

Kidney Cancer UK 2020 Patient Survey



**Kidney
Cancer UK**

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

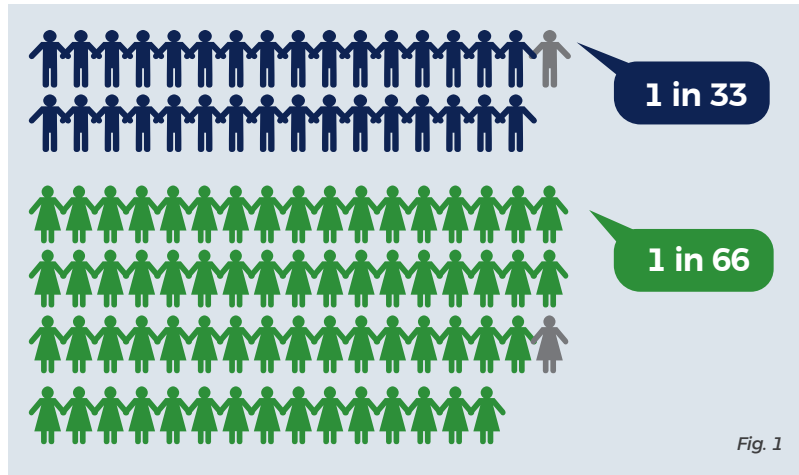
Published February 2021

Kidney Cancer: the facts

Kidney cancer is the 7th most common cancer in the UK¹.

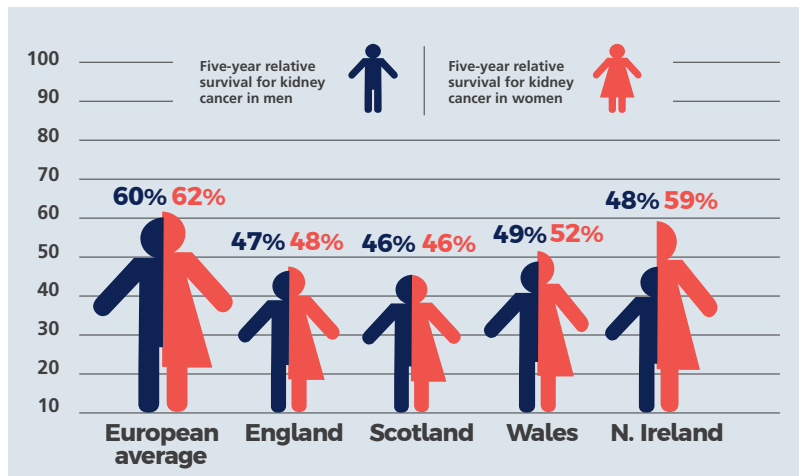
Incidence is increasing

The European age-standardised (AS) incidence rates for kidney cancer in females and males combined increased by 87% in the UK between 1993-1995 and 2015-2017².



Survival rates in the UK are some of the worst in Europe

Kidney Cancer (C64-C66, C68), Age-Standardised Five-Year Relative Survival, Adults (Aged 15+), European Countries, 2000-2007³.



The UK mortality rate rose by 73% between 1971-1973 and 2015-2017

There were 4,591 kidney cancer deaths in the UK in 2017⁴, that is over twelve deaths every day.

Kidney cancer European age-standardised (AS) mortality rates for females and males combined increased by 73% in the UK between 1971-1973 and 2015-2017⁵.

'13,056 kidney cancer cases in 2017'

¹ <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/kidney-cancer/risk-factors#heading-Zero>

² <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/kidney-cancer/incidence#heading-Two>

³ <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/kidney-cancer/survival#heading-Four>

⁴ <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/kidney-cancer/mortality#heading-Zero>

⁵ <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/kidney-cancer/mortality#heading-Two>

Executive summary

In this report percentages have been rounded to the nearest whole figure. Not all questions in the survey required answers from all. Figures with n= indicate how many people responded to that question.

Early diagnosis is essential but not achieved in nearly half of cases

The survey findings over the last three years show there has been no improvement in this situation. In almost half of cases, diagnosis is not confirmed until the cancer has reached its later stages. A positive outcome for the patient is less likely if late diagnosis means treatment is not started until stage 4. Better awareness of risk factors and early symptoms is needed and work on an effective, simple diagnostic test must be intensified.

Less invasive and more cost effective treatment options underutilised

Patients are often unable to benefit from effective less invasive treatments because they are not widely available despite being supported by a large body of evidence and extensive experience in other countries.

The information needs of many patients are not being met

At each of the main stages in the diagnosis and treatment pathway, a significant proportion of patients are not provided with all the information they need or are not signposted to reliable information sources that they could access when they need to. Some patients report being confused as to where to access information.

Patient support is variable and often not integrated with the care programme

Patients need to be supported from initial referral to diagnosis and beyond. Whilst patients do receive support, it is not always available throughout their journey and some important support services such as counselling, is often not offered.

Kidney cancer services have been maintained during the COVID-19 pandemic

Very few new patients diagnosed during the pandemic, reported delays to treatment. This represents an incredible effort from health professionals working in kidney cancer.

A clinical guideline and quality standard for England is urgently needed

Most of the issues identified in this survey could be significantly improved in England by the development of a clinical guideline, focusing specifically on kidney cancer.

In Scotland, Quality Performance Indicators must drive service improvements

Scotland has the benefit of quality performance indicators (QPIs) designed to measure specifically kidney cancer services. These must act as the driving force for service improvements and the sharing of best practice between regional cancer networks and emulate effective QPI's across the UK.

'Almost half the respondents said kidney cancer diagnosis was only confirmed at stage 3 or 4'

Survey design

The 2020 survey is the seventh in a series of annual patient surveys. There were 72 questions in the survey, which was made available for completion on-line and in hard copy.

Responses were collected between 30th September 2019 and 3rd November 2019.

The profile of the responders was broadly similar to previous years:

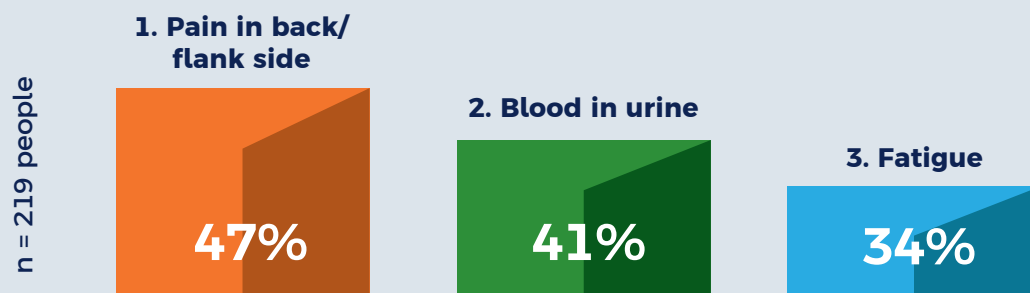
- **Total number of responders: 381 including 352 patients, as well as 15 family members and 13 carers completing on behalf of a patient.**
- **200 were female and 181 were male.**
- **87% were aged between 45 and 74.**
- **Those who responded to 'where do you live' 363; 315 from England, 40 from Scotland, 4 from Wales, 4 from Northern Ireland and 18 chose not to answer.**

Early diagnosis is essential but not achieved in nearly half of cases

In common with other types of cancer, outcomes depend on early treatment, which requires early diagnosis. However, almost half of survey respondents said their diagnosis in kidney cancer was not confirmed until the cancer is at stage 3 or 4. It is particularly disappointing that this figure has not improved over the last 3 years*.

Known symptoms provide valuable clues but are often missed

The most common symptoms reported in our survey before diagnosis were:



Though not exclusively, all are associated with kidney cancer – especially if the patient has all or more than one. In addition, there are known risk factors which can be identified through the patient's medical history. Common symptoms are smoking and obesity; others are shown in the table above.

No specific simple diagnostic test has been developed

Early detection of kidney cancer is more difficult because no specific simple diagnostic test has been developed. Many patients show no symptoms until the cancer has progressed to late stages – in our survey 46% of patients said they had no symptoms when diagnosed. So even if symptoms and risk factors are picked up, confirming diagnosis often requires a CT scan (**50% of cases** n=278) or ultrasound (**39% of cases** n=278). Accurate referral to a kidney cancer specialist is a huge challenge.

Almost half of cases not diagnosed until late stages when difficult to treat

Early diagnosis is difficult, so many cases are not diagnosed until they are well advanced. The progress and severity of kidney cancer is classified by 4 stages. **46%** (n=259) said their cancer was already in its late stages (stages 3 or 4) by the time it was diagnosed. This figure has shown no improvement over the last 3 years – the equivalent in 2019 was 45% and in 2018 47%, (a surge from 2017's figure of 31%). Generally, treatment is more effective the earlier kidney cancer is treated so, late diagnosis impairs outcomes.

Almost half of kidney cancer diagnoses are incidental findings

The other startling consequence of the lack of diagnostic tools and awareness, unless a patient is given a specialist referral, is that many cases are not even suspected until the patient is undergoing a completely unrelated test that happens to show up the cancer. **49%** (n=278) of responders to our survey said their kidney cancer was only diagnosed when they went for tests for unrelated health conditions.

Some risk factors for kidney cancer:

- **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.**

Less invasive, more cost-effective treatment options underutilised

Kidney cancer treatment has made significant steps forward over the last decade or more. However, the treatments developed are underutilised and are often perceived as still experimental even though they have a large body of evidence supporting their use. They should have become part of the standard range of treatment options as they have done in other countries.

Surgery



Most patients (85% (n=259)) had surgery. 86% (n=212) had a whole kidney removed, rather than just a part. In many cases, there are clinical reasons why a whole kidney would be removed regardless of the stage of the cancer. It is not possible to tell from this survey, but it would be useful to assess how many of these kidneys might have been saved in part, had the patient been diagnosed earlier.

The partial removal of a kidney is much less invasive, as surrounding fatty tissue and lymph nodes, adrenal gland and upper end of the ureter are not removed as they are in a radical or “total” nephrectomy procedure.

Drug treatment



35% (n=251) of patients had received drug treatment. This may be instead of surgery or in addition to it, depending on the clinical situation.

However, the survey suggests that relatively few patients took part in clinical trials of new drugs (**10%** (n=244))



‘New’ treatments



There are a number of treatment options that are still referred to as ‘new’. These include robotic surgery, cryoablation and radiofrequency ablation. These are no longer new treatment options. The National Institute of Health and Care Excellence (NICE) produced guidance on radiofrequency ablation in kidney cancer as long ago as 2004 and updated this in 2010¹. The same year NICE produced an overview of percutaneous cryotherapy for renal cancer².

However, the use of these less invasive treatment options appears to remain very low. In this survey only **1.83%** (n=219) had robotic surgery, **0.91%** (n=219) had cryoablation and **0.46%** (n=219) had radiofrequency ablation. These techniques are widely used throughout Europe and other countries, so this level of use in the UK must raise questions as to why it is so low.

¹ IPG353 Percutaneous radiofrequency ablation for renal cancer <https://www.nice.org.uk/guidance/ipg353>

² IP934 Interventional procedure overview of percutaneous cryotherapy for renal cancer <https://www.nice.org.uk/guidance/ipg402/documents/percutaneous-cryo-therapy-for-renal-tumours-overview2>

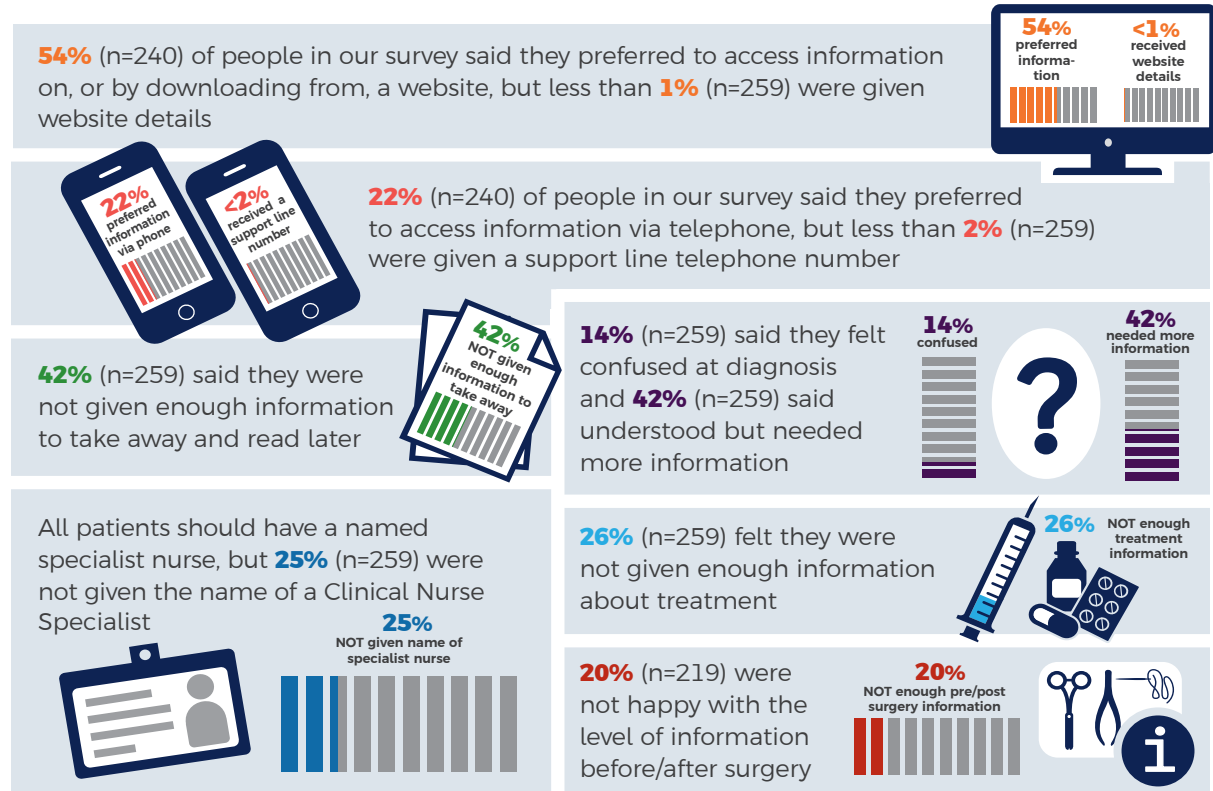
The information needs of many patients are not being met

'the internet is the preferred information source'

The information needs of patients vary and change as they progress through their journey. It is important that access to information is offered at the beginning of each stage of diagnosis and treatment, and the information offered is relevant to the specific stage. This must be done in such a way that patients do not feel forced to take the information if they do not wish to, but can access it whenever they decide to.

As a positive, **80%** (n=259) of patients felt their opinions were taken into account when deciding on future treatment options. However, the proportion of patients in this survey who were unhappy with the level of information they received may suggest that some patients could be involved in treatment decisions without realising they are not fully informed of all their options.

The survey shows that throughout the diagnosis and treatment pathway a significant proportion of patients, detailed below, were not satisfied with the information provided for them.



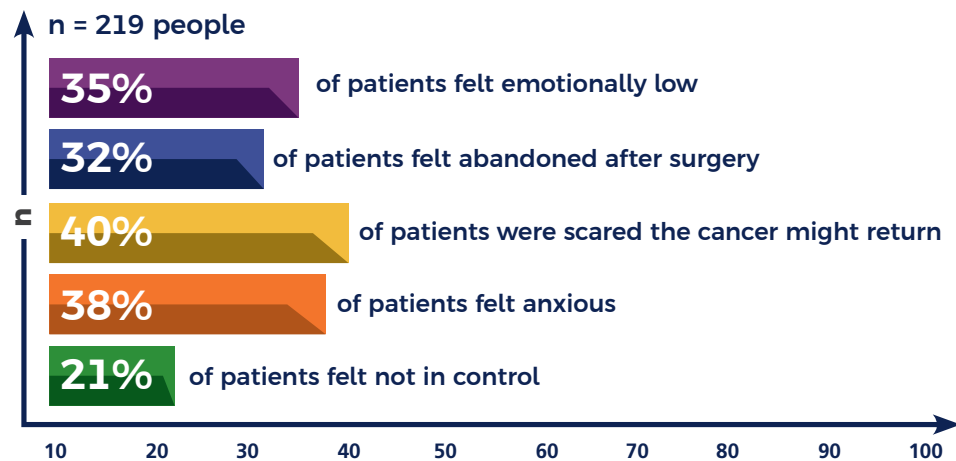
When patients are seeking support and information, the clinical nurse specialist is the most common source (**37%** (n=240) in our survey). **30%** (n=240) said they would go to websites (though only **1.25%** (n=240) mentioned NHS Direct) and a further **11%** (n=240) would go to an online discussion forum. When asked what their preferred information source would be, the internet was by far the most popular (**54%** (n=240)). Signposting patients to reliable sources of information is highly important at the start of the patient journey.

Patient support is variable and often not integrated with care

Support for kidney cancer patients is particularly important. Receiving news that you have cancer is highly stressful for most people who will require time and support to come to terms with the news. However, for the significant proportion of kidney cancer patients who receive this news whilst being tested for something else, the news is totally unexpected and comes as an even greater shock. Clinical nurse specialists are especially valuable in providing support throughout diagnosis and treatment and must be involved from the initial diagnosis.



As with their needs for information, patients will need varying levels of support, which will change as they progress through their journey. Communication with patients is vital at all stages to make sure their needs are being met, but also to provide reassurance. Our survey showed that considerable proportions of patients were coping with negative emotions after surgery.



Follow up after treatment is provided in most cases. **85%** (n=110) of patients reported they were being scanned after treatment to check there was no recurrence – mostly 6-monthly or yearly (**85%** (n=93)).

Counselling is helpful to almost half (**49%** (n=67) in our survey) who received it, but is vastly underutilised. Counselling may be offered at various points throughout the patient journey, most commonly at follow up appointments. The majority of patients (**67%** (n=239) in our survey) said they had never been offered counselling.

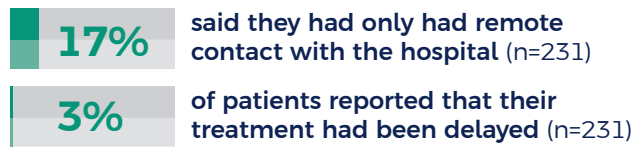
Kidney cancer services maintained during COVID-19 pandemic



Note: this section reflects results at the time the survey was carried out (Oct/Nov 2020) Questions were optional and 231 patients agreed to complete this section

Our survey shows that services for kidney cancer have been maintained at a near normal level, despite the massive strain placed on NHS staff and services by the pandemic.

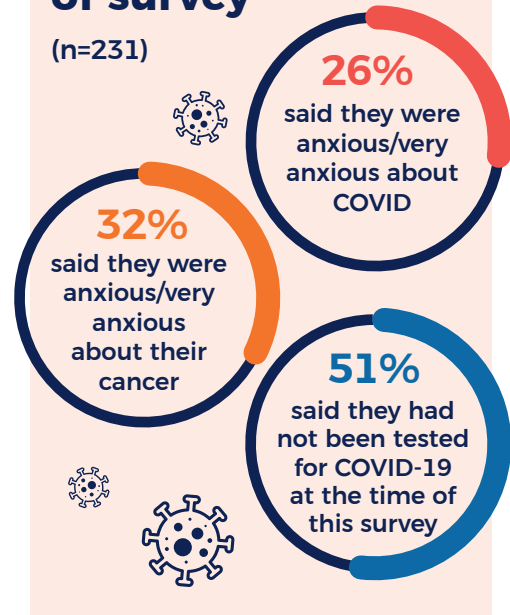
87 patients who completed this section had been diagnosed during the pandemic, (March to November 2020).



This is an incredible overall achievement by NHS health professionals and those working in kidney cancer services.

COVID 19 worried patients, but many not tested at the time of survey

(n=231)



A clinical guideline and quality standard is urgently needed



Kidney cancer is the 7th most common cancer in the UK, but Government policy is variable throughout the four devolved countries.

Scotland^{1,2}



Has existing quality performance indicators (QPIs) integrated into Scotland's long-term cancer strategy, more work needed, including improved communications between regional cancer networks, but this can be guided by the QPIs.

England^{3,4}



Woefully lacking in any Government-led policy or objectives in kidney cancer. The 21 Cancer Alliances are focusing on the 5 specific cancers in their assigned priorities for 2019/20. Cancer section of NHS Long-Term Plan does not mention kidney cancer.

We have taken the initial step of publishing the first stage of our Kidney Cancer Accord⁵ to act as a consensus statement on the quality of kidney cancer services in England.

We are calling on the Government and NHS England to join us by commissioning NICE to produce an evidence-based clinical guideline and quality standard and integrate it into NHS England planning.

¹ <https://consult.gov.scot/nhs/renal-cancer-qpis/>

² <https://www.gov.scot/publications/beating-cancer-ambition-action-2016-update-achievements-new-action-testing-change/>

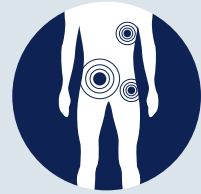
³ <https://www.longtermplan.nhs.uk/online-version/chapter-3-further-progress-on-care-quality-and-outcomes/better-care-for-major-health-conditions/cancer/>

⁴ <https://www.england.nhs.uk/cancer/cancer-alliances-improving-care-locally/>

⁵ <https://www.kcuk.org.uk/kidney-cancer-accord-consensus-statement/>

Recommendations from Kidney Cancer UK

- 1. An ongoing awareness drive of all aspects of kidney cancer to health professionals:** The known symptoms associated with a higher risk of kidney cancer should be made more widely known – particularly amongst health care professionals who may refer patients for further investigation for kidney cancer.



- 2. Wider availability of novel, cost effective treatments:** Kidney cancer specialists must have access to a full range of effective treatments including robotic surgery, cryoablation and radio-frequency ablation that meet the criteria for patients.



- 3. Enhanced access to Clinical Nurse Specialists:** All patients must be given access to a named Clinical Nurse Specialist (CNS) on diagnosis.



- 4. Wider availability of counselling:** All patients should be offered the opportunity of receiving counselling and should be able to request it at any point in the patient pathway.



- 5. Better availability of a full range of patient support materials:** At all stages of the pathway, patients must be offered access to sources of reliable information on all aspects of kidney cancer, especially via the internet, but also including telephone helplines and local patient groups.



- 6. The introduction of clear kidney cancer guidelines:** NICE should produce a clinical guideline and quality standard specifically on kidney cancer to collate existing guidance and provide authoritative, evidence-based advice for kidney cancer experts and non-experts.



About Kidney Cancer UK and Scotland

As the UK's leading kidney cancer charity our focus is on reducing the harm caused by kidney cancer for patients and their families and reducing its prevalence and impact for future generations. To achieve this, we work closely with patients, nurses and doctors to identify patients' needs, and help ensure they are being met by delivering many varied professional and educational programmes. We also deliver and support awareness programmes that are aimed at changing at-risk lifestyle factors and encouraging an earlier diagnosis, which makes a significant difference on survival rates.

Free Careline and counselling service

We operate a free telephone Careline for kidney cancer patients, their carers and families run by our health professional team.

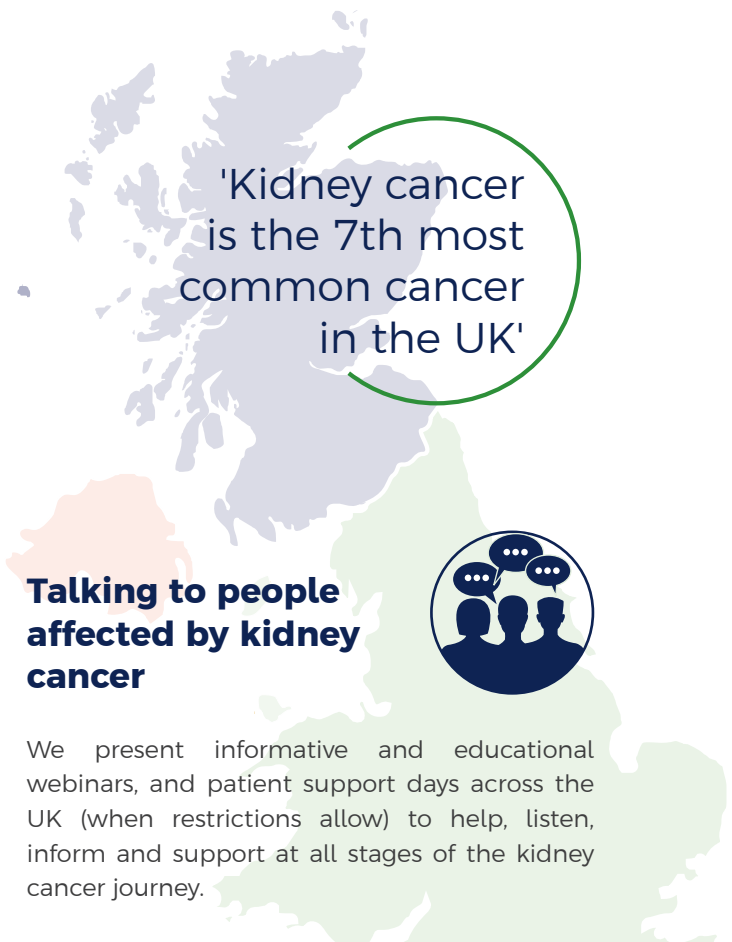
We also offer the UK's first dedicated free kidney cancer counselling service. This free one-to-one counselling service is available by telephone from our own qualified counsellor for patients, carers and close family.

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.

Supporting patients

We provide patient grants to assist with a range of financial issues that may present at this difficult time. We can help with many areas including bills, equipment, respite on a case-by-case basis.



'Kidney cancer is the 7th most common cancer in the UK'

Talking to people affected by kidney cancer



We present informative and educational webinars, and patient support days across the UK (when restrictions allow) to help, listen, inform and support at all stages of the kidney cancer journey.

We also:

- **provide a closed Facebook patient and carer forum** where people can share their knowledge and thoughts with each other.
- **provide a closed Facebook group for Health Professionals** to interact and share knowledge and experiences.
- **run annually the only UK patient-focused kidney cancer survey** (now in its 7th year).
- **National Kidney Cancer Awareness Week**, now in its 6th year runs annually through first week of February and culminates in Green Friday.



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Here to support



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