

FINAL

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Equality and health inequalities assessment (EHIA)

**NATIONAL INSTITUTE FOR HEALTH AND CARE
EXCELLENCE**

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 Peplow and Stephen Sharp

Date: 31/07/2023

Approved by committee chair: Baljit Singh

FINAL

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 Peplow 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