National Institute for Health and Care Excellence

Kidney cancer: diagnosis and management

[D] Evidence review for information needs

NICE guideline [number]
Evidence review underpinning recommendations 1.1.1 to 1.1.9, 1.7.1, 1.12.1, 1.16.4 and 1.16.6 in the NICE guideline

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Draft for consultation

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1 Information needs

1.1 Review question

What information do adults with suspected or confirmed RCC want before, during and after treatment, when do they want it, and from which healthcare provider would they want to receive it?

1.1.1 Introduction

People with suspected or confirmed renal cell carcinoma navigate many aspects of the healthcare system and are in contact with many healthcare professionals throughout their care pathway. This review aims to address their information needs throughout their treatment journey.

1.1.2 Summary of the protocol

Table 1: SPIDER inclusion criteria

Sample	Adults (18 years or over) with confirmed or suspected renal cell carcinoma
Phenomenon of interest	Information needs of patients with suspected or confirmed RCC during diagnosis and management. Areas of interest may include: • Requirement for information about: o Accessing support, for example psychological and emotional support, financial and practical support o Lifestyle and wellbeing o Symptom management, including related to medication o Test results, scheduled appointments, treatments, and follow up. • When people prefer to receive information (for example in relation to diagnosis). • Who people prefer to receive information from, for example clinical nurse specialists.
Design	Qualitative studies using interviews (structured or semi-structured) or focus groups
Evaluation	Preferences for receiving information: which areas, when, and from whom (e.g., clinical nurse specialists)
Research type	UK based qualitative evidence

For the full protocol see appendix A.

1.1.3 Methods and process

This evidence review was developed using the methods and process described in Developing NICE guidelines: the manual. Methods specific to this review question are described in the review protocol in appendix A and the methods document.

Declarations of interest were recorded according to NICE's conflicts of interest policy.

1.1.3.1 Search methods

The searches for the effectiveness evidence were run on 13/03/2025. No reruns were performed for this question. The following databases were searched: Cochrane CDSR (Wiley), Emcare (Ovid), Embase (Ovid), Epistemonikos (Epistemonikos), Medline ALL (Ovid) and PsycInfo (Ovid). Limits were applied to remove animal papers, non-english language papers and conference abstracts. Filters were used to limit to UK and qualitative studies.

The database searches were supplemented with additional search methods. Forward citation searching were conducted on CitationChaser using 2 seed references identified from scoping stage. A broad search was carried out on Medline ALL (Ovid) and Embase (Ovid). These searches were carried out prior to the effectiveness searches.

A NICE senior information specialist (SIS) conducted the searches. The MEDLINE strategy was quality assured by another NICE SIS. All translated search strategies were peer reviewed to ensure their accuracy. Both procedures were adapted from the 2015 PRESS Guideline Statement. Further details and full search strategies for each database are provided in appendix B.

1.1.4 Qualitative evidence

1.1.4.1 Included studies

A systematic search carried out to identify potentially relevant studies found 594 references (see appendix B for the literature search strategy).

These 594 references were screened at title and abstract level against the review protocol, with 572 excluded at this level. 10% of references were screened separately by two reviewers with 100% agreement.

The full texts of 22 primary qualitative studies were ordered for closer inspection. Four of these studies met the criteria specified in the review protocol (appendix A). For a summary of the 4 included studies see Table 2.

The clinical evidence study selection is presented as a PRISMA diagram in appendix C.

See section 1.1.14 References – included studies for the full references of the included studies.

1.1.4.2 Excluded studies

Details of studies excluded at full text, along with reasons for exclusion are given in appendix H.

1.1.5 Summary of studies included in the qualitative evidence

Table 2 Summary of studies included in the qualitative evidence

Study details	Setting/Location	Population	Aim of the study	Themes	Methodological limitations
Beyer (2025) N=6 Data collection methods: Focus groups and semi-structured interviews	Setting: Online Location: United Kingdom (study included participants from The Netherlands and Germany, but these participants were not relevant to this review)	People with a kidney cancer diagnosis	To understand how patients experience decision making for treatment options for kidney cancer	• Health literacy and information needs • Source of support • Trust in the treatment options and treating HCP • Importance and aspects of shared decision-making • Administrative issues	Researcher relationship with participants, and analysis not described in sufficient depth.
Harrison (2023) N=14 Data collection: Focus groups	Setting: Online Location: United Kingdom	People who had previously had surgery for kidney cancer	To explore the experience of follow-up care after kidney cancer surgery	• Feelings of abandonment • Uncertainty about the plan • Anxiety about appointments • A need for information • A need for emotional support	Researcher relationship with participants not explored in depth.

Study details	Setting/Location	Population	Aim of the study	Themes	Methodological limitations
Ranieri (2024) N=50 Data collection: semi-structured interviews	Setting: telephone or video conferencing software Location: United Kingdom	People diagnosed with kidney cancer and clinicians.	To understand the barriers and facilitators to the implementation of biopsy for diagnosis of renal tumours.	• Information pertaining to RTB • Access to/capacity for RTB • Experiences of prior biopsy and RTB	Relationship between researcher and participants not explored in depth.
Zhou (2023) N=15 Data collection: interviews	Setting: Patient's home or phone Location: United Kingdom	People with symptoms that could indicate bladder and kidney cancer according to NICE guideline NG12	To explore the characteristics of missed diagnostic opportunities in patients at increased risk of bladder and kidney cancer.	• Missing information gathered about urinary symptoms • Lack of clinical review in patients with recurrent UTIs • Difficulty obtaining urine culture results	Researcher relationship with participants, and analysis not described in depth.

RTB: renal tumour biopsy

See appendix D for full evidence tables

1.1.6 Summary of the qualitative evidence

Table 3: Summary of qualitative findings

Theme	Number of studies	Overall confidence	Explanation of GRADE-CERQual assessment
Theme 1.1 Requirement for information relevant to diagnostic pathway: early diagnosis Patients feel that there is a need for information on the investigations that will follow when presenting to primary care with symptoms, and they would like the results to be delivered by a doctor.	1 study (Zhou 2023)	Moderate	Downgraded because we had minor concerns regarding methodological limitations, and minor concerns regarding adequacy of the data.
Theme 1.2 Requirement for information relevant to diagnostic pathway: biopsy People valued information on biopsy including risks of the procedure and side-effects.	1 study (Ranieri 2024)	Moderate	Downgraded because we had minor concerns regarding adequacy of the data.
Theme 2: Requirement for information regarding treatment options Information on treatment options helped people to decide which treatment was right for them.	2 studies (Beyer 2025; Harrison 2023)	High	No or very minor concerns across all domains.
Theme 3: Requirement for information on risk of recurrence The need and preference for information on survival is person-specific, and support is needed for people to deal with information on the risk of recurrent disease.	1 study (Harrison 2023)	Moderate	Downgraded because we had minor concerns regarding adequacy of the data.
Theme 4: Requirement for information on follow-up and aftercare	1 study (Harrison 2023)	Moderate	Downgraded because we had minor concerns regarding the adequacy of the data.

There is a need for information to be provided after treatment regarding follow-up schedule, imaging and practical aspects of aftercare.			
Theme 5: Need for emotional support There is a requirement for more information on how people can access emotional support, and this could be given during appointments with doctors or nurses.	2 studies (Beyer 2024; Harrison 2023)	Moderate	Downgraded because we had minor concerns regarding methodological limitations and adequacy of the data.
Theme 6: Requirement for information on practical and financial support There is a need for information on the healthcare system, when to expect follow-up information, financial support as well as sick leave.	1 study (Beyer 2025)	Low	Downgraded because we had minor concerns regarding methodological limitations and moderate concerns regarding adequacy of the data.

See appendix E for full GRADE-CERQual tables and a more detailed exploration of the themes summarised here.

1.1.7 Economic evidence

We did not conduct economic evidence review for this question as it is a qualitative review for information provision rather than comparing different interventions.

1.1.8 Unit costs

The committee highlighted the importance of staff capacity, especially the clinical nurse specialist (CNS), in the pathway. The unit cost for different healthcare professionals has been sourced from PSSRU and is provided below.

Table 4: Unit costs for hospital-based staff

Category	Unit cost per working hour	Source
Nurse specialist (including qualifications)	Band 6: £62 Band 7: £73	Jones et al. (2024)
Consultant: medical (including qualifications)	£103	
Consultant: surgical (including qualifications)	£111	

1.1.12 The committee's discussion and interpretation of the evidence

1.1.12.1. The issues that matter most

The committee agreed that it is important to understand people's experiences of the kidney cancer pathway in the NHS to identify areas that could be improved by making recommendations around providing information and support where needed in the pathway as part of this guideline.

They discussed that people's experiences of the kidney cancer pathway can vary depending on several factors which might include which stage of the care pathway they are in, the severity of the disease, and their support network. For example, they expressed an interest in identifying information needs in areas such as where people could access support, information on lifestyle and wellbeing, and information on their symptoms. They also expected that people would require information on test results, appointments and treatments that are available to them. The committee also discussed that as well as finding out what areas people would like to receive information on, other important themes would include when they would like to receive this information, and which healthcare professional they would prefer to receive the information from.

The committee expected that there would be themes in the evidence around what format people wanted information to be provided in, and in which settings. They agreed that these themes were important, but they did not include them in the recommendations as they were aware these were adequately covered in existing NICE guidance.

Evidence was identified on the following themes that were listed in the protocol: requirement for information about accessing emotional, financial and practical support; requirement for information on treatments and follow up, and who people prefer to receive information from.

The evidence showed that people felt there was a need for information on investigations early in the diagnosis pathway. The evidence also showed people valued information on the risks and the procedure of a biopsy, as well as information on the different treatment options available to them. The evidence highlighted the importance of receiving information on the risk of recurrent disease and aspects related to follow-up. There were also themes in the evidence that explored the support needs of people relevant to emotional support as well as practical and financial support. The committee discussed that the themes in the evidence reflected the views and experiences of committee members who have used services. They noted that there was some variability in how much information people wanted to receive, and that this had been captured in the evidence as well as in discussions with committee members with lived experience.

The committee had expressed an interest in and expected to see evidence for the following areas: lifestyle and wellbeing and when people prefer to receive information. They discussed that treatment for kidney cancer often meant big changes to lifestyle and there were mentions from the committee for a need for adequate information to be given at the correct times. However, no evidence was identified for these themes.

The committee also agreed that it is important to know who people prefer to receive information from. Receiving information from the same person over time would lead to continuity of care, and the opportunity to build a relationship in a supportive environment where the person with kidney cancer feels able to ask questions. There were several mentions of who should provide information in the evidence base, and when (for example, a GP during initial investigations in primary care) but continuity of care relating to the provision of information was not mentioned.

1.1.12.2 The certainty of the evidence

Most of the evidence was rated as moderate using GRADE-CERQual, with some rated high, and some rated low. When there were concerns, most of the evidence was downgraded for adequacy, as some review findings were supported by data from a single study, so the review finding was not rich. Some of the evidence was downgraded for methodological concerns where there was limited information on the relationship between the researcher and participants, or there was not enough detail describing the data analysis process. There were no concerns for coherence as the review findings were judged to be a cogent fit with the data presented in the studies. One study was found to be partially relevant, as the aim of the study was not to explore information needs of participants.

Although there were only 4 studies identified, the sample size ranged from 14 up to 50 and the evidence was mostly of moderate quality, and the committee concluded that this was sufficient to make recommendations for information and support, and that it could be supplemented by committee experience. This was because the lay members on the committee noted that the findings reflected their own and other people’s experiences of the kidney cancer patient pathway. They also highlighted the variation in experiences, with some more positive than others, supporting the view that there are inconsistencies around what, when and how information is provided.

1.1.12.3 Advantages and disadvantages

General information and support for people suspected or confirmed RCC

There was moderate-certainty evidence from 1 study that suggested there was a need for information to be available in primary care about investigations that are carried out when there is a suspicion that the person could have kidney cancer. The lay members on the committee agreed with this statement based on their experience of lack of information provided around the diagnostic period. This gap in information and support was thought to be related to the usual process of assigning a designated healthcare professional after diagnosis.

The committee discussed the importance of providing people about to undergo investigations for suspected or confirmed kidney cancer with information of what to expect during the diagnostic process. They noted that this is covered by the NICE guideline on Suspected cancer (NG12), which has recommendations on providing information and support to people, including safety netting during initial referral and investigations for suspected cancer, and agreed to cross refer to this guidance.

The committee also highlighted the difficulty in diagnosing suspected kidney cancer in primary care based on symptoms and signs alone because some of these may be shared by other conditions. There is also limited awareness of kidney cancer and when to seek help amongst the general public. They noted that there are campaigns to raise awareness of cancer, including kidney cancer, that encourage people to contact their GP practice if they experience symptoms that may indicate cancer for three weeks or more. For example, the Help Us Help You 2025 Campaign highlights symptoms that could trigger investigations for multiple cancers including kidney cancer. Symptoms that trigger referral for the suspected cancer pathway for a suspected urological cancer are covered in the NICE guideline on Suspected cancer (NG12).

The committee considered it very important that people with kidney cancer are provided with ongoing information and support throughout the patient pathway. The committee discussed that people's needs for information and support will vary on an individual basis so recommended that it should be based on a personalised assessment of the person's needs. They were aware of existing NICE guidance that supported principles relevant to information and support and referred to them in their discussions and the recommendations.

The committee agreed that the package of information should be balanced, accurate, up to date and relevant to the person's circumstances and stage of condition so that they have the information that best supports their individual situation at the right time. To avoid overwhelming people with information, the committee agreed that information and support should be provided on an ongoing basis and be available when needed. They also discussed that information and support should be delivered in a caring and sensitive fashion and is tailored to the person's needs. They agreed that for this to be successful, this support must take into consideration the person's views and preferences, the involvement of family members and carers and enabling people to be actively involved in their care. The committee also agreed that the person should be reassured about being able to bring someone with them to appointments to support them if they wish to, as this may be particularly helpful when a lot of information is being provided, complex decisions are being made or the individual needs additional support to attend appointments or understand information. The committee were aware of the NICE guideline on patient experience in adult NHS services (CG138) which provides recommendations to support these fundamental principles and agreed to cross refer to this guidance. In particular, it contains recommendations about tailoring communication and the provision of information to the individual's needs.

No evidence was identified on when information should be provided specifically but some inferences could be made based on the findings on information requirements at diagnosis, about biopsy and during follow up. Based on experience, the committee, and particularly the lay members, stressed that healthcare professionals need to be mindful of the timing and amount of information given to prevent overwhelming the person. This is especially important at certain times, for example, at diagnosis, when the person may not be able to process all the information being given to them. The committee were aware that the recommendations in the NICE guideline on patient experience in adult NHS services (CG138) support the principles related to providing the right level of information at the right times.

Similarly, the committee discussed the importance of involving the person in the decisions around their care which is facilitated by discussions around risks, benefits and consequences of various diagnostic or treatment options in the care pathway. The committee were aware of NICE's guideline on shared decision making (NG197), which provides recommendations on putting shared decision making into practice, and NICE's guideline on people's experience in adult social care services (NG86), which covers overarching principles related to enabling people who are receiving social care to make decisions. They agreed to cross refer to these guidelines to support all of the shared decision-making recommendations they have made during the development of the kidney cancer guidelines. They were also aware that there was useful guidance on communication and shared decision making for clinicians in the Getting it Right First Time (GIRFT) guideline Urology: Towards better care for patients with kidney cancer and decided to cross refer to this too. The committee also included a cross reference to the NICE guideline on workplace health because this covers how to help people return to work after long-term sickness absence.

Evidence was identified that suggested specific information that people would like related to diagnosis, treatments and follow up. The committee made separate recommendations for some topics. For example, there are separate recommendations for information to be provided at follow up in the review on follow up strategies (see evidence review F). The committee discussed what people would want to have information on based on the evidence and their experiences, noting that the appropriate topics for discussion would vary across the pathway. Topics included type, stage and grade of kidney cancer, likely prognosis, and where to find high-quality information that would be relevant at diagnosis and throughout the patient pathway. The committee highlighted the importance of this to avoid the person seeking information elsewhere which might not be applicable to them, or that could be inaccurate or misleading, leading to unnecessary anxiety and distress. The committee noted that if the person thinks that information is not being given to them at appropriate times, it could reduce their trust in their care team, which could undermine the shared decision-making process. The evidence also highlighted that when there was not enough information, or information was conflicting between different healthcare professionals, people felt overwhelmed and unable to make an informed decision.

The need for information about treatment options and the potential complications of treatment were identified by the committee and supported by the evidence. Evidence of high confidence from 2 studies highlighted that people valued having as much information as possible about their treatment, including information about the risks and side effects. This reflected the experiences that the lay members in the committee described. In addition, the committee agreed that it is important that the person is made aware of potential of disease symptoms and side effects of treatment and how to manage them to maximise their wellbeing. The committee noted that providing information relevant to a person’s condition and treatment options, as well as where they can find high-quality information, were principles of good practice, and that the NICE guideline on patient experience in adult NHS services (CG138) provides recommendations that support these principles. They agreed that cross referring to this guidance was important.

No evidence was identified on who should provide information and support to people with kidney cancer. However, the committee noted that in practice some people with kidney cancer are assigned a designated healthcare professional, usually a Clinical Nurse Specialist (CNS) at the point of diagnosis. The CNS is usually allocated for the entire duration of the treatment pathway in secondary care, but there may be a different CNS specific to either the non-metastatic or metastatic setting, dependant on resource availability. The committee agreed that CNS are best placed to be the main point of contact for information and support both at the initial diagnosis and as needs arise during the treatment pathway. They also highlighted that there is variation in practice around CNS availability. Some areas lack access to them, in other areas people may need to travel long distances for appointments to see a CNS, and some centres use remote access to a CNS, such as via a voicemail system. However, the committee agreed that having CNS support in secondary care is best practice and decided to recommend that CNS support for the duration of the pathway, from diagnosis, during management and during follow up or palliative care, should be offered to all people with kidney cancer. They recommended that the CNS act as the key worker to address the person’s information and care needs and that they also needed to be specialised in kidney cancer care. They acknowledged that this is an area with limited resourcing and where patient volume is increasing, and that there would be the need for specialist training in kidney cancer to provide this service (see section 1.1.12.4 Cost effectiveness and resource use). They also discussed the importance of ensuring that people have the contact details for a cancer care navigator if that service is available as this would help facilitate access to essential information. As cancer care navigators guide people through the cancer care pathway and can signpost people to support services, this role, where available, can help bridge the gap in support needs where CNS availability is limited. They stressed that any cancer care navigator support would be in addition to the CNS role and would not replace it.

Evidence of moderate confidence from 2 studies was identified that highlighted the requirement for information on how people can access emotional support. Similarly, evidence of low confidence from 1 study described the need for information on practical and financial support during treatment and follow-up. The committee agreed that the need for support is particularly important to people with kidney cancer during their treatment, follow up and after discharge, but there is limited capacity to provide emotional support in the NHS. There are cancer charities that may be better placed to provide access to emotional support or information about how to access this. These include Macmillan cancer support, Maggie's, Kidney cancer UK, and Action kidney cancer. They also provide information on accessing financial and other practical support. The use of charities to provide support was also mentioned in the qualitative evidence.

The committee acknowledged that people with kidney cancer may require mental health support, in addition to the emotional support that is provided by charities and other support networks. They agreed that it is important that people are signposted to support services provided by charities and that referral to NHS mental health support services may be beneficial to some people. They also included a cross reference to the NICE guideline on depression in adults with a chronic physical health problem (CG91) for information on identifying, treating and managing depression in people aged 18 and over who have a chronic physical condition such as cancer.

Although no evidence was identified on lifestyle advice, this was an area of information that the committee agreed was important. They agreed that the NICE guideline on patient experience in adult NHS services (CG138) provided relevant recommendations relevant to providing the person with information and support to promote self-care and management and agreed that the earlier cross reference to this guidance covered this. As an extension of the lifestyle advice covered in the cross reference to NICE guidance, the committee also recommended that support to stop smoking should be offered to all people with kidney cancer who smoke and cross referred to NICE's guideline on tobacco: preventing uptake, promoting quitting and treating dependence (NG209) as smoking may lead to multiple smoking related co-morbidities that affect available treatment options and overall health.

The committee discussed that throughout the patient pathway, individuals will require care and support in both primary and secondary care. To ensure continuity of care and support, the committee agreed that clinicians involved in the caring of people with kidney cancer should ensure that there is close liaison between the different care settings. The committee agreed that this was adequately covered by recommendations in the NICE guideline on patient experience in adult NHS services (CG138) that was cross referred to in the earlier recommendations. They also discussed the importance of using continuous quality improvement processes to improve people's experiences of the kidney cancer pathway and that this could involve the use of annual kidney cancer patient satisfaction surveys. They highlighted in the recommendation that people with kidney cancer should play a key role in developing these surveys with their urology multidisciplinary team.

Information about biopsy

Evidence was identified on the need for information on biopsy in this review. See evidence review J on renal biopsy for the committee discussion about this and the recommendation they drafted to address this information need.

Information for people with advanced RCC

The committee discussed the information needs of people with advanced RCC (which is defined in this guideline as metastatic RCC or locally advanced and inoperable RCC) and agreed that these would be similar in nature to people with localised or locally advanced RCC in general but differ in the specifics. For example, people with advanced RCC might also want to know about the stage of their disease, their prognosis and treatment options, but the specifics of these treatment options would be different to those that are suitable for people with less advanced RCC. Therefore, they agreed that the principles covered in the recommendations under the general information section also applied to people with advanced RCC. However, they agreed that the provision of information around palliative care and supporting end of life is important here and were aware that existing NICE guidance covered these topics. They therefore recommend that palliative care is discussed with the person with advanced RCC and that this covers what it is and when it may be needed, for example, to control pain and other symptoms and included cross references to the relevant NICE guidance would support these discussions. These include recommendations on assessing holistic needs, supporting carers and providing information in NICE's guideline on End of life care for adults. They were also aware of recommendations on communication and shared decision making in NICE's guideline on care of dying adults in the last days of life.

They were also aware of recommendations on psychological support services in the NICE cancer service guidance on Improving supportive and palliative care for adults with cancer (CSG4).

Information for people before and after kidney surgery

As noted above, the evidence highlighted that people want to have access to information about their treatment options, including information about the risks involved while carrying out procedures, and any side effects associated with them. The committee discussed this in relation to surgery and drafted a recommendation to cover information to be provided before surgery. They agreed that the information provided at this stage should include which surgical approach is to be used (minimally invasive or open techniques), the short-term side effects (symptoms during recovery related to that approach and to surgery in general) as well as the expected recovery time. People should also be provided with information on potential complications of surgery and practical aspects such as wound care and pain management. (This point was not included specifically in the recommendation because it is covered by the general principles of discussing treatment options in the NICE core guidelines and these are cross referred to in the general information section of the kidney cancer guideline). In addition, they agreed that people should be provided with information on what to expect after surgery in the mid to longer term, such as information about lifestyle changes to help protect remaining kidney function and the likely impact of nephrectomy on kidney function. They agreed that the removal of part or all of a kidney will likely reduce kidney function, but for many people this is unlikely to be of clinical significance. The committee highlighted that there may be some people who have changes in their medical record after surgery, for example, mention of chronic kidney disease (CKD) and if this is of concern, they should speak with their healthcare provider. They also included a cross reference to the Information and education for people with CKD in the NICE guideline on Chronic kidney disease for people who go onto be diagnosed with CKD after their surgery.

The committee highlighted the importance of receiving this information prior to surgery but recognised that there might be information overload, and so it was key to reiterate some of this information after surgery too. They also were aware of useful patient information drafted by NHSE and KCUK as part of the work on the Getting it Right First time document on Urology: Towards better care for patients with kidney cancer that includes 2 patient facing leaflets. These are as follows: Kidney Cancer Fact Sheet: Consent Consultation General Information – Planning for Surgery and Beyond and Kidney Cancer Fact Sheet: Post Nephrectomy and Follow Up. They included these cross references in the guideline.

Information for people with RCC who have suspected or confirmed heritable RCC predisposition syndromes

The committee discussed the information needs of people with RCC who have suspected or confirmed heritable RCC predisposition syndromes. They agreed that the information and principles underlying what information to share, communication and shared decision making in the general information section also applied to people with suspected or confirmed RCC predisposition syndromes who have RCC. However, they agreed that there were additional points specific to these syndromes that were important to highlight. The committee were able to draw on their experiences to inform recommendations. They discussed the information that is important to share with people with RCC before testing, or when referring for testing for a heritable RCC predisposition syndrome. They agreed that it is important to discuss the likelihood of having a negative or positive test, and what this could mean for the person and the family. They recognised that this is likely to be a very stressful time for the person with RCC and that they will need access to specialist genetic services for ongoing support and advice to help them understand and process the information provided, which is likely to be complex. The committee were also aware that some people decline the test initially and wanted to emphasise that the test could be taken at a later date if they change their mind. The committee drafted a recommendation for information to provide at this stage in the genetic assessment pathway reflecting these points.

The committee agreed that some of the same information should be reiterated after diagnosis, including what the results could mean for family members, and where they can access support. They also discussed the importance of sharing information about other conditions that people with a RCC who are diagnosed with a hereditary RCC predisposition syndrome have an increased chance of developing. They agreed that it is essential people know how and where these will be managed to ensure that they are aware that they need, and are able to access, this additional care. These points were included in a recommendation about information to provide after diagnosis with a heritable RCC predisposition syndrome.

The committee noted that these recommendations should be considered alongside recommendations on genetic assessment made as part of review G (evidence review for the criteria for genetic assessment and management of RCC associated with heritable renal cell carcinoma syndromes.)

1.1.12.4 Cost effectiveness and resource use

No economic evidence review was conducted as this is a qualitative review for information provision. The committee highlighted some considerations regarding the potential impact on resources.

The committee acknowledged the essential role of the clinical nurse specialist (CNS) and agreed that they should be available throughout the entire patient pathway. People with kidney cancer should be informed about the duration of CNS support. The committee noted that CNS are usually equipped with different specialties in the localised and/or metastatic RCC settings respectively and emphasized that more training in the area of kidney cancer should be offered to staff. The committee also noted that most CNS roles fall within band 6 or 7, depending on the individual’s experience and area of specialisation. While CNS are typically remunerated at band 6, those senior CNS working in complex treatment pathways such as renal or lung services could be compensated under band 7. Costs associated with CNS-led interventions could be, at least partially, offset by downstream savings in the care pathway. For instance, during follow-up, the CNS remains the primary point of contact, coordinating aftercare and ensuring continuity of care. Their involvement through monitoring, education and early intervention can help reduce avoidable hospital or GP visits that may otherwise occur in the absence of such support. In addition to CNSs, cancer care navigators play a vital role in supporting patients throughout their cancer care journey. These non-clinical personnel assist with appointment coordination, provide information and emotional support, and liaise with CNSs and other clinical services. By handling many administrative and supportive tasks, cancer care navigators enable CNSs to focus more on clinical responsibilities. The availability of cancer care navigators varies by region, with funding sources ranging from the NHS to charities and local partnerships such as Macmillan. The committee discussed that these recommendations could help support business cases in local NHS centres which would be a stepping stone to get more experienced CNS who are specialised in kidney cancer and therefore increase the capacity of highly skilled staff, especially CNS across the NHS.

The committee welcomed the involvement of charities at both local and national level. These charities can signpost people throughout the whole pathway by offering information and education. They also provide psychological support, helping people to relieve stress and anxiety. The collaboration between clinics and charities can ensure a delivery of high-quality care for individuals with kidney cancer in community, whilst limiting the resource impact on the NHS.

1.1.12.5 Other factors the committee took into account

The committee agreed that it was important that people with kidney cancer have opportunities to be involved in research at their centre or others, to allow them access to novel treatments that are only available in clinical trials and to help address uncertainties in the evidence base underlying specific treatments for the benefit of future patients. They therefore recommended that opportunities for kidney cancer research are discussed with the person. The committee acknowledged that being involved in clinical trials might be difficult for some people to access, particularly if they live in remote areas or have to travel long distances to the centre. Despite this, they agreed that people should have the opportunity, even if they decided to decline.

1.1.13 Recommendations supported by this evidence review

This evidence review supports recommendations 1.1.1 to 1.1.9, 1.7.1, 1.12.1, 1.16.4 and 1.16.6. It also provided support for recommendation 1.3.13 that is covered by review J on renal biopsy.

1.1.14 References – included studies

1.1.14.1 Qualitative

Beyer, K., Venderbos, L.D.F., Roobol, M.J. et al. (2025) Navigating choices: understanding the decision-making journey of patients with localised kidney cancer. BJU International

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Zhou, Yin, Singh, Hardeep, Hamilton, Willie et al. (2023) Improving the diagnostic process for patients with possible bladder and kidney cancer: a mixed-methods study to identify potential missed diagnostic opportunities. The British journal of general practice : the journal of the Royal College of General Practitioners 73(733): e575-e585

1.1.15 References – other

Jones, Karen C., Weatherly, Helen, Birch, Sarah et al. (2025) Unit Costs of Health and Social Care 2024 Manual. Technical report. Personal Social Services Research Unit. Available from: https://www.pssru.ac.uk/unitcostsreport/ (date accessed 02.07.2025).

Appendices

Appendix A – Review protocols

Review protocol for information needs

ID	Field	Content
1.	Review title	Information, communication, and support needs for adults with confirmed or suspected renal cell carcinoma
2.	Review question	What information do adults with suspected or confirmed RCC want before, during and after treatment, when do they want it, and from which healthcare provider would they want to receive it?
3.	Objective	To explore what information adults with suspected or confirmed renal cell carcinoma (RCC) want to receive from their healthcare providers at all stages of diagnosis and treatment, and when the information should be given.
4.	Searches	The following databases will be used for clinical searches: • Cochrane Database of Systematic Reviews (CDSR) • Embase • Emcare • MEDLINE All • Epistemonikos • PsycInfo Database functionality will be used, where available, to exclude: • Animal studies • Editorials, letters, news items and commentaries • Conference abstracts and posters

		• Registry entries for ongoing clinical trials or those that contain no results • Theses and dissertations • Papers not published in the English language. • Non-UK papers Date limits: No date limits will be applied The following standard NICE filters will be used, where available, to limit results by study type: systematic reviews Searches will also be limited to qualitative studies using appropriate filters where available The information services team at NICE will quality assure the principal search strategy. Any revisions or additional steps will be agreed by the review team before being implemented. The full search strategies for all databases will be published in the final review.
5.	Condition or domain being studied	Confirmed or suspected renal cell carcinoma
6.	Population	Adults (18 years or over) with confirmed or suspected RCC: • Suspected RCC refers to cases where there is clinical suspicion or diagnostic findings on CT or MRI suggestive of RCC but where a definitive diagnosis has not yet been made. • Confirmed RCC refers to definitive diagnosis according to the pathological TNM classification, through histopathological examination of tissue samples obtained from biopsy or surgery.
7.	Phenomenon of interest	Information needs of patients with suspected or confirmed RCC during diagnosis and management. Areas of interest may include:

		• Requirement for information about: ○ Accessing support, for example psychological and emotional support, financial and practical support ○ Lifestyle and wellbeing ○ Symptom management, including related to medication ○ Test results, scheduled appointments, treatments, and follow up. • When people prefer to receive information (for example in relation to diagnosis). • Who people prefer to receive information from, for example clinical nurse specialists. Information formats, methods of communication, and requirement for shared decision making will not be covered in this review. Existing NICE core guidelines will be cross referred to when they already adequately cover relevant themes. • Shared decision making (NG197) • Patient experience in adult NHS services (CG138)
9.	Types of study to be included	For any areas specific to RCC which cannot be addressed by existing guidance, qualitative evidence syntheses and primary qualitative studies conducted in the UK will be included. Studies using interview (semi-structured or structured) or focus group methods will be included. The qualitative element of mixed methods studies will be included where the qualitative data meets the criteria above and can be extracted and analysed by NICE.
10.	Other exclusion criteria	• Abstracts, conference presentations and theses • Non-human studies • Non-English language studies • Non-UK studies • Data from surveys that report the qualitative analysis of responses to open ended questions • Papers that do not include methodological details will not be included as they do not provide sufficient information to evaluate risk of bias/ study quality.

		• Surveys only reporting answers to closed questions or which quantify open ended answers for analysis. • Mixed methods studies where the qualitative data is not in an extractable format or does not meet our inclusion criteria for method of collection.
11.	Context	Communication and shared decision-making are essential to patient-centred care. People with confirmed or suspected RCC have specific needs in relation to the information and support received during diagnosis, treatment, follow-up and into end of life care. In this context, patients' emotions and vulnerable condition impact their skills to obtain, understand, process and apply information about health and healthcare even more. If healthcare providers meet these needs, it could enhance patient experience and shared decision making. Therefore, this review aims to identify the information, communication and support needs and the measures needed to meet these needs.
12.	Data extraction (selection and coding)	All references identified by the searches and from other sources will be uploaded into EPPI reviewer and de-duplicated. 10% of the abstracts will be reviewed by two reviewers, with any disagreements resolved by discussion or, if necessary, a third independent reviewer. The full text of potentially eligible studies will be retrieved and will be assessed in line with the criteria outlined above. For included studies, the following study characteristics will be extracted : study details (reference, country where study was carried out, type and dates), participant characteristics, inclusion and exclusion criteria, details of the interventions if relevant, setting and follow-up, and source of funding. Study themes and related quotes will also be extracted.
13.	Risk of bias (quality) assessment	As described in Developing NICE guidelines: the manual: • Qualitative studies will be assessed using the CASP qualitative checklist. • Any mixed methods studies with qualitative data that can be extracted separately will be assessed using the CASP qualitative checklist.

		• Risk of bias of systematic reviews of Qualitative studies will be assessed using the ROBIS Systematic Review checklist.
14.	Strategy for data synthesis	Where multiple qualitative studies are identified for a single question, information from the studies will be combined using a thematic synthesis. Once all of the included studies have been examined and coded, the resulting themes and sub-themes will be evaluated to examine their relevance to the review question, the importance given to each theme, and the extent to which each theme recurs across the different studies. The qualitative synthesis will use these 'descriptive themes' to develop 'analytical themes', which will be interpreted by the reviewer in light of the overarching review questions. If more than 15 studies are identified for inclusion, the following approaches will be used to identify which 15 studies to include: • Discussion with the committee about a cut-off date. This will be intended to focus the studies to a context of patient-centred care. • A sampling strategy to ensure that studies on the views of people experiencing health inequalities are included. • Selection of studies with the richest data. GRADE- CERQual will be used to assess the confidence we have in the summary findings of each of the identified themes. Evidence from all qualitative study designs (interviews, focus groups etc.) is initially rated as high confidence and the confidence in the evidence for each theme will be downgraded from this initial point. The overall confidence in evidence about each theme or sub-theme will be rated on four dimensions: methodological limitations, applicability, coherence and adequacy of data. Methodological limitations refer to the extent to which there were problems in the design or conduct of the studies and will be assessed with the Critical Appraisal Skills Programme (CASP) checklist for qualitative studies. Applicability/relevance of evidence will be assessed by determining the extent to which the body of

<table>
<tr><td></td><td></td><td colspan="3">evidence from the primary studies are applicable to the context of the review question. Coherence of findings will be assessed by examining how well the data from the study fits the review finding. Adequacy of data will be assessed by looking at the degree of richness and quantity of findings. The more complex the finding, the more detailed the supporting data need to be.</td></tr>
<tr><td>15.</td><td>Analysis of sub-groups</td><td colspan="3">As this is a qualitative review, formal subgroup analysis is not appropriate.</td></tr>
<tr><td>16.</td><td>Type and method of review</td><td colspan="3">Intervention
Diagnostic
Prognostic
X Qualitative
Epidemiologic
Service Delivery
Other (please specify)</td></tr>
<tr><td>17.</td><td>Language</td><td colspan="3">English</td></tr>
<tr><td>18.</td><td>Country</td><td colspan="3">England</td></tr>
<tr><td>19.</td><td>Anticipated or actual start date</td><td colspan="3">December 2024</td></tr>
<tr><td>20.</td><td>Anticipated completion date</td><td colspan="3">March 2026</td></tr>
<tr><td rowspan="3">21.</td><td rowspan="3">Stage of review at time of this submission</td><td>Review stage</td><td>Started</td><td>Completed</td></tr>
<tr><td>Preliminary searches</td><td>X</td><td>X</td></tr>
<tr><td>Piloting of the study selection process</td><td>X</td><td>X</td></tr>
</table>

		Formal screening of search results against eligibility criteria	X	X
		Data extraction	X	X
		Risk of bias (quality) assessment	X	X
		Data analysis	X	X
22.	Named contact	**5a. Named contact** Centre for Guidelines, NICE **5b Named contact e-mail** kidneycancerguideline@nice.org.uk **5e Organisational affiliation of the review** National Institute for Health and Care Excellence (NICE) and Guideline Development Team.		
23.	Review team members	From the Guideline Development Team: • Steve Sharp, Technical adviser • Marie Harrisingh, Topic Lead • Sarah Boyce, Senior technical analyst • Agnesa Mehmeti, Technical analyst • Lindsay Claxton, Health economics adviser • Hannah Tebbs, Health economist • Yuanyuan Zhang, Health economist • Amy Finnegan, Senior Information specialist		

24.	Funding sources/sponsor	This systematic review is being completed by the Guideline Development Team which receives funding from NICE.
25.	Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.
26.	Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of Developing NICE guidelines: the manual. Members of the guideline committee are available on the NICE website: Kidney Cancer (GID-NG10398).
27.	Other registration details	None
28.	Reference/URL for published protocol	None
29.	Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as: • notifying registered stakeholders of publication • publicising the guideline through NICE's newsletter and alerts • issuing a press release or briefing as appropriate, posting news articles on the NICE website, using social media channels, and publicising the guideline within NICE.
30.	Keywords	Renal cell carcinoma, information, communication
31.	Details of final publication	www.nice.org.uk

Appendix B – Literature search strategies

Background and development

Search design and peer review

A NICE Senior Information Specialist (SIS) conducted the literature searches. The MEDLINE strategies below were quality assured (QA) by another NICE SIS. All translated search strategies were peer reviewed to ensure their accuracy. Both procedures were adapted from the Peer Review of Electronic Search Strategies Guideline Statement (for further details see: McGowan J et al. PRESS 2015 Guideline Statement. *Journal of Clinical Epidemiology*, 75, 40-46).

The principal search strategies were developed in MEDLINE (Ovid interface) and adapted, as appropriate, for use in the other sources listed in the protocol, taking into account their size, search functionality and subject coverage.

This search report is based on the requirements of the PRISMA Statement for Reporting Literature Searches in Systematic Reviews (for further details see: Rethlefsen M et al. PRISMA-S. *Systematic Reviews*, 10(1), 39).

Review management

The search results were managed in EPPI-Reviewer v5. Duplicates were removed in EPPI-R5 using a two-step process. First, automated deduplication is performed using a high-value algorithm. Second, manual deduplication is used to assess "low-probability" matches. All decisions made for the review can be accessed via the deduplication history.

Prior work

A broad preliminary search was performed across Medline and Embase to gage the volume of evidence and how relevant the evidence was to the review question. Citation searching was also performed on two known key papers. The preliminary searches brought back 143 unique results, of which 7 were identified as includes and 136 as excludes. These results were added and deduped against the searches that are detailed in this appendix. The results were added to the final review as additional records identified through scoping.

Search limits and other restrictions

Formats

Limits were applied in adherence to standard NICE practice (as set out in the Identifying the evidence chapter of the manual) and the eligibility criteria listed in the review protocol to exclude:

- Animal studies
- Editorials, letters, news items and commentaries

- Conference abstracts and posters
- Registry entries for ongoing clinical trials or those that contain no results
- Theses and dissertations
- Papers not published in the English language.

The limit to remove animal studies in the searches was the standard NICE practice, which has been adapted from:

> Dickersin K, Scherer R & Lefebvre C. (1994) Systematic reviews: identifying relevant studies for systematic reviews. *BMJ*, 309(6964), 1286.

Date limits

No date limits were applied, in adherence to the review protocol.

Search filters and classifiers

Effectiveness searches

The qualitative filters used were terms used for qualitative studies are standard NICE practice that have been developed in house and the University of Pittsburgh Health Sciences Library filter for qualitative studies (updated 13 may 2024).

The NICE UK filters were used without modification:

Ayiku L et al. (2017) The MEDLINE UK filter: development and validation of a geographic search filter to retrieve research about the UK from OVID MEDLINE. *Health Information and Libraries Journal*, 34(3), 200-216.

Ayiku L et al. (2019) The Embase UK filter: validation of a geographic search filter to retrieve research about the UK from OVID Embase. *Health Information and Libraries Journal*, 36(2), 121-133.

Key decisions

Economic cost effectiveness searches were not carried out for this question.

No reruns were performed for the clinical effectiveness searches.

Clinical searches

Database results

Database	Date searched	Database Platform	Database segment or version	No. of results downloaded

Cochrane Database of Systematic Reviews (CDSR)	13/03/2025	Wiley	Issue 3 of 12, March 2025	6
Emcare	13/03/2025	Ovid	1995 to 2025 Week 10	134
Embase	13/03/2025	Ovid	1974 to 2025 March 12	277
Epistemonikos	13/03/2025	Epistemonikos	n/a	118
MEDLINE ALL	13/03/2025	Ovid	1946 to March 12, 2025	191
PsycINFO	13/03/2025	Ovid	1806 to March 2025 Week 1	13

Additional search methods

Additional methods	Date searched	No. of results downloaded
Preliminary search	17/02/2025	143
CitationChaser (forward)	17/02/2025	17
Embase (Ovid)	17/02/2025	126
Medline ALL (Ovid)	17/02/2025	27

Search strategy history

Database name: Cochrane Database of Systematic Reviews (CDSR)

Searches
#1 MeSH descriptor: [Kidney Neoplasms] explode all trees 1988
#2 (Kidney* NEAR/2 (cancer* or carcinoma* or carcinosarcoma* or adenocarcino* or neoplas* or tumor* or tumour* or mass or metastat* or malignan* or sarcoma* or parenchyma*)):ti,ab 979
#3 (collecting-duct* NEAR/2 (cancer* or carcinoma* or carcinosarcoma* or adenocarcino* or neoplas* or tumor* or tumour* or mass or metastat* or malignan* or sarcoma* or parenchyma*)):ti,ab 15
#4 (renal-cell* or RCC or ccRCC or renal-carcinoma* or renal-cancer* or Renal-mass* or renal-tumor* or renal-tumour* or grawitz-tumor* or grawitz-tumour* or hypernephroma* or nephrocarcinoma*):ti,ab 4215
#5 (Kidney* NEAR/2 (Transitional-cell* or cell or urothelial* or duct or advanc*) NEAR/2 (cancer* or carcinoma* or carcinosarcoma* or adenocarcino* or neoplas* or tumor* or tumour* or mass or metastat* or malignan* or sarcoma* or parenchyma*)):ti,ab 69
#6 {or #1-#5} 5188
#7 MeSH descriptor: [Consumer Health Information] this term only 200
#8 MeSH descriptor: [Needs Assessment] this term only 506
#9 MeSH descriptor: [Patient Education as Topic] this term only 10769
#10 MeSH descriptor: [Patient Education Handout] this term only 0

Searches
#11 MeSH descriptor: [Health Communication] this term only 385
#12 MeSH descriptor: [Decision Making, Shared] this term only 218
#13 MeSH descriptor: [Patient Participation] this term only 2184
#14 MeSH descriptor: [Health Knowledge, Attitudes, Practice] this term only 8349
#15 MeSH descriptor: [Communication] this term only 3636
#16 MeSH descriptor: [Communication Barriers] explode all trees 150
#17 MeSH descriptor: [Information Dissemination] explode all trees 360
#18 MeSH descriptor: [Information Literacy] explode all trees 748
#19 MeSH descriptor: [Information Seeking Behavior] this term only 79
#20 MeSH descriptor: [Internet Access] this term only 6
#21 MeSH descriptor: [Internet Use] this term only 16
#22 MeSH descriptor: [Reminder Systems] this term only 1229
#23 MeSH descriptor: [Patient Preference] this term only 1184
#24 MeSH descriptor: [Professional-Patient Relations] explode all trees 3530
#25 ((met or unmet or need* or suboptimal* or optimal* or support*) NEAR/4 (emotional* or physical* or care* or psychological* or social* or interpersonal* or personal* or intima* or communicat* or family or families or health-system* or spiritual* or daily-living* or practical* or cogniti* or expect* or sexual* or financial* or nutrition* or living or palliative* or information* or educat* or literat* or literac* or patient* or inpatient* or outpatient* or client* or user* or customer* or consumer* or perceiv* or tailor* or assessment* or instrumental* or advoca*)):ti,ab 103512
#26 (support* NEAR/4 (met or unmet or need* or suboptimal* or optimal* or requirement* or assess* or seek* or access* or barrier* or service* or information*)):ti,ab 14973
#27 ((sexual* or financial* or nutrition* or symptom* or medication or living or palliative* or lifestyle* or wellbeing or well-being) NEAR/4 (support* or barrier* or concern* or advice*)):ti,ab 13835
#28 ((information* or educat* or languag* or translat* or knowledge*) NEAR/4 (require* or support* or seek* or access* or disseminat* or barrier* or service* or concern* or prefer* or obtain* or provision* or provide* or benefit* or ongoing or on-going or disclos* or receive* or receipt* or relevant* or personalised* or personalized* or timepoint* or time-point* or timing* or timeliness* or time-fram* or priorit*)):ti,ab 59728
#29 ((information* or educat* or knowledge*) NEAR/4 (diagnos* or results* or prognos* or progress* or recur* or side-effect* or manage* or prevent* or symptom* or assessment* or medica* or health* or treatment* or appointment* or scan* or followup* or follow-up*)):ti,ab 57489
#30 ((patient* or inpatient* or outpatient* or client* or user* or customer* or consumer*) NEAR/4 (information* or advice or advis* or requirement* or support* or access* or service* or educat* or learn* or literac* or teach* or train* or concern* or prefer* or knowledge)):ti,ab 84287
#31 ((relationship* or partnership*) NEAR/4 (doctor* or caregiver* or care-giver* or specialist or consultant or clinician* or provider* or healthcare* or health-care* or physician* or nurse* or surgeon* or therapist* or patient* or inpatient* or outpatient* or client* or user* or customer* or consumer* or person*)):ti,ab 5708
#32 {or #7-#31} 253713
#33 #6 and #32 520
#34 #6 and #32 in Cochrane Reviews 6

Database name: Emcare

Searches
1 exp kidney tumor/ (27667)
2 (Kidney* adj2 (cancer* or carcinoma* or carcinosarcoma* or adenocarcino* or neoplas* or tumo?r* or mass or metastat* or malignan* or sarcoma* or parenchyma*)).ti,ab. (3199)
3 (collecting-duct* adj2 (cancer* or carcinoma* or carcinosarcoma* or adenocarcino* or neoplas* or tumo?r* or mass or metastat* or malignan* or sarcoma* or parenchyma*)).ti,ab. (73)
4 (renal-cell* or RCC or ccRCC or Renal-mass* or renal-tumo?r* or grawitz-tumo?r* or hypernephroma* or nephrocarcinoma*).ti,ab. (13825)
5 (Kidney* adj2 (Transitional-cell* or cell or urothelial* or duct or advanc*) adj2 (cancer* or carcinoma* or carcinosarcoma* or adenocarcino* or neoplas* or tumo?r* or mass or metastat* or malignan* or sarcoma* or parenchyma*)).ti,ab. (185)
6 or/1-5 (30627)
7 consumer health information/ or needs assessment/ or patient education/ or medical information/ or information dissemination/ or shared decision making/ (132023)
8 patient participation/ or attitude to health/ or exp interpersonal communication/ or exp communication barrier/ or exp information dissemination/ or exp information literacy/ or exp information seeking/ or internet access/ or reminder system/ or patient preference/ or professional-patient relationship/ (543622)
9 ((met or unmet or need* or suboptimal* or optimal* or support*) adj4 (emotional* or physical* or care* or psychological* or social* or interpersonal* or personal* or intima* or communicat* or family or families or health-system* or spiritual* or daily-living* or practical* or cogniti* or expect* or sexual* or financial* or nutrition* or living or palliative* or information* or educat* or literat* or literac* or patient* or inpatient* or outpatient* or client* or user* or customer* or consumer* or perceiv* or tailor* or assessment* or instrumental* or advoca*)).ti,ab. (501658)
10 (support* adj4 (met or unmet or need* or suboptimal* or optimal* or requirement* or assess* or seek* or access* or barrier* or service* or information*)).ti,ab,kf. (98445)
11 ((sexual* or financial* or nutrition* or symptom* or medication or living or palliative* or lifestyle* or wellbeing or well-being) adj4 (support* or barrier* or concern* or advice*)).ti,ab,kf. (58327)
12 ((information* or educat* or languag* or translat* or knowledge*) adj4 (require* or support* or seek* or access* or disseminat* or barrier* or service* or concern* or prefer* or obtain* or provision* or provide* or benefit* or ongoing or on-going or disclos* or receive* or receipt* or relevant* or personalised* or personalized* or timepoint* or time-point* or timing* or timeliness* or time-fram* or priorit*)).ti,ab,kf. (328471)
13 ((information* or educat* or knowledge*) adj4 (diagnos* or results* or prognos* or progress* or recur* or side-effect* or manage* or prevent* or symptom* or assessment* or medica* or health* or treatment* or appointment* or scan* or followup* or follow-up*)).ti,ab,kf. (310343)
14 ((patient* or inpatient* or outpatient* or client* or user* or customer* or consumer*) adj4 (information* or advice or advis* or requirement* or support* or access* or service* or educat* or learn* or literac* or teach* or train* or concern* or prefer* or knowledge)).ti,ab,kf. (291363)
15 ((relationship* or partnership*) adj4 (doctor* or caregiver* or care-giver* or specialist or consultant or clinician* or provider* or healthcare* or health-care* or physician* or nurse* or surgeon* or therapist* or patient* or inpatient* or outpatient* or client* or user* or customer* or consumer* or person*)).ti,ab. (54307)
16 or/7-15 (1587650)

Searches
17 (interview: or qualitative).tw. or exp health care organization/ (1358943)
18 document analysis/ or information processing/ or exp interview/ or verbal communication/ or qualitative research/ or ((depth or face or group or guided or indepth or informal or semistructured or structured or unstructured) adj4 (discussion or discussions or questionnaire or questionnaires)).ti,ab,kf,kw. or (ethnographic or ethnography or (field adj1 work) or fieldwork or (focus adj1 (group or groups)) or (key adj1 (informant or informants)) or (qualitative adj2 (research or studies or studies or synthesis))).ti,ab,kf,kw. (512183)
19 exp Questionnaire/ (419388)
20 exp Observational Method/ (6756)
21 Narrative/ (37587)
22 health care survey/ (10731)
23 (narrative* or narration* or survey*).tw. (559459)
24 (metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them*).tw. (2688)
25 "critical interpretive synthes*".tw. (195)
26 (realist adj (review* or synthes*)).tw. (902)
27 ((thematic or framework) adj synthes*).tw. (1961)
28 or/17-27 (2080058)
29 6 and 16 and 28 (809)
30 exp United Kingdom/ (168773)
31 (national health service* or nhs*).ti,ab,in,ad. (198383)
32 (english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab. (33090)
33 (gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jx,in,ad. (1094334)
34 (bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in,ad. (867963)

Searches
35 (bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in,ad. (41036)
36 (aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in,ad. (115485)
37 (armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in,ad. (17824)
38 or/30-37 (1328635)
39 (exp "arctic and antarctic"/ or exp oceanic regions/ or exp western hemisphere/ or exp africa/ or exp asia/) not (exp united kingdom/ or europe/) (1104965)
40 38 not 39 (1223372)
41 29 and 40 (142)
42 limit 41 to english language (142)
43 42 not (letter or editorial).pt. (139)
44 43 not nonhuman/ not (human/ and nonhuman/) (135)
45 44 not conference*.db,pt,su. (134)

Database name: Embase

Searches
1 exp kidney tumor/ (185945)
2 (Kidney* adj2 (cancer* or carcinoma* or carcinosarcoma* or adenocarcino* or neoplas* or tumo?r* or mass or metastat* or malignan* or sarcoma* or parenchyma*)).ti,ab. (25200)
3 (collecting-duct* adj2 (cancer* or carcinoma* or carcinosarcoma* or adenocarcino* or neoplas* or tumo?r* or mass or metastat* or malignan* or sarcoma* or parenchyma*)).ti,ab. (765)
4 (renal-cell* or RCC or ccRCC or Renal-mass* or renal-tumo?r* or grawitz-tumo?r* or hypernephroma* or nephrocarcinoma*).ti,ab. (112279)
5 (Kidney* adj2 (Transitional-cell* or cell or urothelial* or duct or advanc*) adj2 (cancer* or carcinoma* or carcinosarcoma* or adenocarcino* or neoplas* or tumo?r* or mass or metastat* or malignan* or sarcoma* or parenchyma*)).ti,ab. (1293)
6 or/1-5 (213860)
7 consumer health information/ or needs assessment/ or patient education/ or medical information/ or information dissemination/ or shared decision making/ (293111)
8 patient participation/ or attitude to health/ or exp interpersonal communication/ or exp communication barrier/ or exp information dissemination/ or exp information literacy/ or exp information seeking/ or internet access/ or reminder system/ or patient preference/ or professional-patient relationship/ (1077217)
9 ((met or unmet or need* or suboptimal* or optimal* or support*) adj4 (emotional* or physical* or care* or psychological* or social* or interpersonal* or personal* or intima* or communicat* or family or families or health-system* or spiritual* or daily-living* or practical* or cogniti* or expect* or sexual* or financial* or nutrition* or living or palliative* or information* or educat* or literat* or literac* or patient* or inpatient* or outpatient* or client* or user* or customer* or consumer* or perceiv* or tailor* or assessment* or instrumental* or advoca*)).ti,ab. (1258178)
10 (support* adj4 (met or unmet or need* or suboptimal* or optimal* or requirement* or assess* or seek* or access* or barrier* or service* or information*)).ti,ab,kf. (201904)

Searches
11 ((sexual* or financial* or nutrition* or symptom* or medication or living or palliative* or lifestyle* or wellbeing or well-being) adj4 (support* or barrier* or concern* or advice*)).ti,ab,kf. (137274)
12 ((information* or educat* or languag* or translat* or knowledge*) adj4 (require* or support* or seek* or access* or disseminat* or barrier* or service* or concern* or prefer* or obtain* or provision* or provide* or benefit* or ongoing or on-going or disclos* or receive* or receipt* or relevant* or personalised* or personalized* or timepoint* or time-point* or timing* or timeliness* or time-fram* or priorit*)).ti,ab,kf. (943530)
13 ((information* or educat* or knowledge*) adj4 (diagnos* or results* or prognos* or progress* or recur* or side-effect* or manage* or prevent* or symptom* or assessment* or medica* or health* or treatment* or appointment* or scan* or followup* or follow-up*)).ti,ab,kf. (748643)
14 ((patient* or inpatient* or outpatient* or client* or user* or customer* or consumer*) adj4 (information* or advice or advis* or requirement* or support* or access* or service* or educat* or learn* or literac* or teach* or train* or concern* or prefer* or knowledge)).ti,ab,kf. (841413)
15 ((relationship* or partnership*) adj4 (doctor* or caregiver* or care-giver* or specialist or consultant or clinician* or provider* or healthcare* or health-care* or physician* or nurse* or surgeon* or therapist* or patient* or inpatient* or outpatient* or client* or user* or customer* or consumer* or person*)).ti,ab. (116247)
16 or/7-15 (4006096)
17 (interview: or qualitative).tw. or exp health care organization/ (3082050)
18 document analysis/ or information processing/ or exp interview/ or verbal communication/ or qualitative research/ or ((depth or face or group or guided or indepth or informal or semistructured or structured or unstructured) adj4 (discussion or discussions or questionnaire or questionnaires)).ti,ab,kf,kw. or (ethnographic or ethnography or (field adj1 work) or fieldwork or (focus adj1 (group or groups)) or (key adj1 (informant or informants)) or (qualitative adj2 (research or studies or studies or synthesis))).ti,ab,kf,kw. (916691)
19 exp Questionnaire/ (1046106)
20 exp Observational Method/ (7887)
21 Narrative/ (23080)
22 health care survey/ (26819)
23 (narrative* or narration* or survey*).tw. (1295475)
24 (metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them*).tw. (3347)
25 "critical interpretive synthes*".tw. (233)
26 (realist adj (review* or synthes*)).tw. (1210)
27 ((thematic or framework) adj synthes*).tw. (2730)
28 or/17-27 (4933000)
29 6 and 16 and 28 (2839)
30 exp United Kingdom/ (487898)
31 (national health service* or nhs*).ti,ab,in,ad. (526344)
32 (english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab. (68984)
33 (gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jx,in,ad. (3966533)

Searches
34 (bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in,ad. (3123481)
35 (bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in,ad. (128692)
36 (aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in,ad. (429809)
37 (armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in,ad. (60478)
38 or/30-37 (4858990)
39 (exp "arctic and antarctic"/ or exp oceanic regions/ or exp western hemisphere/ or exp africa/ or exp asia/) not (exp united kingdom/ or europe/) (3782075)
40 38 not 39 (4575952)
41 29 and 40 (481)
42 limit 41 to english language (480)
43 42 not (letter or editorial).pt. (472)
44 43 not nonhuman/ not (human/ and nonhuman/) (452)
45 44 not conference*.db,pt,su. (277)

Database name: Epistemonikos

Searches
(kidney* AND (cancer* or carcinoma* or carcinosarcoma* or adenocarcino* or neoplas* or tumor* or tumour* or mass or metastat* or malignan* or sarcoma* or parenchyma*)) OR (collecting-duct* AND (cancer* or carcinoma* or carcinosarcoma* or adenocarcino* or neoplas* or tumor* or tumour* or mass or metastat* or malignan* or sarcoma* or parenchyma*)) OR (renal-cell* or rcc or ccrcc or renal-carcinoma* or renal-cancer* or renal-mass* or renal-tumor* or renal-tumour* or grawitz-tumor* or grawitz-tumour* or hypernephroma* or nephrocarcinoma*) OR (kidney* AND (transitional-cell* or cell or urothelial* or duct or advanc*) AND (cancer* or carcinoma* or carcinosarcoma* or

Searches
adenocarcino* or neoplas* or tumor* or tumour* or mass or metastat* or malignan* or sarcoma* or parenchyma*)) AND ((met or unmet or need* or suboptimal* or optimal* or support*) AND (emotional* or physical* or care* or psychological* or social* or interpersonal* or personal* or intima* or communicat* or family or families or health-system* or spiritual* or daily-living* or practical* or cogniti* or expect* or sexual* or financial* or nutrition* or living or palliative* or information* or educat* or literat* or literac* or patient* or inpatient* or outpatient* or client* or user* or customer* or consumer* or perceiv* or tailor* or assessment* or instrumental* or advoca*)) OR (support* AND (met or unmet or need* or suboptimal* or optimal* or requirement* or assess* or seek* or access* or barrier* or service* or information*)) OR ((sexual* or financial* or nutrition* or symptom* or medication or living or palliative* or lifestyle* or wellbeing or well-being) AND (support* or barrier* or concern* or advice*)) OR ((information* or educat* or languag* or translat* or knowledge*) AND (require* or support* or seek* or access* or disseminat* or barrier* or service* or concern* or prefer* or obtain* or provision* or provide* or benefit* or ongoing or on-going or disclos* or receive* or receipt* or relevant* or personalised* or personalized* or timepoint* or time-point* or timing* or timeliness* or time-fram* or priorit*)) OR ((information* or educat* or knowledge*) AND (diagnos* or results* or prognos* or progress* or recur* or side-effect* or manage* or prevent* or symptom* or assessment* or medica* or health* or treatment* or appointment* or scan* or followup* or follow-up*)) OR ((patient* or inpatient* or outpatient* or client* or user* or customer* or consumer*) AND (information* or advice or advis* or requirement* or support* or access* or service* or educat* or learn* or literac* or teach* or train* or concern* or prefer* or knowledge)) OR ((relationship* or partnership*) AND (doctor* or caregiver* or care-giver* or specialist or consultant or clinician* or provider* or healthcare* or health-care* or physician* or nurse* or surgeon* or therapist* or patient* or inpatient* or outpatient* or client* or user* or customer* or consumer* or person*)) AND experiences or qualitative or interview* or narrative* or narration* or survey* or metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or (realist AND (review OR synthes*)) or ((thematic OR framework) AND synethes*) or "critical interpretative" Limit to systematic reviews Title - 0 Abstract -118

1 **Database name: Medline ALL**

Searches
1 exp Kidney Neoplasms/ (88930)
2 (Kidney* adj2 (cancer* or carcinoma* or carcinosarcoma* or adenocarcino* or neoplas* or tumo?r* or mass or metastat* or malignan* or sarcoma* or parenchyma*)).ti,ab. (17112)

Searches
3 (collecting-duct* adj2 (cancer* or carcinoma* or carcinosarcoma* or adenocarcino* or neoplas* or tumo?r* or mass or metastat* or malignan* or sarcoma* or parenchyma*)).ti,ab. (514)
4 (renal-cell* or RCC or ccRCC or renal-carcinoma* or renal-cancer* or Renal-mass* or renal-tumo?r* or grawitz-tumo?r* or hypernephroma* or nephrocarcinoma*).ti,ab. (82165)
5 (Kidney* adj2 (Transitional-cell* or cell or urothelial* or duct or advanc*) adj2 (cancer* or carcinoma* or carcinosarcoma* or adenocarcino* or neoplas* or tumo?r* or mass or metastat* or malignan* or sarcoma* or parenchyma*)).ti,ab. (907)
6 or/1-5 (126334)
7 Consumer Health Information/ or Needs Assessment/ or Patient Education as Topic/ or Patient Education Handout/ or Health Communication/ or Decision Making, Shared/ (137044)
8 Patient Participation/ or Health Knowledge, Attitudes, Practice/ or Communication/ or exp communication barriers/ or exp information dissemination/ or exp information literacy/ or information seeking behavior/ or internet access/ or "internet use"/ or reminder systems/ or patient preference/ or exp Professional-Patient Relations/ (426737)
9 ((met or unmet or need* or suboptimal* or optimal* or support*) adj4 (emotional* or physical* or care* or psychological* or social* or interpersonal* or personal* or intima* or communicat* or family or families or health-system* or spiritual* or daily-living* or practical* or cogniti* or expect* or sexual* or financial* or nutrition* or living or palliative* or information* or educat* or literat* or literac* or patient* or inpatient* or outpatient* or client* or user* or customer* or consumer* or perceiv* or tailor* or assessment* or instrumental* or advoca*)).ti,ab. (866175)
10 (support* adj4 (met or unmet or need* or suboptimal* or optimal* or requirement* or assess* or seek* or access* or barrier* or service* or information*)).ti,ab,kf. (147315)
11 ((sexual* or financial* or nutrition* or symptom* or medication or living or palliative* or lifestyle* or wellbeing or well-being) adj4 (support* or barrier* or concern* or advice*)).ti,ab,kf. (92657)
12 ((information* or educat* or languag* or translat* or knowledge*) adj4 (require* or support* or seek* or access* or disseminat* or barrier* or service* or concern* or prefer* or obtain* or provision* or provide* or benefit* or ongoing or on-going or disclos* or receive* or receipt* or relevant* or personalised* or personalized* or timepoint* or time-point* or timing* or timeliness* or time-fram* or priorit*)).ti,ab,kf. (735334)
13 ((information* or educat* or knowledge*) adj4 (diagnos* or results* or prognos* or progress* or recur* or side-effect* or manage* or prevent* or symptom* or assessment* or medica* or health* or treatment* or appointment* or scan* or followup* or follow-up*)).ti,ab,kf. (579454)
14 ((patient* or inpatient* or outpatient* or client* or user* or customer* or consumer*) adj4 (information* or advice or advis* or requirement* or support* or access* or service* or educat* or learn* or literac* or teach* or train* or concern* or prefer* or knowledge)).ti,ab,kf. (537783)
15 ((relationship* or partnership*) adj4 (doctor* or caregiver* or care-giver* or specialist or consultant or clinician* or provider* or healthcare* or health-care* or physician* or nurse* or surgeon* or therapist* or patient* or inpatient* or outpatient* or client* or user* or customer* or consumer* or person*)).ti,ab. (85622)
16 or/7-15 (2600268)
17 interview:.tw. or px.fs. or exp health services administration/ (5167306)
18 "Document Analysis"/ or focus groups/ or interviews as topic/ or narration/ or qualitative research/ or ((depth or face or group or guided or indepth or informal or semistructured or structured or unstructured) adj4 (discussion or discussions or

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questionnaire or questionnaires)).ti,ab,kf,kw. or (ethnographic or ethnography or (field adj1 work) or fieldwork or (focus adj1 (group or groups)) or (key adj1 (informant or informants)) or (qualitative adj2 (research or studies or studies or synthesis))).ti,ab,kf,kw. (326444)
19 Nursing Methodology Research/ (16439)
20 exp Interviews as topic/ (72735)
21 Questionnaires/ (615218)
22 Health Care Surveys/ (34377)
23 (narrative* or narration* or survey*).tw. (1040347)
24 (metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them*).tw. (3108)
25 "critical interpretive synthes*".tw. (226)
26 (realist adj (review* or synthes*)).tw. (1147)
27 ((thematic or framework) adj synthes*).tw. (2503)
28 or/17-27 (6007308)
29 6 and 16 and 28 (1687)
30 exp United Kingdom/ (403083)
31 (national health service* or nhs*).ti,ab,in. (310417)
32 (english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab. (140892)
33 (gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jw,in. (2650057)
34 (bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in. (1925702)
35 (bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in. (78258)

Searches
36 (aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in. (283224)
37 (armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in. (37977)
38 or/30-37 (3401435)
39 (exp africa/ or exp americas/ or exp antarctic regions/ or exp arctic regions/ or exp asia/ or exp australia/ or exp oceania/) not (exp United Kingdom/ or europe/) (3541896)
40 38 not 39 (3186478)
41 29 and 40 (200)
42 limit 41 to english language (197)
43 limit 42 to (letter or historical article or comment or editorial or news or case reports) (6)
44 42 not 43 (191)
45 animals/ not humans/ (5281562)
46 44 not 45 (191)
47 46 not overall.pt. (191)

Database name: PsycInfo

Searches
1 neoplasms/ and exp Kidneys/ (44)
2 (Kidney* adj2 (cancer* or carcinoma* or carcinosarcoma* or adenocarcino* or neoplas* or tumo?r* or mass or metastat* or malignan* or sarcoma* or parenchyma*)).ti,ab. (132)
3 (collecting-duct* adj2 (cancer* or carcinoma* or carcinosarcoma* or adenocarcino* or neoplas* or tumo?r* or mass or metastat* or malignan* or sarcoma* or parenchyma*)).ti,ab. (0)
4 (renal-cell* or RCC or ccRCC or renal-carcinoma* or renal-cancer* or Renal-mass* or renal-tumo?r* or grawitz-tumo?r* or hypernephroma* or nephrocarcinoma*).ti,ab. (354)
5 (Kidney* adj2 (Transitional-cell* or cell or urothelial* or duct or advanc*) adj2 (cancer* or carcinoma* or carcinosarcoma* or adenocarcino* or neoplas* or tumo?r* or mass or metastat* or malignan* or sarcoma* or parenchyma*)).ti,ab. (2)
6 or/1-5 (484)
7 exp Health Information/ or exp Needs Assessment/ or exp Client Education/ or exp Health Education/ or exp Communication/ or exp Shared Decision Making/ (452964)
8 exp Client Participation/ or exp Knowledge Level/ or exp Health Knowledge/ or exp Health Personnel Attitudes/ or exp Health Attitudes/ or exp Communication Barriers/ or exp Information Dissemination/ or exp Information Literacy/ or exp Health Care Seeking Behavior/ or exp Information Seeking/ or exp Internet Access/ or exp Internet Usage/ or exp Digital Divide/ or exp Client Satisfaction/ or exp Preferences/ or exp Client Participation/ (170691)
9 ((met or unmet or need* or suboptimal* or optimal* or support*) adj4 (emotional* or physical* or care* or psychological* or social* or interpersonal* or personal* or intima* or communicat* or family or families or health-system* or spiritual* or daily-living* or practical* or cogniti* or expect* or sexual* or financial* or nutrition* or living or palliative* or information* or educat* or literat* or literac* or patient* or inpatient* or outpatient* or client* or user* or customer* or consumer* or perceiv* or tailor* or assessment* or instrumental* or advoca*)).ti,ab. (405138)

Searches
10 (support* adj4 (met or unmet or need* or suboptimal* or optimal* or requirement* or assess* or seek* or access* or barrier* or service* or information*)).ti,ab. (85931)
11 ((sexual* or financial* or nutrition* or symptom* or medication or living or palliative* or lifestyle* or wellbeing or well-being) adj4 (support* or barrier* or concern* or advice*)).ti,ab. (41867)
12 ((information* or educat* or languag* or translat* or knowledge*) adj4 (require* or support* or seek* or access* or disseminat* or barrier* or service* or concern* or prefer* or obtain* or provision* or provide* or benefit* or ongoing or on-going or disclos* or receive* or receipt* or relevant* or personalised* or personalized* or timepoint* or time-point* or timing* or timeliness* or time-fram* or priorit*)).ti,ab. (285137)
13 ((information* or educat* or knowledge*) adj4 (diagnos* or results* or prognos* or progress* or recur* or side-effect* or manage* or prevent* or symptom* or assessment* or medica* or health* or treatment* or appointment* or scan* or followup* or follow-up*)).ti,ab. (183056)
14 ((patient* or inpatient* or outpatient* or client* or user* or customer* or consumer*) adj4 (information* or advice or advis* or requirement* or support* or access* or service* or educat* or learn* or literac* or teach* or train* or concern* or prefer* or knowledge)).ti,ab. (145555)
15 ((relationship* or partnership*) adj4 (doctor* or caregiver* or care-giver* or specialist or consultant or clinician* or provider* or healthcare* or health-care* or physician* or nurse* or surgeon* or therapist* or patient* or inpatient* or outpatient* or client* or user* or customer* or consumer* or person*)).ti,ab. (69830)
16 or/7-15 (1347053)
17 (experiences or qualitative or interview:).ti,ab. (770696)
18 (narrative* or narration* or survey*).tw. (500995)
19 (metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them*).tw. (2195)
20 "critical interpretive synthes*".tw. (124)
21 (realist adj (review* or synthes*)).tw. (318)
22 ((thematic or framework) adj synthes*).tw. (1162)
23 or/17-22 (1140407)
24 (national health service* or nhs*).ti,ab,in,cq. (39113)
25 (english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab. (104948)
26 (gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jx,in,cq. (573000)
27 (bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or

Searches
manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in,cq. (455999)
28 (bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in,cq. (23562)
29 (aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in,cq. (56998)
30 (armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in,cq. (7759)
31 or/24-30 (751885)
32 6 and 16 and 23 and 31 (13)

Additional search methods

Forward citation searching

Date of search	17 02 2025
How the seed references were identified	Scoping stage
Sources and tools used	CitationChaser
Date of last update	07 02 2025
How results were managed and selected	All exported as a RIS file
No. of results	17
List of seed references used	Harrison, H et al (2023) Patient experience of follow-up after surgery for kidney cancer: a focus group study. BJU International 132: 47-55 O'dea, A et al (2022) Identifying the unmet supportive care needs of people affected by kidney cancer: a systematic review. Journal of Cancer Survivorship 16:1279-95

Broad preliminary searches

Database name: Medline ALL

Searches
1 exp *Kidney Neoplasms/ (76128)
2 (Kidney* adj2 (cancer* or carcinoma* or carcinosarcoma* or adenocarcino* or neoplas* or tumo?r* or mass or metastat* or malignan* or sarcoma* or parenchyma*)).ti,ab. (17046)
3 (collecting-duct* adj2 (cancer* or carcinoma* or carcinosarcoma* or adenocarcino* or neoplas* or tumo?r* or mass or metastat* or malignan* or sarcoma* or parenchyma*)).ti,ab. (511)
4 (renal-cell* or RCC or ccRCC or Renal-mass* or renal-tumo?r* or grawitz-tumo?r* or hypernephroma* or nephrocarcinoma*).ti,ab. (74817)
5 (Kidney* adj2 (Transitional-cell* or cell or urothelial* or duct or advanc*) adj2 (cancer* or carcinoma* or carcinosarcoma* or adenocarcino* or neoplas* or tumo?r* or mass or metastat* or malignan* or sarcoma* or parenchyma*)).ti,ab. (905)
6 or/1-5 (113311)
7 Qualitative Research/ (99176)
8 Nursing Methodology Research/ (16439)
9 exp Interviews as topic/ (72251)
10 Questionnaires/ (612181)
11 Narration/ (11060)
12 Health Care Surveys/ (34356)
13 (qualitative$ or interview$ or focus group$ or questionnaire$ or narrative$ or narration$ or survey$).tw. (2216183)
14 (ethno$ or emic or etic or phenomenolog$ or grounded theory or constant compar$ or (thematic$ adj4 analys$) or theoretical sampl$ or purposive sampl$).tw. (174974)

Searches
15 (hermeneutic$ or heidegger$ or husser$ or colaizzi$ or van kaam$ or van manen$ or giorgi$ or glaser$ or strauss$ or ricoeur$ or spiegelberg$ or merleau$).tw. (14572)
16 (metasynthes$ or meta-synthes$ or metasummar$ or meta-summar$ or metastud$ or meta-stud$ or metathem$ or meta-them$).tw. (3081)
17 "critical interpretive synthes*".tw. (226)
18 (realist adj (review* or synthes*)).tw. (1137)
19 (noblit and hare).tw. (122)
20 (meta adj (method or triangulation)).tw. (49)
21 (CERQUAL or CONQUAL).tw. (584)
22 ((thematic or framework) adj synthes*).tw. (2474)
23 or/7-22 (2454509)
24 6 and 23 (2244)
25 Consumer Health Information/ or Needs Assessment/ or Patient Education as Topic/ or Patient Education Handout/ or Health Communication/ or Information Dissemination/ or Decision Making, Shared/ (155396)
26 (support* adj3 (need* or requirement* or assess* or seek* or access* or barrier* or service*)).ti,ab,kf. (100847)
27 ((sexual* or financial* or nutrition* or living or palliative*) adj3 (need* or support* or barrier* or concern* or advice*)).ti,ab,kf. (64425)
28 ((information* or educat*) adj3 (need* or requirement* or support* or seek* or access* or disseminat* or barrier* or service* or concern*)).ti,ab,kf. (175181)
29 ((patient* or inpatient* or outpatient* or client* or user* or customer* or consumer*) adj3 (information* or advice or advis* or need* or requirement* or support* or access* or service* or educat* or learn* or teach* or train* or concern*)).ti,ab,kf. (477345)
30 or/25-29 (861193)
31 24 and 30 (156)
32 exp United Kingdom/ (402471)
33 (national health service* or nhs*).ti,ab,in. (308784)
34 (english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab. (139860)
35 (gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jw,in. (2641339)
36 (bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or

Searches
"plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in. (1918000)
37 (bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in. (77917)
38 (aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in. (282170)
39 (armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in. (37798)
40 or/32-39 (3389942)
41 (exp africa/ or exp americas/ or exp antarctic regions/ or exp arctic regions/ or exp asia/ or exp australia/ or exp oceania/) not (exp United Kingdom/ or europe/) (3531080)
42 40 not 41 (3175959)
43 31 and 42 (27)

Database name: Embase

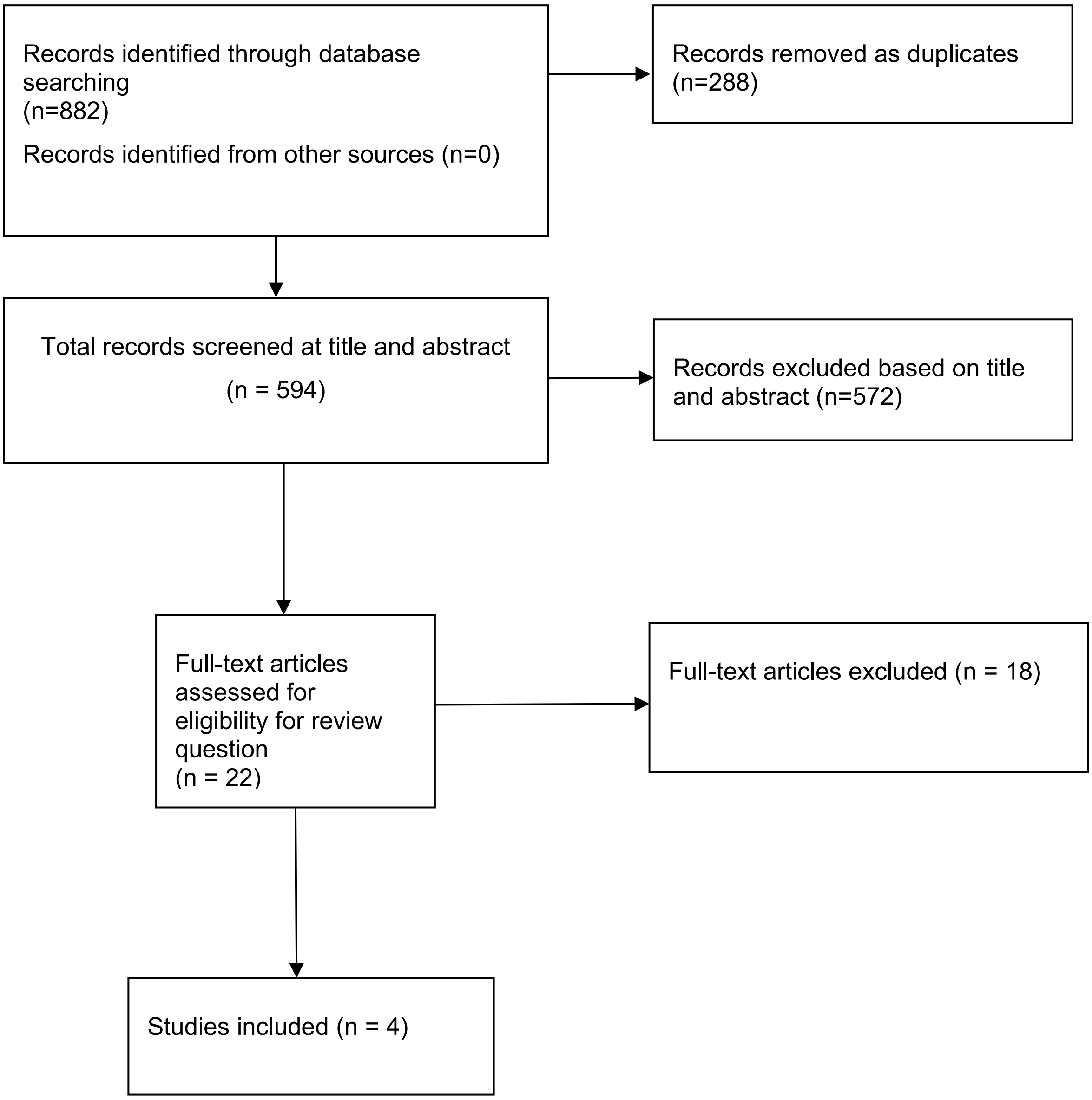
Searches
1 exp kidney tumor/ (184922)
2 (Kidney* adj2 (cancer* or carcinoma* or carcinosarcoma* or adenocarcino* or neoplas* or tumo?r* or mass or metastat* or malignan* or sarcoma* or parenchyma*)).ti,ab. (25047)
3 (collecting-duct* adj2 (cancer* or carcinoma* or carcinosarcoma* or adenocarcino* or neoplas* or tumo?r* or mass or metastat* or malignan* or sarcoma* or parenchyma*)).ti,ab. (760)
4 (renal-cell* or RCC or ccRCC or Renal-mass* or renal-tumo?r* or grawitz-tumo?r* or hypernephroma* or nephrocarcinoma*).ti,ab. (111659)
5 (Kidney* adj2 (Transitional-cell* or cell or urothelial* or duct or advanc*) adj2 (cancer* or carcinoma* or carcinosarcoma* or adenocarcino* or neoplas* or tumo?r* or mass or metastat* or malignan* or sarcoma* or parenchyma*)).ti,ab. (1288)
6 or/1-5 (212625)
7 consumer health information/ or needs assessment/ or patient education/ or medical information/ or information dissemination/ or shared decision making/ (291848)
8 (support* adj3 (need* or requirement* or assess* or seek* or access* or barrier* or service*)).ti,ab,kf. (139063)
9 ((sexual* or financial* or nutrition* or living or palliative*) adj3 (need* or support* or barrier* or concern* or advice*)).ti,ab,kf. (97172)
10 ((information* or educat*) adj3 (need* or requirement* or support* or seek* or access* or disseminat* or barrier* or service* or concern*)).ti,ab,kf. (229572)

Searches
11 ((patient* or inpatient* or outpatient* or client* or user* or customer* or consumer*) adj3 (information* or advice or advis* or need* or requirement* or support* or access* or service* or educat* or learn* or teach* or train* or concern*)).ti,ab,kf. (756551)
12 or/7-11 (1315850)
13 Qualitative Research/ (141498)
14 exp Interview/ (417635)
15 exp Questionnaire/ (1039775)
16 exp Observational Method/ (7857)
17 Narrative/ (23020)
18 (qualitative$ or interview$ or focus group$ or questionnaire$ or narrative$ or narration$ or survey$).tw. (2844908)
19 (ethno$ or emic or etic or phenomenolog$ or grounded theory or constant compar$ or (thematic$ adj4 analys$) or theoretical sampl$ or purposive sampl$).tw. (206723)
20 (hermeneutic$ or heidegger$ or husser$ or colaizzi$ or van kaam$ or van manen$ or giorgi$ or glaser$ or strauss$ or ricoeur$ or spiegelberg$ or merleau$).tw. (17551)
21 (metasynthes$ or meta-synthes$ or metasummar$ or meta-summar$ or metastud$ or meta-stud$ or metathem$ or meta-them$).tw. (3321)
22 or/13-21 (3178263)
23 6 and 12 and 22 (640)
24 exp United Kingdom/ (485016)
25 (national health service* or nhs*).ti,ab,in,ad. (523319)
26 (english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab. (68485)
27 (gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jx,in,ad. (3936308)
28 (bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in,ad. (3100394)

Searches
29 (bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in,ad. (127882)
30 (aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in,ad. (426629)
31 (armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in,ad. (60091)
32 or/24-31 (4823054)
33 (exp "arctic and antarctic"/ or exp oceanic regions/ or exp western hemisphere/ or exp africa/ or exp asia/) not (exp united kingdom/ or europe/) (3759235)
34 32 not 33 (4541868)
35 23 and 34 (126)

Appendix C –Qualitative evidence study selection

Figure 1: PRISMA diagram



Appendix D –Qualitative evidence

Beyer, 2025

Bibliographic Reference	Beyer, K.; Venderbos, L.D.F.; Roobol, M.J.; Giles, R.H.; Verhagen, P.; Barod, R.; Wintner, L.M.; Jewett, M.A.S.; Van Hemelrijck, M.; Kinsella, N.; Navigating choices: understanding the decision-making journey of patients with localised kidney cancer; BJU International; 2025

Study Characteristics

Study type	Qualitative study
Aim of study	To understand how patients experience decision making for different treatment options for kidney cancer.
Theoretical approach	NR
Study location	Netherlands, Germany and the United Kingdom. Only data and themes relevant to participants from the United Kingdom were extracted.
Study setting	Online
Study dates	Not reported
Sources of funding	Grant from Royal Marsden Charity and Kidney cancer UK
Data collection	Focus groups and semi-structured interviews • Participants were recruited using a selective sampling method. • Participants aged older than 18 were invited based on their initial kidney cancer diagnosis via e-mail.

	• Microsoft Teams was used to conduct and record the online focus groups and one on one interviews.
Method and process of analysis	Thematic analysis • A treatment decision-making framework (by Glatzer et al) was used to develop a semi-structured interview guide. • The guide structured the focus groups and interviews. • The framework centred around 3 domains: kidney cancer-specific characteristics, decision maker-related factors, and contextual factors. • Focus groups were the primary focus. Participants who were not able to attend the focus groups or preferred a one-to-one conversation were given the option of an interview. • A codebook was developed using the framework (by Glatzer et al. as the underlying structure). .
Population and sample collection	N=21 individuals The Netherlands (n = 11), Germany (n = 4) and the United Kingdom (n = 6) Individuals participants in either 4 online focus groups or 7 online semi-structured interventions that lasted 2 hours. Only data from UK participants will be extracted and analysed.
Inclusion Criteria	Criteria 1 • Over 18 years old • Kidney cancer diagnosis
Exclusion criteria	None reported

Relevant themes	Theme: Health literacy and information needs • Subtheme: (Feeling) passive in their treatment decision-making • Subtheme: Comprehension of information Theme: Source of support • Subtheme: Psychological/emotional support • Subtheme: Charity support • Subtheme: Rushed to make a treatment decision Theme: Trust in the treatment option and treating HCP • Subtheme: Trust in the treating clinician Theme: Importance and aspects of shared decision-making • Subtheme: Shared decision-making • Subtheme: Clear communication and particularly the use of lay language • Subtheme: Understanding the next steps • Subtheme: Understanding the side effects Theme: Administrative issues • Subtheme: Social benefits and sick leave

Critical appraisal - Critical Appraisal - CASP qualitative checklist V2

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	High *(Researcher bias or influence during the formulation of the research questions or data collection not described in-depth, and analysis not described in-depth.)*
Overall risk of bias and relevance	Relevance	Highly relevant

Harrison, 2023

Bibliographic Reference	Harrison, Hannah; Stewart, Grant D; Usher-Smith, Juliet A; Patient experience of follow-up after surgery for kidney cancer: a focus group study.; BJU international; 2023; vol. 132 (no. 1); 47-55

Study Characteristics

Study type	Qualitative study
Aim of study	To explore the experiences of follow-up care in those who have had kidney cancer surgery
Theoretical approach	NR
Study location	United Kingdom
Study setting	Online
Study dates	January 2022
Sources of funding	Kidney Cancer UK

Data collection	Focus groups • Participants recruited through advertisement on Kidney Cancer UK Facebook groups, and twitter feed. Advert also placed in a newsletter distributed to people with a history of kidney cancer. • Two focus groups were held via videoconferencing software. • Participants completed a short questionnaire before attending the focus group. • Questionnaire information included demographic information and follow-up they had received. • Focus groups lasted 1 hour and were facilitated by members of the research team.
Method and process of analysis	Thematic analysis • Focus groups were recorded and the video recordings transcribed by an external company (identifying information was removed). • Transcripts were analysed using thematic analysis. • A provisional coding framework was developed by one author based on initial impressions of the discussions. • The transcripts were then coded by 2 authors, and the coding framework revised through discussion between authors. • Codes were then grouped into themes. • Themes were reviewed by the whole team.
Population and sample collection	N=14 participants attended the focus groups. • n=8 women • all self-reported White ethnicity • aged between 40 and 80 years old. • n=10 participants <60 years old • n= 11 participants <2 years post-surgery • n=1 participants >5 years post-surgery • n=12 attended at least one follow-up appointment.

Inclusion Criteria	Criteria 1 • Adults with previous surgery for kidney cancer living in the UK.
Exclusion criteria	None reported
Relevant themes	• Feelings of abandonment • Uncertainty about the plan • Anxiety about appointments • A need for information • A need for emotional support

Critical appraisal - Critical Appraisal - CASP qualitative checklist V2

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Low
Overall risk of bias and relevance	Relevance	Highly relevant

Ranieri, 2024

Bibliographic Reference	Ranieri, Veronica; Warren, Hannah; Florez, Isabella; Neves, Joana B; Walkden, Miles; Bernstein, Darryl E; Santiapillai, Joseph; Williams, Norman; Wildgoose, William H; Patki, Prasad; Stewart, Grant D; Kinsella, Netty; Pizzo, Elena; Barod, Ravi; Bex, Axel; Mumtaz, Faiz; El-Sheikh, Soha; Gurusamy, Kurinchi; Tran, Maxine G B; Identifying the facilitators and barriers to implementation of renal tumour biopsy in the diagnostic pathway for small renal masses.; BJU international; 2024; vol. 134 (no. 5); 796-804

Study Characteristics

Study type	Qualitative study
Aim of study	Understand the barriers and facilitators to the implementation of renal tumour biopsy for diagnosis of renal tumours.
Theoretical approach	Phenomenological approach
Study location	United Kingdom
Study setting	Remote interviews via telephone or conferencing software.
Study dates	November 2020 to September 2022
Sources of funding	Funded by the UK National Institute for Health and Care Research
Data collection	Semi-structured interviews • Interviews were held remotely. • Interviews were recorded and transcribed verbatim and coded using a data management system.
Method and process of analysis	Phenomenological approach and thematic analysis • Thematic analysis using a 6-phase method was used to generate themes. • Themes were explored by 2 researchers and disagreements discussed and resolved. • Interviews were stopped when saturation was reached.
Population and sample collection	N=50 individuals took part in interviews

	n=23 patients n=22 clinicians. Data from clinicians only extracted if relevant to patient views. Male: n=16 (total population of those who took part in interviews including clinicians) Age: 41 to 60 (total population of those who took part in interviews including clinicians) Patients were purposively sampled for diversity in gender, age, ethnicity and comorbidity.
Inclusion Criteria	Criteria 1 • Patients who had a kidney tumour diagnosed and/or treated at one of five tertiary centres in England
Exclusion criteria	None reported
Relevant themes	• Information pertaining to RTB • Access to/capacity for RTB • Experiences of prior biopsy and RTB

Critical appraisal - Critical Appraisal - CASP qualitative checklist V2

Section	**Question**	**Answer**
Overall risk of bias and relevance	Overall risk of bias	Low
Overall risk of bias and relevance	Relevance	Highly relevant

Zhou, 2023

Bibliographic Reference	Zhou, Yin; Singh, Hardeep; Hamilton, Willie; Archer, Stephanie; Tan, Sapphire; Brimicombe, James; Lyratzopoulos, Georgios; Walter, Fiona M; Improving the diagnostic process for patients with possible bladder and kidney cancer: a mixed-methods study to identify potential missed diagnostic opportunities.; The British journal of general practice : the journal of the Royal College of General Practitioners; 2023; vol. 73 (no. 733); e575-e585

Study Characteristics

Study type	Qualitative study
Aim of study	Explore the characteristics of missed diagnostic opportunities in patients at increased risk of bladder and kidney cancer, for the development of targeted interventions.
Theoretical approach	NR
Study location	United Kingdom
Study setting	At the patient's home and phone
Study dates	Recruitment between June 2018 and October 2019. First group of interviews in May 2019 (at home), second group of interviews in May 2020 (phone).
Sources of funding	Wellcome Trust primary care clinician PhD fellowship
Data collection	Semi-structured interviews • Interviewees were asked about their experiences of the diagnostic process • interviews took place at home or on the phone • interviews were performed by 2 researchers using a semi-structured interview schedule • interview schedule developed and informed by the literature.

Method and process of analysis	Thematic analysis • Interviews were recorded and transcribed verbatim. • All transcripts were read by one researcher, and subsets of the data were reviewed by two other researchers. • The dataset was fine-coded, and themes identified using thematic analysis • Findings were discussed with the wider team that included clinicians to reach an interpretation of the findings.
Population and sample collection	• Patients recruited from 9 primary care practices. • Electronic search of databases to identify patients who had presented with relevant symptoms according to NICE symptoms for possible bladder and kidney cancer. • A research nurse or GP reviewed each identified patients records to determine inclusion and exclusion criteria for eligibility. N=15 n= 11 female n= 4 male Aged between 45 and 84 years old n=8 with UTI symptoms n=5 with haematuria n=2 with both UTI symptoms and haematuria

Inclusion Criteria	Criteria 1 - Patients with symptoms/signs listed in NICE guidelines for suspected cancer
Exclusion criteria	Criteria 1 - Already diagnosed kidney, bladder, or prostate cancer - Deemed lacking capacity to provide informed consent by practice clinician
Relevant themes	- Missing information gathered about urinary symptoms. - Lack of clinical review in patients with recurrent UTIs. - Difficulty obtaining urine culture results.

Critical appraisal - Critical Appraisal - CASP qualitative checklist V2

Section	**Question**	**Answer**
Overall risk of bias and relevance	Overall risk of bias	Moderate *(Researcher bias not adequately considered and analysis not described in-depth.)*
Overall risk of bias and relevance	Relevance	Partially relevant

Appendix E – GRADE-CERQual tables

Table 5: GRADE-CERQual

Study information	Description of review finding	CERQual Quality Assessment				
		Methodological limitations	Coherence of finding	Adequacy	Relevance of evidence	Overall confidence
Theme 1: Requirement for information relevant to diagnostic pathway						
Subtheme 1.1: Early diagnosis						
1 study (Zhou 2023) Interviews. N=15 patients who had presented with relevant symptoms according to NICE symptoms for possible bladder and kidney cancer	Data from 1 study suggested there was a need for information on the investigations and treatments that followed when presenting to primary care, with symptoms that might be suspicious of kidney cancer. The importance of having this information delivered by a doctor was highlighted. 'It would be nice if when you phoned up and said you've got a water infection that the GP actually phones you to find out, instead of keep the receptionist doing it all … because then you could ask them the question, couldn't you?' [Quote: Zhou 2023 p.e580]	Minor concerns[1]	No or very minor concerns	Minor concerns[2]	No or very minor concerns	MODERATE
Subtheme 1.2: Biopsy						
1 study (Ranieri 2024) Semi-structured interviews and	Data from 1 study highlighted that people valued enough information about biopsy, such as information on the procedure, the risks associated with	No or very minor concerns	No or very minor concerns	Minor concerns[2]	No or very minor concerns	MODERATE

focus groups. N= 50 patients who had a kidney tumour diagnosed and/or treated and clinicians	the procedure and information related to side-effects. Clinicians also described that people preferred being given all the relevant information before deciding on whether to proceed with biopsy. When not enough information was given, people described feelings of fear. ‘(Regarding renal tumour biopsy) I am not an expert but I didn’t want them to spread, disturb the cancer cells and then it travels somewhere else in my body. . . I don’t know, just had the fear’. [Quote: Ranieri 2024 p.799]					
Theme 2 – Requirement for information regarding treatment options						
2 studies (Beyer 2025, Harrison 2023) Thematic analysis with semi-structured interviews and focus groups. N= 20 participant with a kidney cancer diagnosis or had kidney cancer surgery	Data from 2 studies highlighted that people valued having as much information as possible on their treatment options. Information on their individual diagnosis helped with the decision-making process for choosing the best treatment option for them. People valued information on the long-term risks of going ahead with treatment, and this allowed them to weigh up the risks and benefits of proceeding with treatment compared with active surveillance. The evidence in the studies also highlighted that people want to receive	No or very minor concerns	No or very minor concerns	No or very minor concerns	No or very minor concerns	HIGH

	information about the risks involved while carrying out procedures, and any side effects associated with them. When there was not enough information, or information was conflicting between different healthcare professionals, people felt overwhelmed and unable to make an informed decision. ‘(The consultant) refused to give a clear opinion on what was medically best for me. Instead, he told me I could either have a total nephrectomy or do nothing and just keep it under surveillance. This overwhelmed me—I couldn't process any additional information because everyone suggested something different.’ ‘I think the information helped me to make the treatment decision because it indicated to me that my cancer is a very small form…it is not doing any harm’. ‘There are tips and tricks that you can notice Facebook and that can be extremely useful to understand how to deal with the side effects.’					

	[Quotes: Beyer 2025 (UK participant) supplementary p.7-8]					
Theme 3: Requirement for information on risk of recurrence						
1 study (Harrison 2023) Thematic analysis with focus groups. N=14 participants who had kidney cancer surgery.	Data from 1 study suggested that the need and preference for information related to risk of recurrent disease and survival was person specific. Some people valued receiving scan results, but others were frustrated they had not been offered them. The evidence alluded to a need for the information to be offered, but support with dealing with the results was required. '...not just kind of throw science at me and then not explain' 'I think I would have been scared to death if he [the consultant] had told me 85% [survival] chance in the next 5 years. . . 'I want to be educated but at the same time I want to be a bit oblivious.' [Quotes: Harrison 2023 p.50-51]	No or very minor concerns	No or very minor concerns	Minor concerns[2]	No or very minor concerns	MODERATE
Theme 4: Requirement for information on follow-up and aftercare						

1 study (Harrison 2023) Thematic analysis with focus groups. N=14 participants who had kidney cancer surgery	Evidence from 1 study highlighted that there was a need for information to be provided after treatment, regarding the follow-up schedule, imaging and practical aspects of aftercare. Some participants felt confident about the transition from treatment to follow-up which could be an indication of adequate information being received. When participants reported a lack of contact immediately following their surgery, they described feeling unsure about their care plan and reported that it was difficult to 'keep in the loop'. Participants described feeling concerned that metastatic disease might be missed during the follow-up period, which could have been attributed to the lack of information provided regarding the change of imaging type as reported by one participant. There was also concern that insufficient information was provided about the practical aspects post-surgery such as wound care and pain management, as well as care regarding living with one kidney.	No or very minor concerns	No or very minor concerns	Minor concerns[2]	No or very minor concerns	MODERATE

	‘How do you live with one kidney? I did not really get too much explanation it has been a bit hit and miss’. [Quote: Harrison 2023 p.50)					
Theme 5: Need for emotional support						
2 studies (Beyer 2025, Harrison 2023) Thematic analysis with semi-structured interviews and focus groups. N= 20 participant with a kidney cancer diagnosis or had kidney cancer surgery	Evidence from 2 studies highlighted the requirement for more information on how people can access emotional support, in particular mental health. Participants felt a need for support at the point of contact with healthcare professionals, indicating that information on resources should be given during appointments with doctors or nurses. The data suggested that useful resources for information on access to support can be found through charities such as Kidney Cancer UK and Maggie centres. ‘But there wasn't much in terms of (emotional support- nobody asked me:) “OK, how are you going to cope with this information?’ [Quote: Beyer 2025 supplementary p.6]	Minor concerns[1]	No or very minor concerns	Minor concerns[2]	No or very minor concerns	MODERATE
Theme 6: Requirement for information on practical and financial support						

1 study (Beyer 2025) Thematic analysis with semi-structured interviews and focus groups. N= 6 participant with a kidney cancer diagnosis	Evidence from 1 study described a need for information about the healthcare system and information on when to expect information regarding follow up. There was also a need for information on social benefits and sick leave. "Then he just told me the hospital would get in touch with me and I heard nothing, and I went to our local Maggie's Cancer Centre and broke down crying?" "I wish I had known someone to get the correct information about my pension, about monetary things. It took me about a year to find out." [Quotes: Beyer 2025. Supplementary p9]	Minor concerns[1]	No or very minor concerns	Moderate concerns[3]	No or very minor concerns	LOW

1 Minor concerns regarding methodological limitations due to no information on relationship between researcher and participants, or no in-depth discussion on the analysis, or no consideration of ethical concerns

2 Minor concerns regarding adequacy as the richness of data was good but quantity of data was limited and came from one study.

3 Moderate concerns regarding adequacy due to some richness in the data, and quantity of data was limited and came from one study

Appendix F – Economic evidence study selection

Review of economic evaluations was not conducted for this review question.

Appendix G– Economic evidence tables

Review of economic evaluations was not conducted for this review question.

Appendix H– Excluded studies

Table 6: Excluded qualitative studies

Study	Reason
Benjamin, David J and Rezazadeh Kalebasty, Arash (2023) Patient preferences in the treatment of genitourinary cancers. Nature reviews. Urology 20(9): 513-514	- Study design - Does not use interview (semi-structured or structured) or focus group methods
Bentley, Sarah, Johnson, Chloe, Exall, Elizabeth et al. (2021) Improving patient-clinician communication following nephrectomy in renal cell carcinoma: Development, content validation and pilot testing of a conversation aid tool. Patient education and counseling 104(1): 99-108	- Study design - Does not use interview (semi-structured or structured) or focus group methods
Bird, J. and Hayter, M. (2009) A review of the literature on the impact of renal cancer therapy on quality of life. Journal of Clinical Nursing 18(20): 2783	- Study design - Does not use interview (semi-structured or structured) or focus group methods *Literature review*
Boele, F., Harley, C., Pini, S. et al. (2024) Cancer as a chronic illness: support needs and experiences. BMJ Supportive and Palliative Care 14(e1): e710	- Study design - Does not use interview (semi-structured or structured) or focus group methods
Colvin, Ellen, Ng, Stephanie, Hepworth, John et al. (2023) Hereditary renal cancer patient and public involvement group: A collaborative, consensus decision process to develop a communication tool for patient use. Journal of clinical and translational science 7(1): e115	- Study design – not a qualitative research study that derives themes.
Derry-Vick, H.M., Heathcote, L.C., Glesby, N. et al. (2023) Scanxiety among Adults with Cancer: A Scoping Review to Guide Research and Interventions. Cancers 15(5): 1381	- Systematic review - no relevant studies matching the protocol
Dwarswaard, J, Bakker, EJ, van Staa, A et al. (2016) Self-management support from the perspective of patients with a chronic condition: a thematic synthesis of qualitative studies. Health expectations : an international journal of public participation in health care and health policy 19(2): 194-208	- Population - not suspected or confirmed renal cell carcinoma *A qualitative review: included studies not specific to renal cell carcinoma*

Study	Reason
MacLennan, S.J.; Murdoch, S.E.; Cox, T. (2017) Changing current practice in urological cancer care: Providing better information, advice and related support on work engagement. European Journal of Cancer Care 26(5): e12756	- Population - not suspected or confirmed renal cell carcinoma *Participants with kidney cancer grouped together with other cancers. Unclear if themes relevant to kidney cancer participants.*
Merrick, S., Rush, H.L., Daniels, S. et al. (2024) Hit it hard: qualitative patient perspectives on the optimisation of immune checkpoint inhibition. British Journal of Cancer 131(3): 515	- Themes - no relevant themes matching protocol
O'Dea, Amy, Gedye, Craig, Jago, Belinda et al. (2022) Identifying the unmet supportive care needs of people affected by kidney cancer: a systematic review. Journal of cancer survivorship : research and practice 16(6): 1279-1295	- Systematic review - no relevant studies matching the protocol
Porta, C., Bellmunt, J., Eisen, T. et al. (2010) Treating the individual: The need for a patient-focused approach to the management of renal cell carcinoma. Cancer Treatment Reviews 36(1): 16	- Study design - Does not use interview (semi-structured or structured) or focus group methods
Skea, Z.C., MacLennan, S.J., Entwistle, V.A. et al. (2011) Enabling mutual helping? Examining variable needs for facilitated peer support. Patient Education and Counseling 85(2): e120	- Themes - no relevant themes matching protocol
South, A., Hanley, B., Gafos, M. et al. (2016) Models and impact of patient and public involvement in studies carried out by the Medical Research Council Clinical Trials Unit at University College London: Findings from ten case studies. Trials 17(1): 376	- Themes - no relevant themes matching protocol
Taylor, K (2002) Researching the experience of kidney cancer patients. European journal of cancer care 11(3): 200-4	- Study design - Does not use interview (semi-structured or structured) or focus group methods
Taylor, L.C., Hutchinson, A., Law, K. et al. (2023) Acceptability of risk stratification within population-based cancer screening from the perspective of the general public: A mixed-methods systematic review. Health Expectations	- Country - Study not in the UK *Meta-analysis of studies. Studies relevant for kidney cancer not in the UK*
Usher-Smith, Juliet A, Masson, Golnessa, Godoy, Angela et al. (2024) Acceptability of	- Population - not suspected or confirmed renal cell carcinoma

Study	Reason
adding a non-contrast abdominal CT scan to screen for kidney cancer and other abdominal pathology within a community-based CT screening programme for lung cancer: A qualitative study. PloS one 19(7): e0300313	*Study on a screening programme*
Zhou, Y., Singh, H., Hamilton, W. et al. (2023) Improving the diagnostic process for patients with possible bladder and kidney cancer:. British Journal of General Practice 73(733): e575	- Duplicate
Zhou, Y, van Melle, M, Singh, H et al. (2019) Quality of the diagnostic process in patients presenting with symptoms suggestive of bladder or kidney cancer: a systematic review. BMJ open 9(10): e029143	- Systematic review - no relevant studies matching the protocol