



Kidney Cancer UK Patient Survey 2023

Welcome to the tenth year of the only UK focused annual kidney cancer patient survey

Thank you for agreeing to take our annual survey, your participation is greatly appreciated.

This is an important and vital survey as gathering a broad range of patient experiences and issues allows us to continue to focus on delivering positive changes and support for patients and their families across the UK. Gathering this information annually allows us to build a long-term picture of the kidney cancer patient experience and how it has changed over the last nine years. The insights you share with us will help us target our resources to provide the very best support to you and your loved ones throughout your journey.

IMPORTANT PLEASE READ:

- It may be useful to have a list of any drugs or treatments you may have been on or are on to hand
- This survey should be completed by or on behalf of a kidney cancer patient, regardless of the stage of their journey.
- The questions are all tick box or multiple choice with options to leave comments on certain questions.
- The whole survey should take no more than 15 minutes to complete.
- All questions do require answering but there are 'NA' (not applicable) box options to tick so you can move on if a question is not applicable to you.
- Not all sections may apply to you, for instance if you've not had surgery or are not on drug treatment, please skip through that section to your save time.
- Please ensure you complete the survey through to the very end.
- We are very grateful for your support in taking part in this important survey.

Once fully completed please return via Freepost to

Freepost
Kidney Cancer UK

Thank you.

**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 are you a carer/ family member completing this survey on behalf of a patient?
 1. patient
 2. carer
 3. family member and carer
 4. family member
 5. Other

Please note all questions from this point on are related to and are to be answered by a patient or on behalf of a patient (current or past). If you are completing this on behalf of a patient please remember to answer for the patient not for you. Thank you for your support with this survey.

2. Are you (the patient) male or female?
 1. female
 2. male

3. Which age bracket are you in?

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 +

4. When were you diagnosed

1. In the past 3 months
2. In the past 6 months
3. In the past 12 months
4. In the past 18 months
5. 2 Years or more
6. 3 years or more
7. 4 years or more
8. 5 years or more;
9. 10 years +

5. How has your treatment been funded?

1. NHS
2. work private health care
3. personal private health care
4. part funded by NHS & private health care
5. part funded by NHS & drug company
6. part of a drugs trial
7. originally part of a drugs trial now NHS
8. originally part of a drugs trial now private health care
9. originally part of a drugs trial now part funded by NHS & drug company
10. Other _____

6. Up to the time of diagnosis what type of work did you do ?

1. office based
2. within the NHS - medical frontline -e.g. Dr, Nurse, Pharmacist, Consultant, paramedic etc
3. within the NHS - non-medical - e.g clerical, cleaner, support
4. health and social care (not NHS)
5. emergency services
6. engineering/ building
7. motor mechanic
8. heavy industry
9. driver
10. shop/ retail/ hairdressing/ publican
11. academic
12. student
13. media/ entertainment
14. teaching
15. social worker
16. within the pharmaceutical industry
17. Retired
18. Other _____

7. How are you completing this survey?

1. desktop computer
2. laptop
3. iPad or android Tablet
4. iPhone or android phone
5. paper copy
6. Other

Where do you live?

8. Which Country do you live in

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

9. Which best describes the region of England you live in?

1. Northwest
2. Northeast
3. West midlands
4. East midlands
5. East Anglia
6. Southwest
7. Southeast
8. London

10. Which best describes the region of Scotland you live in

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

11. Which best describes the region of Wales you live in

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

12. Which best describes the region of Northern Ireland you live in?

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

About the patient's diagnosis

13. How did you find out you had kidney cancer?

1. I visited my GP because I was feeling unwell and was sent for more tests
2. I visited A&E because I was feeling unwell and was sent for more tests
3. I found out during a medical scan or test that was unrelated to kidney cancer
4. Other _____

14. Which type of scan or test did you receive to FIRST diagnose your kidney cancer?

1. ultrasound scan
2. MRI scan
3. CT scan
4. regular x-ray
5. percutaneous kidney biopsy
6. don't know
7. Other _____

15. Did you feel unwell before being diagnosed with kidney cancer?

1. yes I felt unwell but my symptoms were NOT related to kidney cancer
2. yes and my symptoms were related to kidney cancer
3. no
4. picked up through a general health check-up, no illness.

16. Which symptoms did you experience BEFORE being diagnosed with 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. Other _____

17. How long did it take from first feeling unwell and seeking medical advice to receiving a diagnosis ?

1. 1 month or less
2. Between 1 and 3 months
3. Over 3 months.
4. I did not visit my GP or A&E service before diagnosis
5. Comment
6. Don't know

18. Was kidney cancer your first diagnosis or were you initially misdiagnosed?

1. It was my first diagnosis
2. I was initially misdiagnosed

19. If initially misdiagnosed, what was your first 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 _____

20. How long ago were you diagnosed with kidney cancer?

1. less than 2 years ago
2. 2 and 4 years ago
3. 4 and 6 years ago
4. 6 and 8 years ago
5. 8 and 10 years ago
6. 10 and 12 years ago
7. over 12 years ago
8. Would you like to leave a comment?

About your kidney cancer

21. Have you had a biopsy

1. Yes,
2. No

22. Do you know what type of kidney cancer you were 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. don't know
9. Other _____

23. Staging is used to describe how big a cancer is and how far it has already spread. Could you tell us which stage was your cancer diagnosed at ?

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

24. Grading is used to describe how different the cancer is to the structure of a normal cancer cell. Could you tell us the Grade of your cancer ?

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

Care during your diagnosis

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

1. Yes
2. No, it should have been said in a more sensitive way
3. No, it felt rushed
4. No, I needed more information
5. I was too shocked and don't remember
6. don't remember
7. Add a comment if you wish _____

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

1. Yes, I understood everything and didn't want any more information
2. Yes, I understood everything but still wanted more information
3. No, I was confused
4. I was too shocked and don't remember
5. don't remember

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

1. Yes
2. No
3. I was too shocked and don't remember
4. don't remember

28. If you were given information at diagnosis what was given?

1. I had a conversation with consultant or nurse
2. I had a conversation with consultant or nurse and given bag with information leaflets in
3. I was given bag with information leaflets in
4. I was given a single leaflet
5. I was given details of website to look at
6. I was given support line telephone number
7. I was not given any information
8. don't know
9. Other _____

Your treatment at hospital

29. What type of treatment did you receive or are you due to have for kidney cancer? (tick all that apply)
1. surgery
 2. drug treatment - taken orally
 3. drug treatment - taken intravenously
 4. drug trial
 5. cryoablation
 6. radiofrequency ablation
 7. radiotherapy
 8. active surveillance following scans
 9. active surveillance following treatment or surgery
 10. don't know
 11. Other _____
30. Do you feel your opinions were taken into account when the medical team was deciding future treatment options?
1. yes
 2. yes, to a certain extent
 3. no
 4. not sure
 5. don't know
 6. Add a comment if you wish _____
31. Were you given the name of a Clinical Nurse Specialist (CNS) or key worker who would be in charge of your care?
1. yes
 2. no
 3. yes but I had to wait until one was available
 4. not applicable
32. Do you feel you were given enough information about your treatment?
1. yes
 2. no
33. What type of information did you receive when you were told about your 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. no information given
 8. don't know
 9. Other _____

34. How far do, or did, you have to travel (round-trip) for your regular treatment?

1. 0-10 miles
2. 11-20 miles
3. 21-30 miles
4. Over 30 miles
5. don't know

35. Have you had surgery?

1. yes
2. no

About your surgery

36. How much of your kidney was 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

37. What type of surgery have you received or are you due to have?(tick all that apply)

1. traditional (open) surgery was used
2. keyhole (laparoscopic) surgery was used
3. robotic techniques were used
4. they froze the tumour (cryoablation)
5. radiofrequency ablation
6. waiting to hear what type of surgery I will have
7. Other _____

38. Were you happy with the information and support you received before and after your surgery?

1. yes
2. If no, tell us what other information and/or support would have helped _____

39. Which statements describe how you felt after surgery? (tick all that apply)

1. I felt supported by the health professionals looking after me
2. I felt abandoned after surgery and wished there was more contact with health professionals
3. I didn't need or want any more support after surgery
4. I was scared of the cancer reoccurring
5. I was happy in the knowledge that the cancer had been removed and didn't want to think about it any more
6. I received all the support required from cancer charities
7. I received all the support required from friends and family
8. I felt emotionally low
9. I felt anxious
10. I did not feel in control
11. I felt pressured
12. If you were unhappy with the support received after surgery, please let us know what type of support would have been useful

40. Have you received drug treatment - in tablet or intravenous drip form - for kidney cancer?

1. yes
2. no
3. Do not wish to share information

About your drug treatment for kidney cancer

41. Which medicines have you taken for kidney cancer?

1. axitinib (Intyla)
2. avelumab and axitinib
3. durvalumab
4. durvalumab and tremelimumab
5. cabozantinib (Cabometyx)
6. everolimus (Afinitor)
7. everolimus and lenvatinib
8. interleukin 2
9. lenvatinib
10. nivolumab (Opdivo)
11. nivolumab and cabozantinib
12. nivolumab and ipilimumab
13. pazopanib (Votrient)
14. pembrolizumab and axitinib
15. sunitinib (Sutent)
16. tivozanib (Fotivda)
17. Don't know
18. Other _____

42. Have you received adjuvant clinical trial therapy? This is treatment that you have been given in addition to your primary (initial) treatment by entering a clinical trial.

1. Yes
2. No

43. Please tell us which drugs you received in your adjuvant clinical trial and if were they given as a 1st, 2nd ,3rd or 4th line treatment. Please note: Some of these treatments are only available in certain regions to eligible participants in a specific clinical trial. We have included these to help us with our analysis.

Click each of the drop-down boxes relevant to you. Tick N/A line of treatment does not apply to you durvalumab

1. durvalumab and tremelimumab
2. Other _____
3. NA

1st line treatment *Click each of the drop-down boxes relevant to you. Tick N/A line of treatment does not apply to you*

1. avelumab and axitinib
2. cabozantinib
3. nivolumab and cabozantinib
4. nivolumab and ipilimumab
5. pazopanib
6. pembrolizumab and axitinib
7. sunitinib
8. tivozanib
9. Other _____
10. NA

2nd line treatment *Click each of the drop-down boxes relevant to you. Tick N/A line of treatment does not apply to you*

1. axitinib
2. cabozantinib
3. lenvatinib and everolimus
4. nivolumab
5. Other _____
6. NA

3rd line treatment *Click each of the drop-down boxes relevant to you. Tick N/A line of treatment does not apply to you*

1. axitinib
2. cabozantinib
3. lenvatinib and everolimus
4. nivolumab
5. Other _____
6. NA

4th line treatment Please state or scroll past if line of treatment does not apply to you

44. How long have you been, or were you 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. over 5 years

45. Were you given enough information on drug side-effects?

1. yes
2. no

46. Have you ever been involved in a kidney cancer clinical drug trial?

1. yes
2. no
3. offered but not interested
4. yes but not suitable for me
5. I don't know how to access a clinical trial
6. not interested

47. If you have taken part in trial, please provide trial name if possible or scroll to go past:

About your scans once you have finished treatment

48. Have you finished treatment?

1. Yes
2. No - You will skip this section

49. Are you having regular scans to check there is no recurrence/spread?

1. yes
2. no - You will skip the remaining scan questions

50. How often are you being scanned

1. monthly
2. 3 Monthly
3. 6 monthly
4. yearly
5. Other

51. What type of scans are you having(tick all that apply)

1. MRI
2. CT
3. Ultrasound
4. X-Ray
5. Other

52. How long do you typically wait for your scan results in weeks

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

Your general support

53. If you wanted support or information about kidney cancer where would you turn first?

1. oncology/ urology clinic or my CNS
2. my GP
3. NHS direct
4. friend
5. visit the Kidney Cancer UK or Kidney Cancer Scotland website
6. ring Kidney Cancer UK Careline
7. ask Kidney Cancer UK closed Facebook group community
8. ask Kidney Cancer UK Coffee Cake & Chat& online group
9. attend Kidney Cancer UK/ Scotland & Living with Kidney Cancer & Webinar
10. contact Kidney Cancer UK Counsellor
11. the internet
12. another charity website
13. another charity support line
14. other online discussion forum
15. social media, ask questions in another Facebook group
16. visit local support group
17. Other, please state _____

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

1. website
2. download from a website
3. telephone
4. email
5. Facebook
6. webinars
7. face-to-face local support groups
8. face-to-face education sessions
9. post
10. Not required
11. If other please state _____

Counselling

55. Were you, or have you been, offered counselling

1. yes via the NHS
2. yes via private counsellor
3. yes via a charity
4. no
5. rather not say
6. not interested

56. If you were offered counselling did you take it

1. yes
2. no, I don't feel I needed it
3. no, I don't like to talk about my feelings
4. no, I was worried about the costs
5. Other _____

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

1. GP Practice
2. at diagnosis
3. prior to surgery
4. at follow up appointments
5. sought own private counsellor
6. Other

58. If you are happy to, please share who provided your counselling or scroll to go past:

59. If you did receive counselling, do you feel it was of benefit?

1. yes
2. no
3. Please expand on your answer

60. Are you aware Kidney Cancer UK offers a free counselling service?

1. Yes
2. No

61. Do you have any feedback to help us improve this survey? It will be most welcomed.

How can Kidney Cancer UK help you?

62. Lastly, we have a few questions relating to Kidney Cancer UK and Kidney Cancer Scotland and would be grateful for your feedback. Would you be happy to help ?

1. yes
2. no

63. How did you find out about Kidney Cancer UK or Kidney Cancer Scotland?

1. health professional
2. social network such as Facebook/ X (twitter)
3. Kidney Cancer UK Booklet or fact sheet displayed at clinic
4. via media such as television or newspaper
5. from a friend
6. using a search engine
7. at an event
8. Other _____

64. How could Kidney Cancer UK or Kidney Cancer Scotland support you better?
1. very happy with the support
 2. I use other charity for support
 3. tell us how we can better help you _____
65. Are you aware that Kidney Cancer UK provide and monitor five closed Facebook groups for patients, carers and family members?
1. Yes
 2. No
66. If your answer is Yes to question 68 are you currently a member of any of our closed Facebook groups?(Click 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. North Wales Patient Support Group
 6. Not a member but aware of them
67. Which aspects of Kidney Cancer UK's work are you aware of?
1. Kidney Cancer UK's free telephone Support Line
 2. Kidney Cancer UK's free kidney cancer counselling service
 3. Kidney Cancer UK's series of free Understanding Kidney Cancer booklets
 4. Kidney Cancer UK's downloadable fact sheets
 5. campaigning/lobbying for improvements in patient care
 6. providing local support groups
 7. speaking out in the media
 8. providing information on our website
 9. providing online support such as our closed Facebook group
 10. our Coffee, Cake & Chat online sessions
 11. our #LWKC Webinars
 12. our Living With Kidney Cancer Days
 13. Other _____



68. Would you like to learn more about becoming a volunteer, 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.

Please Tick the way you would like to help and fill out your details on the next page and we will contact you. Thank you

- 1. join our mailing list
- 2. volunteer
- 3. community collector
- 4. apply for funding to start a local support group
- 5. be a case study and share your story in a video or blog
- 6. Suggest another way you would like to help us in our work

Your Contact Details

**By supplying these details, you are agreeing for Kidney Cancer UK to contact you.*

**Your details will NOT be sold on or past to 3rd parties.*

First Name

Last Name

Phone

Email Address

Address 1

Address 2

City or town/ County

Post code

Thank you for taking our Kidney Cancer UK Patient Survey2023.