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Equality and health inequalities assessment (EHIA)

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NICE guidelines

Equality and health inequalities assessment (EHIA)

Kidney Cancer: diagnosis and management

The considerations and potential impact on equality and health inequalities have been considered throughout the guidance development, maintenance and update process according to the principles of the NICE equality policy and those outlined in Developing NICE guidelines: the manual.

This EHIA relates to:

Kidney cancer

Appendix 1: equality and health inequalities assessment (EHIA)

GID-NG10398 Diagnosis and management of kidney cancer

STAGE 2. Informing the scope

(to be completed by the Developer, and submitted with the draft scope for consultation, if this is applicable)

Diagnosis and management of kidney cancer

Date of completion: August 2023

Focus of guideline or update: Diagnosis and management of kidney cancer

2.1 What approaches have been used to identify potential equality and health inequalities issues during the check for an update or during development of the draft scope?
A thorough approach was undertaken to understand the breadth of equality and health inequalities issues affecting the diagnosis and management of kidney cancer. We reviewed the published evidence from a literature search of systematic reviews and other relevant sources of intelligence during the mapping process to understand the equality and health inequalities issues affecting people with suspected or diagnosed kidney cancer. Furthermore, we collated information during scoping meetings, including any data provided by stakeholders.

2.2 What potential equality and health inequalities issues have been identified during the check for an update or during development of the draft scope?
Age The incidence of kidney cancer increases with age in both men and women, rising from the age of 35-39 years and peaking at 80-85 years in both sexes. Mortality from kidney cancer also increases with age, in particular from age 70-74 years (Cancer Research UK). During the development of recommendations, it will be important to consider any implications of age-related co-morbidities and treatments for those conditions, on the intervention options for diagnosing and managing kidney cancer. As people get older, they may face difficulties engaging in and accessing healthcare. Reasons for this include increasing frailty, reduced physical activity and conditions of old age. They may live alone or be residents in a care home. They may rely on carers

to help them attend appointments and some older people have little access to social and practical support. In addition, older people may have caring responsibilities for partners or grandchildren and delay or cancel their treatment because of these responsibilities.

If recommendations are made about support needs before, during and after treatment, older people may have additional needs that the committee may need to consider relating to the issues above. Other issues such as transport, cost, and distance to specialist centres, may also need to be considered.

Kidney cancer in children is rare. but Wilms tumour is the most common type. Around 85 children between the ages of 0 and 14 years are diagnosed with Wilms tumour each year in the UK. They are most common in children under 5. Rarely they can develop in older children and very rarely, in adults.

We will not cover recommendations about kidney cancers in children in this guideline because they are managed and treated as paediatric cancers and in a different pathway.

Disability

Some people with disabilities and their carers may have additional needs for support before, during and after treatment for kidney cancer. If the committee makes recommendations around information and advice, it may need to consider issues such as accessible formats for people with learning disabilities and for people with sensory disabilities. Additional support may be needed when using written information about treatment options and the information may need to be provided in easy to read or alternative formats. It may also be important to consider whether people with sensory impairments are able to access and use online resources.

Some people with dementia or learning disabilities may need support to understand the treatment options available (for example radiotherapy regimens). People with hearing and/or visual impairments may need additional support to ensure that they are able to participate fully in the decision-making process. Advocates, family members or carers may be needed to support decision-making or make decisions on behalf of some people where legally allowed (for example, where a family member has a legal power of attorney for health). Some people with disabilities may need support to travel to and attend appointments and to receive their treatments.

Many people with cancer will experience depression or anxiety, and may require psychological assessment and intervention. Research has shown that some patients with cancer are not receiving timely access to mental health support. Barriers include lack of staff time and training in assessing needs for mental health support and lack of awareness as to the potential sources of support that might be available.

Gender reassignment

While no specific issues relating to kidney cancer have been identified, the Macmillan Cancer Support website highlights some additional concerns that may be faced by trans people undergoing diagnosis and treatment for cancer in general. These include concerns about being treated with respect and dignity during discussions about gender identity and gender history, and concerns about being admitted to single or mixed-sex hospital wards. People who are undergoing transition may have concerns about the impact of cancer treatments on their plans for transition and concerns about the impact of any gender-affirming treatments on any treatments for cancer.

Race

Data from Cancer Research UK from 2013-2017, shows that the incidence of kidney cancer is higher in white ethnic groups than in people from Black or Asian groups, and people with multiple ethnicities. However renal medullary carcinoma, a rare form of renal cell carcinoma, predominantly affects young adults with African and African-Caribbean heritage, who have sickle cell trait, sickle cell disease or other haemoglobinopathies which cause sickling of the red blood cells.

Although not specifically related to kidney cancer, a study by Williams et al 2019 highlighted by Macmillan Cancer Support, noted that women from some minority ethnic groups have some cultural barriers to reporting cancer-related symptoms to healthcare professionals.

Limited English proficiency may also mean that some people face additional challenges in navigating the healthcare system and in understanding and making informed choices about treatment options. If the committee make recommendations about information and support, it may need to consider that some people may need additional support in this area and for information to be provided in alternative formats.

Pregnancy and maternity

Most diagnostic tests and treatments for kidney cancer are likely to be delayed until after pregnancy. Many systemic anticancer drugs would mean breastfeeding would need to be avoided.

Religion or belief

Some people have cultural and religious preferences to keep their kidneys and so have partial nephrectomies. Issues such as these may need to be considered by the committee in making recommendations on communication and support.

Sex

Data from Cancer Research UK show that more men than women in the UK develop and die from kidney cancer. Data from 2017-2019 show that 63% of kidney cancers occurred in men compared to 37% in women and that 62% of kidney cancer-related deaths occurred in men compared to 38% in women. However, a study by Zhou et al 2019 in high-income countries, found that women were more likely than men to experience delays in diagnosis. Kidney cancer in both sexes tends to be diagnosed either through incidental findings of investigations for other conditions, or at advanced stages.

Sexual orientation

No specific issues have been identified in relation to this guideline.

Socio-economics factors

The incidence of kidney cancer and mortality from kidney cancer is linked to deprivation, in particular among women. In England, the incidence of kidney cancer in women is 40% higher in the most deprived quintile compared to the least deprived quintile. In men, the incidence is 17% higher. Mortality from kidney cancer is 44% higher for females and 28% higher for males from the most deprived quintiles when compared to the least deprived quintiles (Cancer Research UK).

An audit of kidney cancer services carried out in England by Kidney Cancer UK in 2022, using data from the National Disease Registration Service 2017 and 2018, found marked variation in the quality of kidney cancer services for 6 quality performance indicators when analysed by NHS Trust and Cancer Alliance. These occurred throughout the pathway and included variations in the proportion of diagnoses made at a stage when tumours were curable, the type of surgery patients received for tumours at a particular stage, and the proportion of patients with metastatic kidney cancer that received systemic pharmacotherapies.

People on lower incomes may find it harder to take time off work to attend appointments, for example, if they are on zero-hours contracts or only have access to statutory sick pay. People on lower incomes or who live in areas of deprivation may have reduced access to online resources offering information and support.

Geographical factors

A study by Harrison et al 2023 focused on follow-up care after surgery for kidney cancer and identified concerns about variations in the content and quality of follow-up care, among different hospitals and treatment centres in the UK. In addition, there is regional variation in access to care. People who do not live near tertiary centres may not be offered all options for the management of kidney cancer if they are not available locally. Difficulties in travelling longer distances due to cost, disabilities, or caring responsibilities, may limit some people’s access to a broader range of treatment options.

Other definable characteristics

Literacy and health literacy entail people's knowledge, motivation, and competence to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention, and health promotion to maintain or improve the quality of life during their life course While some people from higher socio-economic groups may experience poor health literacy, those from lower socioeconomic backgrounds or deprived communities may be disproportionately affected. Poor health literacy may result in people from deprived groups presenting with later-stage cancers and requiring more extensive treatment. In addition, people with low levels of literacy and health literacy may find it harder to understand the treatment options that are available to them.

2.3 How can the identified equality and health inequalities issues be further explored and considered at this stage of the development process?

The aim is that the membership of the committee will represent various perspectives and expertise so that equalities considerations are adequately considered throughout the development of the guideline. For example, we want to ensure that there is expertise in the committee around the most prominent equality and health inequalities issues identified. We also want to ensure different viewpoints by appointing lay members with different perspectives and expertise and experience.

The guideline aims to give special considerations for the subpopulations identified in box 2.2 by taking these groups into consideration when developing review protocols and making recommendations. The committee will consider whether evidence specific to the subpopulations should be sought and whether data should be analysed separately. The committee will consider on a case by case basis whether separate recommendations are required for specific subpopulations to promote equity.

Cross references to relevant other guidelines that may cover issues specific to the groups identified in box 2.2 may be made.

2.4 Do you have representation from stakeholder groups that can help to explore equality and health inequalities issues during the consultation process including groups who are known to be affected by these issues? If not, what plans are in place to address gaps in the stakeholder list?

Engagement with voluntary sector organisations will be key in accessing and engaging with people with lived experience and we aim to provide needed adjustments to facilitate any engagement and participation by people who have lived experience of kidney cancer. We will work with the NICE Public Involvement Programme (PIP) team to encourage representation from stakeholder groups that can help to explore equality and health inequalities issues.

2.5 How will the views and experiences of those affected by equality and health inequalities issues be meaningfully included in the guideline development process going forward?

We will recruit lay members to obtain contributions to the final scope of the guideline on health equity and inequalities. We will also consider asking specific questions during guideline consultation addressing people with lived experience in order to gain as much insight from their perspective as possible. This could potentially be facilitated by having direct contact with voluntary/charity sector organisations who engage with people with lived experience.

In order to facilitate lay members' (people with lived experience) participation in the committee meetings, we will consider offering additional support, depending on their situations and needs. For example, some adjustments may be necessary with logistical issues such as providing space, computer, and internet access to attend the (virtual) meetings, providing support workers may be needed, and support before and after meetings could be considered. If needed, we will consider doing this, for example, by liaising with a kidney cancer charity with which the lay member might already be engaging.

2.6 If applicable, what questions will you ask at the draft scope stakeholder consultation about the guideline/update and potential impact on equality and health inequalities?

No specific questions are planned about equality and health inequalities issues, but stakeholders will be invited to comment on the subgroups within the draft EHIA.

2.7 Has it been proposed to exclude any population groups from the scope? If yes, how do these exclusions relate to any equality and health inequalities issues identified?

Children and young people under 18 years of age. As discussed in section 2.2, kidney cancer in children and young people is rare and is managed in a paediatric cancer pathway.

Completed by developer: Karen Peploe and Stephen Sharp

Date: 31/07/2023

Approved by committee chair: Baljit Singh

Date: 02/08/2023

Approved by NICE quality assurance lead: Kate Kelley

Date: 15/08/2023

STAGE 3. Finalising the scope

Kidney cancer: Diagnosis and management

Date of completion: October 2023

Focus of guideline or update: Diagnosis and management of kidney cancer

3.1 How inclusive was the consultation process in terms of response from stakeholders who may experience inequalities related to the topic (identified in 2.2)?
In total 64 potential stakeholder organisations were identified for this guidance and were invited to participate in the consultation. As the consultation was made available on the NICE website, other organisations were also able to register and submit comments if they chose to. Comments were received from 12 organisations and 2 non-registered individuals. The responding organisations included professional bodies and interest groups, NHS organisations at national and local level, commercial organisations and the voluntary sector. Two of the key voluntary sector organisations specialising in supporting UK patients with kidney cancer responded to the consultation. Their comments accounted for around half of the comments received overall. While some of these focused on the technical aspects of the draft scope, others focused on equalities issues. One of the organisations also included links to findings of their annual patient survey which describes the experiences of people living with kidney cancer, including their experience of diagnosis, treatment and the information and support they had and had not been offered.

3.2 Have any additional equality and health inequalities issues been identified during consultation? If so, what were they and what potential solutions/changes were suggested by stakeholders to address them?

Stakeholders identified various issues, most of which provided further detail or considerations in relation to issues identified prior to consultation. These included the following:

Age

While poor health literacy may affect people of any age (see ‘other definable characteristics’ in section 2.2), one stakeholder noted that some older people may be more likely to have poor health literacy. For this reason, they may present with later stage kidney cancer and have difficulty in understanding treatment options. Information may need to be provided in accessible formats and face-to-face appointments held, to ensure that they are able to fully engage in the decision-making process and make informed choices about treatment options.

It was also noted that difficulties travelling to specialist or tertiary care centres, due to mobility issues, cost and availability of transport and in some cases the need to be accompanied by a carer, may limit the availability of a full range of treatment options for some older people.

One stakeholder noted that younger adults may face some additional costs associated with attending appointments, if they have to pay for childcare. This would be in addition to the other costs that were previously identified in section 2.2.

Disability

Reasonable adjustments were noted by one stakeholder as being a legal requirement and it was suggested that the guideline makes reference to the Reasonable Adjustment Digital Flag .

In relation to communication, a stakeholder highlighted that some people with disabilities may not be able to communicate verbally and suggested that in some cases, using pictures could be a helpful way of providing information in an alternative format.

During discussions around communication, the committee noted that this can be particularly challenging when treating patients with dementia. As many patients who are diagnosed with kidney cancer are older people, this is an important consideration as it can affect the person’s ability to understand and make decisions about treatment options and to comply with treatment.

A stakeholder provided a link to a report which focuses on premature and avoidable deaths among people with learning disabilities. The report highlights that the average age of people with learning disabilities who died in 2021 is lower than that of the general population (61 years compared to 83 years in men and 60 years compared to 86 years in women). It also highlights that half of the people with learning disabilities who died in

2021, lived in areas from the two most deprived quintiles. The report focuses on avoidable deaths and highlights that 49% of deaths among people with a learning disability were rated as 'avoidable' compared to 22% among the general population. 8% of these avoidable deaths were linked to all cancers and 16% to kidney problems. Although not specific to kidney cancer, the report highlights that some people with learning disabilities experience multiple inequalities in health (LeDer annual report 2021).

Race

One stakeholder noted that information and support materials may need to be provided in alternative languages, as well as alternative formats as has been previously noted.

Religion or belief

One stakeholder noted that for some people, religious or cultural barriers may prevent them discussing some of the symptoms of kidney cancer such as blood in their urine, with their doctor.

Geographical variation

A stakeholder highlighted an addendum to the previously referenced audit conducted by Kidney Cancer UK in 2022, which found marked variation in the quality of kidney cancer services for 6 quality performance indicators when analysed by NHS Trust and Cancer Alliance (see section 2.2). The addendum provides an additional analysis on survival rates. The findings suggests that variations in treatments offered and the timing with which they are offered, affects survival rates. The results of an annual patient survey also highlighted variation in practice, particularly around the provision of mental wellbeing support for patients with kidney cancer (Kidney Cancer UK 2022).

Other definable characteristics

Access to technology, or difficulty using technology, was raised by one stakeholder as a potential barrier to being able to use online resources providing information and support about kidney cancer. While this was raised specifically in relation to older people who may not have access to technology, it is recognised that this may also affect people for a variety of other reasons. These include disability, socio-economic or financial reasons and geographical factors, such as lack of, or limited access to the internet in some rural areas. Some people may need additional support to access and use online resources, or where internet access is unavailable or limited, resources may need to be provided via alternative means.

3.3 Have any changes been made to the scope as a result of the consultation and equality and health inequalities issues identified in 2.2 and 3.2? Were any other changes made to the scope that may impact on equality and health inequalities?
No changes were made to the scope as a result of the comments received at consultation in relation to equality and health inequalities considerations. Other changes made to the scope were few and were minor points of clarification that do not impact on equalities issues. No changes were made that relate to equality and health inequalities considerations as the issues raised by stakeholders are not issues which the guideline is likely to be able to address. However, the committee may need to consider these issues when making recommendations, to ensure the guideline is widely implemented.

Completed by developer: Karen Peploe and Stephen Sharp

Date 20/10/23

Approved by committee chair: Baljit Singh

Date 01/11/23

Approved by NICE quality assurance lead: Kate Kelley

Date 02/11/23

STAGE 4. Development of guideline or topic area for update

Kidney cancer: Diagnosis and management

Date of completion: July 2025

Focus of guideline or update: Diagnosis and management of kidney cancer

4.1 From the evidence syntheses and the committee's considerations thereof, what were the main equality and health inequalities issues identified? Were any **further** potential issues identified (in addition to those identified during the scoping process) or any gaps in the evidence for any particular group?
Protected characteristics outlined in the Equality Act 2010 - **Age** In addition to issues affecting older adults (who may find accessing treatment difficult for issues of frailty, requirement for support during travel, or having caring responsibilities themselves – see previous sections), the committee highlighted potential inequalities facing younger adults (children aged 17 years or younger are outside of the scope of this guideline). For example, people with heritable RCC predisposition syndromes are likely to have RCC at a younger age, and younger adults may face additional costs associated with attending appointments if they have to pay for childcare. The committee also noted that people diagnosed with RCC at a young age, especially those with a heritable RCC predisposition syndrome, may receive imaging for general surveillance of their syndrome, active surveillance and follow up for renal lesions for long or repeated periods over their lifetime. These groups will face cumulative risks from any imaging (such as radiation from CT). Age was included as a subgroup of interest in many of the reviews, but there was either no evidence identified for the specific categories of interest, or where evidence was identified it was confined to a single age group (for example, over 65 year olds) that overlapped with the mean ages in the other included studies and so subgroup analysis was not possible. - **Disability** CT and MRI machines have an upper weight limit due to safety and the design of the equipment. Therefore, some people with obesity may have reduced options available for imaging for diagnosing RCC, for conducting active surveillance or follow-up after treatment. - **Gender reassignment**

No further issues were identified

- **Pregnancy and maternity**

It has been noted in sections above that many diagnostic tests and treatments for RCC are likely to be delayed until after pregnancy. The committee noted that certain types of imaging are not suitable for pregnant women and being pregnant can affect the choice of imaging used during diagnosis, as well as for during active surveillance or during follow-up after treatment.

- **Race**

No further issues were identified. Very little evidence according to ethnicity was identified for reviews undertaken in this guideline. The committee did not include ethnicity as a subgroup of interest in the review protocols so no analysis by race was attempted, but if it had been included it would probably not have been possible given the very limited evidence base.

- **Religion or belief**

No further issues were identified

- **Sex**

No further issues were identified.

- **Sexual orientation**

No further issues were identified

Socio-economic deprivation

It has been noted in sections above that people on lower incomes may find it harder to take time off work to attend appointments, for example, if they are on zero-hours contracts or only have access to statutory sick pay. The committee noted that this may be particularly relevant to people undergoing active surveillance or follow-up after treatment, both of which usually require repeated appointments over a number of years. This is also particularly relevant for people with RCC who have a heritable RCC predisposition syndrome as they may require constant imaging across their lifetime for multiple RCCs.

The expense of travel for diagnosis or management options which may only be offered at tertiary centres – for example biopsy, partial nephrectomy, minimally invasive radical nephrectomy – can also create barriers to access. Difficulty attending appointments may be exacerbated by other equalities issues such as disability or caring responsibilities, creating cumulative burden.

Geographical variation

Earlier sections of the EHIA described variations in quality of care due to regional variation in availability of some options for management of kidney cancer. The committee discussed this throughout the development of the guideline. They noted that availability of contrast-enhanced ultrasound for diagnosis of RCC is limited due to availability of trained radiologists to conduct the scan. Biopsy is usually performed in tertiary centres as many local centres do not have the capacity or capabilities to offer biopsy. Some surgeries for treating RCC – such as partial nephrectomy, minimally invasive total nephrectomy, and cytoreductive nephrectomy – are still most commonly available in some areas at specialist or tertiary centres. There is also limited availability of Clinical Nurse Specialists (CNS). This presents barriers to access for people living in rural or remote areas, or far away from tertiary centres. Other equalities characteristics which may make travel difficult will exacerbate these issues.

Other definable characteristics

People who do not have knowledge of their family background, for example if they are adopted and do not have contact with or information about birth parents, may be disadvantaged as they would be unaware of any family history of renal cancer, which is a criterion for when to suspect a heritable RCC predisposition syndrome.

4.2 How have the committee's considerations of equality and health inequalities issues identified in 2.2, 3.2 and 4.1 been reflected in the guideline or update and any draft recommendations?

The committee's discussions about equality and health inequalities issues are included in evidence reviews under the section on other factors the committee took into account in the committee's discussion of the evidence.

Many of the issues identified by the committee were societal in nature and not within the remit of this guideline to be able to address. The committee agreed that there were barriers to accessing care options only offered at tertiary or specialist centres, and that some people are not offered these options (seer reviews A, B, C, H1 and H2, J for more information). However, they agreed that it remained important to give patients information about all suitable and relevant treatment options and services that they are entitled to, even if they are not provided locally as they can be referred for treatment elsewhere. They acknowledged that this is already a recommendation in NICE's guideline on patient experience in adult NHS services (1.3.3) and so did not replicate it in the current guideline.

The committee were able to make recommendations to address some of the issues raised above. These recommendations can be grouped into 2 overarching areas:

1. Shared decision making and providing information to support this process

To facilitate the decision-making process and ensure that patients are able to fully participate in this, the committee added cross references to relevant sections of some core NICE guidelines in the overarching section of the kidney cancer guideline that covers information needs (see review D for more information). These were the section on patient information and support in NICE’s guideline on suspected cancer, NICE's guideline on patient experience in adult NHS services, NICE's guideline on shared decision making, NICE’s guideline on workplace health and NICE's guideline on people's experience in adult social care services.

In particular, NICE's guideline on patient experience in adult NHS includes recommendations about knowing the patient as an individual with recommendations on taking the person’s circumstances into account, Tailoring healthcare services for each patient with recommendations on taking the person’s view and preferences into account and on involving family members or carers.

Other recommendations about specific information to share with people with suspected or confirmed RCC were made for the following areas: biopsy (see review J for more information); non-pharmacological options for people with localised RCC (Review B) and before surgery (Reviews D); active surveillance (Review E), follow-up (Review F), risk prediction tools (Reviews K and L), diagnosis of heritable RCC predisposition syndromes (review D).

2. Types of imaging and scheduling imaging

There are recommendations in the guideline for imaging at multiple stages of the diagnosis and treatment pathway, and similar equalities issues and potential solutions applied across these stages.

During diagnosis, the committee made recommendations about using contrast-enhanced CT imaging as the first option but also included options for MRI, contrast-enhanced ultrasound and sestamibi scans for people who can’t have CT. This could be because of a need to avoid/ reduce radiation exposure (for example, during pregnancy), obesity, allergy to the contrast agents or other reasons (Review I2). There were similar recommendations in the section on active surveillance (review E), with the choice of imaging from CT, MRI or ultrasound to be based on the lesion’s and the person's clinical characteristics (such as kidney function). The recommendations on imaging during follow up after treatment also offer MRI as an alternative to CT if CT should be avoided to reduce radiation exposure.

The committee also noted that MRI may not be available in all areas or there may be limited capacity in the system. By listing a range of types of imaging that could be suitable in the recommendation the committee tried to ensure that people would not be disadvantaged by having to wait for access to MRI imaging if it is not readily available in their area. For example, during diagnosis sestamibi imaging could be used after CT and MRI, or alternatively after CT or MRI if diagnostic uncertainty remains.

The committee made separate recommendations about imaging during active surveillance and follow up for people with RCC who have a heritable RCC predisposition syndrome. They recommended MRI or ultrasound imaging instead of CT for active surveillance to limit radiation exposure over the long term (see review G for more information). For follow up they recommended abdominal MRI and chest CT. Because of the potential impact of receiving imaging throughout their life as part of routine surveillance and to monitor other complications associated with their syndrome, the committee recommended that for people with heritable RCC predisposition syndromes imaging should be coordinated between departments to prevent duplication and minimise the number of hospital appointments required.

For people without heritable RCC predisposition syndromes, the committee recommended that both active surveillance and follow-up approaches should not usually go on indefinitely (see reviews E and F for more information). They made recommendations about when to consider discharge, which would reduce negative impacts of repeated imaging, compared with continued imaging, especially for people who are diagnosed with RCC at a young age.

a. Could any draft recommendations potentially increase inequalities?

Yes, some of the draft recommendations could potentially increase inequalities where types of imaging or treatments are only available in bigger specialist centres. Even if people are told about their full range of options and can be referred not everyone will be able to travel. The committee are unable to make recommendations to mitigate some of these issues because they are beyond NICE's remit. However, we have recommended a range of imaging options at diagnosis, during active surveillance and during follow up to try to address situations where certain types of imaging are unsuitable for specific individuals or unavailable. We have also recommended a range of treatment options for people with localised or locally advanced RCC.

b. How has the committee's considerations of equality and health inequalities issues identified in 2.2, 3.2 and 4.1 been reflected in the development of any research recommendations?

Due to the uncertainty about the impact of ethnicity and sex on the accuracy of risk prediction models for people with localised or locally advanced, and metastatic RCC the committee made several research recommendations for prediction tools that:

- could predict the risk of recurrence in people who have not had surgery of the primary tumour, or who had chromophobe RCC for people with localised or locally advanced RCC
- could predict the risk of progression or metastasis in people with localised or locally advanced RCC who are undergoing active surveillance
- could predict survival and progression in people with metastatic RCC.

In all cases, they suggested that the research should look at a broad population with different characteristics (for example ethnicity and sex).

c. Based on the equality and health inequalities issues identified in 2.2, 3.2 and 4.1, do you have representation from relevant stakeholder groups for the guideline or update consultation process, including groups who are known to be affected by these issues? If not, what plans are in place to ensure relevant stakeholders are represented and included?
We have reviewed the list of stakeholder organisations to ensure that key patient groups are included (such as Action Kidney Cancer, Kidney cancer UK) and patient groups representing people with heritable RCC predisposition syndrome have also been invited to register as stakeholders (for example, the Birt-Hogg-Dubé Foundation and VHL UK/Ireland)

d. What questions will you ask at the stakeholder consultation about the impact of the guideline or update on equality and health inequalities?
No specific questions will be asked about equality and health inequalities, but we will ensure that any comments from relevant stakeholders are considered and discussed with the committee, and changes will be made where necessary.

Completed by developers: Olivia Crane and Marie Harrisingh

Date: 31/7/25

Approved by committee chair: Baljit Singh

Date: 05/09/2025

Approved by NICE quality assurance lead: Kate Kelley

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