



Kidney Cancer UK

25 years as the UK's leading kidney cancer charity

**TWELFTH ANNUAL**

# Kidney Cancer Patient Survey 2025



Published February 2026

## 1 Kidney Cancer UK Patient Survey Report 2025

This survey was produced with financial support from Boston Scientific, Ipsen, Merck, MSD, Pfizer and Telix Pharmaceuticals. Funders had no input into the questions, structure, analysis or content of the survey or this report.

### Foreword

Our 2025 Patient Survey is the largest ever. We received almost 1,000 responses, nearly 700 of which had completed the survey all the way through. I would like to thank everyone who took part in it for taking the time to complete it. In 2026, learning from your experiences as patients, carers or families of patients will be particularly important as we see the publication of the first NICE Clinical Guideline on kidney cancer, brought about exclusively through the hard work of this charity.

### The ongoing National Kidney Cancer Audit will play a unique and vital role in measuring resulting service quality improvements.

Based on what you have told us in this survey, we have produced a series of eight recommendations for healthcare professionals. When the NICE guideline is published, the responsibility for implementing it will be theirs, though, wherever possible, Kidney Cancer UK will support them in doing so.

Finally, in addition to our eight recommendations, I should like to make two overarching requests to all healthcare professionals who diagnose, treat or care for people with kidney cancer:

- When the NICE Clinical Guideline and Quality Standard are published, please follow their evidence-based recommendations.
- Use the dashboard published quarterly by the National Kidney Cancer Audit to compare the quality performance of your Trust against others and regularly monitor your progress.

Thank you to every patient who took part in this increasingly important survey. Know that you make a difference.



**Malcolm Packer**  
Chief Executive Officer  
Kidney Cancer UK



Almost  
**1000**  
responses to  
this survey



Nearly  
**700**  
Surveys  
fully completed



**13,900**  
new cases every year



## Recommendations to healthcare professionals

- 1 Develop a research strategy to find a simple, inexpensive test for use in primary care to identify people who should be referred for suspected kidney cancer testing.
- 2 Optimise diagnostic accuracy by using all relevant techniques, including biopsy.
- 3 Consider carrying out, or referring patients for, nephron-sparing surgery or minimally invasive treatments where clinically relevant.
- 4 Offer SACT to a wider group of patients where clinically relevant.
- 5 Increase participation in clinical trials.
- 6 Ensure patients are able to make an informed decision on their treatment from a full range of appropriate, licenced treatment options, regardless of where they may be provided.
- 7 Provide access to a named Clinical Nurse Specialist (CNS) for all patients as soon as diagnosed.
- 8 As early as possible, make patients aware of the contact details of reputable kidney cancer charities that can augment information and patient support provided by the NHS.

NHS kidney cancer services in England and Wales are at a seminal moment. This year, in 2026, the first ever Clinical Guideline and Quality Standard for kidney cancer will be published by the National Institute for Health and Care Excellence (NICE). This will define the quality agenda for kidney cancer services moving forwards. In parallel, the National Kidney Cancer Audit (NKCA) will continue to measure quality and drive improvements.

However, this major development comes at a time when urological cancers (including kidney cancer) are lagging behind in meeting the Faster Diagnosis Standard (FDS). In England, the target is for 75% of patients to receive a diagnosis (or have cancer ruled out) within 28 days of an urgent GP referral.

Around 70% of patients have urological cancer ruled out within 28 days, but the picture in patients who are diagnosed with kidney cancer is different. Performance has been decreasing steadily from around 40% in

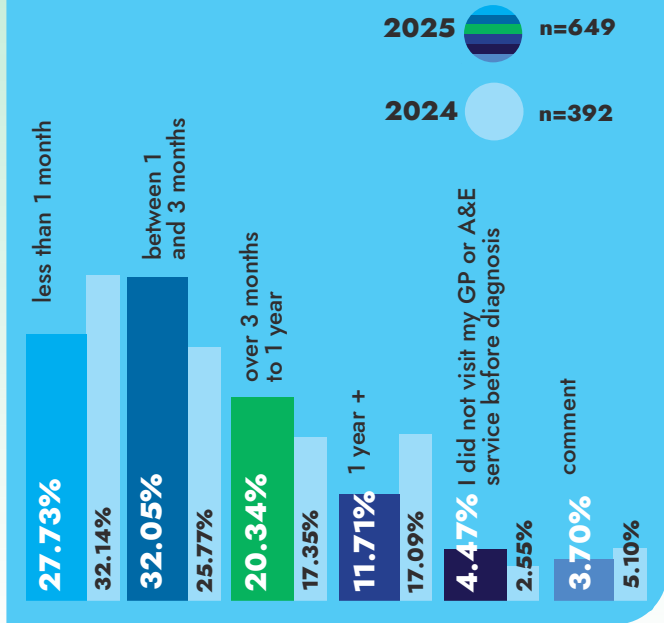
2021 to 28.6% in July 2025. The performance gap between the two cohorts is one of the largest at a tumour level at around 35 – 40% pts[1].

So, the question mark looming over kidney cancer is 'can both diagnostic speed and service quality be improved or will one jeopardise the other?'

Our annual Kidney Cancer UK Patient Survey has been measuring service quality for the last 12 years. The results of this latest survey contain clues of the challenges ahead.

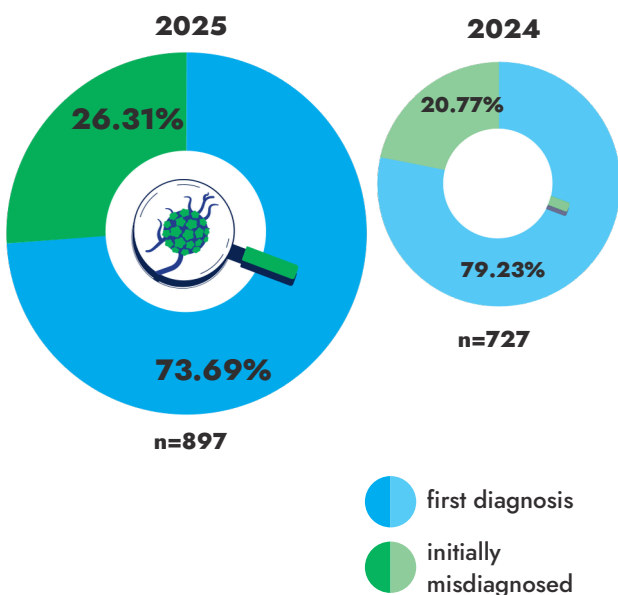
Our survey measures the time from first feeling unwell and seeking medical advice to receiving a diagnosis. Unlike the FDS, this includes the time it takes for the patient to be identified as 'at risk of kidney cancer' and referred for specialist investigations. Latest results show 32% of patients waited more than 3 months – virtually no improvement from the previous year (34%) (Fig. 1).

**Fig. 1** How long did it take from first feeling unwell and seeking medical advice to receiving a kidney cancer diagnosis?



In the period before referral for diagnosis (which is outside the FDS), more than one in four patients are initially diagnosed with a different condition, a marked increase on the previous year (Fig. 2). This adds to the overall time it takes for a diagnosis to be made.

**Fig. 2** Was kidney cancer the first diagnosis or was the patient initially misdiagnosed with another illness?



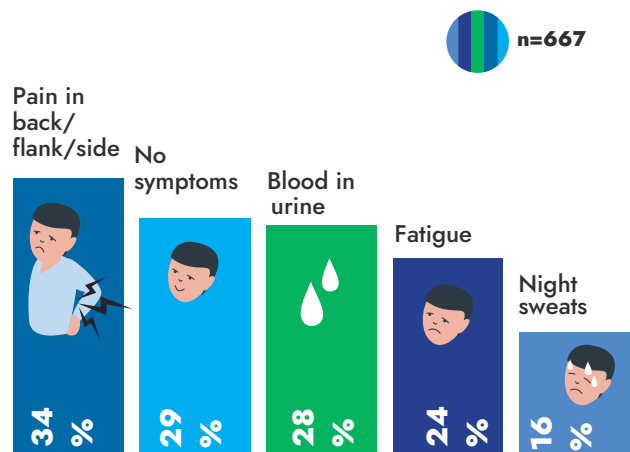
## Patient identification – improving quality could save time

If earlier, more accurate referral from primary care could be achieved it would cut down the time taken for referral of a person with suspected kidney cancer for testing. It could also reduce the strain on capacity of diagnostic services by reducing the number of people who, having undergone a diagnostic process, have cancer ruled out.

## Often symptomless

However, suspected kidney cancer is extremely difficult to identify – frequently it is symptomless, especially at an early stage. Healthcare professionals working in primary care need more support to do this. NICE guidance on suspected cancer only lists haematuria as a sign of kidney cancer. Our survey has shown consistently that the picture is more complex. In our survey, patients report a range of symptoms they experienced before being diagnosed with kidney cancer. These symptoms are often explained as being due to metastases – our survey shows that one in five patients are diagnosed at stage 4. However, comparing results from people in our survey who were diagnosed at stage 4 with those diagnosed at an earlier stage shows that patients who did not have metastases when they were diagnosed still reported a wide range of symptoms (Fig. 3).

**Fig. 3** The most common symptoms reported by patients



## More than half diagnoses are incidental

This situation leads to many people being diagnosed with kidney cancer as an incidental finding when having a scan for a different unrelated condition. Our survey shows this to be over half (54%) of patients, no improvement on the same number in the previous year.

A simple, inexpensive test that can be used in primary care to identify people who are at risk of kidney cancer and should be referred for further investigation is needed urgently and warrants a concerted research strategy. In the meantime, improvement of prompts and flags on decision support software used in primary care, together with better guidance, training and awareness on kidney cancer could improve the situation. [See recommendation 1.](#)



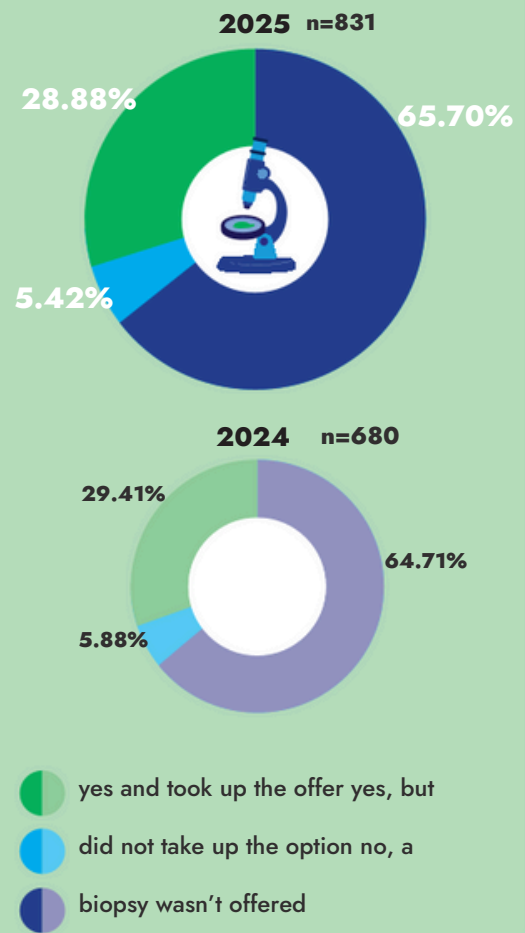
## Faster diagnosis pressures must not jeopardise service quality

The NICE draft clinical guideline on kidney cancer recommends better use of biopsies to confirm a lesion is cancerous before removing part of or the entire kidney. Separately, the National Kidney Cancer Audit has identified under-utilisation of biopsies.

### Unnecessary surgery

The benefit to patients of increasing the use of biopsies is that it would significantly reduce the number of cases in which a person underwent surgery for the removal of a lesion that was found to be non-malignant after removal. Unnecessary surgery of this kind reduces the kidney function of a patient for no benefit. It also wastes valuable NHS resources in providing a treatment that is not required. In the Kidney Cancer UK Patient Survey, two thirds (65.7%) said they were not offered a biopsy – a similar figure to the previous year (Fig. 4). Of those that had a biopsy, the outcomes showed that the lesion was malignant in 95% of patients in our survey. It is impossible to say how many patients had a full or partial nephrectomy that was not necessary. However, NICE estimates that currently 600 people with lesions 4cm or smaller have a biopsy, but this figure should be doubled.

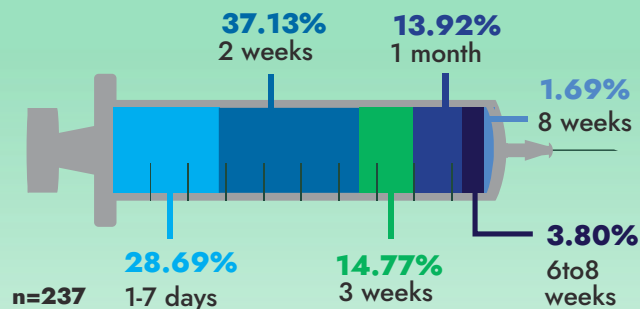
Fig. 4 Was or has the patient been offered a biopsy?



## Biopsy often crucial but lengthens diagnostic wait

The downside to this picture is that a biopsy adds time to the diagnostic wait, which may mean more patients miss the Faster Diagnosis Standard. Our survey shows that almost two thirds (65.8%) of people waited two weeks or less for results (Fig. 5). The majority of the remainder waited between three weeks and a month (the FDS states that 75% of patients should receive a diagnosis (or have cancer ruled out) within 28 days of an urgent GP referral). It is not clear what would be the impact on workloads of an additional 600 biopsies per year, as estimated by NICE, but given the current pressures on pathology laboratories, it could lengthen some of these waiting times.

Fig. 5 How long did you wait for the biopsy result



### See recommendation 2

Whilst rapid diagnosis is undoubtedly important, the key thing must surely be that the diagnosis is as accurate as possible and is based on all relevant diagnostic techniques.

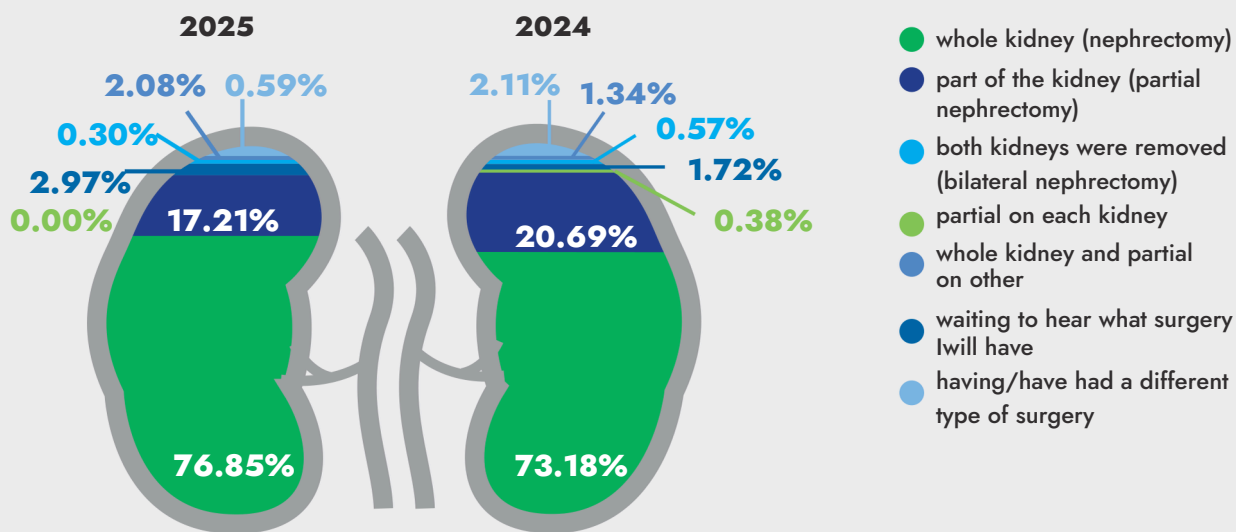
## In surgery, preservation of kidney function is crucial wherever possible

The results of our survey show that 87% of the people underwent surgery. This is the same figure as in the previous year.

Of these, 77% had the entire kidney removed, an increase of 4 percentage points on the previous year

(Fig. 6). In contrast, 17% had a partial nephrectomy, a fall of 3% points compared with 2024. Interpretation of these figures needs careful consideration, but they do raise a question as to whether nephron-sparing surgery is considered wherever possible.

Fig. 6 How much of the kidney was, or will be, removed?



It is known that kidney function gradually declines in everyone as we age. Most of us have sufficient margin in our kidney function to cope with this and experience no problems. Some people develop chronic kidney disease in which the reduction is greater than normal and the margin is insufficient.

## If nephrectomy is not inevitable, consider the benefits of nephron-sparing surgery

The removal of part or all of a kidney obviously reduces

a person’s overall kidney function. The degree of reduction depends on the amount of tissue removed. Most people have sufficient capacity to live normally with this reduction and to cope with gradual further decline that everyone experiences with age. However, to ensure that this is the case, it is important the removal of kidney tissue to excise a lesion is kept to the minimum. In many cases there is no option but to remove the entire kidney. However, if nephrectomy is not inevitable, the benefits of nephron-sparing surgery should be considered – even if this means referring the patient to a specialist centre. **See recommendation 3.**

### SACT has a larger role to play

As mentioned previously, there is evidence that SACT is currently underutilised. Our survey results support this. We asked patients who had stage 4 (metastatic) kidney cancer if they had been offered, or had received, or were due to receive SACT. Just under 40% said they had (Fig. 7).

There are many valid reasons why SACT might not be offered, but the proportion in our surveyed patients seems low. We believe that SACT should be offered more widely.

A relatively new additional use for SACT is in adjuvant therapy. This is usually in people with a localised lesion that has a medium- or high-risk of recurrence. Our survey results show that uptake has been relatively good with 37% of patients for whom it is applicable receiving it.

**Fig. 7** If diagnosed with Stage 4 (metastatic) kidney cancer, has the patient been offered, received, or due to receive drug treatment - in tablet or intravenous drip form - for kidney cancer?

Response	Percentage
no	41.61%
yes	39.75%
don't wish to share information	8.70%
I don't know if drug treatment will be offered yet	9.94%

n=161

## Where are the clinical trials?

Clinical trials are an opportunity for clinicians to gain early experience with new treatments. We have been monitoring access to clinical trials for some years by asking patients if they had ever been involved in a kidney cancer clinical drug trial. The number of people saying they had not has always been high (last year it was 73%). The latest survey results show this has increased further and is now almost 80% (Fig. 8).

**Fig. 8** Has the patient ever been involved in a kidney cancer clinical drug trial?

- yes, for kidney cancer that has spread
- yes, after surgery for localised kidney cancer
- no
- offered but not interested
- yes but not suitable
- don't know how to access a clinical trial
- not interested

Year	n	yes, for kidney cancer that has spread	yes, after surgery for localised kidney cancer	no	offered but not interested	yes but not suitable	don't know how to access a clinical trial	not interested
2025	351	0.57%	5.13%	79.77%	3.13%	1.14%	3.70%	6.55%
2024	229	0.44%	3.06%	72.49%	7.86%	0.87%	6.99%	8.30%

This is a serious concern. Clinical trials are also a chance for suitable patients to benefit from the latest treatments. These results strongly suggest this opportunity is being denied to many patients. It is our wish to see clinical trials participation greatly increase. **See recommendation 5.**

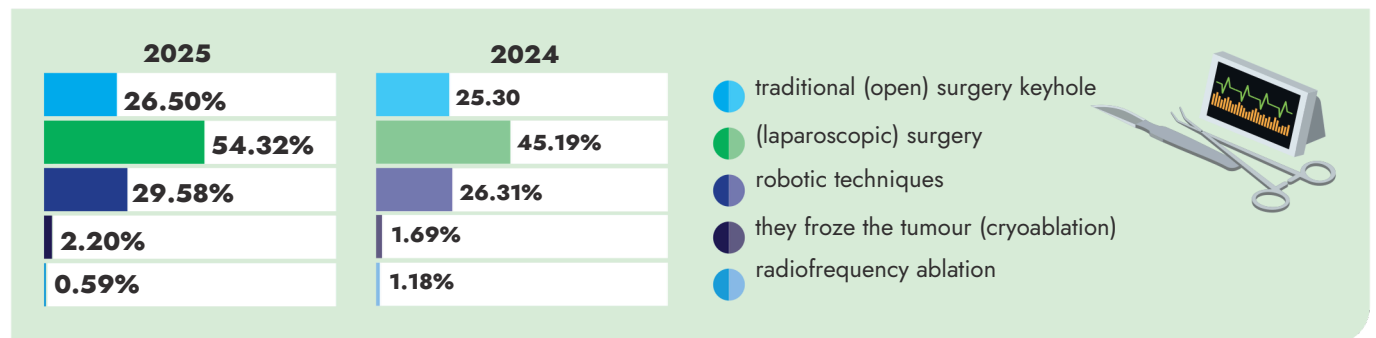
## Choice of treatment from a full range of options

The range of treatments for kidney cancer is widening – not just in terms of Systemic Anti-Cancer Treatment (SACT), but also in tumour excision by surgery or other means. This is good news for patients, but it represents a challenge for NHS services, which must provide them.

### Slow uptake of important additional treatments

Tumour excision used to mean surgery and nothing else. However, there are now several other options – Radio Frequency ablation (RF), cryoablation and targeted radiotherapy (Stereotactic Ablative Radiotherapy or SABR). The uptake of these important additional treatment options has been very slow, and our latest figures reflect this (Fig. 9). One of the many anticipated effects of the NICE guideline will be evidence-based recommendations on when and how these treatments should be used.

**Fig. 9** What type of surgery has the patient received or due to have?

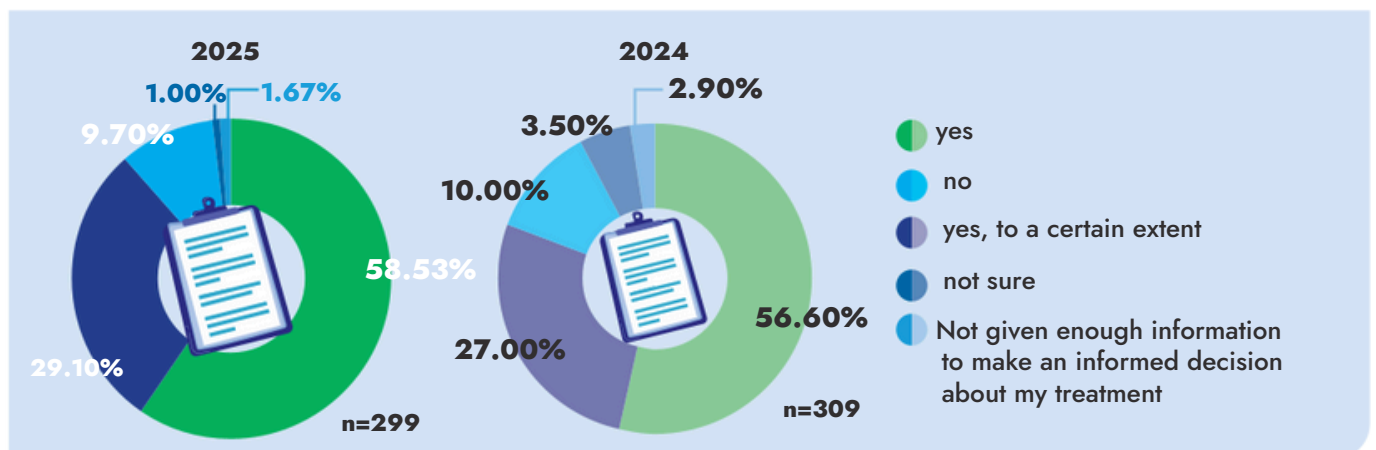


## Inform patients about the complete list of clinically relevant treatments available to them

Each new technique requires investment by local or regional NHS services in equipment, in training and in space. This process is slow but must not stand in the way of patients being able to access these options if they are not available locally. If patients are to make an informed choice about the treatment they prefer, they must be able to choose from a complete list of all clinically relevant treatments, regardless of whether or not they are provided locally. If the patient selects a treatment not locally available, their treating centre should provide measures to mitigate problems associated with travelling for treatment. This should be done taking into consideration the patient’s Holistic Needs Assessment. Failing to do so results in a health inequality. Achieving this means patients must be fully informed and involved in their treatment decision, which our survey reports is the case in only just above half of patients (58.5%) (Fig.10).

See recommendation 6 .

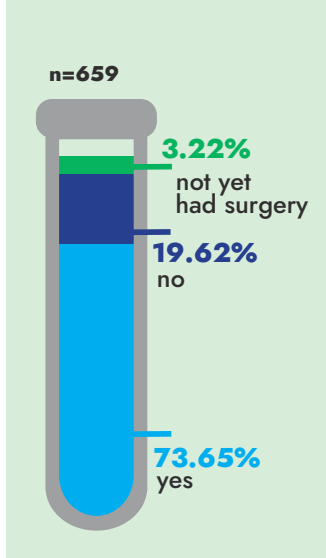
**Fig. 10** Was the patient involved in decisions regarding their treatment?



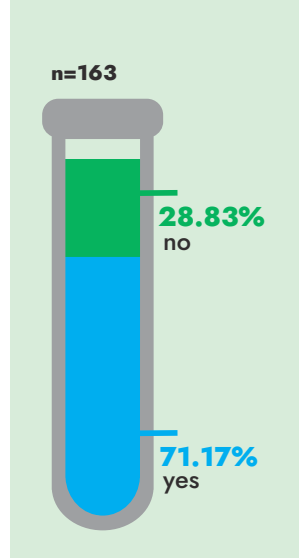
## Informed decisions depend on patient information

The need for information varies from one patient to another, as does the point in the pathway at which they need it, the level of detail required, and the frequency with which they need to access it. NHS services cannot be expected to address all these needs for all patients. However, patients may be making decisions about their treatment based on incomplete information (Figs. 11 & 12).

**Fig. 11** Was the patient happy with the information and support received before and after surgery?



**Fig. 12** Was enough information on drug side-effects given?



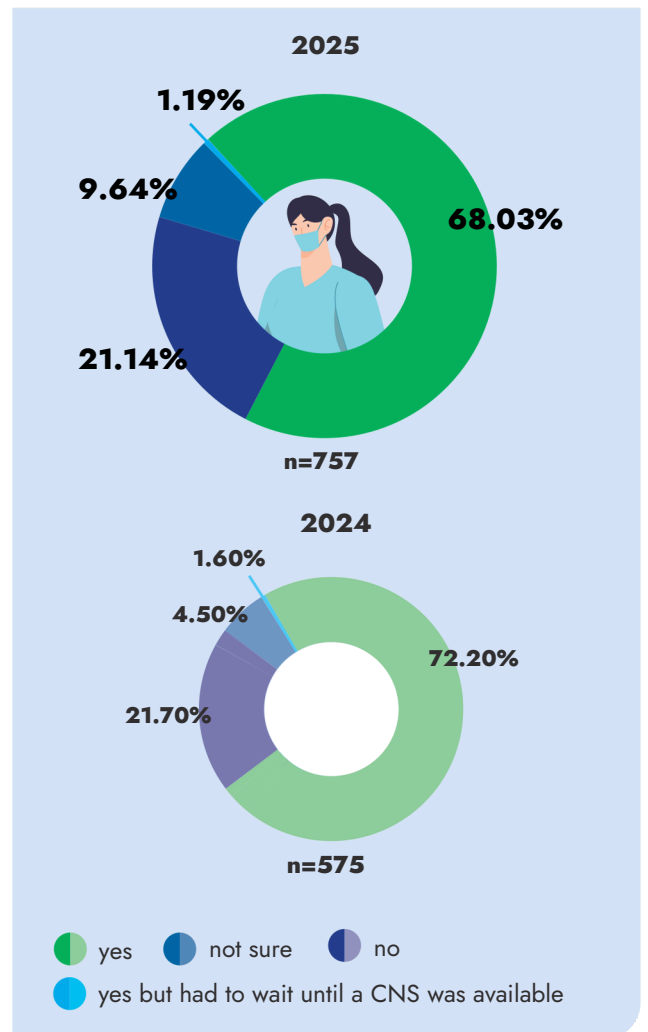
Taking into consideration the speed at which information technology is developing, we looked at the data in figures 11 and 12 to see if there were any differences between patients diagnosed in the last four years compared with those diagnosed earlier. In both cases fewer people diagnosed in the last four years said they were happy and had enough information (a drop of 9 percentage points before and after surgery and 11 percentage points regarding drug side-effects). More people diagnosed in the last four years were not satisfied (an increase of 8 and 11 percentage points respectively). There are numerous potential explanations for this; people’s expectations may have increased over the last four years and the time available to healthcare professionals to pass on the information may have reduced.

## Patient charity support line and website details not signposted

One thing that is clear is that NHS services are not passing on the contact details of patient charities that would be able to help fill the information gap. Details of a website to look at or a support line number were virtually never given out. The additional risk here is that people will often search for information on the internet. If not signposted to a source of reliable information, they may access wrong and sometimes disturbing information. As part of the process, patients should be made aware of the contact details of reputable kidney cancer charities as early as possible.

See recommendation 7.

**Fig. 13** Was the name of a Clinical Nurse Specialist (CNS) or key worker responsible for the patient’s care provided?



## We must find time to support patients

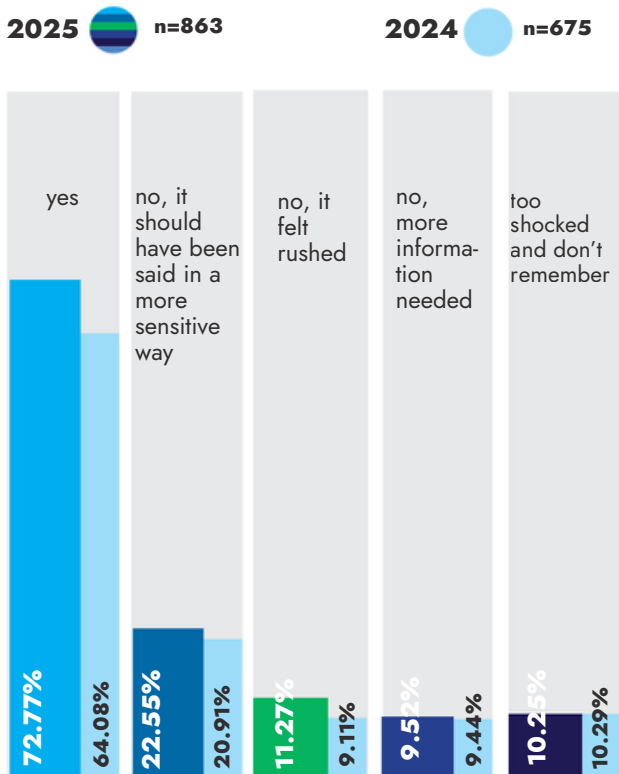
The Clinical Nurse Specialist (CNS) is pivotal in both informing and supporting patients. All patients should have access to a named CNS, but more than one in five patients do not (Fig. 13). [See recommendation 7.](#)

We compared patients diagnosed within the last four years with those diagnosed before this and there were no significant differences. This serious shortfall is a long-term problem that we hope will be addressed when the NICE Clinical Guideline is published, supported by measurement in the National Kidney Cancer Audit.

Time is the scarce resource when supporting patients. The limited opportunities healthcare professionals have to interact with patients, caused by time pressures, have a serious impact on patient support. (Fig. 14).

Nevertheless, either the NHS must provide patient support services or patients should be signposted towards other organisations that can provide it to them. [See recommendation 8.](#)

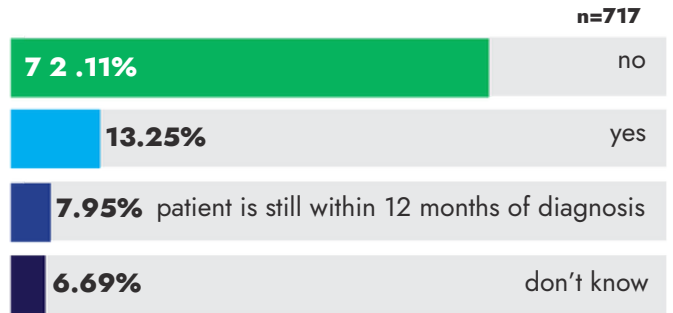
**Fig. 14** Was the news of having suspected kidney cancer shared appropriately?



**Free Support Line  
0800 002 9002**

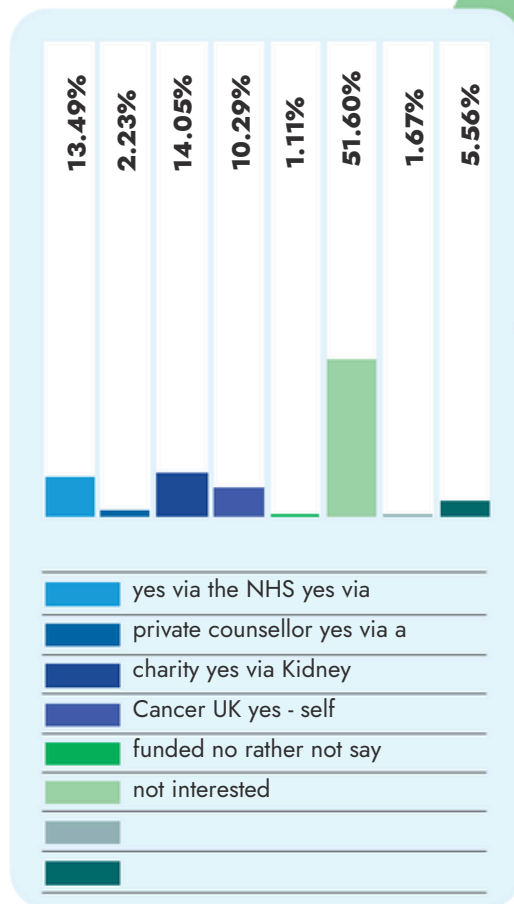
The removal of incentives for GPs to provide Cancer Care Reviews means these are seldom offered (Fig. 15), resulting in little or no support in the community.

**Fig. 15** Is the patient aware of receiving a 'Cancer Care Review' with a member of staff from their GP surgery within 12 months of diagnosis?



Counselling is similarly scarce on the NHS, only 13% of people in our survey said they were offered it. Many people are forced to seek other sources or pay for it themselves (Fig. 16).

**Fig. 16** Was, or has the patient been, offered counselling?



n=719



## About Kidney Cancer UK

### Our website is full of information

Our comprehensive website provides a wide range of trusted kidney cancer information, including downloadable or printed booklets and reports, as well as over 100 short videos on treatment and care. Last year, the site received 64,000 visits, highlighting its value to patients and families. We also run a dedicated website for healthcare professionals, offering an exclusive kidney cancer training programme, up-to-date treatment news, and a peer-to-peer support forum.

### Support Line, open to patients, families & carers

We operate a free telephone Support Line on 0800 002 9002 for kidney cancer patients, carers, family members and friends. Calls are answered by our experienced healthcare professional team.

### Our counselling service is free

We offer the UK's first free, dedicated kidney cancer counselling service. One-to-one support is available by telephone or Zoom for patients, carers and close family members. Last year, we delivered around 500 hours of counselling.

### Our Facebook pages

We manage an open Facebook page with almost 5,000 followers, updated around 40 times each month. We also host three closed groups with over 3,000 members, providing safe, moderated peer-to-peer support, with

healthcare professionals available to respond to queries.

### Webinars

We deliver regular educational webinars featuring leading UK experts in kidney cancer diagnosis, treatment and patient support.

### Virtual support groups

We run regular virtual Localised and Metastatic patient support groups via Zoom, as well as face-to-face support groups.

### Healthcare Professional Training

We offer an online kidney cancer training programme for GPs and healthcare professionals. The self-learning course qualifies for CPD points, with around 180 participants last year.

### Patient Survey / Kidney Cancer Awareness Week

Each year, we run the UK's only kidney cancer survey focused solely on UK patients and lead Kidney Cancer Awareness Week in February to raise national awareness.

### Patient advocates

We represent patient voices in national policy programmes, including the NICE (The National Institute for Health and Clinical Excellence) clinical guideline for kidney cancer and the National Kidney Cancer Audit, and contribute to government consultations and research.

## About kidney cancer

### Kidney cancer is a growing threat

- Kidney cancer is the sixth most common cancer in men and women in the UK.<sup>[2]</sup>
- Data from 2017-19, the latest available figures, show that the European Age-Standardised (AS) Incidence Rate is 22.2 per 100,000 population.<sup>[3]</sup>
- The 2017-19 figures show that there are around 38 new cases every day, amounting to a total of 13,900 annually. Around 5,100 of these new cases are in women and 8,800 new cases in men. Incidence rates in the UK due to kidney cancer have increased by 94% since the early 1990s.<sup>[3]</sup>
- Around 5,100 people die from kidney cancer each year, which is about 14 people every day. Since the early 1970s, kidney cancer mortality rates have increased by 77% in the UK.<sup>[4]</sup>
- 55.6% people in the UK survive kidney cancer for 10 or more years.<sup>[5]</sup>

<sup>2</sup> Incidence for common cancers. Cancer Statistics Data Hub. Cancer Research UK [https://crukancerintelligence.shinyapps.io/CancerStatsDataHub/\\_w\\_3fcbaae1cc564876b67093aefabc-ecde/\\_w\\_a3f5f2563b1946cfb4ac68cfd7d1ac4/?\\_inputs\\_&nav=%22Incidence%20Common%20Cancers%22&app\\_select\\_CancerSite=%22Kidney%22&app\\_select\\_Country=%22United%20Kingdom%22](https://crukancerintelligence.shinyapps.io/CancerStatsDataHub/_w_3fcbaae1cc564876b67093aefabc-ecde/_w_a3f5f2563b1946cfb4ac68cfd7d1ac4/?_inputs_&nav=%22Incidence%20Common%20Cancers%22&app_select_CancerSite=%22Kidney%22&app_select_Country=%22United%20Kingdom%22) Last viewed Dec 2025

<sup>3</sup> Kidney cancer incidence, Cancer Statistics Data Hub Cancer Research UK [https://crukancerintelligence.shinyapps.io/CancerStatsDataHub/\\_w\\_7e3652d1a0344a1f83ad3a260f52ef1d/?\\_inputs\\_&nav=%22Incidence%20Breakdowns%20and%20Trends%22&app\\_select\\_CancerSite=%22Kidney%22&app\\_select\\_Country=%22United%20Kingdom%22](https://crukancerintelligence.shinyapps.io/CancerStatsDataHub/_w_7e3652d1a0344a1f83ad3a260f52ef1d/?_inputs_&nav=%22Incidence%20Breakdowns%20and%20Trends%22&app_select_CancerSite=%22Kidney%22&app_select_Country=%22United%20Kingdom%22) Last viewed Dec. 2025

<sup>4</sup> Kidney cancer mortality – Trends over time. Cancer Statistics Data Hub. Cancer Research UK [https://crukancerintelligence.shinyapps.io/CancerStatsDataHub/\\_w\\_7e3652d1a0344a1f83ad3a260f52ef1d/?\\_inputs\\_&nav=%22Mortality%20Breakdowns%20and%20Trends%22&app\\_select\\_CancerSite=%22Kidney%22&app\\_select\\_Country=%22United%20Kingdom%22](https://crukancerintelligence.shinyapps.io/CancerStatsDataHub/_w_7e3652d1a0344a1f83ad3a260f52ef1d/?_inputs_&nav=%22Mortality%20Breakdowns%20and%20Trends%22&app_select_CancerSite=%22Kidney%22&app_select_Country=%22United%20Kingdom%22) Last viewed Dec. 2025

<sup>5</sup> Kidney Cancer Statistics. Cancer Statistics Data Hub. Cancer Research UK. <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/kidney-cancer> Last viewed Dec. 2025

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# Kidney Cancer UK

25 YEARS AS THE UK'S LEADING KIDNEY CANCER CHARITY

[www.kcuk.org.uk](http://www.kcuk.org.uk)

General Enquiries: 0233 870 008

Free Support Line: 0800 002 9002

**Help us to continue our work to support everyone affected by kidney cancer.**

Donate today at  
[kcuk.org.uk/donate](http://kcuk.org.uk/donate)



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