS Cancer Programme for England	Guideline	General	General	This guideline uses the term 'thermal ablation', which covers two distinct treatment types – radiofrequency ablation and cryoablation. We recommend adding a glossary section which delineates between the two, or add in another reference within the document which makes clear that these are not the same treatments.	<p>Thank you for your comment. The committee agreed to add the term "thermal ablation" to the terms used section of the guideline to clarify what types of ablation are included (cryoablation, microwave ablation and radiofrequency ablation).</p>

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NHS Cancer Programme for England	Guideline	006	007	This line should be amended to flag that these conversations need to take place throughout the pathway. This line should also advise signposting to relevant voluntary and community sector support.	Thank you for your comment. The committee agreed that discussions with the person with renal cell carcinoma regarding emotions and coping should be taking place at regular points throughout the pathway. To reflect this they have amended the wording of the recommendation. They have also added text to the recommendation to support signposting to voluntary and community services for emotional support and NHS services for psychological support.
NHS Cancer Programme for England	Guideline	015	004	This section should be updated to advise consideration of percutaneous selective renal artery embolization in advanced renal cancer where intractable haematuria persists. This may be of particular relevance in the context of inoperable disease, and may require inpatient transfer to a specialist centre if not locally available.	Thank you for your comment. Embolisation in advanced renal cell carcinoma was not within the scope of the reviews undertaken for this guideline. However, if you have evidence to support its inclusion in future work, please can you share it with us by submitting a topic suggestion through our topic prioritisation process. See here for information on the prioritisation process and the submission form: <ul style="list-style-type: none"> <li>• <a href="#">Prioritising our guidance topics</a></li> <li>• <a href="#">Topic suggestion</a>.</li> </ul>
NHS Cancer Programme for England	Guideline	023	002	We recommend that a bullet point is added to recommend that clinicians discuss the impact of adjuvant SACT, given this can have implications for the patient which are distinct from the surgical procedure itself.	Thank you for your comment. The committee agreed that people should be aware before surgery that adjuvant systemic anticancer treatment may be an option after surgery. Therefore, we have added this to the recommendation on information given to people before and after surgery. However, the committee agreed that it would be difficult to discuss the impact of adjuvant SACT at this point in the pathway because it would not be clear until pathological findings are considered after surgery, whether adjuvant SACT could be a suitable treatment option. Therefore, they made another recommendation in the section on Adjuvant SACT to discuss the potential impact of

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					SACT on future treatments when adjuvant SACT is an option.
NHS England	General	General	General	<p>People with a learning disability and autistic people experience significant health inequalities such as those as highlighted in LeDeR reports (Learning from Lives and Deaths of people with learning disability and autistic people) <a href="https://www.kcl.ac.uk/research/leder">https://www.kcl.ac.uk/research/leder</a> and so it is important that consideration is given to their particular needs and to ensuring equality of access, experience and outcomes in healthcare services.</p> <ul style="list-style-type: none"> <li>We suggest including a reference to making reasonable adjustments to care on the basis of disability. This is a legal requirement in the Equality Act 2010 and is important to help you make the right diagnostic and treatment decisions for an individual. You can ask the person and their carer or family member what reasonable adjustments should be made. Adjustments aim to remove barriers, do things in a different way, or to provide something additional to enable a person to receive the assessment and treatment they need. Possible examples include; allocating a clinician by gender, taking blood samples by thumb prick rather than needle, providing a quiet space to see a patient away from excess noise and activity. Resources are available such as <a href="#">NHS England » Sensory-friendly resource pack</a> and <a href="#">NDTi   Green Light Toolkit 2022</a>.</li> <li>Ensuring information and advice is in formats that is accessible and can easily be understood is essential In line with the <a href="#">NHS England » Accessible information standard</a></li> </ul>	<p>Thank you for your comments. The points you raise about making reasonable adjustments have been added to section 5.2 of the Equality and Health Inequalities Assessment, which accompanies the scope.</p> <p>The <a href="#">NICE guideline on Patient experience in adult NHS services</a> includes recommendations about knowing the patient as an individual that cover taking the requirements of the Equality Act 2010 into account and making sure NHS services are equally accessible and supportive for everyone using them. The published guideline will include cross reference to this guideline.</p>

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				<p>Be aware of diagnostic overshadowing: This occurs when the symptoms of physical ill health are mistakenly either attributed to a mental health or behavioural problem or considered inherent to the person's learning disability or autism diagnosis. People with a learning disability or autistic people have the same illnesses as everyone else, but the way they respond to or communicate their symptoms may be different and not obvious. More information can be found in this guidance: <a href="#">NHS England » Clinical guide for front line staff to support the management of patients with a learning disability and autistic people – relevant to all clinical specialties</a></p>	
NHS England – Renal CRG	Guideline	018	001	<p>We agree with the emphasis on preserving renal function during surgical decision-making. We recommend an explicit requirement to inform the local renal service if there is an expectation that renal replacement therapy may be needed either perioperatively or in the long term. This is particularly important when residual renal function in the remaining kidney is limited. Early notification enables renal services to initiate vascular access planning and pre-dialysis counselling.</p>	<p>Thank you for your comment. The committee agreed it would be important to notify local renal services if renal replacement therapy is anticipated. Therefore, they made a new recommendation in the section on surgery, thermal ablation, active surveillance or SABR for pole with localised RCC, to liaise with local renal services if there is any expectation that renal replacement therapy might be needed. They also made a similar recommendation in the section on surgery for suspected or confirmed locally advanced RCC.</p>
NHS England – Renal CRG	Guideline	026	022	<p>We recommend that urine ACR and eGFR tests should also be performed before starting treatment, to support decision-making regarding surgical options and the risk of dialysis or progressive chronic kidney disease. We also recommend that urine ACR and eGFR testing be incorporated into routine follow-up assessments to identify the development or progression of CKD early.</p>	<p>Thank you for your comment. The committee highlighted that ACR may be required before surgery if there is reduced eGFR, as it would be part of routine monitoring if a person has reduced renal function in the long term. They also noted that eGFR can provide information to aid discussion on risks of surgery and complications after surgery. However, they agreed that both of these tests are not mandatory before surgery and therefore decided not to include a recommendation for them pre-surgery.</p>

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					<p>However, the committee agreed that it is important to try to detect renal insufficiency and the risk of deterioration that may require separate management at the start of follow up after surgery or other treatment with curative intent. They agreed that assessment of eGFR is required after treatment and if low, ACR testing should be carried out in primary care. The recommendations were revised to reflect these points more clearly.</p> <p>They also acknowledged the existence of a full <a href="#">NICE guideline on Chronic Kidney Disease</a> that provides more detailed guidance on the management of CKD including the <a href="#">referral criteria</a> for specialist assessment and agreed to provide a link to this in the guideline.</p>
PTSD UK	Guideline	006	004-007	<p>A growing body of evidence highlights that a cancer diagnosis and its associated treatments can be traumatic experiences, leading to PTSD or C-PTSD in a significant proportion of people. This includes people with no prior history of trauma, as well as those with pre-existing vulnerabilities. PTSD is frequently under-recognised in oncology settings, especially when symptoms such as avoidance, hypervigilance, and emotional numbing are mistaken for depression or anxiety.</p> <p>By explicitly referencing PTSD and C-PTSD, this recommendation will help ensure that trauma-related distress is not overlooked and that people are directed to the most appropriate, trauma-informed support. Early recognition and intervention can</p>	<p>Thank you for your comment. The committee agreed that a cancer diagnosis and its associated treatments can be traumatic experiences for the patient. They noted that these issues are not specific to kidney cancer but apply to people with other types of cancer as well.</p> <p>The guideline section on general information includes a recommendation about discussing emotions with people with renal cell carcinoma and signposting or referring them to psychological support services if appropriate.</p> <p>This guideline has not reviewed the evidence around psychological distress and psychological support for people with kidney cancer, and we are therefore unable to make more detailed recommendations on this topic. However, if you have evidence to support the inclusion of this topic in</p>

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				greatly improve psychological recovery, quality of life, and long-term engagement with healthcare services	<p>future work, please can you share it with us by submitting a topic suggestion through our topic prioritisation process. See here for information on the prioritisation process and the submission form:</p> <ul style="list-style-type: none"> <li>• <a href="#">Prioritising our guidance topics</a></li> <li>• <a href="#">Topic suggestion.</a></li> </ul>
PTSD UK	Guideline	026	001-020	<p>The post-treatment period can be emotionally complex. Many people report experiencing delayed psychological responses — including symptoms of PTSD or C-PTSD — once active treatment has ended. This may include intrusive memories, fear of recurrence, hypervigilance, emotional detachment, or a sense of being "stuck" in survival mode. These symptoms can often be misattributed to general anxiety or depression and may go unrecognised in follow-up care.</p> <p>By including screening for PTSD and C-PTSD as part of the personalised care plan during follow-up, healthcare professionals are better equipped to identify people in need of trauma-informed mental health support. This not only improves emotional recovery and quality of life but also helps ensure people remain engaged with their ongoing care, reducing the risk of avoidable distress or disengagement from the healthcare system.</p> <p>Suggested amended wording (to follow 1.10.2 or be integrated as an additional bullet point):</p> <ul style="list-style-type: none"> <li>• screening and support for the person's emotional wellbeing, including the potential for post-traumatic</li> </ul>	<p>Thank you for your comment. The committee already recommended in the "Information and Support" section of the guideline that a discussion should be had with the person about how they are coping with their emotions during their care and referring or signposting to psychological support services as needed.</p> <p>The provision of specialist psychological support and screening for PTSD and C-PTSD was not evaluated as part of this guideline and is out of scope of this current piece of work. However, if you have evidence to support its inclusion in future work for kidney cancer, or at a wider level for people with cancer in general, please can you share it with us by submitting a topic suggestion through our topic prioritisation process. See here for information on the prioritisation process and the submission form:</p> <ul style="list-style-type: none"> <li>• <a href="#">Prioritising our guidance topics</a></li> <li>• <a href="#">Topic suggestion.</a></li> </ul>

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				stress disorder (PTSD) or Complex PTSD (C-PTSD), particularly where treatment has been experienced as traumatic or the person is experiencing persistent psychological distress.	
RM Partners – West London Cancer Alliance	Guideline	009	002	<p>Section 1.3 – Renal mass biopsy for all patients:</p> <p>Offering biopsy to all patients is mitigated by the caveat 'if it changes management'. However, the way this section is presented is somewhat back-to-front and could be structured more clearly.</p> <p>The guidelines should lead with biopsy should be considered in all patients although there are some for whom it may not be a suitable option. We feel that this change would make the intent clearer.</p>	Thank you for your comment. The committee reviewed the recommendations related to biopsy and agree that the section on biopsy already leads with offering biopsy to patients first, and then proceeds to refer to situations in which biopsy would not be suitable. They did not make changes to the recommendations.
RM Partners – West London Cancer Alliance	Guideline	013	008	<p>Section 1.4 – Bosniak 3 vs 4 lesions: Question whether upfront treatment of Bosniak 3 lesions should be the default, as implied. Bosniak 3 and 4 cysts should not necessarily be considered the same entity. Agree that the focus on nodularity as a treatment consideration is good but note the lack of evidence supporting active surveillance for all Bosniak 3s.</p>	<p>Thank you for these comments. The committee agreed that Bosniak 3 and 4 cysts have different probabilities of malignancy. There was no evidence in the relevant reviews (reviews A and B) that was specific to Bosniak cysts, as studies considered localised RCC only (some of which may be as part of a cyst, and others not).</p> <p>The committee discussed Bosniak 3 and 4 cysts further and agreed that Bosniak 3 cysts should usually be managed differently to Bosniak 4 cysts and solid renal masses. They therefore removed Bosniak 3 cysts from the recommendation to offer surgery, and wrote a new recommendation for Bosniak 3 cysts 2 cm and larger in diameter which recommends that active surveillance should</p>

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					<p>be considered initially, with surgery as an option for when active surveillance is declined.</p> <p>They also noted that renal lesion factors (including size of the solid nodule for cysts) are already included in the list of things to take into account when deciding which management options are suitable for localised RCC and Bosniak 3 and 4 cysts. They also agreed to add text to the rationale and impact section for these recommendations to explain that Bosniak 3 cysts have a lower chance of malignancy and that the best management pathway for cysts is less clear from the literature.</p>
RM Partners – West London Cancer Alliance	Guideline	013	010	Section 1.41 - Active surveillance for oncocytoma: Younger patients may prefer treatment for oncocytoma than years of surveillance so this discussion should be included.	Thank you for your comment. The committee agreed that a person's preference should be taken into account when making a decision about management of oncocytomas. This recommendation includes discussing the option of treatment with the person if they decline active surveillance and would apply to people of any age, including younger patients. Therefore, no changes were made to the recommendation.
RM Partners – West London Cancer Alliance	Guideline	021	021	Section 1.5.18 – Discharge after 5 years of surveillance for solid or Bosniak 3+4 cysts: The evidence section notes no data on when to transition from active surveillance to discharge. Suggest tailoring discharge to individual patient factors e.g. older patients may be discharged after 5 years, whereas younger, fitter patients should remain under long-term surveillance.	Thank you for your comment. The committee agreed with your suggestion that discharge of people with RCC from active surveillance should be tailored to individual patient factors. Therefore, the committee added some text to the recommendation on factors to take into account when considering discharge from active surveillance, including age and fitness.
RM Partners – West London Cancer Alliance	Guideline	029	009	Section 1.10.16 – Discharge after treatment: No timeframe is given for post-treatment discharge. Consider specifying 10 years as a pragmatic cutoff, aligning with common clinical practice. The RECUR	Thank you for your comment. The committee discussed this and agreed that 10 years might be a pragmatic time to stop follow up for people with intermediate or high risk of recurrence. They made a new recommendation to reflect

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				database (PMID 29525381) shows recurrence up to 7 years; most units discharge high and intermediate-risk patients after 10 years, low-risk after 5 years.	this. However, they noted that for some people who have had RCC it may be appropriate to continue follow up for longer. They therefore added factors such as the person's age, fitness and other clinical characteristics to the recommendation as factors to take into account when making this decision.
RM Partners – West London Cancer Alliance	Guideline	064	003	Consider using wording as 'ablation' instead of 'thermal ablation' to allow inclusion of cryotherapy and/or include cryotherapy as a treatment option.	Thank you for your comment. The committee agreed to add the term "thermal ablation" to the terms used section of the guideline to clarify what types of ablation are included (cryoablation, microwave ablation and radiofrequency ablation). They decided not to use the term 'ablation' alone to avoid implying that non-thermal ablation types had also been considered in the evidence review.
Royal College of General Practitioners	Guideline	019 (026, 039, 041)	1.5.10 (and related sections 1.10.2, 1.17.6, 1.20.2)	<p>We support the inclusion of a personalised care plan shared with both the patient and their GP, including details of when primary care cancer care reviews will take place and what these will involve. However, this section would benefit from further clarification on how these reviews are determined and delivered. Specifically, we strongly believe that it would be helpful to clarify whether the timing and content of primary care reviews are defined nationally, locally, or on a case-by-case basis; whether these activities are funded or considered part of the core GP contract; and what is meant by "cancer care reviews" in this context, to ensure expectations are realistic and deliverable within general practice.</p> <p>We are concerned that secondary care-defined plans without agreed local mechanisms for delivery could create practical difficulties and lead to variation in implementation. Clear allocation of responsibilities and funding would prevent this.</p>	<p>Thank you for your comments. The committee discussed your comment and noted that although cancer care reviews were previously included in primary care QOF they are no longer part of general medical services. The committee acknowledged that although primary care cancer care reviews are still encouraged as good practice and should be completed where possible, it is not currently included in primary care core contract or quality outcomes framework. Therefore, the committee agreed to remove this from the recommendations.</p> <p>The committee agreed that follow-up should be managed by the secondary care team and not primary care. Therefore, an additional bullet has been added to the recommendations on agreeing a personalised care plan in the 'follow-up for localised and locally advanced RCC' and 'follow-up of localised or locally advanced RCC in people with a heritable RCC predisposition syndrome' sections of</p>

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				<p>In addition, we do not think it is reasonable for GPs to be expected to arrange follow-up radiological investigations or to interpret these against criteria for active surveillance or intervention thresholds. This would represent a significant increase in workload compared to current practice and introduces clinical risk. Patients affected by RCC should have discussions regarding surveillance imaging, interpretation, and the balance of risks and benefits with an appropriately trained urology specialist rather than in primary care.</p> <p>There are parallels with benign ovarian cyst monitoring, where GPs may be involved in surveillance prior to malignancy being detected; however, this guideline relates to post-diagnosis and treatment surveillance, where the risks of missing recurrence are considerably higher. We therefore suggest that the guideline authors clarify the respective responsibilities of primary and secondary care, ensuring that specialist urology teams retain responsibility for radiological surveillance and interpretation.</p> <p>We also suggest that it would be useful to confirm that imaging and other investigations forming part of ongoing surveillance remain the responsibility of secondary care. Without explicit clarification, there is a risk that this could be interpreted as shifting responsibility to primary care, which would be inconsistent with current pathways.</p>	<p>the guideline to inform the person that follow-up will be managed by the secondary care team.</p> <p>Active surveillance is one of the management options for renal lesions and is carried out by the secondary care team. Clarification of this point was added to the active surveillance information recommendation. Primary care becomes the primary point of contact after discharge, which is reflected in the recommendations in the 'stopping active surveillance' and the 'moving from active surveillance to treatment or discharge for renal lesions 4 cm in diameter or smaller' sections.</p>

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Royal College of General Practitioners	Guideline	007-008	1.2	<p>We note that Section 1.2 does not include guidance for GPs on how and when to suspect renal cell carcinoma (RCC), or on the appropriate referral pathways. Given that most RCCs are detected incidentally or at a late stage, clear information for primary care would be valuable to support earlier diagnosis and timely referral.</p> <p>We recommend including brief guidance or signposting for primary care. For example, common clinical presentations, relevant investigation findings, and thresholds for urgent referral. This would enhance the utility of this section and strengthen integration across the diagnostic pathway.</p>	<p>Thank you for your comment. The symptoms that would lead a clinician to suspect renal cell carcinoma in primary care are covered by the <a href="#">NICE guideline on Suspected cancer: recognition and referral</a> (NG12) and are out of scope for the kidney cancer guideline. However, the committee have included a cross reference to NG12 at the start of the diagnosis section.</p> <p>If you would like to suggest an update to the renal cancer recommendations in NG12 then please submit a topic suggestion through our topic prioritisation process. See here for information on the prioritisation process and the submission form:</p> <ul style="list-style-type: none"> <li>• <a href="#">Prioritising our guidance topics</a></li> <li>• <a href="#">Topic suggestion</a>.</li> </ul>
Royal College of General Practitioners	Guideline	023	1.7	<p>We recommend that this section explicitly recognises that post-nephrectomy CKD monitoring will often be undertaken in primary care. To support safe and consistent follow-up, the guidance should include information on the expected monitoring parameters and frequency (for example, eGFR and ACR testing frequency) and clear blood pressure management thresholds for GPs.</p>	<p>Thank you for your comment. The section of the guideline you refer to covers information to discuss with the person with RCC before and after surgery. This is therefore not a suitable place to provide guidance for clinicians about post-nephrectomy chronic kidney disease (CKD) monitoring. However, in the section on follow up there are recommendations about estimated glomerular filtration rate (eGFR) creatinine testing to detect any renal insufficiency that might need separate management. This section includes a cross reference to <a href="#">NICE's guideline on chronic kidney disease</a> (NG203). The details of how CKD should be monitored and managed are out of scope for the kidney cancer guideline but are covered in detail by the CKD guideline.</p>
Royal College of General Practitioners	Guideline	029	1.10.16	<p>We support the recommendation that patients should be advised that primary care will be their main point of contact after discharge and should be given</p>	<p>Thank you for your comment. The committee agreed that providing some examples of symptoms that could prompt a person to contact primary care will be beneficial and these</p>

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				examples of when to contact their GP (for example, if they experience persistent symptoms). To strengthen this, we recommend that this information is to be documented in the discharge summary shared with primary care, providing a clear reference for both the GP and the patient. We also recommend that secondary care provides clear guidance on when re-referral to specialist services is appropriate. This would promote integrated communication between primary and secondary care and ensure consistent, safe follow-up and management.	<p>were added to the discharge recommendation. They were also added to the recommendation about information to be provided to the person (and their GP) at the start of follow up.</p> <p>The committee were unable to provide more detailed guidance about the symptoms that should lead to re-referral to secondary care because we didn't look at the evidence for this. If you would like to suggest this as a topic for a future update, please submit a topic suggestion through our topic prioritisation process. See here for information on the prioritisation process and the submission form:</p> <ul style="list-style-type: none"> <li>• <a href="#">Prioritising our guidance topics</a></li> <li>• <a href="#">Topic suggestion</a>.</li> </ul>
Royal College of General Practitioners	Guideline	14,15, 21	1.4.7, 1.4.8, 1.5.1, 1.5.18	<p>We welcome the clarity provided on when it may be appropriate to stop active surveillance and discharge people with oncocytomas or Bosniak 2F cysts back to primary care. However, we recommend that these sections include clearer guidance on the information and advice that should be provided to both the patient and their primary care team at the point of discharge. This should include whether any ongoing monitoring or review is required in primary care, and what this should entail, as well as the circumstances in which re-referral to specialist services would be appropriate, with clear clinical criteria. It should also include key symptoms or signs that should prompt further assessment or escalation.</p> <p>We believe that providing this information will help ensure safe continuity of care and avoid uncertainty about ongoing management responsibilities. We note that section 1.5.10 of the guideline sets a strong</p>	<p>Thank you for your comments. The committee agreed that for people who have completed a period of active surveillance, or follow-up according to the recommended schedule or are no longer eligible for treatment, ongoing monitoring or review is not required after discharge. So, they agreed that these people do not need to be discharged to primary care but would be discharged from routine follow up and informed to contact primary care if they have any symptoms or concerns. Therefore, discharging to primary care has been removed from the related recommendations and a new recommendation has been added to Section 1.4 of the guideline about explaining to the person why they have been discharged and to contact primary care if they have symptoms or concerns.</p>

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				precedent for this approach, with a clear description of the information that should be shared with patients and GPs as part of a personal health plan. Similar detail in these discharge-related sections would be welcomed to support consistent and safe practice.	
Royal College of Surgeons Edinburgh	Guideline	General	General	<p>The committee should be commended for a comprehensive and well-structured guideline on the management of renal cell carcinoma. This guideline covers diagnosis of kidney cancer, management of localised locally advanced and metastatic renal cell carcinoma. It uses evidence base, where available, and expert opinion from an experienced committee giving a strong foundation for ensuring high quality patient care.</p> <p>The only general comment was whether there should be guidelines on the structure and case volume of the multidisciplinary team discussion? There are references throughout the document recommending MDM discussion and the key participants in some specialist section. Many regions will have a tertiary referral specialist RCC MDM but it is not clear if this is universal. Anecdotally, access to complex surgery (RAPN, IVC thrombectomy), ablation and trials is dependent on the case volume and expertise of the MDM. A statement recommending appropriate composition, experience and expertise of the MDM to ensure equity of access to all treatment modalities and clinical trials may be useful. It is appreciated that this may be out with the scope or the guidelines.</p>	<p>Thank you for your comment and support for this guideline.</p> <p>Although the committee recognised the variation in expertise between multidisciplinary teams in tertiary centres of expertise and some local centres and impact this can have on the management options available to people with renal cell carcinoma (RCC), it is outside the scope of this guideline to specify the exact composition of multidisciplinary teams (MDTs), or their training and case volumes. However, in some places in the guideline where they thought it was particularly important, the committee have included examples of the specialties that may be involved and their expertise (for example, in managing renal lesions in people with locally advanced RCC, advanced RCC and RCC in people who have a heritable RCC predisposition syndrome), although they were unable to provide details of what this expertise entailed.</p>

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Royal College of Surgeons Edinburgh	Guideline	7	3	1.2.1 -Many patients will present with an abdominal CT such as CT colon, where there is sufficient characterisation to confirm an enhancing renal mass with adequate staging and anatomical data to guide appropriate management. Clearly triple phase CT is the optimal test, however, acknowledging the risks of unnecessary radiation and NHS resources, if CT demonstrates an enhancing mass with enough detail for staging and surgical planning, repeat formal triple CT kidneys may not be required. This could be reflected in the guidelines.	Thank you for your comment. The committee agreed with your comment and have added some clarification to the recommendation that multi-phasic CT or MRI should be offered where there is not enough information from any previous imaging to inform next steps. Based on other stakeholder comments, the committee changed triple phase CT to multiphasic CT to be less prescriptive.
Royal College of Surgeons Edinburgh	Guideline	7	16	1.2.3 - There is retrospective data to suggest pulmonary metastases in the absence of intra-abdominal nodal or visceral metastases in RCCs <4cm is uncommon and rare in <3cm (Mains et al JCU 2024, <a href="https://doi.org/10.1177/20514158231223363">https://doi.org/10.1177/20514158231223363</a> ; Voss et al BJU 2020 DOI: <a href="https://doi.org/10.1111/bju.15001">10.1111/bju.15001</a> ). Consideration should be given to removing pre-op CT chest in patients <3cm to reduce radiation, pressure on resource and the need for patients to reattend radiology).	Thank you for your comment. The committee agreed that chest CT provides a baseline imaging that can be useful after treatment for comparison. They agreed with your comment that chest CT may not have as much uptake in small lesions. They also acknowledged that contrast may not be required. However, they considered that carrying out chest CT before surgery may have some benefit in providing certainty that pulmonary (lung) metastases are not being missed. Additionally, it is often pragmatic to have a CT chest undertaken at the same time as the CT abdomen to ensure full staging. Therefore, the committee agreed that CT of the chest and pelvis should be carried out at this stage ideally with contrast where possible.
Royal College of Surgeons Edinburgh	Guideline	15	1	1.4.8 Consider stopping active surveillance and discharging the person with an oncocytoma or Bosniak 2F cyst back to primary care if the renal lesion remains stable for 5 years. There is currently a Scottish National Follow-up protocol for Bosniak IIF cysts. This recommends follow-up for 4 years rather	Thank you for your comment. The committee noted that the outcomes from the paper cited was based on an older classification of Bosniak 2F cysts. They agreed that as there is no randomised study to provide reliable evidence on the duration of active surveillance for Bosniak 2F cyst, continuing active surveillance for at least 5 years is more conservative and aligned with related follow-up durations.

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				than 5. Their recent outcomes have been published (DOI: <a href="https://doi.org/10.1002/bco2.70094">10.1002/bco2.70094</a> ).	But they also recognised that this is an area that should be watched as this may change in the future as the evidence grows. Therefore, the committee agreed not to make any changes to the recommendation.
Royal College of Surgeons Edinburgh	Guideline	15	8	1.5 There should perhaps be an acknowledgement that the size of any solid component is likely to be more significant than the overall size of the cyst and this should be taken into consideration when discussing management strategies with patients. A 5cm tumour with 1cm solid enhancing component is more likely to behave like a 1cm tumour than a 5cm tumour.	Thank you for your comment. The committee agreed that the size of the solid component is an important factor when assessing renal cysts to deciding which management options are suitable and this is highlighted in the recommendation on deciding which management options are suitable for suspected or confirmed localised RCC and Bosniak 3 and 4 cysts. This has also been reiterated in the recommendation for people with Bosniak 4 cysts 2 cm in diameter or larger who cannot have surgery or decline it.
Royal College of Surgeons Edinburgh	Guideline	17	18	<p>1.5.4 Renal lesions 2 cm in diameter and larger. Offer surgery for people with localised solid renal masses, or Bosniak 3 or 4 cysts, that are 2 cm in diameter and larger after:</p> <ul style="list-style-type: none"> <li>• imaging for diagnosis and staging and</li> <li>• discussion with a multidisciplinary team.</li> </ul> <p>There is reasonable evidence that the larger the size of the tumour the greater the risk of re-treatment with ablative therapies. However, I have concern that 2cm tumour is the recommended cut off for consideration of surgery. I would argue that (taking into consideration patient co-morbidities and preferences as well as tumour factors) ablative therapies could be considered up to 4cm and certainly if there was a more conservative cut-off I would think 3cm would be more reasonable.</p>	<p>Thank you for your comments. The committee saw evidence (reviews A and B) about the effectiveness of surgery compared with thermal ablation, stereotactic ablative radiotherapy (SABR) and active surveillance. The evidence suggested that surgery may result in improved recurrence and survival outcomes compared with the non-surgical interventions, and the committee agreed that surgery would usually be the first intervention to think about. However, another recommendation in the same section recommends considering thermal ablation for people with solid renal masses between 2 and 4 cm in diameter who cannot have surgery or decline it.</p> <p>The committee noted that the recommendation on factors to take into account when deciding which management options are suitable for suspected or confirmed localised RCC and Bosniak 3 and 4 cysts already allows for treatments other than surgery to be chosen as the initial treatment. (We also note that Bosniak 3 cysts have been</p>

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					removed from the recommendation to offer surgery.) These factors include the person's clinical characteristics and personal preferences. The committee decided to expand on this to include comorbidities and frailty as well. The same recommendation talks about balancing the risk of complications from surgery with the risks of non-surgical options. Therefore, the committee considered that there is sufficient flexibility to not choose surgery as the initial treatment if it is justified, whilst still recognising it as the treatment which may be, according to the evidence reviews A and B, most effective in terms of recurrence and survival.
Royal College of Surgeons Edinburgh	Guideline	26	22	1.10.3 After completing treatment and before starting follow-up, offer estimated glomerular filtration rate (eGFR) creatinine and albumin–creatinine ratio (ACR) testing to detect any renal insufficiency that might need separate management. ACR testing is only indicated if evidence of CKD and should not be recommended as part of routine post-operative follow-up unless as part of CKD assessment along with BP surveillance.	<p>Thank you for your comment. The committee agree that ACR testing may not be required unless where there is evidence for CKD. They therefore amended the recommendations to make it clearer when ACR testing should be carried out (if eGFR is below 60 ml/min/1.73m<sup>2</sup> after treatment) and where (in primary care).</p> <p>They also acknowledged the existence of a full <a href="#">NICE guideline on Chronic Kidney Disease</a> that provides more detailed guidance on the management of CKD including the <a href="#">referral criteria</a> for specialist assessment and agreed to provide a link to this in the guideline.</p>
Royal College of Surgeons Edinburgh	Guideline	26	29	1.10.4 Suggested follow-up schedules are given for ablation and chromophobe RCC. There is no recommendation of follow-up schedule if there is a positive surgical margin at RAPN. Should this be included? Would the panel recommend consideration to more intensive renal imaging with sparing of CT chest dependent on clinical and pathological risk of local recurrence v systemic recurrence.	<p>Thank you for your comment. The committee agreed that having a positive surgical margin after a partial nephrectomy does increase the risk of recurrence. Therefore, they decided to align with the <a href="#">GIRFT kidney cancer guideline</a> that suggests using the next level risk status follow-up schedule when there is a positive surgical margin after partial nephrectomy. A new recommendation was added to the section on follow up for localised and</p>

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					locally advanced RCC to reflect these points. The committee were not aware of any evidence to support omitting the CT chest in patients with increased risk of local or systemic recurrence in follow-up.
Royal College of Surgeons Edinburgh	Guideline	38	1	1.17 Having had PPI meetings with VHL patients, un-coordinated appointments for surveillance have a significant impact on their QoL. If possible, there should be an acknowledgement of this and a statement recommending co-ordination of surveillance schedules across specialties (CNS,HPB, endocrine, urology) whenever possible. I note this is subsequently acknowledged in 1.20.2 but it would be helpful to acknowledge this earlier as part of AS.	Thank you for your comment. In the section on active surveillance for suspected or confirmed localised RCC in people with heritable RCC predisposition syndrome we already have a recommendation for coordinating imaging with other specialities such as endocrinology and within the urology multidisciplinary team.
Royal College of Surgeons Edinburgh	Guideline	40	9	1.18.2 It is noted that PN is the recommended primary treatment modality. Given the likely frequency of treatment, many patients (and high volume RCC urology departments) would use ablation as their preferred and primary treatment in VHL associated RCC. This is also true for other (non-HLRCC) when the pathology may be more indolent. Given the balance of short-term complication risk, recovery and frequency of treatment, then consideration should be given to the strength of this recommendation. Ablation should be offered as an alternative first line treatment acknowledging the potential for multiple treatments. If patients proceed to surgery for an index tumour 3cm or greater, then consideration to resection of other surgically accessible tumours in the ipsilateral kidney should also be given.	Thank you for your comments. The evidence identified for managing renal lesions in people with a heritable predisposition to RCC was very limited. Therefore, the committee could only make consensus recommendations based on their experience and expertise. The committee agreed that partial nephrectomy would be the preferred first option in most cases. This is because, as detailed in the supporting rationale, it can be difficult to perform partial nephrectomy on a kidney that has already undergone thermal ablation or SABR due to the renal tissue inflammation that these procedures can cause. However, there is also a consensus recommendation that suggests that ablative therapies can be used if they can completely destroy the lesion where partial nephrectomy is not suitable. The committee agreed with your suggestion that should someone require surgery; other surgically accessible lesions should be removed. Therefore, they amended the recommendation to cover multiple lesions.

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UK Renal Oncology Group	Guideline	017	013	<p>Rec 1.5.2 The statement that SABR may be used when surgery and ablation are unsuitable should cite the <b>FASTRACK II</b> and <b>STAR-TREK</b> prospective trials for local control rates &gt; 90%, ensuring radiotherapy is represented with equal evidentiary weighting to ablation.</p> <p>The statement 'compared with surgery thermal ablation and SABR have a higher risk of recurrence' is unreferenced and potentially misleading. Current comparative evidence (Uhlig J et al., <i>Eur Urol Oncol</i> 2023; 6: 443-452; Siva S et al., <i>Eur Urol</i> 2022; 81: 251-259) shows that well-selected T1a-b renal lesions treated with SABR or cryoablation can achieve local-control rates &gt; 90%, approaching surgical outcomes. The guideline should cite supporting data or rephrase to indicate that long-term oncological equivalence is still under evaluation rather than implying inferiority</p>	<p>Thank you for your comments. The committee discussed the risk of recurrence between different treatment methods. The related evidence review (review B) compared thermal ablation (as a single intervention with subgroups to investigate the different effects of the types of thermal ablation, where possible), partial nephrectomy, total nephrectomy, stereotactic ablative radiotherapy (SABR) and active surveillance. There was some evidence to suggest that partial and total nephrectomy have lower local recurrence than thermal ablation, and the committee considered that in their experience this applied to SABR as well.</p> <p>We have considered the references provided in this comment and note that Siva et al. 2022 has a sample of people with oligometastatic disease, whereas these recommendations are about people with localised RCC. We were unable to identify the Uhlig 2023 paper from the information provided. We also note that the FASTRACK II trial is non-comparative and the STAR-TREC trial is of people with rectal cancer. Neither of these trials meet the inclusion criteria for review B (which was only of comparative studies in people with RCC).</p> <p>The committee agreed to amend the statements about risk of recurrence to make them less definite in recognition of the variation within intervention types and the limited amount of long-term data. They also added text to the related rationale and impact to clarify this.</p>
UK Renal Oncology Group	Guideline	034	16-21	<p>Rec 1.15.2 correctly confines cabozantinib+nivolumab (TA964), lenvatinib+pembrolizumab (TA858), and</p>	<p>Thank you for your comment. The TA recommendation outlines these treatments are only for advanced RCC with an intermediate or poor risk as defined in the IMDC.</p>

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				nivolumab+ipilimumab (TA780) to IMDC intermediate/poor. Suggest an explicit sentence stating these are not commissioned for favourable-risk disease (to minimise misapplication)	
UK Renal Oncology Group	Guideline	034	8-21	Please add an explicit statement on first-line metastatic choices after prior adjuvant pembrolizumab (a frequent scenario): e.g., consider VEGFR-TKI or IO-TKI according to commissioning, with MDT-guided selection.	The guideline and visual summaries outline all available treatment options in advanced RCC, as part of TA incorporation. Choice should be based on shared decision making.
Urologic Malignancies Programme, University of Cambridge	Guideline	General	General	The move to increasing numbers of biopsies will likely have quite an impact on IR/radiology services. This will be especially true in smaller DGHs that have limited numbers of radiologists that can perform such procedures.	Thank you for your comment. The committee considered the impact that increasing numbers of biopsies will have on interventional radiology services. They agreed that interventional radiology provision would need to increase in some places, including more staff. The committee anticipate that increasing the use of biopsies will help reduce the number of unnecessary surgeries, which in turn could offset some of the resource pressures by delivering associated cost savings and improving patient outcomes. Please refer to the sections on 'How the recommendation might affect practice' that accompany the biopsy recommendations in the rationale and impact section of the guideline for more information. See also the section on 'cost effectiveness and resource' use in the committee discussion in evidence review J on biopsy for more details.
Urologic Malignancies Programme, University of Cambridge	Guideline	General	General	The R.E.N.A.L., or equivalent, scoring systems are not mentioned for decision making on partial nephrectomy? Does this reflect a lack of evidence, or at times subjective nature of their application? Likewise the Clear Cell Likelihood score (ccLs) for MRI evaluation of renal lesions is not mentioned (and lacks robust evidence). I agree it has limitations, i.e. does not definitively state the lesion is of clear cell	Thank you for your comments. The committee did not review the evidence for the Clear Cell Likelihood score or the use of scoring systems for decision making about partial nephrectomy and were therefore unable to make specific recommendations about using them. They noted that R.E.N.A.L and other scoring systems for decision making on partial nephrectomy are more commonly used in research than current clinical practice.

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				<p>origin and a low score does not imply a benign lesion (i.e. can still be another malignant tumour type). There is also currently no clear role in management, such as stratification for AS or avoiding biopsy.</p> <p>- Should either/both be mentioned, even if just to clarify their lack of inclusion and/or point to future directions/research questions?</p>	<p>However, they agreed to add some text in the related rationale to acknowledge that they may help to understand the complexity of renal lesions when decisions are being made about partial nephrectomy, whilst making it clear that they had not reviewed the evidence for them.</p>
Urologic Malignancies Programme, University of Cambridge	Guideline	General	General	<p>Recommendations for further research:</p> <ul style="list-style-type: none"> <li>○ Efficacy of adjuvant pembrolizumab in settings other than clear cell RCC. The KN564 data was only ccRCC, but NHSE approval of adjuvant pembro is for a wider population.</li> <li>○ Alternate durations of adjuvant pembrolizumab eg 6 vs 12 months. The selection of 12 months for the KN564 study is arbitrary. In other types of solid cancer (eg breast, lung, colorectal) shorter durations of adjuvant therapy have been shown to be as effective for patients, but causes less side effects, allows patients to complete treatment sooner and is less costly to healthcare funders (eg the NHS).</li> <li>○ Optimal systemic treatment after relapse on or soon after (&lt;6 months) adjuvant immunotherapy with pembrolizumab.</li> <li>○ In metastatic RCC, research into the optimal sequencing</li> </ul>	<p>Thank you for your comment. It was not within the guideline scope to include evidence on adjuvant treatment or treatment in advanced RCC as the TAs for these drugs were incorporated into the guideline without an evidence review. Therefore, the committee were unable to make research recommendations on these topics.</p>

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				We liked the research question of using SABR to the renal primary if the patient is otherwise in remission on systemic therapy, although this is confined to patients with inoperable renal masses which we think is too narrow.	
Urologic Malignancies Programme, University of Cambridge	Guideline	007	002	Consider CECT or MRI imaging of the brain at (at least) diagnosis of stage IV disease and with each progression event. Brain mets are common in patients with metastatic RCC and treatments have improved significantly for them.	<p>Thank you for your comment. The evidence review on CT imaging (review I1) did not aim to assess CT imaging for the detection of any metastases. It aimed to assess the diagnostic accuracy of CT scan or MRI for diagnosing renal lesions. Therefore, we are unable to make a specific recommendation about the use of CT for detecting brain metastases.</p> <p>However, we discussed this with the committee and agreed to cross refer to the NICE guidelines on <a href="#">brain tumours and brain metastases (NG99)</a> and <a href="#">spinal metastases and metastatic spinal cord compression (NG234)</a> and explicitly signpost to the sections on imaging investigations in both guidelines. This has been included in the 'imaging' section of the kidney cancer guideline.</p>
Urologic Malignancies Programme, University of Cambridge	Guideline	007	018	We question whether contrast enhanced CT chest necessary at all? Our radiologists suggest contrast adds nothing in the search for mets in the chest.	<p>Thank you for your comment. The committee discussed this and agreed with your comment that the use of contrast may not be required with chest CT imaging especially for small lesions. However, they considered that carrying out chest CT at this stage may provide some benefit prior to surgery to increase certainty that pulmonary metastases are not being missed. Also, they noted that CT of the chest and pelvis will ideally be done at the same time preferably with contrast except the use of contrast is contraindicated. In such circumstances, chest CT without contrast would still be helpful. Therefore, the committee decided that CT of the</p>

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					chest and pelvis should be carried out at this stage, ideally with contrast and amended the recommendation to reflect this.
Urologic Malignancies Programme, University of Cambridge	Guideline	008	006	We are not sure that the 99mTc-sestamibi single-photon emission computed tomography CT (SPECT/CT) scan is widely available.	Thank you for your comment. The committee confirmed that SPECT/CT is widely available in the UK and will usually be available in hospitals that have a nuclear medicine department. It is commonly used in current practice for the identification and localisation of parathyroid adenomas, and to detect perfusion abnormality in the heart. They also acknowledged that the recommendation for use of SPECT/CT in diagnosis will only be relevant to a smaller population of people who have already had CT or MRI but need more information on whether the lesion is an oncocytic renal lesion or are unable to have a biopsy. Therefore, they agreed not to make any changes to the recommendation.
Urologic Malignancies Programme, University of Cambridge	Guideline	008	014	Clarify whether/that discharge is only if AML is solitary and small rather than bilateral or large?	Thank you for your comment. The committee agreed that angiomyolipomas are benign lesions and are not considered cancer. Therefore a person with angiomyolipoma would not be managed on the cancer pathway. However, they acknowledged that there are instances where a person with angiomyolipoma should not be discharged completely but monitored for longer. This is covered by a recommendation in the imaging section of the guideline for the person to be monitored outside the cancer pathway. This would also apply to an angiomyolipoma that is bilateral and large. Therefore, no changes were made to this recommendation.

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Urologic Malignancies Programme, University of Cambridge	Guideline	008	015	AML - where do you define high risk complications – is it only women (women, transmen, non-binary, registered female at birth) who are childbearing/ Would you not intervene in anyone?	Thank you for your comment. The committee decided to broaden this recommendation to specify that you would discharge someone with a benign renal lesion if the person is not at higher risk of complications <i>and</i> does not have symptoms that need management. Complications could include bleeding, which is now given as an example in the recommendation. Women, trans men and non-binary people registered female at birth who are of childbearing age and people with an angiomyolipoma with a predominantly vascular component are given as examples in the rationale, but this is not an exhaustive list. Symptoms that need management might include pain, and this is also listed as an example in the recommendation. More examples of symptoms that might need separate management may exist.
Urologic Malignancies Programme, University of Cambridge	Guideline	008	016	Bosniak 1 & 2 - where do you define who is at risk of complications – is it just pain and would you attribute pain to say a small cyst?	Thank you for your comment. The committee decided to broaden this recommendation to specify that you would discharge someone with a benign renal lesion if the person is not at high risk of complications <i>and</i> does not have symptoms that need management. Complications could include bleeding, which is now given as an example in the recommendation. Women, trans men and non-binary people registered female at birth who are of childbearing age was given as an example in the rationale, but this is not an exhaustive list. Symptoms that need management might include pain, and this is also listed as an example in the recommendation. More examples of symptoms that might need separate management may exist.
Urologic Malignancies Programme,	Guideline	009	003	- The ACR white paper (Herts, et al. JACR 2018; 15:264–273) only recommends biopsy for lesions 1-4 cm in size. For “solid, enhancing masses <1 cm”, surveillance with follow-up imaging is advised.	Thank you for your comment. The committee agreed that the situations listed in the recommendation for when a biopsy should not be offered sufficiently cover the technical challenges with sampling a lesion that is smaller than 1cm.

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University of Cambridge				- Clearly technical challenges exist with sampling lesions less than 1 cm, and location (UP/LP, medial/lateral, endo/exo-phytic) are often equally important. This is likely covered/implied (albeit less explicitly) by 1.3.3 Do not offer biopsy if any of the following apply ... getting a tissue sample is not possible	They expand on these reasons, with examples of situations when enough tissue cannot be obtained in the rationale section of the guideline. The committee also noted that in some cases, the size of the lesion may not be the only feature that would determine the ability to obtain a sample and decided against including a lower size limit in the recommendation.
Urologic Malignancies Programme, University of Cambridge	Guideline	009	024-025	What is the difference between in a location that is not accessible for biopsy/getting a tissue sample is not possible? (this sounds a little arbitrary as the radiologist usually says bigger chance of non-diagnostic biopsy but not that they won't do it?)	Thank you for your comment. The committee agree that the recommendation referring to situations when not to offer a biopsy could be made clearer. They agree with your comment that the 2 criteria listed overlap and have made edits to the wording of the recommendation to merge these 2 points into 1 bullet.
Urologic Malignancies Programme, University of Cambridge	Guideline	012	006	As we might change the tumour type to/from ccRCC when we have the final surgical pathology, propose adding: <i>The biopsy represents only a very small sample of the lesion and, whilst the results are usually accurate, there may be some differences in the final tumour pathology result for those undergoing subsequent surgery.</i>	Thank you for your comment. The committee noted that the purpose of this recommendation is to enable people to make informed decisions about whether to have a biopsy if it is suitable for them. They agreed that biopsy results for any lesion can be heterogeneous, and this is not unique to renal cancers. The committee decided that including this detail in the recommendation could cause confusion for patients, but acknowledged its importance for clinician discussions. To address this, they decided to add explanatory text to the rationale that accompanies the biopsy information recommendation instead.
Urologic Malignancies Programme, University of Cambridge	Guideline	012	006	This part of the guidance does not mention that a biopsy may make subsequent partial nephrectomy surgery more challenging.	Thank you for your comment. The committee discussed that, while it may sometimes be harder to conduct a partial nephrectomy after biopsy, this was not necessarily the case and it would not stop partial nephrectomy from being an option in their experience. Therefore they chose not to add this point to the recommendations.
Urologic Malignancies	Guideline	013	008	Add: <i>Oncocytic lesions that are in a borderline category (between oncocytoma and chromophobe</i>	Thank you for your comment. The committee agreed with your comment that oncocytic renal neoplasms of low

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Programme, University of Cambridge				<i>RCC) and are regarded as an 'oncocytic renal neoplasm of low malignant potential, NOS', in the WHO classification (currently 5<sup>th</sup> Edition, 2022) may be managed in a similar way to an oncocytoma.</i>	malignant potential, not otherwise specified, may be managed in a similar way to an oncocytoma. Therefore, a new recommendation has been added to the 'active surveillance for oncocytomas' section of the guideline to specify that active surveillance management options applicable to oncocytomas may also be used for oncocytic renal neoplasm of low malignant potential, not otherwise specified.
Urologic Malignancies Programme, University of Cambridge	Guideline	013	020	There is a contradiction in saying if there is a growth rate of >5mm/year discussing biopsy or intervention or then say they can continue active surveillance. I think you need to decide if you are going to state a specific growth rate that it is either raising enough concern to advise a further biopsy or intervention but not just continuing with the status quo - if the patient won't or can't have a biopsy are you not going to recommend intervening?	Thank you for your comment. The recommendation suggests a specific growth rate of 5mm or more per year as the threshold for intervening, ideally by performing a biopsy to assess whether the oncocytoma is malignant. If malignant, the recommendations on treatment of renal cell carcinoma would apply. However, if a person declines biopsy or is unable to have one, the alternative options are either to remain on active surveillance or treat the oncocytoma, and the decision will be based on clinical judgement and patient preference. If the person has a biopsy and the lesion is found to be benign the same options apply. The committee decided against ranking treating the oncocytoma over active surveillance and therefore the recommendation is not tiered.
Urologic Malignancies Programme, University of Cambridge	Guideline	014	005	Is there any point at which you can advise discharging oncocytomas i.e. what do you mean by 'no substantial changes have been recorded after 5 years surveillance'?	Thank you for your comment. For oncocytomas this is when the oncocytoma does not have a growth rate greater than 5 mm in diameter per year. For Bosniak 2F cysts this is when the cyst has not progressed to Bosniak stage 3 or 4. This information has been added to the recommendation.
Urologic Malignancies Programme,	Guideline	014	019	The terms "progresses" and "remains stable" are not clearly defined in the following sections: 1.4.6 If the Bosniak 2F cyst progresses during active surveillance, follow the relevant	Thank you for your comment. For oncocytomas remaining stable is when the oncocytoma does not have a growth rate greater than 5 mm in diameter per year. For Bosniak 2F cysts this is when the cyst has not progressed to Bosniak

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University of Cambridge				<p>recommendations for ... [management options] 1.4.8 Consider stopping active surveillance and discharging the person with an oncocytoma or Bosniak 2F cyst back to primary care if the renal lesion remains stable for 5 years.</p> <p>- Although it is noted that these definitions are later implied in other sections: (Section 1.5.13) "... being discharged if there are no triggers for moving to treatment" (Page 59) "Discussing moving to treatment would only happen if there was progression to a Bosniak 3 or 4 cyst, or to a localised, locally advanced or advanced renal cell carcinoma (RCC)."</p>	stage 3 or 4. Progression of a Bosniak 2F cyst is the inverse of this (i.e. becoming a Bosniak 3 or 4 cyst). This information has been added to the recommendations to make this clearer.
Urologic Malignancies Programme, University of Cambridge	Guideline	015	001	Does this include an AML?	Thank you for your comment. This section does not apply to angiomyolipoma. There is a separate recommendation in section 1.2 on imaging to discharge a person from the cancer care pathway if imaging suggests that the renal lesion is benign, and this includes angiomyolipoma as an example.

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Urologic Malignancies Programme, University of Cambridge	Guideline	015	003	Does a biopsy proven oncocytoma need 5y surveillance? Not sure it does if patient is counselled well.	<p>Thank you for your comment. There was no evidence that met the inclusion criteria for this review (E on active surveillance), so the committee used their expertise to draft consensus recommendations about the mode and duration of active surveillance. The committee noted that oncocytomas can be fast growing and may require treatment if the growth rate exceeds 5mm in diameter per year. This would also apply to biopsy-proven oncocytomas.</p> <p>The committee agreed that 5 years was a reasonable amount of time to monitor an oncocytoma because if the suspected oncocytoma is actually a malignant mass, it is likely that it would be detected during that time.</p> <p>The committee noted that this reflected current practice in their centres but might be a change in practice elsewhere. However, in response to other stakeholder feedback they agreed that age, fitness, preferences and clinical characteristics should also be taken into account when deciding to stop active surveillance. The recommendation was changed to reflect these points and provide clarity what is meant by oncocytoma and Bosniak 2F cysts remaining stable.</p>
Urologic Malignancies Programme, University of Cambridge	Guideline	015	010	I think Bosniak 3 and 4 are different groups, 4 intervention should be advised (if possible) whereas 3 should be advised to go on surveillance (EAU guidance) and my experience is that is the right approach, particularly as 50% turn out to be benign. You have followed some of AUA guidance I believe but this is not strong evidence. Not sure why you would not feel AS is reasonable particularly in the predominantly cystic groups and initially see what	<p>Thank you for these comments. The committee agreed that Bosniak 3 and 4 cysts have different probabilities of malignancy. There was no evidence in the relevant reviews (reviews A and B) that was specific to Bosniak cysts, as studies considered localised RCC only (some of which may be as part of a cyst, and others not).</p> <p>The committee discussed Bosniak 3 and 4 cysts further and agreed that Bosniak 3 cysts should usually be managed</p>

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				<p>growth rate is, as we would do in suspicious solid masses in older groups. Is surgery in these groups associated with both lower local and distant recurrence or just local? Is it true that AS pts have higher rates of metastases?</p>	<p>differently to Bosniak 4 cysts and solid renal masses. They therefore removed Bosniak 3 cysts from the recommendation to offer surgery, and wrote a new recommendation for Bosniak 3 cysts 2 cm and larger in diameter which recommends that active surveillance should be considered initially, with surgery as an option for when active surveillance is declined.</p> <p>They also noted that renal lesion factors (including size of the solid nodule for cysts) are already included in the list of things to take into account when deciding which management options are suitable for localised RCC and Bosniak 3 and 4 cysts. They also agreed to add text to the rationale and impact section for these recommendations to explain that Bosniak 3 cysts have a lower chance of malignancy and that the best management pathway for cysts is less well covered by the literature.</p> <p>The evidence for lower recurrence after surgery compared with thermal ablation was specifically about local recurrence (rather than distant), so the committee agreed to add this to the recommendation on shared decision making and the recommendation on factors for the healthcare professional to take into account when deciding which management options are suitable for suspected or confirmed localised RCC and Bosniak 3 and 4 cysts. No evidence was identified for local recurrence in the comparison of SABR with surgery, but the committee agreed it was likely to be higher. The evidence could not show a difference between active surveillance and either partial or total nephrectomy for metastases, although the volume of evidence was low.</p>

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Urologic Malignancies Programme, University of Cambridge	Guideline	016	006	are you advising surgery for a >2cm Bosniak 3 cyst (see above)? Thermal ablation and SABR have a higher risk of any recurrence or just local?	<p>Thank you for these comments. The committee discussed this issue and agreed that Bosniak 3 and 4 cysts have different probabilities of malignancy. There was no evidence in the relevant reviews (reviews A and B) that was specific to Bosniak cysts, as studies considered localised RCC only (some of which may be as part of a cyst, and others not).</p> <p>The committee discussed Bosniak 3 and 4 cysts further and agreed that Bosniak 3 cysts should usually be managed differently. They therefore removed Bosniak 3 cysts from the recommendation to offer surgery, and wrote a new recommendation for Bosniak 3 cysts 2 cm and larger in diameter which recommends that active surveillance should be considered initially, with surgery as an option for when active surveillance is declined.</p> <p>The committee also noted that renal lesion factors (including size of the solid nodule for cysts) are already included in the list of things to take into account when deciding which management options are suitable for localised RCC and Bosniak 3 and 4 cysts. They also agreed to add text to the rationale and impact section for these recommendations to explain that Bosniak 3 cysts have a lower chance of malignancy and that the best management pathway for cysts is less well clear from the literature.</p> <p>The evidence for lower recurrence after surgery compared with thermal ablation was specifically about local recurrence (rather than distant), so the committee agreed to add this to the recommendation. No evidence was identified for local</p>

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					recurrence in SABR compared with surgery, but the committee agreed it was likely to be higher.
Urologic Malignancies Programme, University of Cambridge	Guideline	017	013	Why 2cm? Would it not be more practical to make a distinction based on TNM? i.e. surveillance, ablation and surgery as options for cT1a rather than 2cm cut off. Seems to also suggest that a 2.1cm Bosniak 3 cyst should be offered surgery upfront?	<p>Thank you for this comment. The committee decided against using T1a and T1b as treatment threshold because they wanted to promote the use of active surveillance for renal lesions under 2 cm, which are considered to be very low risk. As the lesion size increases the risk of metastases also increases so the committee recommended surgery as the first option for lesions 2 cm and larger in diameter.</p> <p>The committee discussed Bosniak 3 and 4 cysts further and agreed that Bosniak 3 cysts should usually be managed differently. They therefore removed Bosniak 3 cysts from the recommendation to offer surgery, and wrote a new recommendation for Bosniak 3 cysts 2 cm and larger in diameter which recommends that active surveillance should be considered initially, with surgery as an option for when active surveillance is declined.</p> <p>They also noted that the recommendation on factors to take into account when deciding which management options are suitable for suspected or confirmed localised RCC and Bosniak 3 and 4 cysts has a bullet point covering renal lesion factors, such as location, size of the solid mass (or solid component in a Bosniak 3 or 4 cyst) and type. This outlines how the healthcare professional will use their clinical judgement to decide about whether active surveillance would be more appropriate than surgery in that specific case.</p>
Urologic Malignancies Programme,	Guideline	018	003	State "... Consider.. SABR, if thermal ablation is not suitable and active surveillance is declined." - We cannot see any definitions nor links to (other)	Thank you for this comment. The committee agreed that this decision is likely to be very nuanced and informed by

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University of Cambridge				guidance that detail when thermal ablation is not suitable?	clinician judgement and discussions in a multidisciplinary team. They discussed scenarios in which thermal ablation might not be suitable, but SABR would be, for example where the lesion is central and thermal ablation could create a heat sink effect which would not occur with SABR, or where the potential complications of thermal ablation need to be avoided for reasons specific to that person and their clinical characteristics. However, the committee thought this was too technical to be specified in the guideline. They were also unable to link to any specific guidance about when thermal ablation is not suitable.
Urologic Malignancies Programme, University of Cambridge	Guideline	020	003	Could this follow-up be less frequent?	Thank you for your comment. The committee agreed that based on their clinical expertise and experience (including the opinions of the lay members on the committee) this should ideally be the minimum active surveillance schedule. However, they acknowledged that there was no evidence to determine the most effective active surveillance imaging schedule. The recommendation is therefore a weaker recommendation, denoted by the word 'consider' and healthcare professionals are expected to use their own clinical judgment when deciding what schedule to use in practice.
Urologic Malignancies Programme, University of Cambridge	Guideline	022	010	"if minimally invasive approaches are not suitable" this is very subjective, we are not sure it is useful to include? Other guidelines refer to the expertise in the approach available locally - maybe that could be included?	Thank you for your comment. The committee discussed this and agreed that it is useful to retain the examples provided in this recommendation for when minimally invasive approaches are not suitable. The committee decided against including mention of local expertise because there is an expectation that if there is insufficient local expertise to carry out minimally invasive total nephrectomy for a particular patient that they will be referred to a centre where

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					this is available. Therefore, they decided not to amend the recommendation.
Urologic Malignancies Programme, University of Cambridge	Guideline	023	004	Perhaps include something about functional imaging to assist in decision making for PN v RN?	Thank you for your comment. The committee agreed that considering renal function as detailed in table 1 in the guideline should prompt any functional imaging as required and declined to add this to the recommendations.
Urologic Malignancies Programme, University of Cambridge	Guideline	024	001	<i>Add: The pathology should be reported according to recommendations in UK RCPATH Datasets. For those tumours where there is no commonly used risk prediction tool, ensure that information of potential prognostic significance is included in the pathology report, e.g. tumour necrosis and/or sarcomatoid change for chromophobe RCCs.</i>	<p>Thank you for your comment. The committee have already made recommendations that the pathology report should contain the tumour stage (using the TNM staging system), and all the other relevant pathology information that is needed to calculate a risk score. The committee noted that the suggestion to say that the pathology should be reported according to recommendations in UK RCPATH Datasets is unnecessary because pathology reports already do this routinely.</p> <p>The committee took your comment about tumours where no suitable risk prediction tools exist and other stakeholder comments into account to draft new recommendations in the follow up section to cover the levels of risk to use for people with chromophobe RCC. This recommendation covers prognostic factors (fat invasion, sarcomatoid differentiation, nodal involvement), but we have not added them to the recommendation about things to include in the pathology report because we have been told by the committee that information about the status of these factors is available routinely as part of the histological report already.</p>
Urologic Malignancies Programme,	Guideline	025	018	Perhaps add a sentence on counselling for adjuvant pembro in the pre-operative counselling for RCC? Obviously not essential but likelihood of acceptance	Thank you for your comment. The committee agreed that people should be aware before surgery that adjuvant systemic anticancer treatment may be recommended after

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University of Cambridge				of adjv pembro is higher if preoperative discussion about the possibility has taken place.	surgery. Therefore, we have added this to the section on information given to people before and after surgery.
Urologic Malignancies Programme, University of Cambridge	Guideline	027	021	Table suggests 5 y follow up for low-risk tumours.... is this at odds with EAU guidelines which suggests stopping at 3y for low risk?	Thank you for your comment. The committee agreed to retain the schedule in this table, which is adapted from the GIRFT guideline schedule that is based on consensus taking the EAU and other international guidance into account. Therefore, no changes were made to the table to align specifically with the EAU guideline.
Urologic Malignancies Programme, University of Cambridge	Guideline	028	009	"Consider using the low-risk status follow-up schedule for people with chromophobe RCC" - this is a bit vague - shouldn't follow up of non-clear cell RCC be based on scores such as Leibovich 2018? some chromophobes are deadly.	Thank you for your comment. The committee noted that there was insufficient evidence to recommend a specific tool for predicting the risk of recurrence for people with chromophobe RCC. Leibovich 2018 does not report risk of recurrence but instead reports the risk of progression free survival and cancer specific survival. (See the discussion section of review K on risk prediction for more information about this.) However, they agreed that clinical and pathological characteristics of chromophobe RCC, such as fat invasion, sarcomatoid differentiation and nodal involvement may be associated with an increase in the risk of recurrence and therefore where any of them are present the person may require more frequent follow-up. In response to your comment, this recommendation has been changed to highlight the level of follow-up schedule to be used where a person with chromophobe RCC might be considered at higher risk of recurrence after treatment.
Urologic Malignancies Programme, University of Cambridge	Guideline	029	003	Scan at 5y is at odds with EAU guidelines which suggest surveillance for 10y for int/ high risk.	Thank you for your comment. The committee agreed to the schedule in this table, adapted from the GIRFT guideline ( <a href="#">'Urology: Towards better care for patients with kidney cancer'</a> ), which was considered more appropriate for the UK healthcare system. However, the recommendation is to consider discharging at each scan after 5 years and not a strong recommendation to discharge at 5 years. This will be

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					based on a shared decision between the health professional and the person, and the recommendation has been amended to add some more factors to take into account when making this decision. The expectation is that for most people with intermediate or high risk of recurrence follow up will continue after 5 years and that there will be a discussion after the scan results every 2 years until discharge is agreed by the clinician and patient. However, the committee acknowledged that a potential cutoff date to discharge from follow up may be appropriate for these people. Therefore, a new recommendation has been added to the follow-up for localised and locally advanced RCC section of the guideline suggesting a cutoff of 10 years for follow up after treatment. This is a weaker recommendation because the committee acknowledged that for some people it would be appropriate to keep them under follow up for longer than this.
Urologic Malignancies Programme, University of Cambridge	Guideline	029	004	Does this also include low risk if they want further follow up?	Thank you for your comment. The committee agreed that people with low risk of recurrence do not need to be followed up for longer than 5 years if there hasn't been a recurrence or metastasis by that time. Lay committee members also agreed that remaining on monitoring beyond 5 years when the risk of recurrence is low creates further anxiety. However, they acknowledged that the recommendation to discharge people with low risk of recurrence is a weak recommendation, and clinician judgement could overrule this if there were specific reasons to do so, but the intended action is to discharge at 5 years. Therefore, the committee agreed not to include people with low risk of recurrence in this recommendation. Instead, follow-up frequency and method would be decided based

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					on clinician judgement and the committee agreed not to specify this.
Urologic Malignancies Programme, University of Cambridge	Guideline	033	001	Is a durable partial response enough to justify CN? Am I right in thinking there may be no change in mets with this definition?	Thank you for your comment. The committee noted that the definition of durable partial response (please see the terms used) is linked to the RECIST criteria and it will therefore depend on what lesions were selected as the target lesions. The recommendation specifies a durable partial response in the metastatic sites. They also noted that the recommendation specifies that in order to consider cytoreductive nephrectomy, most of the disease that is left after SACT must be in the primary site. These criteria combined should ensure that there has been a change to the metastases in order to consider cytoreductive nephrectomy.
Urologic Malignancies Programme, University of Cambridge	Guideline	037	021	Is this not best done by the Clinical Genetics team inc counsellors?	Thank you for your comment. The committee agreed that the discussion of genetic test results would not be limited to the clinical genetics team, particularly where the mainstream approach has been used to initiate genetic testing.
Urologic Malignancies Programme, University of Cambridge	Guideline	039	024	I would be uncomfortable if there was a growth of >5mm between scans not to intervene in the less aggressive group especially twice in a row.	Thank you for your comment. The committee confirmed that the size of the lesion in people with a heritable predisposition to RCC should be prioritised over the growth rate. This is because people with a heritable predisposition to RCC are likely to develop multiple lesions over time so minimising the number of interventions needed would be preferable.
Urologic Malignancies Programme, University of Cambridge	Guideline	060	004	"The committee ... agreed that stopping active surveillance should be discussed if no substantial changes have been recorded after 5 years. If the suspected oncocytoma is actually a malignant mass, it is unlikely it would be undetected during that time." - Wording is confusing (double negative). Perhaps	Thank you for your comment. We have rephrased this statement to make our meaning clearer.

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				this is deliberate to further convey uncertainty (?) but consider changing to "likely" and "detected".	
Yorkshire Cancer Research	Guideline	009-015	Sections 1.3 – 1.5	These sections raise concerns around possible issues with variation in access. It is of course vital that different options are discussed with patients to ensure meaningful shared decision making. For this to be possible it is important to ensure that everyone has access to cancer care navigators so that options are presented and discussed in an appropriate manner to enable all patients to make informed decisions about their care.	Thank you for your comment. The cancer care navigator's role encompasses coordinating appointments, offering information, and providing emotional support. However, the information provided is expected to be more about the logistics of accessing treatment, where to find information and support rather than discussing treatment options. These are generally discussed by the clinical nurse specialist and other members of the clinical team. The guideline already recommends that all patients have access to a clinical nurse specialist, and the committee believe that this will help patients make informed decisions about their care. The committee acknowledges that variation in practice exists but expects this guideline to help reduce these disparities by providing a basis for the development of a business case for clinical nurse specialist availability where they are not currently available.
Yorkshire Cancer Research	Guideline	006	Section 1.1.7	<p>There is evidence that the offer of stop smoking support could be strengthened by automatically enrolling people who smoke with renal cell carcinoma (RCC), as well as those with suspected RCC, into smoking cessation services.</p> <p>A suspected cancer diagnosis can act as a 'teachable moment', encouraging people to make positive lifestyle changes. Limiting stop smoking support to those already diagnosed risks missing this important opportunity for intervention. There is evidence from several settings that providing smoking cessation support on referral into cancer services is effective. For example, referral into</p>	<p>Thank you for your comments. The details of how to offer support for smoking cessation are not within the scope of this guideline. For recommendations on <a href="#">Promoting stop-smoking support</a>, please refer to the NICE guidance <a href="#">NG209 Tobacco: preventing uptake, promoting quitting and treating dependence</a>.</p> <p>If you would like to propose an update to the Tobacco guideline focusing on people with RCC or cancer in general, then please can you submit a topic suggestion through our topic prioritisation process. See here for information on the prioritisation process and the submission form:</p> <ul style="list-style-type: none"> <li>• <a href="#">Prioritising our guidance topics</a></li> </ul>

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				<p>smoking cessation services following head and neck urgent suspected cancer referral resulted in a 36% reported quit rate.<sup>1</sup> Moreover, evidence suggests that people who are referred to cancer specialists with suspected cancer are largely willing to accept advice on reducing their risk of future cancer.<sup>2</sup> This this willingness should be capitalised fully for people with suspected RCC.</p> <p>Additionally, people with diagnosed or suspected RCC should not simply be offered support to help to stop smoking. They should instead be automatically enrolled into smoking cessation support. Evidence from settings such as lung health checks, maternity care and hospital inpatient programmes, including from research and services funded by Yorkshire Cancer Research, shows that opt-out, fully integrated approaches are effective.<sup>3,4</sup> If logistics allow, this support should be co-located alongside the primary appointment for optimal impact.</p> <p>Opt-out approaches increase quit attempts and can play a meaningful role in reducing smoking prevalence. For example, the Yorkshire Enhanced Stop Smoking study (YESS) demonstrated that automatically enrolling people who smoke into smoking cessation support as part of their lung screening appointment on the same day is highly effective.<sup>3</sup> Of eligible participants in the YESS study, 89.0% agreed to see an advisor on the unit and 15.0% of all eligible people self-reported quitting after four weeks. This is a higher quit rate than is seen in</p>	<ul style="list-style-type: none"> <li>• <a href="#">Topic suggestion.</a></li> </ul>

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				<p>lung screening units that do not provide such intensive intervention. For example, the UK Lung Screening Pilot provided standard smoking cessation advice leaflets and signposted participants to existing services.<sup>5</sup> At a similar time-point to the 4-week quit rate measured in the YESS study, 9.9% self-reported quitting. Opt-out, fully integrated support is designed and proven to capture people who smoke that may have ignored a leaflet or brief advice to quit by presenting smoking cessation as a standard element of the pathway rather than an optional extra. The CURE Project in Manchester and Yorkshire Cancer Research's QUIT programme further demonstrate that opt-out strategies lead to higher engagement and quit rates compared to traditional opt-in approaches.<sup>6, 7</sup> The QUIT programme automatically enrolled patients in hospitals who smoke into smoking cessation services as part of their routine care. During the period in which the charity co-funded the programme, 2,450 quits were achieved and following this initial funding the programme has been sustained as a key part of prevention work within the ICS, having the potential to save thousands of lives and hospital readmissions each year.</p>	

*\*None of the stakeholders who comments on this clinical guideline have declared any links to the tobacco industry.*

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