Kidney cancer stakeholder workshop discussion Date:25th July 2023		
Area of scope	**Questions for discussion**	**Stakeholder views**
Populations Adults (18 years and older) with suspected or confirmed renal cell carcinoma. **Exclusions** Adults with suspected or confirmed non-renal cell carcinomas, including urothelial cell carcinomas of the upper urinary tract or Wilms tumour.	1. Are you happy with our approach to the population?	1.The stakeholders were broadly content with the proposed approach to the adult population. It was noted that urothelial cell carcinomas (UCC) were more closely related to bladder cancer in terms of their management and were usually managed by different specialists. Representatives of a patient focused kidney cancer charity noted they do not provide advice on UCC, as it is distinct from renal cell carcinoma (RCC). It was noted that the NICE guideline on bladder cancer published in 2015, needs to be updated. It was also noted it does not cover UCC of the upper urinary tract and it was agreed this would be noted for surveillance of that guideline. Stakeholders asked if rarer subtypes of RCC would be included. They noted that evidence was less likely to be found but that follow-up would be important because some subtypes for example renal medullary carcinoma are aggressive and at greater risk of progression. They noted that systemic treatment would be similar to that for other RCCs and that a search for evidence on RCCs should capture any evidence on the rarer subtypes.
	2. Do you agree with the groups that will be covered?	2. There was broad agreement regarding the proposed included population group, as noted above.
	3. Do you agree with the groups	3. There was broad agreement regarding the proposed excluded groups, as noted above. The group discussed the definition of adults as being 18 years

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	we are specifically not covering?	and older and whether RCC tended to affect people below this age, particularly for the inherited sub-types. It was agreed the number of young people affected by RCC was very small, that most would be managed jointly by paediatric and urology specialisms and that little evidence would be likely to be found in this area.
Settings All healthcare settings that provide care to adults with suspected or confirmed renal cell carcinoma, including primary and secondary care and specialist cancer services.	Have we included and excluded the right settings?	The group were content with the settings included in the draft scope and had no further suggestions or comments.
Activities, services or aspects of care 1. Information, communication, advice and support for adults with suspected or confirmed renal cell carcinoma and for their families and carers.	1. Do the topics listed in the scope cover the most important priorities for developing guidance on kidney cancer?	1. The group were broadly content with the proposed areas, but they suggested dividing area 6 'Treatment for locally advanced and metastatic renal cell carcinoma' into 2 areas: 'Treatment for locally advanced renal cell carcinoma' and 'Treatment for metastatic renal cell carcinoma' as treatment is different.

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2. Diagnosis of renal cell carcinoma in adults. – Signs and symptoms, including findings of physical examination and laboratory investigations. – Imaging investigations. – Biopsy of renal tumours. – Histology. – Genetic assessment. 3. Prognosis, including the following factors: – tumour size and characteristics – histological – clinical (including frailty and performance)	2. Are there any important omissions, or any topics on the list that should be deleted?	2. Stakeholders asked if small renal masses would be included and it was proposed that they would be included until diagnosis. Bosniak cysts were discussed, particularly in relation to follow-up as there is variation in practice around this. The group noted that Bosniak cysts 1 and 2 are considered benign and 3 and 4 are treated as tumours. The group highlighted that it would be helpful to have guidance on how to manage 2F Bosniak cysts found on imaging, as these can progress. It was noted that there is also variation in the way in which oncocytomas are managed and that guidance on the safe management of these would be helpful, but it is likely there would be lower-level evidence in this area. The group asked if service delivery and configuration would be covered by the guideline, particularly in the context of addressing inequalities around patient choice and ensuring that everyone is offered all suitable management options regardless of where they live. It was noted that the guideline isn't anticipated to specifically address the organisation and delivery of services as this is addressed by other guideline producers such as the recent 'Getting it right first time' guideline. However, the NICE guideline may cross refer to other relevant guidelines such as this and it was noted that having a NICE guideline in the area of kidney cancer should help to reduce variation in practice. It was also noted that the first area in the draft scope around information, communication, advice and support is important and clear communication can benefit adults with suspected or confirmed RCC and their families and carers.

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– use of prognostic models. 4. Management of localised renal cell carcinoma. – Surgical interventions, including radical and partial nephrectomy (nephron-sparing surgery). – Surgical techniques (open, laparoscopic, robotic). – Non-surgical local interventions, including thermal ablation (for example radiofrequency ablation, cryotherapy, microwave ablation), stereotactic ablative radiotherapy, electroporation. – Active surveillance. – Systemic treatments.		The group also asked if prevention of RCC would be covered and noted that the point of diagnosis is a good opportunity for giving lifestyle advice around risk factors such as smoking, obesity and hypertension. They noted however that the associations are not as strong as for example, lung cancer and smoking and none are specific to Kidney cancer. The NICE team highlighted existing NICE guidance on smoking cessation, physical activity, obesity and weight management, noting that in order to keep the scope manageable and to avoid duplication of recommendations, prevention would not be included.

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a. Neo-adjuvant treatments before surgery. b. Adjuvant treatments after surgery. 5. Follow-up after diagnosis and management of localised renal cell carcinoma. – Risk stratified follow-up approach. – Monitoring for any adverse effects following intervention for localised renal cell carcinoma for example on kidney function. – Monitoring and surveillance for local recurrence.		

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– Monitoring and surveillance for distant metastases. 6. Treatment for locally advanced and metastatic renal cell carcinoma – Local interventions a. surgical interventions for example cytoreductive nephrectomy, removal of lymph nodes, removal of metastases. b. non-surgical interventions for example thermal ablation. (including radiofrequency ablation, cryotherapy, microwave ablation).		

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c. radiotherapy including stereotactic ablative radiotherapy. – Systemic therapies a. targeted drug therapies for example tyrosine kinase inhibitors b. immunotherapies for example immune checkpoint inhibitors – Active surveillance **Areas that will not be covered**		

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• Referral from primary care (this is covered by the NICE guideline on suspected cancer). • Classification and staging of tumours, for example the World Health Organisation Classification of Renal Tumours, the Bosniak system, the Tumour, Node, Metastasis (TNM) classification system. • Palliative and end of life care, including interventions to relieve pain and other symptoms and interventions to provide information and support for patients and for their families and carers (this is covered by the NICE guideline on end of life care for adults, the NICE guideline on the care of dying adults in the last days of life and the NICE cancer		

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service guideline on improving supportive and palliative care for adults with cancer).		
Draft review questions 1. What are the specific information, communication, advice and support needs of adults with suspected or confirmed renal cell carcinoma and those of their carers prior to, during and after treatment? How can these needs be best met? 2. Diagnosis of renal cell carcinoma in adults a. Which investigations and assessments in addition to	1. Do the proposed review questions map effectively to the issues that should be covered in the guideline? 2. Does each issue to be covered in the guideline have an important review question identified? 3. Do the proposed review questions	1. Some attendees felt that draft question 4a, focusing on surgery for localised RCC, would add less value than some other questions, as those working in the field may not need guidance in this area. However, others noted that not all patients were offered all appropriate options, particularly if they were not being treated at tertiary or specialist centres. It was noted that guidance in this area may help to reduce variation in services and it was agreed this draft question should be retained in the draft scope. 2. The group agreed that all the areas to be covered had a review question. 3. The group discussed the draft review questions for each area and whether the questions would enable the committee to make recommendations, if evidence is available, that would address the most important priorities for the guideline. Under Area 2 'Diagnosis' it was noted that draft question 2a was broad and that it would be helpful to focus specifically on the clinical- and cost-effectiveness of imaging investigations, as these are the key diagnostic tests used and no biomarkers are currently available. It was felt there was

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standard care, should be offered to adults with suspected renal cell carcinoma? Under what circumstances and to whom should they be offered? b. What is the clinical and cost-effectiveness of biopsy compared to no biopsy in adults with suspected renal cell carcinoma? How does effectiveness and cost-effectiveness vary according to characteristics of the tumour and of the patient? 3. Prognosis	represent the priorities for developing the guideline, or would some refocussing within the topic areas to be included be appropriate?	little value in comparing imaging investigations as a series of different imaging tests may be used. It was noted that a CT scan of the chest is usually carried out at initial staging, but it is unclear how these changes the management of the patient, the evidence base for this is uncertain and that it would be helpful to assess this for cost-effectiveness. Attendees also asked whether there were similar considerations for CT and MRI scans of the brain. It was agreed that draft question 2a should focus specifically on imaging investigations and that cost-effectiveness should be included. It was agreed that biopsy is also an important management area potentially avoiding invasive surgery and the potential need for renal replacement therapy, and that draft question 2b was useful. Under Area 4 'Management of localised renal cell carcinoma' It was noted that the use of neo-adjuvant therapies is an area of ongoing research and that it would be important to include these within the draft questions. Although the ongoing studies may not complete before the guideline publishes, this would allow research recommendations to be made if the committee considered it appropriate and it would be an important inclusion for the future surveillance of the guideline. Risk of progression – wrong wording should be 'increased risk of progression'. Under Area 5 'Follow-up after diagnosis and management of localised renal cell carcinoma' It was agreed that draft question 5b could be removed as draft question 5a would capture the use of prognostic models. Under Area 6 'Treatment for locally advanced and metastatic renal cell carcinoma', the group agreed this should be split into two sections to reflect the different settings in which they are managed. The group therefore

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a. In newly diagnosed renal cell carcinoma, which factors, including frailty and performance status, can determine if treatment is warranted? b. In newly diagnosed renal cell carcinoma, which factors, including frailty and performance status, can predict outcomes after treatment? 4. Management of localised renal cell carcinoma a. What is the clinical and cost-effectiveness of partial compared to radical nephrectomy according to	4. Which areas are the highest priority for development?	discussed which treatment options needed to be reflected in each section and the allocation of the corresponding questions to those sections. Also under Area 6, the attendees advised that draft review question 6c on the clinical- and cost-effectiveness of classes of drug treatments for metastatic RCC, should focus on treatment regimens to reflect the numerous combination treatments of drugs from different classes. The group suggested that the final draft question in this section (6d) on the sequencing of treatments for adults with metastatic RCC, should include both pharmacological and non-pharmacological treatments. The group cautioned that recommending too many interventions may result in diminishing returns. It was noted that the priority is to establish the clinical and cost effectiveness of interventions according to the sequence in which they are offered. 4.The group were asked to prioritise the areas for review. There were mixed opinions, which as the group noted may reflect their areas of interest and involvement. Treatment for metastatic RCC and sequencing of treatment was suggested by some stakeholders as having the highest priority, reflecting the life-limiting nature of the stage of the carcinoma. Others suggested early detection as being a priority, reflecting the opportunity for early intervention and an aim of the NHS Long Term Plan that by 2028, 75% of cancers will be diagnosed at an early stage. However, it was noted that early detection without clear signs and symptoms is difficult and that this falls into the remit of NICE guideline NG12 on suspected cancer. It was noted however that currently NG12 refers only to haematuria as a trigger for a suspected cancer pathway referral (for an appointment within 2 weeks) and does not cover renal masses found as incidental findings on imaging.

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the size, location and complexity of the tumour(s), and the renal function and performance status of the patient, in adults with renal cell carcinoma? b. What is the effectiveness and cost-effectiveness of different non-surgical interventions for treating adults with localised renal cell carcinoma for example stereotactic radiotherapy, thermal ablation and active surveillance, compared to surgery?		Other stakeholders suggested follow-up after surgery as being important, noting research findings that indicate some patients may feel abandoned at this point in the pathway.

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c. For adults at risk of progression after treatment for localised renal cell carcinoma, what is the clinical and cost-effectiveness of neo-adjuvant and adjuvant treatments? 5. Follow-up after diagnosis and management of localised renal cell carcinoma. a. For adults who have been treated for localised renal cell carcinoma, what is the most clinically and cost-effective method, duration and frequency		

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of follow-up for the early detection of recurrent disease? b. What are the optimal prognostic models for determining which adjuvant treatment to use in adults with confirmed renal cell carcinoma? 6. Treatment for locally advanced and metastatic renal cell carcinoma a. What non-pharmacological interventions are clinically and cost-effective for treating		

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locally advanced renal cell carcinoma in adults? for example radiotherapy including stereotactic ablative radiotherapy, cytoreductive nephrectomy, surgical interventions to remove lymph nodes, thermal ablation, active surveillance. b. What non-pharmacological interventions are clinically and cost-effective for treating metastatic renal cell carcinoma in adults for example radiotherapy		

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including stereotactic ablative radiotherapy, cytoreductive nephrectomy, surgical metastasectomy, thermal ablation, active surveillance. c. What is the clinical- and cost- effectiveness of X class of drug (for example immunotherapies, targeted drug therapies) for first, second and subsequent line treatments for metastatic renal cell carcinoma in adults?		

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d. How should treatments for metastatic renal cell carcinoma in adults be sequenced according to the patient's risk and previous treatment?		
Main outcomes The main outcomes that may be considered when searching for and assessing the evidence are: • survival – cancer-free survival – progression free survival, including local and regional-free survival, second-progression free survival, metastases-free survival	What are the most important outcomes?	The group were content with the main outcomes in the draft scope and had no further suggestions or comments.

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– overall survival • risk of progression • local recurrence • distant metastases • quality of life (validated measures) for example pain, functioning, coping with side effects of treatment • severe adverse events and complications • psychological wellbeing.		
Equalities See the draft equality and health inequalities assessment	1. Do you agree with the points we have captured so far? 2. Have we missed anything that you feel should be included?	1.It was agreed that most health inequalities issues had been captured. 2.Attendees noted that lifestyle factors such as smoking and obesity are risk factors for developing renal cell carcinoma. The NICE team noted, as above, that prevention would not be covered by the guideline, and as such these are not direct inequalities issues that need to be captured in the EHIA for this guideline. The guideline may cross refer to existing NICE guidance on smoking cessation, physical activity, obesity and weight management, and the guidance in development on weight management. One stakeholder noted that renal medullary carcinoma, a rare form of renal cell carcinoma, predominantly affects young adults with African-Caribbean heritage who have sickle cell trait and that this should be captured in the equality and health inequalities assessment.

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Proposed committee constituency ***Core members/ members*** • Chair • Topic adviser • Oncology pharmacist • Urological surgeon • Advanced clinical nurse practitioner or clinical nurse consultant • General practitioner • Histopathologist	1. Are all the suggestions for guideline committee members appropriate and important? Are there any professional roles or other types of members that are missing? 2. Might any of the suggested members be more appropriate as co-opted members (invited to selected meetings that address specific	1.The group suggested that the committee should include: • Both interventional and diagnostic radiologists • 2 urologists • 2 medical oncologists • 2 clinical oncologists, one with renal expertise (including the use of stereotactic ablative radiotherapy) and one with more general oncology expertise to reflect practice outside of tertiary/ specialist centres. • Specialist nurse (oncology) and specialist nurse (urology) • Advanced care practitioner or Clinical nurse consultant 2. It was suggested that the following roles could be co-opted to the committee: • Radiographer • General practitioner

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• Clinical oncologist • Medical oncologist • Radiologist • Therapeutic or diagnostic radiographer • Lay members ***Potential co-opted members*** • Clinical geneticist • Clinical psychologist • Palliative care consultant	aspects of the scope) rather than as full members of the guideline committee (who attend all meetings and formulate recommendations for the entire scope)? 3. Are there any other co-opted members that should be added?	3. It was suggested that the following could also be considered as co-optees to the committee: • Anaesthetist • Nephrologist