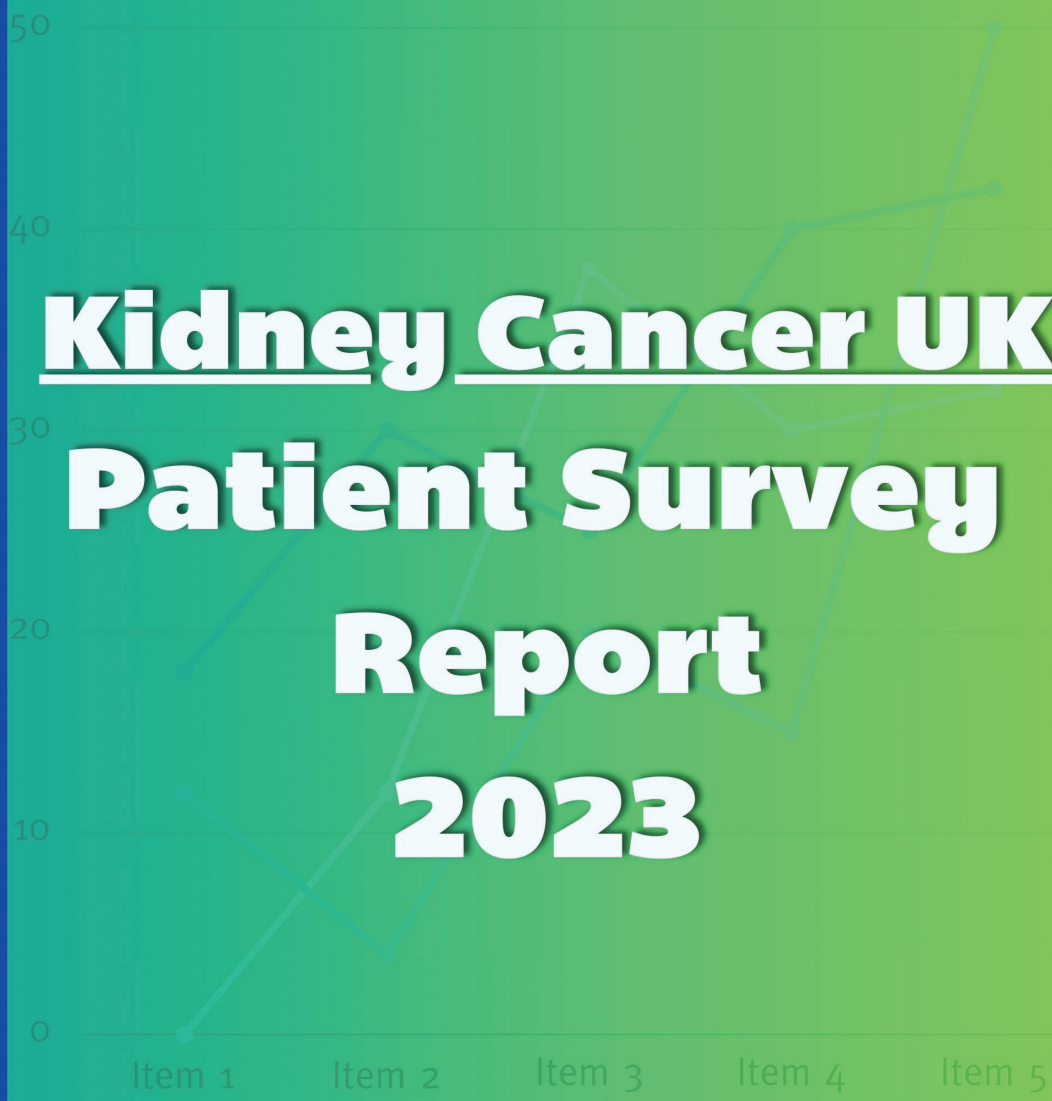


The results of the only UK patient focused kidney cancer survey



Kidney Cancer UK Patient Survey Report 2023



Published February 5, 2024

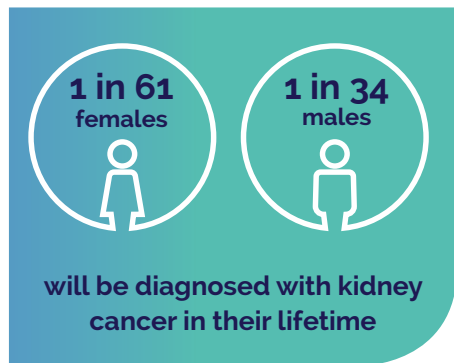
This survey was produced with financial support from Boston Scientific, Bristol Myers-Squibb, EUSA Pharma, Ipsen and the Merck-Pfizer Alliance who had no input into its content.



Around 4,700 people die each year from kidney cancer (around 13 people every day)³

We must improve clinical outcomes in kidney cancer...

- Kidney cancer is the seventh most common cancer in men and women in the UK.¹
- An estimated 46,800 people are living with kidney cancer in the UK today.¹
- 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**.¹

This survey indicates that of the above new cases:

- 4,130 visit their GP due to feeling unwell
- 1,465 go to A&E due to feeling unwell
- 6,395 are diagnosed when having a scan or test for an unrelated condition

Around 4,700 people die each year from kidney cancer (around 13 people every day).³ **In the UK, mortality rates due to kidney cancer have increased by 73% since the 1970s.**³

One of only seven cancers whose **mortality rate is increasing**.⁴

These serious challenges are now being addressed in programmes run by the National Institute for Health and Care Excellence (NICE) and the National Kidney Cancer Audit.



... and we must improve access to support and information for patients

- **More than 1 in 3 patients were unhappy with the way they were told** they had kidney cancer
- **Nearly half of patients were not given enough information** to take away and read later
- **Over 1 in 5 patients were not given the name of a CNS** (Clinical Nurse Specialist)
- **Almost 1 in 4 patients were not given enough information** about their treatment

The NHS provides some, but cannot provide all, of the information and support needed. Outside the NHS, charities can, and do to a very small degree, play a valuable role in filling these gaps, provided the NHS partners with them and signposts patients to their resources.

This is the tenth, and only UK-focused, annual survey of kidney cancer patients. It ran online, from 23rd September 2023 to 12th November 2023 and received 610 responses, 508 of those were completed surveys from kidney cancer patients in the UK.

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

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#heading-One>

4 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

ABOUT KIDNEY CANCER UK



Kidney Cancer UK is a national charity supporting kidney cancer patients, and their families and carers. We are funded by voluntary donations, grants and sponsorship. We do not charge a membership fee and we provide our services free of charge to the patient, family or carer.

Kidney Cancer UK 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.

Our website is full of information

Our website contains lots of useful free information, including a library of booklets and reports on kidney cancer to download or order, and over 100 videos on treatment and care. Last year we had 45,000 hits on our website.

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, answered by our healthcare professional team.

Our counselling service is free

We also offer the UK's first dedicated free kidney cancer counselling service. This 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. Last year we provided almost 500 counselling sessions.

Our Facebook pages

We reach 9,000 a month on Facebook. We also have 5 closed Facebook pages where patients can discuss different aspects of kidney cancer with other patients. One of these is specifically for health care professionals. All our pages are moderated and our own health professionals are available to answer queries.

Webinars

Through our website, 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.

Coffee, cake and chat

We also provide weekly Coffee, Cake and Chat patient support groups via Zoom link.

Online kidney cancer training programme for GPs and all healthcare professionals.

Our online self-learning training course on kidney cancer qualifies for CPD points. Last year around 180 health professionals took part in it.

National Kidney Cancer Awareness Week

Each year in February, we raise public awareness of kidney cancer through our Kidney Cancer Awareness Week. Last year we reached an estimated 10 million people.

Patient advocates

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

- The development of the NICE* clinical guide line for kidney cancer
- The pilot work by NICE* to develop a treatment pathway for kidney cancer
- The National Kidney Cancer Audit

We also provide input to relevant Government consultations and a number of All-Party Parliamentary Groups.

**The National Institute for Health and Care Excellence*

Executive summary

"The NHS does not have the resources to provide its own patient support and information hubs such as dedicated cancer-specific websites and social media pages. Consequently many kidney cancer patients say they are left feeling confused, scared, unsupported and not in control during and following treatment.

In the absence of NHS support and information, we are asking health professionals treating kidney cancer to ensure that patients are given the details of websites and support line numbers that could provide them with the information and support they need."

Malcolm Packer Chief Executive Officer

- **Improved access to support and information for patients is needed** throughout the patient pathway.
 - Most patients (79%) said they were told they had cancer in a way they understood but, **1 in 3 patients are unhappy** with how they were told.
 - Nearly half of patients were not given enough information to take away and read later
 - **1 in 5 patients are not given a named specialist nurse** at the point of diagnosis
- **Lack of information** and support **contributes to patient anxiety**.⁵ The physician's help in providing treatment information contributes to patients' hope.
- **Lack of information is not restricted to patients.** Primary care health professionals need more information to recognise patients who should be referred for specialist diagnosis, and NICE guidance needs to be updated.
- At diagnosis, **most patients are able to have a discussion with the consultant or nurse**, but 43% said they were not given information to take away with them.
- Although more than three quarters of patients said their views were considered when making decisions on treatment, **access to information on treatment is much lower**, which might call into question whether patient choices are fully informed.
- **Most kidney cancer patients choose websites, telephone support lines and Facebook as their first point of contact for information and support.** These are not services the NHS is resourced to provide, but they do exist outside the NHS. Kidney cancer health professionals should be asked to signpost these resources to patients at every reasonable opportunity.
- **Contact and conversations with peer patients is a source of support** for many people, and kidney cancer units should offer this to patients through reputable information partners outside the NHS.
- **Capacity for counselling services is limited in the NHS** and does not provide counselling dedicated to kidney cancer. Kidney cancer units should recommend tailored counselling to suitable patients and should have knowledge of such services offered outside the NHS to which to refer patients.



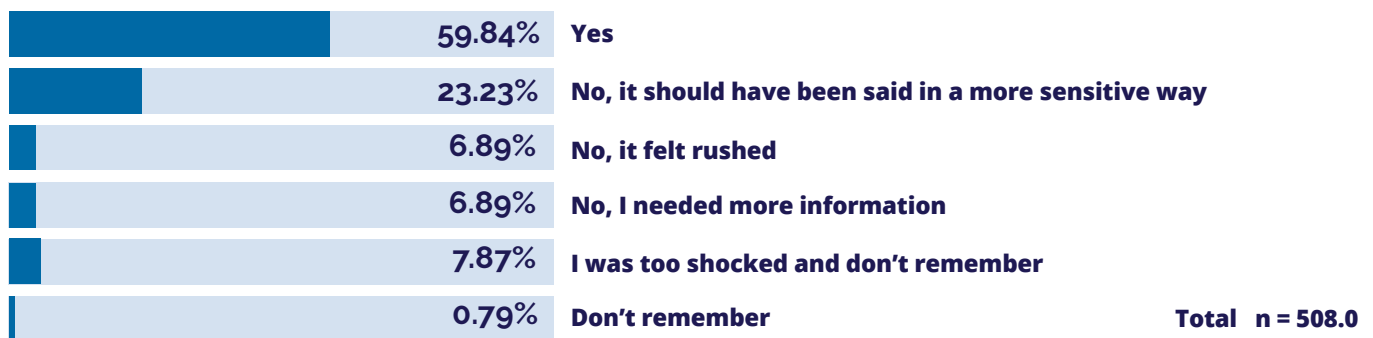
Improved access to support and information for patients is needed.

Lack of information and support increases patient anxiety⁵

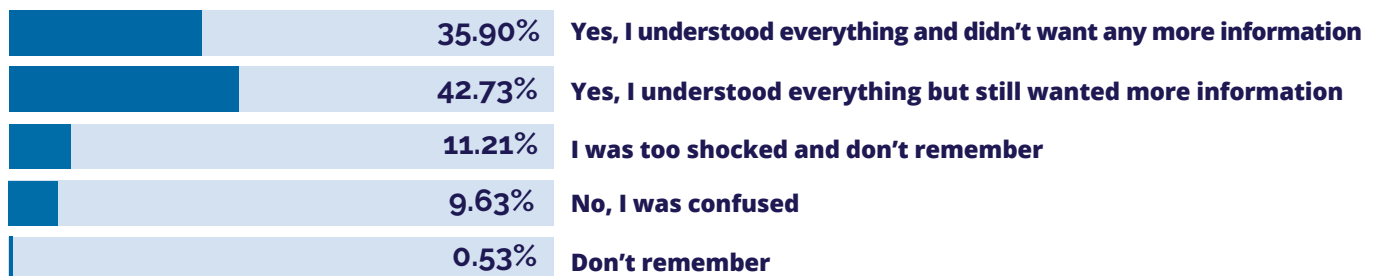
Receiving a diagnosis of cancer is traumatic for anyone. For the 48% of kidney cancer patients who are diagnosed when having a scan or test for an unrelated condition, it comes as an even greater shock. Coupled with the enormous pressures on NHS services, this may often lead to difficulties for health professionals who may be unable to devote as much time to supporting and informing patients as they would like. Our survey shows that 37% of patients were not happy with the way they were told they had kidney cancer.

Was the way in which you were told about having kidney cancer appropriate?

It can also lead to patients feeling they are inadequately informed about their condition.



Was the way you were told you had cancer delivered in a way that was easily understood?



Studies across different cancers suggest a two-way relationship between information satisfaction and anxiety symptoms.⁵ The near 43% of kidney cancer patients stating they wanted more information is concerning. In addition, 31% of patients are waiting longer than 3 months from first feeling unwell and seeking medical advice to receiving a diagnosis, which is likely to make the level of anxiety worse.

Recommendation:

Health professionals should place greater emphasis on the role of patient information and support, and their value relating to patients' wellbeing and outcomes.



The physician's help in providing treatment information contributes more to patients' mental wellbeing than does cheerfulness or optimism.⁶ Our survey shows almost 1 in 4 kidney cancer patients are initially misdiagnosed with a range of more than 10 conditions and these patients require special consideration in order to re-establish trust.⁶

⁵ Goerling U. et al. Information needs in cancer patients across the disease trajectory. A prospective study. Patient Education and Counseling. Volume 103, Issue 1, January 2020, Pages 120-126.

⁶ Peteet JR et al. Presenting a diagnosis of cancer: patients' views. The Journal of Family Practice, 01 Jun 1991, 32(6):577-581 PMID: 2040882

Insufficient information for health professionals to aid referral to specialists

Early in the pathway, better information is needed to help primary care health professionals recognise patients who should be referred for specialist diagnosis. Our survey shows that 23% of kidney cancer patients were initially misdiagnosed before being sent for specialist diagnosis. This results in delays not only in access to specialist diagnosis but also to treatment.

There are several symptoms that many patients experience. However, often the only one that raises suspicion of kidney cancer is the presence of blood in the urine; yet this is actually the third most common symptom.

Recommendation:

NICE guideline NG 12 *Suspected Cancer: Recognition and Referral* should be updated to include all the relatively common symptoms indicative of kidney cancer.



Guidance used by many GPs and produced by the National Institute for Health and Care Excellence (NICE), *NG 12 Suspected Cancer: Recognition and Referral*, also leaves out the two most common symptoms (pain in back/flank/side and fatigue). This should be rectified.

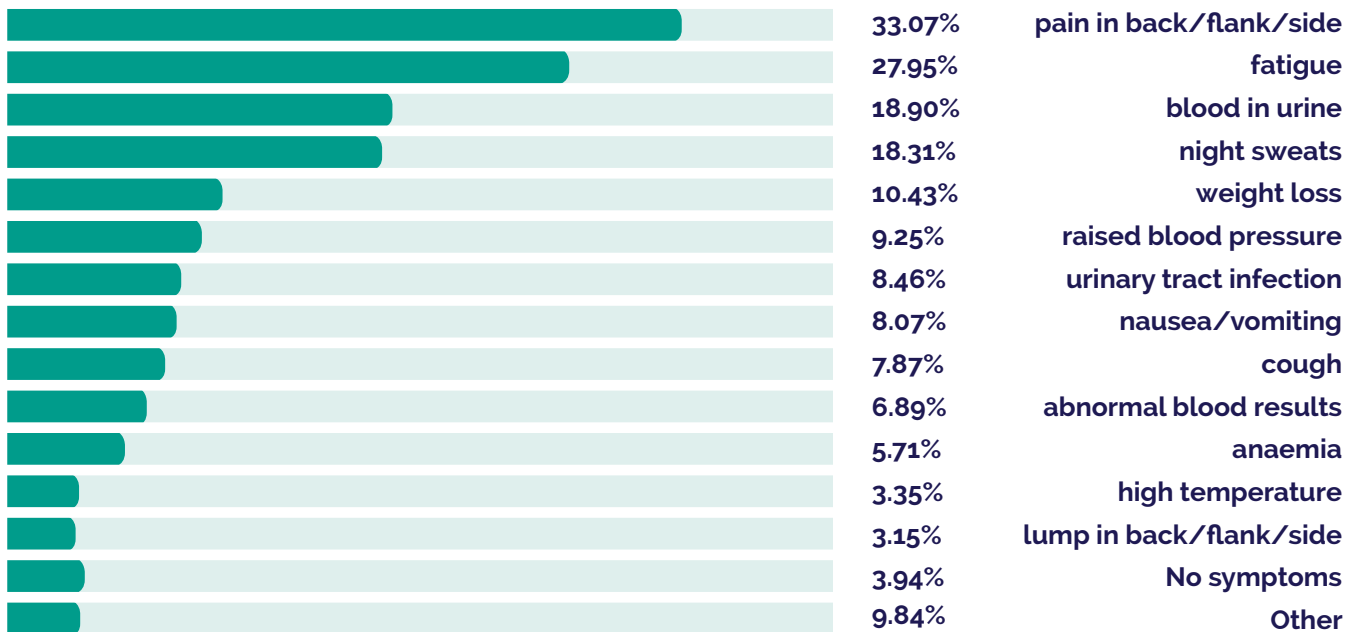
Risk factors for kidney cancer also play a major role in early diagnosis and should be flagged in patients' notes. There is no simple laboratory test for kidney cancer, as yet. So noting risk factors combined with the appropriate symptoms, if applicable, is particularly important in early diagnosis.

Recommendation:

A dedicated kidney cancer website for health professionals would provide a one-stop information source to aid referral and diagnosis.



Which symptoms did you experience BEFORE being diagnosed with kidney cancer?

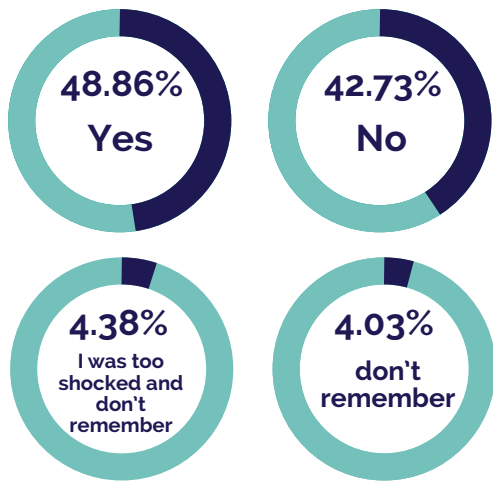


*Kidney Cancer UK has published a booklet on kidney cancer to help health professionals in primary care identify and refer suspected cases.

Not enough information for many patients at diagnosis

Most patients (79%) said they were told they had cancer in a way they understood but, we also know that 37% of patients in this survey did not think the way they were told they had kidney cancer was appropriate and 52% wanted more information.

Only just under half of the patients in our survey recalled being given information about kidney cancer to take away and read after their consultation.



Were you given information about kidney cancer to take away to read later?

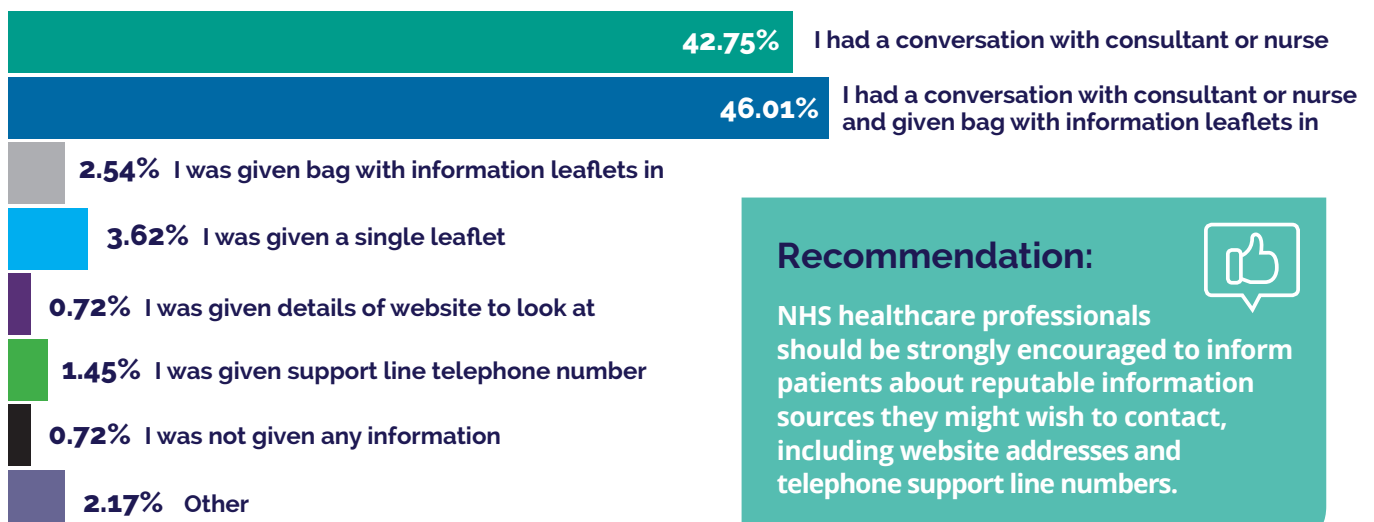
Those who did receive information mostly had a conversation with the consultant or nurse and around half of these were given a bag containing information leaflets.

It is concerning that very few patients were given the means of obtaining further information if they wanted it, for example details of a website or a support line number.

If you were given information at diagnosis what was given?

With staff time at a premium and budgets severely stretched, it is very difficult for clinics to provide a full range of information materials to support diagnosis, or at other points on the kidney cancer patient pathway. In addition, patients may wish to access information in their own time and not at or immediately after their diagnosis. Not being able to do so may increase patient anxiety.

Reliable information resources exist in the third sector and are provided at no cost to patients. These include support lines, websites and increasingly, social media sites. However, our survey results show that clinic staff are not effectively signposting patients toward such sources.



Recommendation:

NHS healthcare professionals should be strongly encouraged to inform patients about reputable information sources they might wish to contact, including website addresses and telephone support line numbers.



More information on treatments is needed to support informed choice

Most patients (77%) said their views were taken into account (partially or completely) when the medical team were deciding on future treatment options. 94% were able to discuss their treatment with the consultant or nurse and 89% said they were given enough information about side-effects.

However, fewer than half were given information to take away with them, only 1% were given details of a support line, less than 1% were given details of a website and almost 5% were given no information at all. This raises the possibility that some patients might not be fully informed when deciding on future treatment.

It may be assumed that in addition, this still leaves 23% whose views were not considered or who were unsure.



77%
of patients
said their views
were taken
into account

What type of information did you receive when you were told about your treatment?

Answer	%
1. discussed with consultant or nurse	60.24%
2. discussed with consultant or nurse and given bag with information leaflets in	33.66%
3. given a pack with information leaflets in	5.12%
4. given a single leaflet	2.76%
5. given a details of website to look at	0.59%
6. given a support line telephone number	1.18%
7. no information given	4.92%
8. dont know	0.59%
9. Other	1.57%

NICE guidance on kidney cancer treatments

8 interventional procedures guidance documents since 2005

18 appraisals since 2009

7 more appraisals yet to be published

Recommendation:



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

Studies on patient participation in decision-making have shown that those who felt they were involved were the most satisfied with treatment and support.⁷ Studies encourage clinicians to ensure they gain an insight into patients' values at key decision points in the pathway and to acknowledge their legitimacy.⁸

This approach is going to be increasingly important going forward, but it is likely to add to the demand for information as more treatment options are reviewed by NICE and become available.

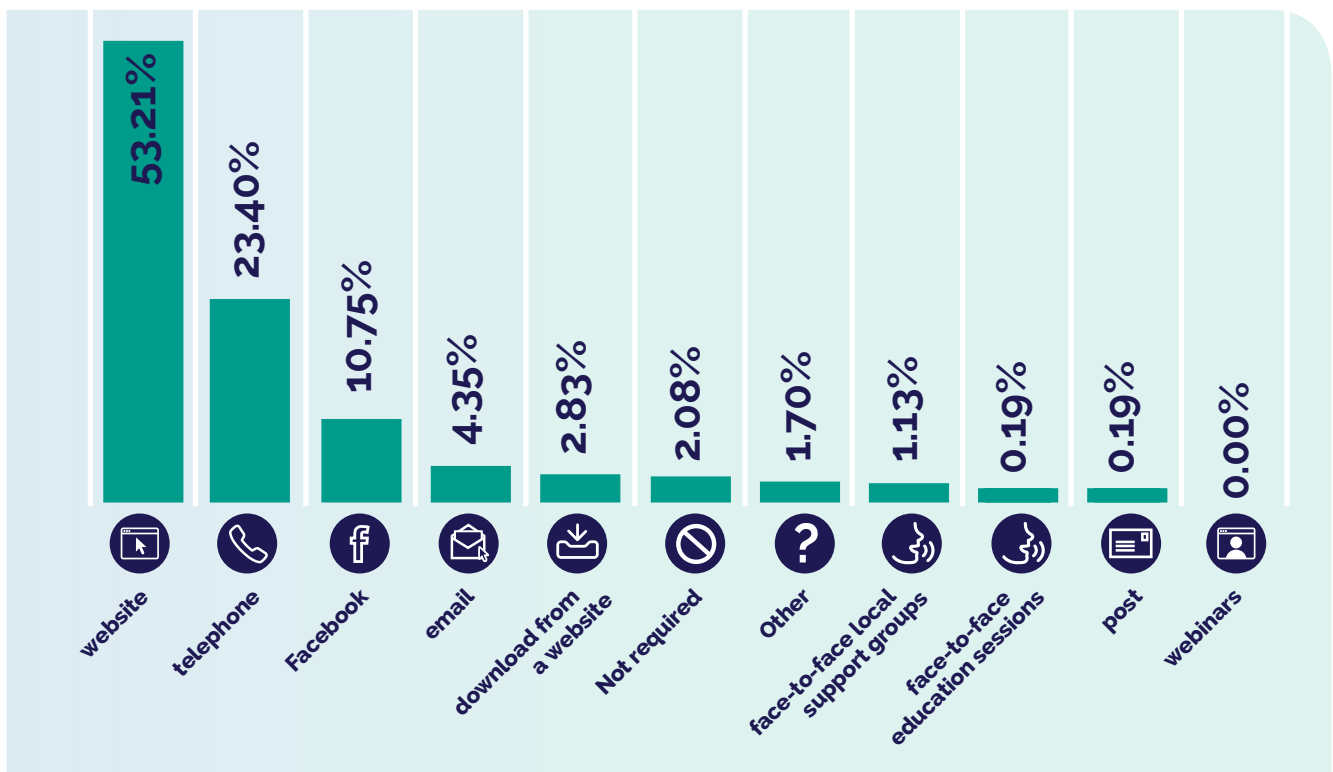
7 Gattellari M et al. Sharing decisions in cancer care. Social Science & Medicine Volume 52, Issue 12, June 2001, Pages 1865-1878.

8 Pieterse, A. H et al (2008). Clinician and cancer patient views on patient participation in treatment decision-making: A quantitative and qualitative exploration. British Journal of Cancer, 99(6), 875-882. <https://doi.org/10.1038/sj.bjc.6604611>

Where do patients go to find information?

Kidney cancer units will always remain the best source of medical information, and the only source about the individual patient. However, patients looking for additional information on other aspects of kidney cancer will almost always go to other sources. In our survey, we asked which ones.

What is your first point of access to information or support?



The preference for information sources that are on the Internet (websites and social media such as Facebook) is not surprising, but it represents a potential challenge for kidney cancer clinics that do not have such a presence online, and do not have the resources to develop and run a website or a Facebook page. The challenge is ensuring patients are signposted to view only reputable, accurate, balanced and relevant websites and social media pages.

Very few patients said they were referred to a website by their kidney cancer unit (less than 1% at diagnosis and when considering treatment).

Recommendation:



Kidney cancer units should make sure they can satisfy patients' information needs no matter what medium is 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.

Recommendation:



Units treating kidney cancer patients need to ensure they know patients' preferences in the media through which they prefer to access information.

Not making recommendations about reputable online sources leaves a gap that patients will fill, but not necessarily in the best way. Of course it is impossible to ensure patients only look at certain websites, but by clearly signposting ones that can be trusted and reinforcing this at each patient contact, the risk of patients picking up the wrong information can be minimised.

Support is not all about information

Social media

In addition to ensuring patients have access to information to help them understand their illness and what to expect from their treatment pathway, supportive care should be available. This should help them achieve a quality of life they recognise as 'normal'.⁹ Kidney Cancer UK's experience of supporting patients tells us this is important not only throughout the entire patient pathway, but also beyond, when treatment ends.



Support may be practical, such as helping patients to make decisions about treatment or to apply for financial support and Government benefits. It may also be to help them cope with the impact of kidney cancer on their closest relationships and their own mental health, such as being able to talk

to other patients about their concerns through patient support groups and counselling.

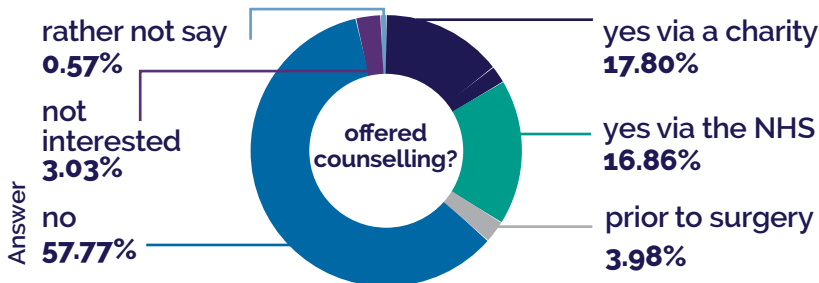
The COVID pandemic meant that online social media groups often replaced face-to-face patient groups. Our latest survey results show that after websites and telephone support lines, Facebook was the third most popular first point of access to information or support (11% of patients) with face-to-face local support groups registering only 1%.

Counselling

Only 17% of patients said they were offered counselling on the NHS, compared with 22% who accessed it privately or via a charity. Of the 200 people who said they did have counselling, 110 (55%) found it useful.



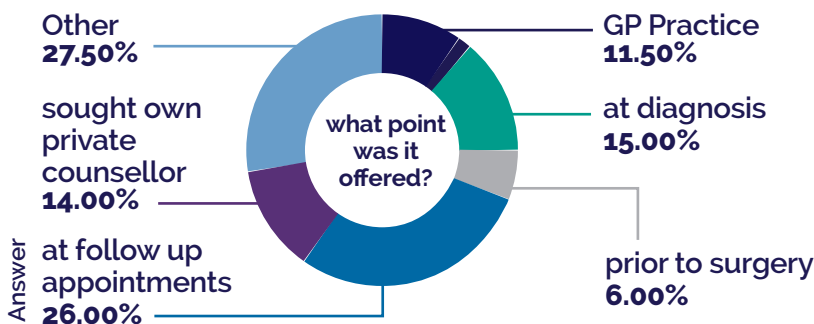
Were you, or have you been, offered counselling?



Supportive care should be available. This should help them achieve a quality of life they recognise as 'normal'.

Counselling should be available throughout the patient pathway. Our survey shows that although this appears to be the case, access is limited at every stage.

If you did receive counselling, at what point was it offered?



Recommendation:



Kidney cancer units should ensure they signpost patients to counselling that is available from charities if it is unavailable or difficult to access on the NHS.

Kidney Cancer UK Recommendations



Health professionals should place greater emphasis on the role of patient information and support, and their value relating to outcomes and wellbeing.



1

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



2

The availability of a dedicated kidney cancer website for health professionals would provide a one-stop information source to aid referral.



3

Health care professionals should be strongly encouraged to inform patients about reputable information sources they might wish to contact, including website addresses and telephone support line numbers.



4

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



5

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



6

Kidney cancer units should make sure they can satisfy patients' information needs no matter what medium is 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.



7

Kidney cancer units should ensure they signpost patients to counselling that is available from charities if it is unavailable or difficult to access on the NHS.



8



Kidney Cancer UK

Support line

& Counselling booking

0800 002 9002

Call free

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

Published February 5, 2024



© 2024 Kidney Cancer Care Ltd.

Kidney Cancer UK, Kidney Cancer Care and Kidney Cancer Scotland are trading titles of Kidney Cancer Care Ltd.

Kidney Cancer Care Ltd is a registered charity in England and Wales (1120146) and Scotland (SC043642)

Registered Office: 4 New Inn Lane, Guildford, Surrey, GU4 7HW.

Company Number England and Wales (05937304)