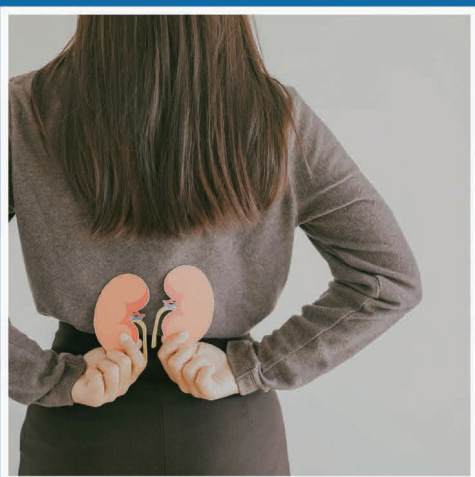
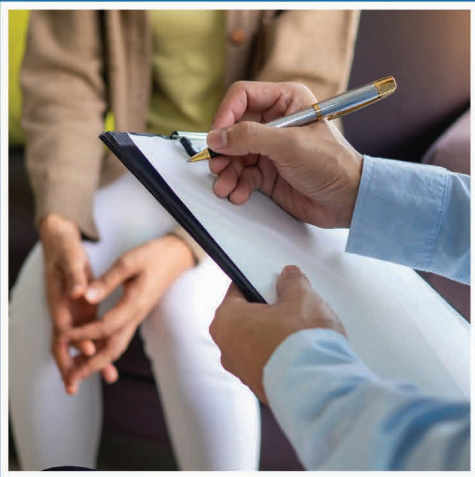




Kidney Cancer UK

THE UK'S LEADING KIDNEY CANCER CHARITY



The 11th Annual Kidney Cancer UK Patient Survey 2024 Report

20 24

The only patient-focused
survey of kidney cancer
in the UK.



Published February 2025

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Kidney cancer is a growing threat

Kidney cancer has now become the sixth most common cancer in men and women in the UK.¹

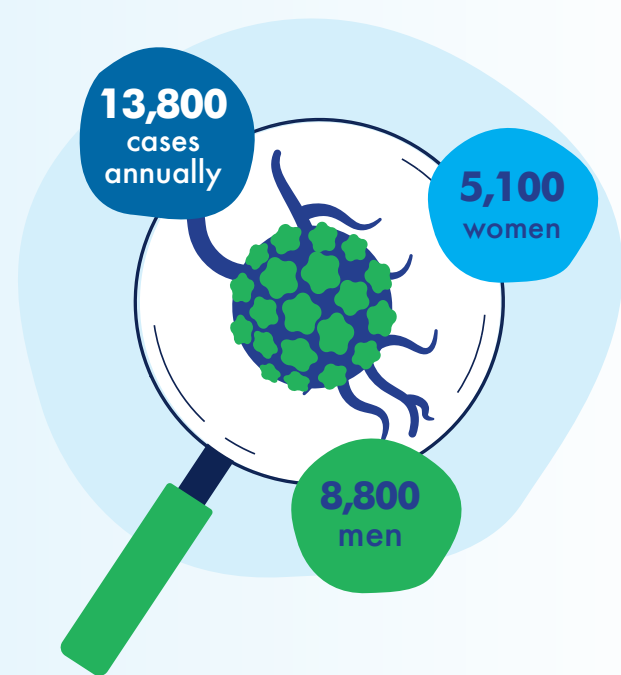
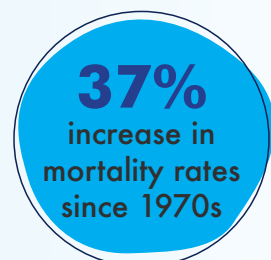
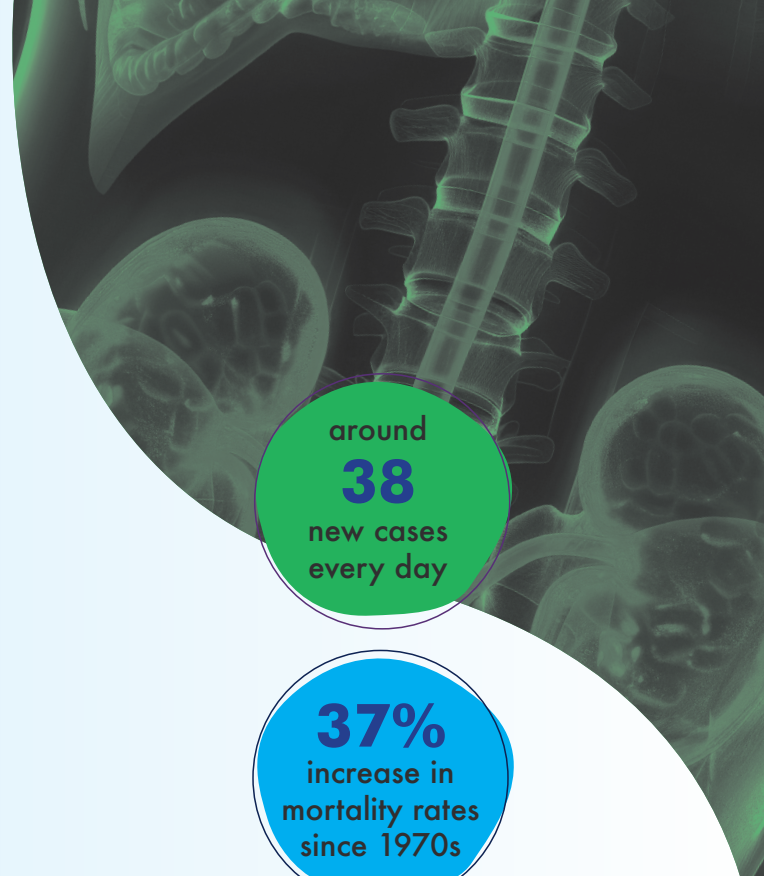
Data from 2017-19, the latest available figures, show that the European Age-Standardised (AS) Incidence Rate is 21.9 per 100,000 population.² This means the relative incidence of kidney cancer compared with other types of cancer has changed from the seventh to the sixth most common cancer in the UK as of July 2024.¹

The 2017-19 figures show that there are around 38 new cases every day, amounting to a total of 13,800 annually. Approximately 5,100 of these new cases are in women and 8,800 new cases in men.

Mortality rates in the UK due to kidney cancer have increased by 73% since the 1970s.³ Around 4,700 people die each year, which is about 13 people every day.

UK incidence rates are still increasing; they have gone up by a quarter (26%) over the last ten years and are projected to rise further in the future.

This is the eleventh, and only patient-focused survey of kidney cancer in the UK. It ran online from 14th September 2024 to 24th November 2024 and received 765 responses.



1 Cancer incidence for common cancers. Cancer Research UK <https://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence/common-cancers-compared#heading-Zero> Last reviewed 19 July 2024. Last viewed Nov 2024

2 Kidney cancer incidence by gender and UK country. Cancer research UK <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/kidney-cancer/incidence#heading-Zero> Last reviewed 29 May 2024. Last viewed Nov. 2024

3 Kidney cancer mortality. Cancer Research UK <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/kidney-cancer#heading-One> Last viewed Nov 2024

Introduction

First, I would like to thank every patient who shared their kidney cancer journey with us during the 11th year of this important survey. This year, we achieved our largest ever response, with over 765 replies. Each response will help Kidney Cancer UK provide the best possible support to patients, carers, and family members through our services, while also influencing decision-makers not only in the UK but around the world.

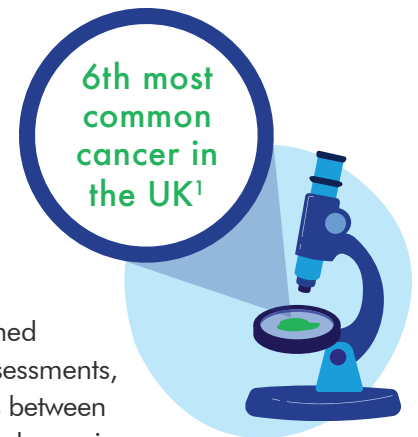
Kidney cancer diagnoses are on the rise. At the time of writing the latest statistics from Cancer Research UK list kidney cancer as the 6th most common cancer in the UK, up from 7th in previous years. The average number of diagnoses per year increased to 13,834 between 2017 and 2019, from the previous figure of 13,322. The number of people losing their lives to kidney cancer remains at around 4,700 per year. If we are to reduce this figure in light of the increasing number of diagnoses, it is crucial that we find more new cases at an earlier stage when the patient outcome is better.

Our annual survey has identified a pressing need for change across kidney cancer diagnosis, treatment, and support pathways.

Currently, the NICE guideline NG12 (Suspected cancer: recognition and referral) identifies blood in the urine as the only early symptom of kidney cancer. It is important that this guideline is updated to reflect the full range of kidney cancer symptoms. According to our survey these are, in order of commonality; pain in the side, fatigue, blood in urine and night sweats. Supporting GPs, nurses and pharmacists in recognising patterns of symptoms would help them to identify patients needing specialist investigation and refer them earlier.

Post-diagnosis, patient care is inconsistent. The GP Cancer Care Reviews—key for tailored

support—are not happening often enough, with well over 50% of patients surveyed not receiving them, or not recognising when they are done. These reviews, informed by Holistic Needs Assessments, can help bridge gaps between hospital discharge and ongoing care.



'Biopsies, critical for confirming tumour types, are underused. Many patients are not offered this choice'

Biopsies, critical for confirming tumour types, are underused. Many patients are not offered this choice, despite its importance in confirming the presence of cancer and in tailoring treatment. Adhering to National Kidney Cancer Audit recommendations and GIRFT guidelines would improve outcomes and reduce unnecessary interventions.

For many years, our surveys have highlighted the urgent need to overhaul the availability of free and reliable support for patients on the NHS. Charities offer a wide range of services and support to assist patients at every stage of their journey. I appeal to everyone in the NHS involved in diagnosing, treating, or caring for kidney cancer patients to collaborate with us and make use of the services we provide.

There is much work ahead to ensure every patient feels informed, cared for, and supported throughout their journey, and together in collaboration we can rise to higher levels of patient support.

Malcolm Packer
Chief Executive Officer
Kidney Cancer UK

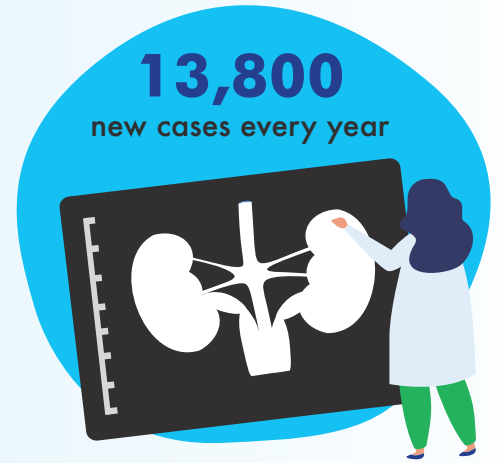
Executive Summary

GPs and other primary care professionals need more help to identify patients who should be referred for specialised diagnosis of suspected kidney cancer.

The low level of patients offered biopsies suggests some patients are treated for kidney cancer sub-optimally, or even unnecessarily.

Many patients complain of inadequate follow-up throughout the kidney cancer treatment pathway, with too little information and support being provided.

Kidney cancer clinics are not reaching out to other agencies and organisations for help in providing information and support for patients that the NHS cannot.



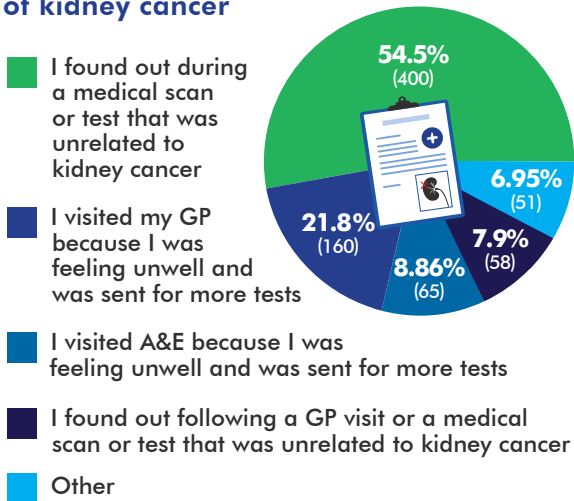
Recommendations

- 1 NICE guideline NG 12 Suspected cancer: recognition and referral should be updated to include all relatively common symptoms indicative of kidney cancer.
- 2 A small kidney cancer training and awareness package should be developed for all primary care health professionals including GPs, nurses and pharmacists.
- 3 A Cancer Care Review should be carried out with all patients within three months of diagnosis and/or within 12 months of acute treatment.
- 4 The recommendations on biopsies in the National Kidney Cancer Audit report and the Getting It Right First Time (GIRFT) guidelines on biopsy for kidney cancer patients with small tumours should be followed more closely.
- 5 Appropriate specialist kidney cancer centres should be encouraged to take part in clinical trials and should publicise this so that a) patients are aware, and b) colleagues in other centres are aware and can refer.
- 6 Kidney cancer units should make sure they can satisfy patients' information needs no matter what medium chosen by the patient, by either providing easily accessible NHS kidney cancer information across all media or sign-posting to reputable external sources such as charities.
- 7 To facilitate patient informed participation in shared decision-making and particularly when obtaining informed consent, clinics should ensure patients have been provided with, or given access to, all information that could influence their decision.
- 8 Holistic Needs Assessments should be carried out with all patients and should include their preferences for receiving information and other support. This information should be shared with their GP and should be fed into the Cancer Care Reviews which should be carried out in Primary Care to ensure support is available and consistent throughout the pathway.

Low level of early patient identification and referral is not improving

More than half of patients are incidentally diagnosed with kidney cancer whilst having a scan or test for another, unrelated condition. This figure has risen from 48.3% to 54.5% in this latest survey, with another 8.9% being diagnosed following tests after presenting to an Accident and Emergency Department feeling unwell.

Routes to diagnosis of kidney cancer



This is around twice the percentage diagnosed following a GP visit or a medical scan/test related to kidney cancer symptoms (29.7% in 2024 which was slightly less than the 31.2% in the previous year).

The majority of new cases are found in patients aged between 60 and 85. These patients should be receiving annual routine health checks, but only 4.4% of kidney cancer cases are picked up in this way.

Although 37.5% of patients had no symptoms, the majority do, although the common ones considered individually, are not specific to kidney cancer. Also there is no convenient, cheap test for kidney cancer. However, helping GPs and other primary care health professionals to identify a pattern of all, or most of, the common symptoms, could encourage them to refer the patient for further tests at an earlier stage.

The NICE Guideline NG12 ‘

Suspected cancer: recognition and referral’ includes only blood in the urine

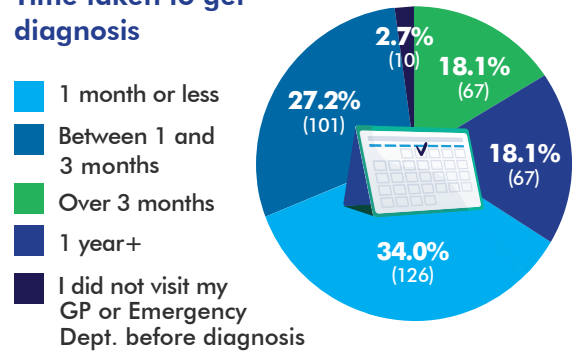
Common kidney cancer symptoms reported in this survey

35.5%	pain in back/flank/side
35.0%	fatigue
21.3%	night sweats
19.1%	blood in urine

as a sign of kidney cancer. A lack of comprehensive early recognition guidance means that kidney cancer may not be immediately identified. 21.0% (1 in 4) of patients in our survey said they were initially misdiagnosed and treated for other illnesses.

Although there are signs of what may be a slight increase since last year, the proportion of patients diagnosed within 3 months from first seeking medical assistance remains at just over half (61.2%), 34.0% being diagnosed within one month. It is very concerning to see that it took more than a year to diagnose 18.1% of patients.

Time taken to get diagnosis



Recommendation

NICE guideline NG 12 Suspected cancer: recognition and referral should be updated to include all the relatively common symptoms indicative of kidney cancer.

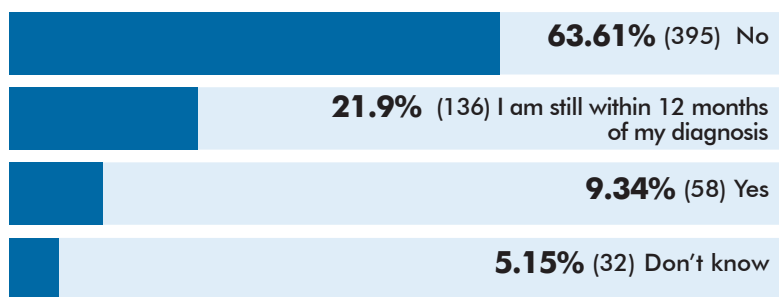
A small training and awareness package should be developed for all primary care health professionals including GPs, nurses and pharmacists.

Local follow-up for patients during, and after, treatment is inadequate

More than one in four patients (27.6%) were not happy when they were discharged from hospital. 15.3% did not feel the decision to discharge them was appropriate and a further 12.3% wanted more information.

After discharge, 57.3% of patients said their GP had not contacted them to offer follow-up support. A further 11.5% said their GP took more than 5 weeks to make contact with them. This suggests not only a lack of support in general, but also the absence of coordinated support around follow-up scans, which can cause patients a great deal of anxiety.

63.3% of patients had not received a Cancer Care Review by their GP 12 months from diagnosis.



A Cancer Care Review is essential to the personalised care of the patient. It consists of a conversation between a patient and a health/social care professional so that the patient understands what help is available to them locally and has all the information they need about their condition. It also gives the health/social professional a picture of the patient's needs and can be usefully informed if the treating centre shares the Holistic Needs Assessment, which they should have carried out soon after receiving the patient. The importance of Cancer Care Reviews are illustrated by their inclusion in NHS England's Quality Outcome Framework (QOF).

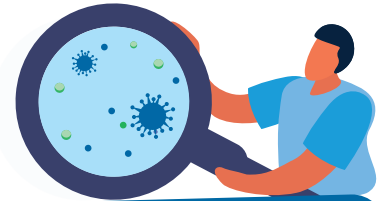
Most patients receiving follow-up said they had scans (51.6%) and a further 39.3% said they had blood tests.

The time taken for scan results to be reported to the patient has improved compared with 2023. However, a small proportion of patients say it still takes longer than 8 weeks to receive their scan results.

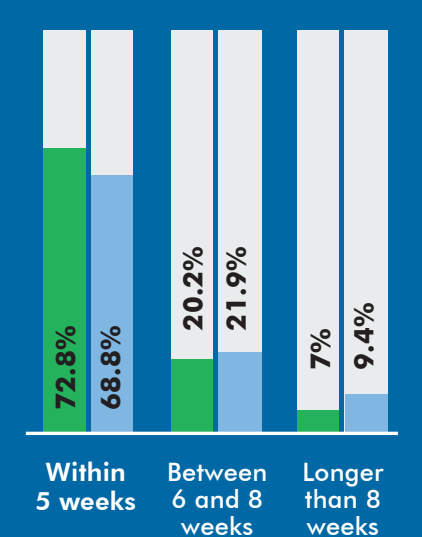
It is also important to note that patients whose cancer does not return will eventually be discharged from follow-up care. These patients need clear information about what to do if symptoms reappear, who to contact, and what additional support is available outside the NHS, such as support groups and charities. To what extent this happens is a potential area for further research.

"...after discharge there was confusion... discharge paper went to temporary GP I was with while I was staying with my daughter previously to hospital stay. It took almost 6 weeks of being bed bound in hospital before they sent me home with a 2-4month prognosis."

Comment from survey



Time from scan to results being reported



Recommendation

A Cancer Care Review should be carried out with all patients within three months of diagnosis and/or within 12 months of acute treatment.

"...I was discharged over the telephone, no information on follow-up checks (i.e. blood tests and MRI Scans) was offered. Information about where to source help would have helped greatly with both my husband and I having pre-existing conditions and disabilities. I felt abandoned..."

Comment from survey

Some patients being treated sub-optimally or inappropriately



"I went straight to partial nephrectomy because a solid tumour was likely to be cancer."
 Comment from survey

According to NHS England’s Getting It Right First Time (GIRFT) programme of guidance, in many cases, imaging and enhancement alone cannot distinguish between malignant and benign masses in the kidney. *“Currently, renal mass biopsy is the only effective method for distinguishing whether a mass is benign or cancerous.”*⁴

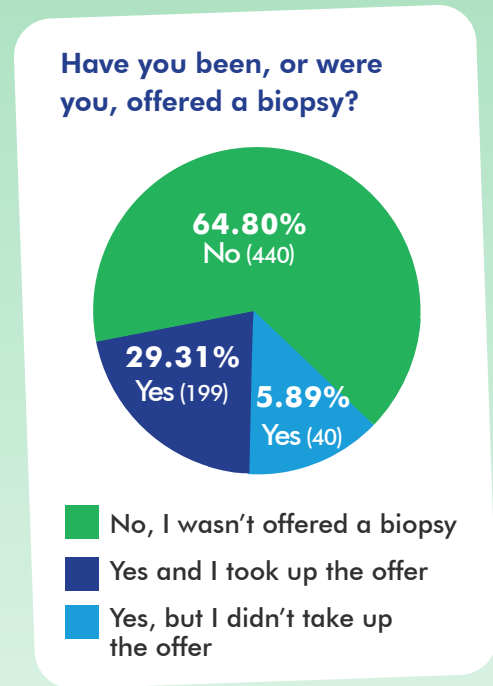
However, our survey shows that over 70% of patients surveyed had not had a biopsy. In fact 63.3% (almost two thirds) of patients said they were not offered one.

Of the 34.4% who were offered a biopsy, 81.9% took up the option and most (75.4%) said the reason for it was clearly explained to them. In the vast majority of cases (82.7%) the biopsy confirmed cancer.

The National Kidney Cancer Audit recommends *“Increase the number of people with a small renal mass who receive a renal mass biopsy to confirm the histological diagnosis, by improving availability of timely diagnostics.”*⁵

(GIRFT) guidance states that *“For all patients with solid small renal masses consider offering biopsy, where technically feasible, if it will impact patient’s choice or clinician’s recommendation on treatment.”*⁴

Biopsy is not suitable for all kidney cancer patients, but if it is underutilised, there is the risk that some patients might not receive optimal treatment because it is not based on a clear grading of the tumour. Even more fundamentally, it means that treatment might be given to some patients without knowing if the tumour was cancerous, which could lead to inappropriate treatments.



Recommendation

The recommendations on biopsies in the National Kidney Cancer Audit report and the Getting It Right First Time (GIRFT) guidelines on biopsy for kidney cancer patients with small tumours should be followed more closely.

"I was offered a biopsy but both my urology consultant and surgeon were almost certain that it was cancer and that a biopsy would be an unnecessary delay. I opted to have the surgery as soon as possible." "

Comment from survey

⁴ Urology: Towards better care for patients with kidney cancer. 2023. NHSE Getting It Right First Time Programme. https://gettingitrightfirsttime.co.uk/wp-content/uploads/2023/06/20230616_Urology_Guidance_Kidney-cancer-FINAL-V1.pdf Last viewed Nov. 2024

⁵ National Kidney Cancer Audit (NKCA) State of the Nation Report 2024 London: National Cancer Audit Collaborating Centre, Royal College of Surgeons of England, 2024

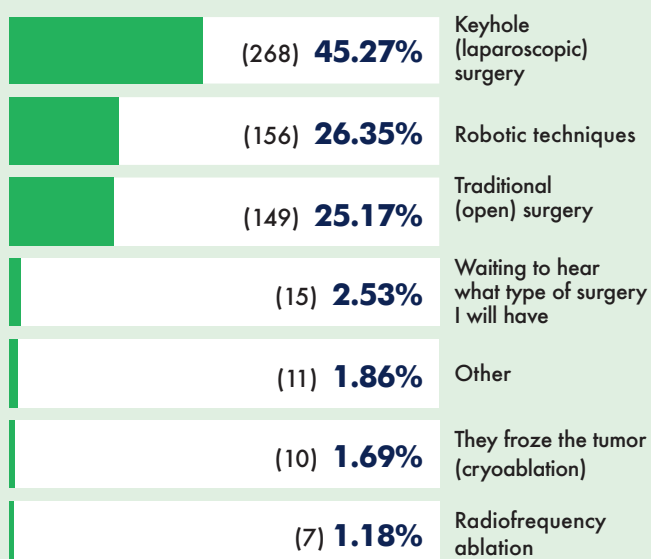
The rate of uptake of new technologies is slow and not improving

In our survey, 87% of patients said they had received, or were going to receive, surgery. Of these, 20.7% had a partial nephrectomy and 73.1% had a nephrectomy.

Of those having surgery, only 25.2% had traditional (open) surgery. Nearly half (45.3%) had it laparoscopically; this figure has remained similar since 2020, but it is worth noting that the first laparoscopic nephrectomy in the UK (and Europe) was performed in 1991,⁶ meaning that it took approximately thirty years for this technique to be used at its current level.

In contrast, robotic surgery has been taken up more quickly. Since being approved for use in the NHS the proportion of patients receiving robotic surgery in our survey has risen from 4% in 2016 to 26.6% in this year's survey.

Type of surgery received or due to be received?

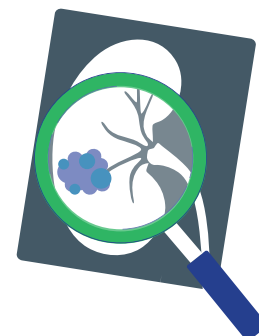


⁶ Virtual Museum: Kidneys -Nephrectomy. The British Association of Urological Surgeons website. <https://www.baus.org.uk/museum/1429/nephrectomy>

"Consultant Urologist said there would be a wait on NHS for Cryoablation but couldn't say how long - this would allow the cancer to grow and become more than stage 1..."

Comment from survey.

The usage of cryoablation and radiofrequency ablation remains very low despite positive recommendations from the National Institute for Health and Care Excellence (NICE).



In relation to systemic treatments, access to clinical trials remains poor. In our survey, 72.5% of patients said they had not been involved in a clinical trial. Although this is fewer than the proportion in 2023 (which was 81.0%), overall access remains low. This is a major concern; not only does it mean patients are unable to use the latest treatments, it also means that clinicians in the UK are not able to gain early experience with new treatments that would lead to greater confidence and appropriate prescribing when the treatment became generally available.

The exception to the trend of slow uptake appears to be adjuvant systemic therapy, which is prescribed following the primary treatment (e.g. surgery, ablation etc.) to reduce the risk of the cancer returning. In 2023, 21.3% of patients taking systemic medicines said it was for adjuvant use. In 2024, this figure has risen to 28.8%.



Recommendation

Appropriate specialist kidney cancer centres should be encouraged to take part in clinical trials and should publicise this so that a) patients are aware, and b) colleagues in other centres are aware and can refer.

Too little patient information and communication throughout the pathway

Patient satisfaction with the information they were given and the way in which key results and information about their own case were communicated to them varies throughout the pathway.

"I wasn't given any information. I got all my information from Facebook groups & Google"
Comment from survey.

Information on drug side-effects has been consistently good throughout our survey results over the last few years. Similarly, involvement in the choice of treatment has been good, but one in five (20.2%) patients said they did not have sufficient information. So there is a significant proportion of patients who might not be able to make an informed choice about their treatment.

Other elements of the pathway where information and communication need to be improved are; the way in which the patient is told they have kidney cancer; the explanation of the results of biopsies (bearing in mind that biopsies appear to be underutilised in kidney cancer); information received before surgery and information provided for patients who are discharged from treatment or follow-up. All of these are key points along the pathway.

The Clinical Nurse Specialist (CNS) has a crucial role in communicating with patients and providing information, but over one in five (21.4%) patients were not given the name of a CNS.

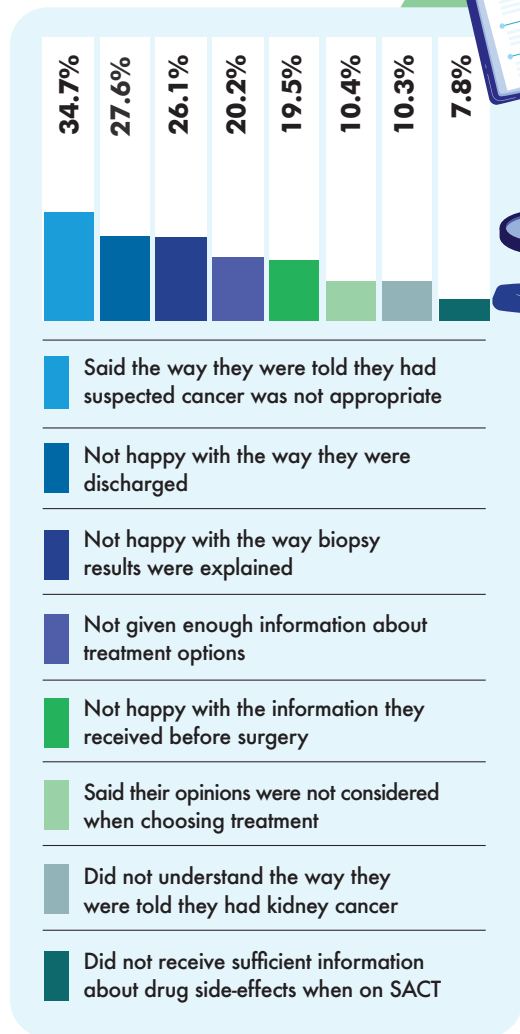
Communication and the provision of information are important in building and maintaining confidence and trust between patients and the health professionals treating them. Consequently, they need to be good throughout the pathway. Whilst there are parts of the pathway where information and communication are good, these may be let down by parts where it is not.

Following surgery, many patients report negative feelings. 31.4% are scared the cancer will return; 31.1% feel anxious; 29.1% feel emotionally low and 24.5% felt abandoned after surgery and wished there was more contact with health professionals.

"I received no support at all after surgery. I felt dismissed and unsupported. I was unsure what was normal or how I could expect to feel after surgery."
Comment from survey.

Survey response

Percentage of patients



"There was no care plan put in place for my return home, I have significant disabilities and am the only carer of my husband who has severe disabilities. I mentioned it several times while in hospital but nothing was done about it."
Comment from survey.

Recommendation

Kidney cancer units should make sure they can satisfy patients' information needs no matter what medium chosen by the patient, by either providing easily accessible NHS kidney cancer information across all media or signposting to reputable external sources such as charities.



The NHS is not reaching out to other agencies that could provide patient support

Like any other cancer, a kidney cancer diagnosis has a major psychological impact in most patients and their mental wellbeing needs to be considered as an integral part of their treatment.⁷

Patients wanting support or information are most likely to contact their treating clinic or Clinical Nurse Specialist if they have one. However, in the current financial climate, the NHS struggles to provide patient information and support. There are other patient support resources, particularly in the Third Sector, some of which are already widely used. These form an underused resource that the NHS could make greater use of.

Our survey shows that a large proportion (62.3%) of people use the internet and/or social media to seek information and support. These have the advantage of being accessible whenever they are needed. Providing patient information via these routes is not a strength in the NHS, but linking to them is simple – as simple as giving out the website details to patients.

Patient counselling is provided on the NHS, but its resources are severely stretched. From this survey we know that many patients (58.3%) are not offered counselling. Yet of those who received counselling, almost two thirds (65.5%) found it was of benefit.

Counselling was most frequently received through a charity (18.2%), with 15.9% receiving their counselling from NHS services.

There is a clear and pressing need for greater collaboration between the NHS and relevant charities to improve the mental health support provided to kidney cancer patients.

Recommendation:

To facilitate patient informed participation in decision-making, clinics should identify and signpost patients towards sources of relevant, balanced and accurate information.



"I was sent a package when I started treatment with oncology that said I could have some kind of therapy, but I needed it when I was first told I had a mass after it was found by ultrasound to check my liver."

Comment from survey

First point of contact for information on Kidney cancer



Oncology / urology clinic or my CNS	(288) 47.14%
Visit the Kidney Cancer UK website	(124) 20.29%
My GP	(49) 8.02%
The internet	(46) 7.53%
Ask Kidney Cancer UK closed Facebook Support Group community	(31) 5.07%
Other, please state	(13) 2.13%
NHS Direct	(12) 1.96%
Ring Kidney Cancer UK Support Line	(12) 1.96%
Ask Kidney Cancer UK online Support Group	(12) 1.96%
Another charity website	(10) 1.64%
Friend	(3) 0.49%
Contact the Kidney Cancer UK Counsellor	(3) 0.49%
Social media, ask questions in another Facebook group	(3) 0.49%
Another charity support line	(2) 0.33%
Other online discussion forum	(2) 0.33%
Visit local support group	(1) 0.16%

Recommendation: Kidney cancer units need to ensure they know patients' preferences regarding the media through which they prefer to access information.

Recommendation: Holistic Needs Assessments should be carried out with all patients and should include their preferences for receiving information and other support. This information should be shared with their GP and should be fed into the Cancer Care Reviews which should be carried out in Primary Care to ensure support is available and consistent throughout the pathway.

⁷ Navigating the psychological impact of kidney cancer, 2024. Kidney Cancer UK <https://www.kcuk.org.uk/wp-content/uploads/2024/09/patient-support-and-mental-health.pdf>

About Kidney Cancer UK

Kidney Cancer UK is a national charity dedicated to supporting kidney cancer patients, their families, and carers. We are funded through voluntary donations, grants, and sponsorships. As a charity, we do not charge a membership fee, and all of our services are provided free of charge to patients, families, and carers.

Kidney Cancer UK's mission is to raise awareness and understanding of kidney cancer, promote early diagnosis, empower patients to make informed choices which lead to the most effective and appropriate treatment for their needs, and to support patients, their families and carers.



Our website is full of information

Our website offers a wealth of valuable information, including a library of informative booklets and reports on kidney cancer that can be downloaded or ordered, as well as over 100 short videos on treatment and care. Last year, our website received 45,000 visits, reflecting its importance as a highly trusted resource for patients, families, and healthcare professionals.

Our Support Line is open to patients, families, and carers

We operate a free telephone Support Line on 0800 002 9002 for kidney cancer patients, carers, families and friends of patients, run by our healthcare professional team.

Our counselling service is free

We are proud to offer the UK's first dedicated, free kidney cancer counselling service. This one-to-one service is provided by our qualified counsellor and is available via telephone or Zoom for patients, carers, and close family members. Last year, we provided nearly 500 hours of counselling to those who needed it.

Our Facebook pages

We manage an open Facebook page, updated approximately 30 times per month, with a membership of over 3,000 people. Additionally, we host three closed Facebook groups where patients can connect with others to discuss various aspects of kidney cancer.

All our pages are actively moderated, with our healthcare professionals available to answer queries and provide support.

We provide a website exclusively for Healthcare Professionals at all levels which includes our exclusive kidney cancer healthcare professional training program, up to date news on treatments

and development and a peer-to-peer support forum.

Webinars

We present regular, informative, and educational webinars on a wide range of topics featuring the UK's leading experts in kidney cancer diagnosis, treatment and patient support.

Virtual support groups

We host regular virtual Localised and Metastatic patient support groups, accessible via Zoom. And we organise and run face-to-face patient support groups.

Training

We offer an online kidney cancer training programme designed for GPs and all healthcare professionals. This self-learning course qualifies for CPD points. Last year, approximately 180 healthcare professionals participated in the programme.

Kidney Cancer Awareness Week

Each year, we raise public awareness of kidney cancer through our UK-wide Kidney Cancer Awareness Week. Held in the second week of February, we aim to spread awareness of kidney cancer as much as possible.

Patient advocates

We represent the voice of patients in major national policy programmes including:

- The development of the NICE* clinical guideline for kidney cancer
- The National Kidney Cancer Audit

We also contribute to relevant government consultations and research studies.

*The National Institute for Health and Care Excellence



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Kidney Cancer UK

THE UK'S LEADING KIDNEY CANCER CHARITY

www.kcuk.org.uk

General Enquiries 0233 870 008

Free Support Line 0800 002 9002

Help us to continue our work to support patients, carers and families affected by kidney cancer.

**Make a donation today at
kcuk.org.uk/donate**



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This survey was conducted independently by Kidney Cancer UK, without any external input or involvement.

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