

# Kidney Cancer UK 12th Annual Patient Survey

# 2025

*the only survey dedicated solely to UK kidney cancer patients*



## Kidney Cancer UK

The UK's leading kidney cancer charity

## **Kidney Cancer UK Patient Survey 2025**

Welcome to the twelfth year of our Annual Kidney Cancer Patient Survey - the only survey dedicated solely to UK kidney cancer patients.

We greatly value your participation. This survey gives a voice to people living with kidney cancer across the UK, capturing a wide range of experiences and challenges. The insights we gather help Kidney Cancer UK to:

- Drive positive change in patient care and support.
- Shape our policies for meetings, conferences, and government discussions.
- Continue delivering exceptional support for patients, their families, and caregivers.

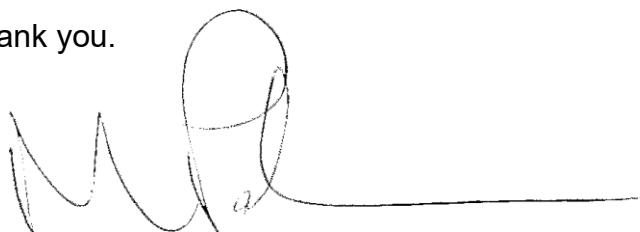
By conducting this survey every year, we build a clear picture of the kidney cancer patient experience over time. Your contribution ensures we can target our resources effectively and provide the best possible support for you and future kidney cancer patients. The results will be published during Kidney Cancer Awareness Week, 2-8 February 2026.

### **Important - Please read before starting**

- This survey should be completed by, or on behalf of, a kidney cancer patient who is at any stage of their pathway.
- Please clearly circle your response
- The survey is for patients treated in the United Kingdom only.
- It may be helpful to have details of any drugs, treatments, or clinical trials you are currently on or have previously had.
- Most questions are tick boxes or multiple choice, with opportunities to leave comments.
- It should take no more than 15 minutes to complete.
- Please make sure you complete the survey right to the very end.

We are very grateful for your support in taking this important survey.

Thank you.

A handwritten signature in black ink, appearing to read "Malcolm Packer", with a long horizontal line extending to the right.

Malcolm Packer  
Chief Executive Officer- Kidney Cancer UK

*\*This survey is confidential; no personal information is made public or shared in any form with third parties, we will not contact you unless you specifically give us your consent.*

## About You

1. Are you a patient (current or past) completing this, or a family member or a carer completing this survey on behalf of a patient?

1. patient
2. family member or carer
3. Other

2. Have you completed the Kidney Cancer UK Patient Survey in previous years?

1. Yes
2. No

Please note that all questions from this point on are related to current or past patients and should be answered by them or on their behalf. If you are answering on behalf of a patient please remember to answer for the patient, not for you. Thank you for your support with this survey.

3. Sex

1. female
2. male
3. prefer not to answer

4. Age bracket?

1. under 18 years old
2. 18 to 24
3. 25 to 34
4. 35 to 44
5. 45 to 54
6. 55 to 64
7. 65 to 74
8. 75 +

## Where do you live?

5. Country in the United Kingdom?

1. England
2. Scotland
3. Wales
4. Northern Ireland

6. Region of England?

1. Northwest
2. Northeast
3. Yorkshire and Humber
4. West Midlands
5. East Midlands
6. East Anglia
7. Southwest
8. Southeast
9. London

7. Region of Scotland?

1. Glasgow and West of Scotland
2. Edinburgh and East of Scotland
3. Dundee, Perth and Tayside
4. Inverness, Highlands and islands
5. Aberdeen City and Shire
6. South of Scotland

8. Region of Wales?

1. North Wales
2. Mid Wales
3. South Wales
4. Southeast Wales

9. Region of Northern Ireland?

1. Antrim
2. Armagh
3. Down
4. Fermanagh
5. Londonderry
6. Tyrone

## About the patient's diagnosis

10. How did the patient find out they had kidney cancer?

1. visited my GP because of feeling unwell and was sent for more tests
2. visited A&E because of feeling unwell and sent for more tests
3. found out during a medical scan or test that was unrelated to kidney cancer
4. found out following a GP visit or a medical scan or test that was related to kidney cancer symptoms
5. Other \_\_\_\_\_

11. Which symptoms did the patient experience BEFORE receiving a diagnosed of kidney cancer?  
(tick all that apply)

1. no symptoms (please don't click any other boxes)
2. blood in urine
3. pain in back/flank/side
4. lump in back/flank/side
5. night sweats
6. high temperature
7. fatigue
8. cough
9. nausea/vomiting
10. weight loss
11. anaemia
12. abnormal blood results
13. urinary tract infection
14. raised blood pressure
15. lump in neck
16. other \_\_\_\_\_

12. How long did it take from first feeling unwell and seeking medical advice to receiving a kidney cancer diagnosis?
1. Less than 1 month
  2. between 1 and 3 months
  3. over 3 months to 1 year.
  4. 1 year+
  5. I did not visit my GP or A&E service before diagnosis
  6. Comment
13. Was kidney cancer the first diagnosis or was the patient initially misdiagnosed with another illness?
1. first diagnosis
  2. initially misdiagnosed
14. If initially misdiagnosed with another illness, what was the initial diagnosis? (tick all that apply)
1. kidney stone
  2. cough/ asthma/ breathing issues
  3. gynaecological issues
  4. back pain
  5. urine infection
  6. broken or fractured bone
  7. bladder infections
  8. kidney cysts
  9. irritable bowel syndrome
  10. muscular
  11. Other \_\_\_\_\_
15. How long ago was the patient diagnosed with kidney cancer?
1. less than 2 years ago
  2. between 2 and 4 years ago
  3. between 4 and 6 years ago
  4. between 6 and 8 years ago
  5. between 8 and 10 years ago
  6. between 10 and 12 years ago
  7. over 12 years ago

## About the patient's kidney cancer

16. What type of kidney cancer was the patient diagnosed with?
1. clear cell renal cell carcinoma
  2. papillary renal cell carcinoma
  3. chromophobe renal cell carcinoma
  4. collecting duct renal cell carcinoma
  5. unclassified
  6. transitional cell carcinoma
  7. Wilms' tumour
  8. Other \_\_\_\_\_

17. Staging is used to describe the size of the cancer and how far it has spread. At which stage was the cancer diagnosed?

1. stage 1
2. stage 2
3. stage 3
4. stage 4

18. Grading is used to describe the size of the cancer and how far it has spread. At which stage was the cancer diagnosed?

1. Grade 1
2. Grade 2
3. Grade 3
4. Grade 4
5. don't know

## Care during diagnosis

19. Was or has the patient been offered a biopsy?

1. yes and took up the offer
2. yes, but did not take up the option
3. no a biopsy wasn't offered

20. If a biopsy was offered but you did not accept it, please tell us why.

21. If yes, was the reason for performing a biopsy explained?

1. yes, it was explained clearly
2. yes, but did not fully understand the explanation
3. don't remember if it was explained
4. no

22. How long did you wait for the biopsy result

1. 1-7 days
2. 2 weeks
3. 3 weeks
4. 1 month
5. 6 to 8 weeks
6. 8 weeks +

23. Did the biopsy confirm kidney cancer?

1. yes
2. no
3. still awaiting results

24. If the patient is going to have, or has had, a biopsy, is/was the patient satisfied with the way the results were explained to them?

1. yes
2. no: please tell us why

25. Was the news of having suspected kidney cancer shared appropriately?

1. yes
2. no, it should have been said in a more sensitive way
3. no, it felt rushed
4. no more information was needed
5. too shocked and don't remember

26. Leave a comment regarding how the news of suspected kidney cancer was shared if you wish to.

27. Was the news of suspected kidney cancer delivered in a way that was easily understood?

1. yes, understood everything and didn't want any more information
2. yes, understood everything but still wanted more information
3. no, it was confusing
4. too shocked and don't remember
5. don't remember

28. Was information about kidney cancer shared to take away to read later?

1. yes
2. no

29. If given or told information at diagnosis what or how was it shared? (tick all that apply)

1. a conversation with consultant or nurse
2. a conversation with consultant or nurse and given bag with information leaflets in
3. given bag with information leaflets in
4. given a single leaflet
5. given details of website to look at
6. given support line telephone number
7. not given any information
8. don't remember
9. other \_\_\_\_\_

## About the patients cancer treatment

30. What type of treatments, will or did the patient receive for kidney cancer? (tick all that apply)

1. surgery
2. drug treatment - taken orally
3. drug treatment - taken intravenously
4. SABR (Stereotactic Ablative Radiotherapy)
5. drug trial
6. cryoablation
7. radiofrequency ablation
8. radiotherapy
9. active surveillance following scans before treatment
10. follow up following treatment
11. I was/am not suitable for treatment, palliative care only
12. don't know
13. Other \_\_\_\_\_

31. If the patient was on active surveillance, how was the situation resolved?

Active surveillance is the term used for monitoring before a decision is made about whether to treat.

1. still on active surveillance
2. about to be or have been treated following active surveillance
3. surveillance is no longer needed, and I have been discharged
4. not been on active surveillance

32. Was the patient involved in decisions regarding their treatment?

1. yes
2. yes, to a certain extent
3. no
4. not sure
5. not given enough information to make an informed decision about my treatment

33. Add a comment regarding how involved the patient was in their treatment if you wish

34. Was the name of a Clinical Nurse Specialist (CNS) or key worker responsible for the patient's care provided?

1. yes
2. no
3. yes but had to wait until a CNS was available
4. not sure



35. What type of information did the patient receive when told about their treatment?
1. discussed with consultant or nurse
  2. discussed with consultant or nurse and given bag with information leaflets in
  3. given a pack with information leaflets in
  4. given a single leaflet
  5. given details of website to look at
  6. given a support line telephone number
  7. offered counselling
  8. no information given
  9. other \_\_\_\_\_
36. Did travelling for treatment cause any issues?
1. It did not cause any issues
  2. It caused issues – please tell us about them

37. Has the patient had, or is the patient going to have, surgery?
1. yes
  2. no (**Please go to question 41**)
  3. I don't know, waiting to hear(**Please go to question 41**)

## About your surgery

38. How much of the kidney was, or will be, removed?
1. whole kidney (nephrectomy)
  2. part of the kidney (partial nephrectomy)
  3. both kidneys were removed (bilateral nephrectomy)
  4. partial on each kidney
  5. whole kidney and partial on other
  6. waiting to hear what surgery I will have
  7. having/have had a different type of surgery
39. What type of surgery has the patient received or due to have? (tick all that apply)
1. traditional (open) surgery
  2. keyhole (laparoscopic) surgery
  3. robotic techniques
  4. they froze the tumour (cryoablation)
  5. radiofrequency ablation
  6. waiting to hear what type of surgery it will be
  7. rather not say
  8. other \_\_\_\_\_

40. Was the patient happy with the information and support received before and after surgery?
1. yes
  2. not yet had surgery
  3. if no, tell us why
41. Which statements describe how the patient felt during recovery from surgery? (tick all that apply)
1. felt supported by the health professionals looking after me
  2. felt abandoned after surgery and wished there was more contact with health professionals
  3. didn't need or want any more support after surgery
  4. scared of the cancer reoccurring
  5. happy in the knowledge the cancer had been removed and didn't want to think about it any more
  6. received all the support required from cancer charities
  7. received all the support required from friends and family
  8. felt emotionally low
  9. felt anxious
  10. did not feel in control
  11. felt pressured
  12. haven't yet had surgery
  13. if unhappy with the support received during recovery from surgery, please let us know what type of support would have been useful \_\_\_\_\_

### **About the patients drug treatment for kidney cancer**

42. If diagnosed with localised cancer with high or intermediate risk of recurrence, has adjuvant therapy been, or is going to be, offered?
- Adjuvant is a treatment you will be or have been given in addition to your primary (initial) treatment to reduce the risk of recurrence.*
1. yes
  2. no
43. 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?
1. Yes, the cancer had spread
  2. no
  3. don't wish to share information
  4. I don't know if drug treatment will be offered yet
44. How long was, is, or will the patient be on drug treatment for in total?
1. less than 1 year
  2. 1-2 years
  3. 2-3 years
  4. 3-4 year
  5. 4-5 years
  6. 5 years+
  7. don't know
45. Was enough information on drug side-effects given?
1. yes
  2. if no, please expand

46. Has the patient ever been involved in a kidney cancer clinical drug trial?
1. yes, for kidney cancer that has spread
  2. yes, after surgery for localised kidney cancer
  3. no
  4. offered but not interested
  5. yes but not suitable
  6. don't know how to access a clinical trial
  7. not interested
47. If the patient has taken part in a clinical drug trial, please provide the trial name if possible:
1. name of the trial
  2. do not want to share

## About your continued support

48. Has treatment finished?
1. yes, patient fully discharged
  2. yes, but patient is having follow-ups
  3. no the patient is still receiving treatment
49. What follow-up is the patient having, had, or about to have? (tick all that apply) Follow-up is the term used to describe continued monitoring for recurrence/spread after primary treatment such as surgery has taken place.
1. scans
  2. blood tests
  3. I don't know yet
  4. other
  5. Comment
50. Are the regular scans to check there is no recurrence or spread being carried out or planned to be carried out?
1. yes
  2. yes, but patient has finished follow-up and has been discharged
  3. no
51. How often is or were scans being carried out?
1. monthly
  2. 3 monthly
  3. 6 monthly
  4. yearly
  5. I don't know
  6. other \_\_\_\_\_
52. What type of scans is/was the patient having or about to have? (tick all that apply)
1. MRI
  2. CT
  3. Ultrasound
  4. X-Ray
  5. Other \_\_\_\_\_

53. How long typically is/ was the wait for scan results?

1. 1 - 2 weeks
2. 3 - 5 weeks
3. 6 - 8 weeks+
4. 9- 11 weeks
5. 12 weeks+

54. Who carries out blood tests?

1. the hospital
2. my GP surgery
3. I don't know

55. Has the patient been made aware of the importance of regular kidney function tests (e.g. - eGFR and ACR)?

eGFR (estimated Globular Filtration Rate) is the amount of blood filtered by the kidneys per minute, derived from creatinine (a waste product that is produced by the body's muscles) concentrations in the blood and takes into account the person's age, sex, and sometimes height and weight. Low levels can suggest the development of kidney disease or AKI (acute kidney injury). Moderate or high levels can indicate that kidney function is normal, especially for those with fewer than 2 kidneys. ACR (Urine albumin to creatinine ratio) - low values indicate that kidney function is normal if other tests of kidney function, e.g. eGFR, also shows no abnormality. Moderate or high levels can suggest developing kidney disease.

1. Yes, I have regular kidney function tests
2. No, I don't have regular kidney function tests

56. If follow-up has concluded (tick all that apply)

1. the patient has been discharged and have been given the information they feel they need for further support.
2. the patient felt that the decision to discharge was appropriate, and/or that they were given the opportunity to discuss their wishes before the decision was made.
3. the patient has been discharged but were not given the information they feel they need for further support.
4. the patient didn't feel the decision to discharge was appropriate and/or that they were given the opportunity to discuss their wishes before the decision was made.
5. the patient has not been discharged yet.

57. If you were NOT given enough information at discharge, please tell us what information would have been of help to you at that time?

## Primary Care

58. did the patient's GP contact them to offer support after their diagnosis?

1. remained in contact with their GP throughout
2. between 1-4 week
3. between 5-10 week
4. longer than 11 weeks
5. GP has not reached out to patient

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

1. yes
2. no
3. the patient is still within 12 months of diagnosis
4. don't know

## Palliative Care

60. Is the patient receiving palliative care support? Palliative care is the term used to describe services aimed at relieving symptoms and improving quality of life.

1. yes
2. no (**Please go to question 63**)

61. Who is providing care support? (tick all that apply)

1. hospice
2. hospital
3. care in the community
4. family and/or friends
5. nobody

62. Does the patient feel they are receiving appropriate support?

1. yes
2. no
3. if no, please expand

63. if your answer to the previous question was NO, please feel free to leave a comment

## Counselling

64. Was, or has the patient been, offered counselling?

1. yes via the NHS
2. yes via private counsellor
3. yes via a charity
4. yes via Kidney Cancer UK
5. yes - self funded
6. no - you will skip this section
7. rather not say - you will skip this section
8. not interested - you will skip this section

65. If the patient is or was offered counselling did they or will they take it?
1. yes
  2. Offered but I'm still thinking about whether to take it
  3. no, I don't feel I needed it - you will skip this section
  4. no, I don't like to talk about my feelings - you will skip this section
  5. no, I was worried about the costs - you will skip this section
  6. not taken up for other reasons \_\_\_\_\_
66. If counselling was offered, at what point was it offered? (tick all that apply)
1. through GP
  2. at diagnosis
  3. prior to surgery
  4. at follow up appointments
  5. sought own private counsellor
  6. other \_\_\_\_\_
67. If happy to, please share who provided, or will provide the counselling?
1. share with us
  2. no thanks
68. If the patient did receive counselling, was it of benefit?
1. yes
  2. no
  3. please expand on your answer \_\_\_\_\_
69. Are you aware that Kidney Cancer UK offers a free counselling service?
1. yes
  2. no
70. Do you have any feedback to help us improve this survey? It will be most welcome.
1. yes - please share your feedback below
  2. no

## How can Kidney Cancer UK help you?

71. Lastly, we have a few questions relating to Kidney Cancer UK and would be grateful for your feedback. Would you be happy to help ?
1. yes
  2. no – (***Please go to question 76***)

72. How did you find out about Kidney Cancer UK?
1. health professional
  2. using a search engine
  3. social network such as Facebook/ twitter
  4. Kidney Cancer UK Booklet or fact sheet displayed at clinic
  5. via media such as television or newspaper
  6. from a friend
  7. at an event
  8. other \_\_\_\_\_
73. In what ways could Kidney Cancer UK provide better support?
1. very satisfied with the support I have received
  2. not happy with the support received
  3. I use another charity for support
  4. please add comments to help us improve our services
74. Is the patient aware that Kidney Cancer UK provides and moderates five closed Facebook groups for patients, family members and carers givers?
1. Yes and I am part of one
  2. Yes but I'm not participating
  3. I am not aware, please send me more details to the closed groups
  4. no and I don't want anymore details, thank you
75. If your answer is Yes to the previous question are you currently a member of any of our closed Facebook groups? (tick all that apply)
1. Kidney Cancer UK Patient Support Group
  2. Kidney Cancer UK Metastatic Support Group
  3. Kidney Cancer UK Surgery Support Group
  4. Kidney Cancer UK Carers Support Group
  5. Not a member but aware of them
76. Which aspects of Kidney Cancer UK's work is the patient aware of? (tick all that apply)
1. free telephone Support Line
  2. free kidney cancer counselling service
  3. series of free 'Understanding Kidney Cancer' booklets
  4. downloadable fact sheets
  5. localised and metastatic online Support Groups
  6. campaigning/lobbying for improvements in patient care
  7. providing local support groups
  8. speaking out in the media
  9. providing information on our website
  10. providing online support such as our closed Facebook groups
  11. webinars
  12. Other \_\_\_\_\_
77. Does the patient follow Kidney Cancer UK on social media?
1. yes
  2. no - you will skip this section

78. If yes, which platforms are followed? (tick all that apply)

1. TikTok (&#64;kidney.cancer.uk)
2. Instagram (&#64;kidneycanceruk)
3. Facebook (Kidney Cancer UK)
4. Member of the Kidney Cancer UK closed Facebook group
5. LinkedIn (@KidneyCancerUK)
6. X (@kidneycanceruk)
7. None

79. Is the patient or any members of their support network interested in volunteering, getting involved in community collecting, starting a local support group, sharing their story, or joining our mailing list??

1. yes
2. no



## Offer your support

80. Would you like to learn more about becoming a volunteer, a community collector, apply for funding to start a local support group, be a case study and share your story in a video or blog to help others or join our mailing list? If so Please tick the way you would like to support us and supply your contact details below

Tick	Activity
	a volunteer
	a community collector
	apply for funding to start a local support group,
	be a case study and share my story in a video or blog to help others
	join our mailing list

I consent to being contacted in regard to the activity ticked above - YES –  
NO

First Name:

Last Name:

Age:

Phone:

Email Address:

Address:

Town:

County:

Postcode:

Should you have any trouble completing this survey, please contact our office who will be very happy to assist with any issues. Our number is:

**01223-870008 (Mon-Fri 9am-5pm)**

Once complete please return free to (no stamp needed)  
Simply write the following on your envelope and pop it in the post box:

**Freepost Kidney Cancer UK**

If you require further support and would like to talk to one of our healthcare professional nurses, or to book an appointment with our Counsellor, call:

