



**Kidney
Cancer
UK**

The UK's leading kidney cancer
charity for over 20 years



Kidney Cancer UK Patient Survey Report 2022

**Kidney Cancer UK
Support line
0800 002 9002**

www.kcuk.org.uk

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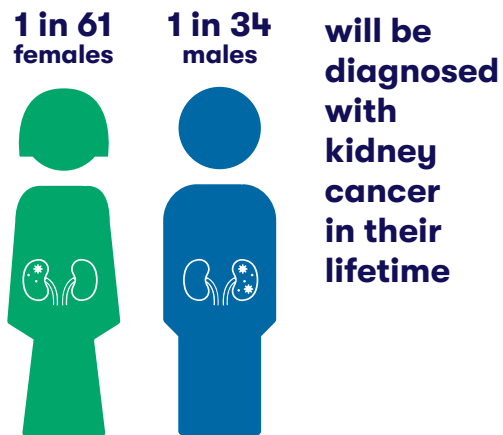
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Around 4,700 people die each year from kidney cancer (around 13 people every day)

Kidney Cancer: A serious and growing problem

Common

- The seventh most common cancer in men and women in the UK.¹
- An estimated 46,000 people are living with kidney cancer in the UK today.
- In the UK, 1 in 34 males and 1 in 61 females will be diagnosed with kidney cancer in their lifetime.²
- There are 13,322 new cases each year.³

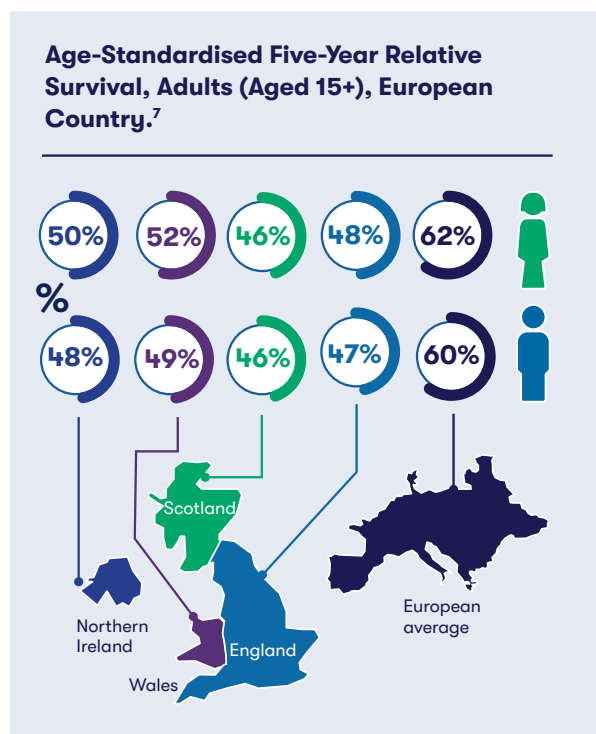


Mortality

- Around 4,700 people die each year from kidney cancer (around 13 people every day).⁴
- Mortality rates in the UK due to kidney cancer have increased by 73% since the 1970s.⁵
- One of only seven cancers whose mortality rate is increasing.⁶
- 1 in every 35 deaths from cancer is due to kidney cancer.⁴

5-year survival rates in the UK are amongst the worst in Europe (2000 - 2007).

- Of 29 European countries for which data are available (2000 - 2007), Scotland ranked 27th, England 26th, N. Ireland 24th and Wales 23rd.



1 Cancer Research UK website: <https://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence/common-cancers-compared#heading-Zero> L

2 Cancer Research UK website: <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/kidney-cancer#heading-Three>

3 Cancer Research UK website: <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/kidney-cancer>

4 Cancer Research UK website: <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/kidney-cancer#heading-One>

5 Cancer Research UK website: <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/kidney-cancer#heading-One>

6 Chief Medical Officer's Annual Report 2020. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/945929/Chief_Medical_Officer_s_annual_report_2020_-_health_trends_and_variation_in_England.pdf

7 Cancer Research UK website: <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/kidney-cancer/survival#heading-Four>

Executive summary

This year's survey received 652 responses, 542 completed surveys from kidney cancer patients in the UK. It ran between 24th September to 24th October 2022, on-line through Kidney Cancer UK & Scotland's social media pages and our website via Question Pro. The results of this year's survey take on an additional significance by highlighting issues that are important to patients which might be addressed in the forthcoming NICE guideline development process, prompted by the work of the Kidney Cancer UK Accord group.

- **Prompt and accurate referral of suspected kidney cancer for confirmatory diagnosis is essential** and referring health professionals should be given greater support to achieve this. It takes more than three months from first seeking help to diagnosis in one in three patients. The current emphasis on blood in the urine as the only symptom indicating kidney cancer is over simplistic and does not encourage clinicians to take into account more common symptoms.
- **Nearly half of kidney tumours are diagnosed at a relatively late stage** and almost half are incidental findings from scans for an unrelated medical purpose.
- **Reporting of scan results often takes a long time.** 31% of patients waiting over 5 weeks for their results.
- **The growth in the number of surgical, ablative and medical treatments over recent years may have created a need for the development of treatment protocols** to help health professionals decide which treatments are appropriate for each patient and in what order.
- **Access to clinical trials is disappointingly low** and should be improved.
- **Information for patients plays a crucial role but often is not signposted or provided in sufficient quantity** at the appropriate time. 51% (n=286) would turn first to their kidney cancer clinic or their Clinical Nurse Specialist

(CNS) for support or information. However, 1 in 4 patients are not given the name of their CNS or key worker.

- **Follow up after surgery is variable: most patients (87% n=249) receive regular scans, but patient wellbeing is often neglected** with many patients experiencing negative feelings such as **anxiety (35% n=192)**, **fear (37% n=199)** and **abandonment (29% n=158)**.
- **Counselling is an avenue of support that many patients who receive it find useful (53% n=96)**, but disappointingly, **63% (n=350) said they were not offered it.**

Patients' wellbeing is often neglected. Many patients experienced negative feelings.



This is our largest survey of kidney cancer patients to-date

This is the ninth, and only UK focused, annual survey of kidney cancer patients. It ran online from 24th September 2022 to 24th October 2022 and received 652 responses, 542 of those were completed surveys from kidney cancer patients in the UK. This represented an increased response rate of over 22% on the previous year.

Significant developments in kidney cancer

As always, the survey results measure patient experiences of kidney cancer services. However, this year they should be interpreted whilst taking into account other work and developments to which this survey will contribute.

NICE guideline on kidney cancer

Collectively, and following the approach from the 'Kidney Cancer UK Accord' group to NHS England, this work has resulted in a commission from NHS England for NICE (the National Institute for Health and Care Excellence) to begin developing the first ever clinical guideline and quality standard for kidney cancer. When completed, this will be used by doctors, nurses and commissioners to optimize the quality of services.

The largest audit of kidney cancer service quality

In parallel with this series of patient surveys, the charity, through its Kidney Cancer UK Accord work, recently published a two-year audit of kidney cancer services using NHS data and involving over 18,000 patients in England. This is believed to be the largest audit of its kind carried out to-date in kidney cancer.

The results showed variations in the quality of many aspects of diagnosis and treatment of kidney cancer between NHS Trusts in different parts of the country.



A call to action

NICE will be developing the kidney cancer guideline over the next two years, together with input from patients and kidney cancer experts.

This survey is a call to action for the guideline development process to address the issues that matter to patients, as highlighted in these results.

NICE guidance applies to Wales and may be taken up in Northern Ireland. Our ambition is to see health professionals working in kidney cancer services in all Nations of the UK supported by national guidelines.



This is the ninth annual, and only UK focused, survey of kidney cancer patients

Referral for diagnosis must be rapid and accurate

The introduction of Rapid Diagnosis Centres (RDCs) potentially allowing the faster completion of all diagnostic tests is intended to shorten the time it takes for a cancer patient to reach the treatment they need. It is too early to say whether they will achieve this goal and whether or not they will be accessible to all. What is certain is that they can only be effective if referrals to them are rapid and accurate. This presents problems for health professionals who may refer suspected cases of kidney cancer.

Over 3 months to receive diagnosis

31% (n=106) of patients surveyed took over 3 months from first seeking medical advice to diagnosis. This suggests many kidney cancer patients may not be receiving a diagnosis within the time stipulated in the NHS Long Term Plan.

Majority have symptoms

Only **4% (n=23)** of patients said they had no symptoms. The majority (almost **75% (n=323)**) reported at least one, with pain in the back, flank or side being the most common as in previous years.

Many risk factors are known

Symptoms combined with risk factors are valuable clues that should trigger further investigation.



Risk factors include:

Smoking and Obesity



Genetic factors and a history of kidney cancer in the family



Certain medical conditions, such as high blood pressure (hypertension) and chronic kidney disease, especially people on long-term kidney dialysis



Exposure to certain chemicals at work e.g. trichloroethylene



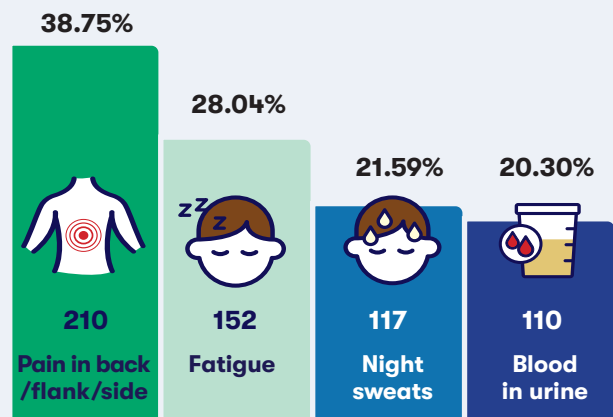
New Information booklet for GPs

The forthcoming NICE guideline will need to deal with referral for diagnosis. Kidney Cancer UK has produced an educational booklet for GPs to help them refer patients for diagnosis earlier by identifying the signs of kidney cancer. GPs should contact Kidney Cancer UK to receive a copy.

Kidney cancer is often misdiagnosed

22% (n=138) of patients in our survey said they had initially been misdiagnosed. Urine infection, kidney cysts and kidney stones were the most common misdiagnoses, but others included gynaecological issues, muscular problems and back pain. This is an important cause of delayed referral for diagnosis of suspected cancer and consequently could be a contributor to late diagnosis.

Common symptoms reported



Early referral guidance leaves out common symptoms

NICE guideline NG12 'Suspected cancer: recognition and referral' only lists blood in the urine as a kidney cancer symptom that indicates the need for referral. It does not mention the three other symptoms that patients in our survey said were more common. Not connecting all four common symptoms could result in kidney cancer cases at an early stage being missed.

Self-awareness of symptoms also important

It may be possible to have one or more symptoms and yet not feel generally unwell. In our survey, **38% (n=237)** of people said they did not feel unwell before they were diagnosed. It is important that patients with these symptoms, have them checked, even if they are not making them feel generally unwell.

The high level of incidental diagnosis must be reduced

Almost half of kidney tumours are found incidentally

In this survey **48% (n=301)** of people who responded said their kidney cancer was only found when they were having tests unrelated to kidney cancer. The finding is cause for concern because it indicates that in nearly half of cases, kidney cancer was not suspected and could have gone undiagnosed until it had reached a later stage when it may have been less treatable.

More research is urgently needed to develop a diagnostic test

More research is needed to develop a simple laboratory test that can be used to indicate if kidney cancer should be considered. To provide a diagnosis, specialist scanning is currently required, which can be costly and may make referral for diagnosis more cautious. Such a test would be invaluable in making a decision at practice level.

Information given at diagnosis

I had a conversation with consultant or nurse and given bag with information leaflets in	136	46.58%
I had a conversation with consultant or nurse	135	46.23%
I was given bag with information leaflets in	8	2.74%
I was given single leaflet	7	2.4%
I was not given any information	3	1.03%
I was given support line telephone number	1	0.34%
don't know	1	0.34%
Other	1	0.34%
I was given details of website to look at	0	0%
Total	292	100%

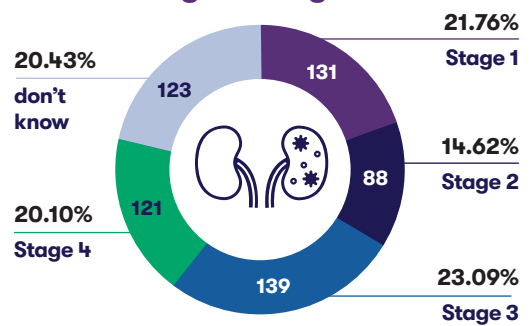
Test used for first diagnosis

CT scan	295
Ultra sound scan	223
MRI scan	58
Regular x-ray	15
Not known	12
Percutaneous kidney biopsy	8
Other	6
Total	627

Nearly half of tumours diagnosed at relatively late stage

As with most other cancers, the earlier kidney cancer is found, the more treatable it is. However, of those who knew the stage of their cancer when diagnosed, **43%** said their stage had already reached stage 3 or stage 4 at diagnosis.

Tumour stage at diagnosis



1 in 3 unhappy with the way they were told they had kidney cancer

34% of patients said they were unhappy with the way they were given their diagnosis. This included **7% (n=37)** who felt it was too rushed and **8% (n=42)** who did not have enough information.

Ten most common symptoms experienced before being diagnosed with kidney cancer

%	Number of mentions	Symptoms
38.75%	210	Pain in back/flank/side
28.04%	152	Fatigue
21.59%	117	Night sweats
20.30%	110	Blood in urine
14.02%	76	Weight loss
10.89%	59	Urinary tract infection
10.15%	55	Raised blood pressure
9.59%	52	Cough
7.75%	42	Abnormal blood results
7.56%	41	Nausea/vomiting

Treatment protocols are needed

Patient involvement before treatment good but often not well informed

78% (n=462) said they felt their opinions were taken into consideration by medical staff when deciding on future treatment. However, **1 in 4 (n=444)** said they were not given enough information.

Treatment received for kidney cancer

Surgery	500	92.25%
Drug treatment - taken orally	118	21.77%
Drug treatment - taken intravenously	108	19.93%
Active surveillance following treatment or surgery	88	16.24%
Active surveillance following scans	50	9.23%
Radiotherapy	43	7.93%
Drug trial	36	6.64%
Cryoablation	16	2.95%
Radiofrequency ablation	14	2.58%
Other	14	2.58%
Don't know	5	0.92%
Total	992	n=542



1 in 4 patients were not given enough information before treatment

Relatively wide range of drug treatment used

33% (n=189) had received drug treatment in the form of tablets or iv drip. **31% (n= 57)** had been on medication for over 3 years. Quite a wide range of medicines was mentioned. Patients recalled 16 different individual drugs or combinations that they had taken or were taking. The NICE guideline may address drug treatment protocols.



Access to clinical drug trials disappointingly low



Only **15% (n= 85)** of patients had been offered the opportunity to take part in a clinical trial and **11% (n= 64)** went on to take part.

This is a disappointingly low level of involvement. Clinical trials can be a valuable way in which treatment centres can offer patients access to the latest treatments.

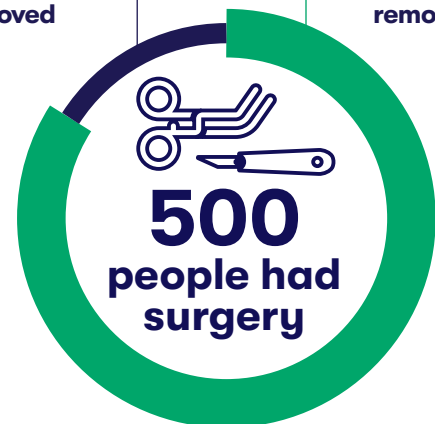
Surgery is most frequent treatment, but ablation hardly used

17%

had part of the kidney removed

83%

had whole kidney removed



500 people (92%) said they had received surgery. Of those who specified the type of surgery they had, **83% (n=405)** had their whole kidney removed and **17%** had part of the kidney removed.

46% (n=251) had keyhole surgery and a further **18% (n=97)** had robotic surgery.

34% (n=185) had open surgery.

However, despite being approved by NICE, the use of cryoablation (**1.29% n=7**) and radio frequency ablation (**1% n=5**) remained very low. Treatment protocols may be needed to help identify how to build in ablation to routine treatment.

Information often not signposted and not sufficient

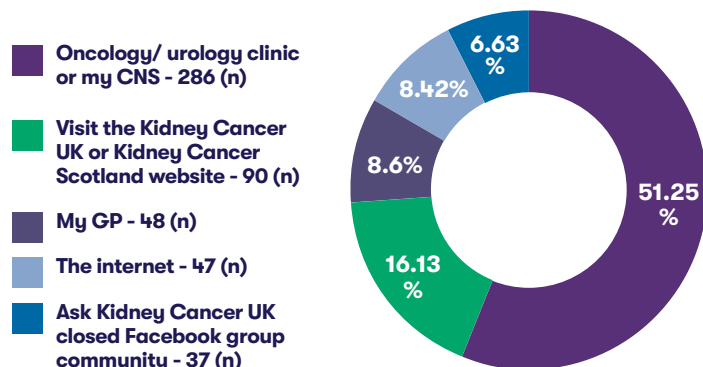
Many patients not happy with information provided at diagnosis

We already know that around 1 in 3 patients were unhappy with the way they were given their diagnosis and many of these people were not given enough information. When asked more directly about information provided at diagnosis, **40% (n= 243)** of patients who were otherwise happy and who said they understood everything they were told at diagnosis, said they needed more information.

Most patients happy with information they were given on side effects

Although many patients did not feel they were given enough information before treatment, **87% (n=161)** said they were happy with the amount of information they were given about drug side-effects.

Top five sources patients would turn to first for advice and support



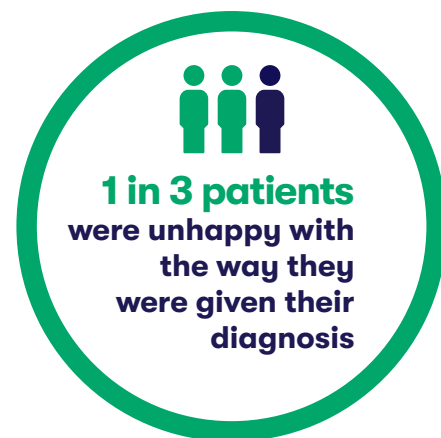
Information needs to be available throughout the pathway

Patients' needs for information vary and it is important that they can access reliable and relevant information whenever they need it. The NICE guideline will be an opportunity to ensure information is fully integrated as part of the care package.

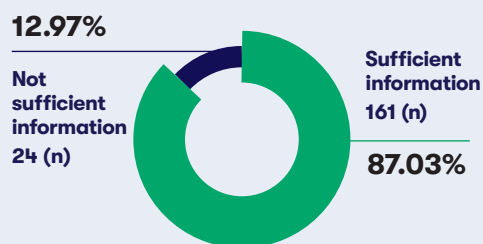
Clinical Nurse Specialists (CNSs) are vital but 1 in 4 patients not given a named CNS

The clinic and the Clinical Nurse Specialist (CNS) are the most likely source or information or support that patients would seek out in the first instance.

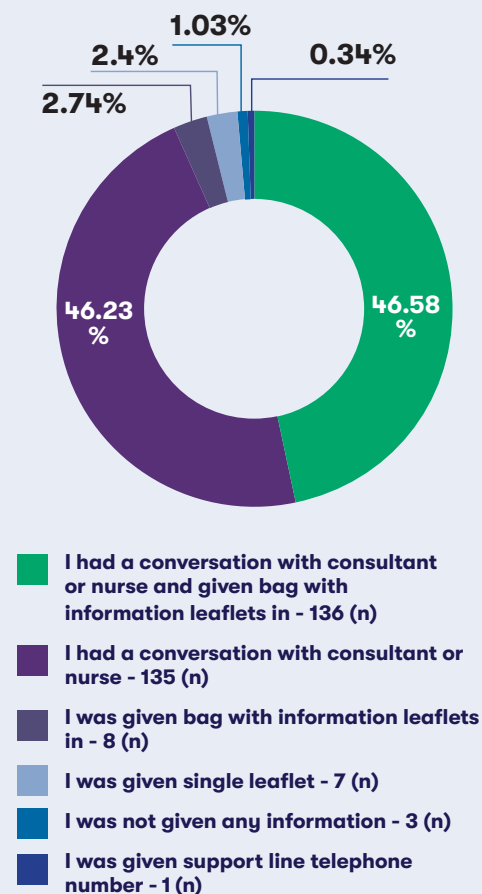
However, **25% (n=145)** said they were not given the name of a CNS or a key worker. A further **2% (n=9)** had to wait until a CNS or key worker became available.



Proportion of patients happy with information on side effects



Information sources offered at diagnosis



Aftercare and support should be available to all patients undergoing and on completing treatment

Follow up after surgery is variable

After surgery, **42% (n=227)** said they felt supported by health professionals. **11% (n= 60)** were happy but did not mention receiving support and **29% (n=158)** felt supported by family and friends. However, negative feelings including anxiety, fear and abandonment were common.

Of the **285 people** who had completed treatment, **249 (87%)** were receiving regular scans.

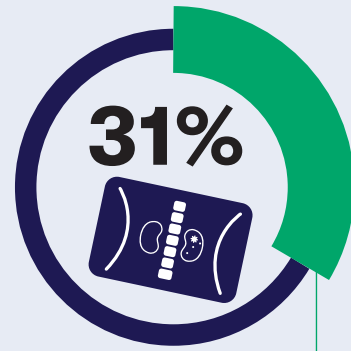
The impact of follow up and aftercare on wellbeing affects the overall benefit of treatment and should be included in the scope of the NICE guideline. This should include recommendations on effective support measures and techniques.

Most common feelings following surgery

I felt supported by the health professionals looking after me	227	41.88%
I was scared of the cancer reoccurring	199	36.72%
I felt anxious	192	35.42%
I felt emotionally low	167	30.81%
I felt abandoned after surgery and wished there was more contact with health professionals	158	29.15%
I received all the support required from friends and family	158	29.15%
I did not feel in control	109	20.11%
I was happy in the knowledge that the tumor had been removed and didn't want to have to think about it any more	60	11.07%

29.15% 158 (n)

felt abandoned after surgery and wished there was more contact with health professionals



31% of patients waited over 5 weeks for scan results

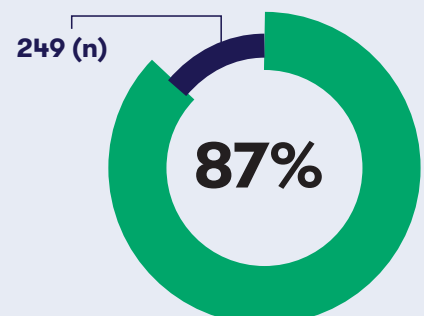
Uptake of counselling (if offered)

Yes	108	19.93%
No, I don't feel I needed it	56	10.33%
Other	9	1.66%
No, I don't like to talk about my feelings	8	1.48%

Counselling is a valuable support but frequently is not offered

Counselling, carried out by trained counsellors with experience in kidney cancer, is important for the wellbeing of many people at various stages of their kidney cancer. However, **63% (n=350)** said they were not offered it. Of those who did receive counselling, **53% (n=96)** found it helpful.

Out of 285 people, **87%** were receiving regular scans



Patient-led recommendations for the NICE guideline on kidney cancer



1

Develop evidence-based guidelines

to help health professionals who see a suspected case of kidney cancer refer the patient promptly for appropriate diagnostic tests.



2

Review advice to GPs on recognising kidney cancer

by expanding common symptoms indicated in NG12 'Suspected cancer: recognition and referral.



3

Enhance kidney cancer referral and diagnosis

to identify cases at earlier (more treatable) stages, reducing the high proportion of cases found incidentally.



4

Develop evidence-based treatment protocols

that define the appropriate use and prioritisation of surgical, ablation and medical treatments.



5

Underline the vital role played by Clinical Nurse Specialists (CNSs)

and the importance of ensuring every patient is given a named CNS or key worker.



6

Integrate the provision of accurate, reliable information

within individual care packages for each patient.



7

Emphasise the benefits of follow up and aftercare

on patient wellbeing including recommendations on effective support measures and techniques that may be used.



About Kidney Cancer UK and Scotland



Free Support Line and counselling service

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. We also offer the UK's first dedicated free kidney cancer counselling service. This free one-to-one counselling service is available by telephone or Zoom call from our own qualified counsellor and is available for patients, carers and close family.

Research and professional training

We actively fund research projects into kidney cancer and we aim to help patients, who wish to do so, to become involved in clinical trials. We also offer online training for nurses. Our course has been awarded 3 CPD hours.

Talking to people affected by kidney cancer

We present regular, informative and educational webinars on a wide range of topics featuring many of the leading lights in kidney cancer treatments in the UK. Kidney Cancer UK and Kidney Cancer Scotland are here to listen, inform and support patients at all stages of the kidney cancer journey along with anyone who is touched by the disease and needs our support. We also provide weekly Coffee, Cake and Chat patients support groups via Zoom link.

We also:

provide four closed Facebook groups where people can share their knowledge and thoughts with each other. We have a General Group, a Surgery Group, a Metastatic Group and a Carers Group.



provide a closed Facebook group for Health Professionals to interact and share knowledge and experiences.



we have an online kidney cancer training programme for GPs and all healthcare professionals.



run annually the only UK patient-focused kidney cancer survey (now in its 9th year).



National Kidney Cancer Awareness Week, now in its 8th year runs annually through first week of February and culminates in Green Friday.



act as patient advocates, speaking as the voice of patients, on behalf of patients, to Governments of all UK nations, health care authorities and the health care industry.



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www.kcuk.org.uk

This survey was independently run by Kidney Cancer UK and Kidney Cancer Scotland.
There was no input to the survey from sources outside the charity.

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