



**Kidney
Cancer
UK**

The UK's leading
specialist kidney
cancer charity



**Kidney
Cancer
Scotland**

Scotland's leading
specialist kidney
cancer charity

**Kidney Cancer UK
Patient Survey
Autumn 2018**

Published 29th October 2018

Executive summary

Almost half (45%) of patients were initially misdiagnosed – their kidney cancer was mistaken for other, non-malignant conditions⁹.

A high proportion of patients say their kidney cancer was discovered as an incidental finding of a scan or test for another unrelated condition⁵.

The need for evidence-based, diagnostic tools and other support to help clinicians identify and refer patients at high risk of kidney cancer are urgently needed.

Surgery remains the most common treatment for kidney cancer¹⁰ with laparoscopic techniques being carried out more frequently than open surgery¹¹.

The use of innovative new techniques such as robotic surgery and cryoablation are very low but increasing very slowly¹¹.

41% of patients said they had received drug treatment¹² with sunitinib, pazopanib and nivolumab being the most widely used¹³.

Information and support at diagnosis is good^{17,18}.

Clinical Specialist Nurses play a crucial role in supporting patients²¹ but a significant proportion of patients are not told the name of their nurse²².

A flexible approach to allow patients to access support and information as and when they need it is likely to be most successful, including informative website(s), telephone access to expert advice (e.g. a Clinical Nurse Specialist) and reassuring peer support through local groups.

Design and sample

The fieldwork for the Kidney Cancer UK Patient Survey Autumn 2018, was carried out as an online survey between 20th August 2018 to 16th September 2018 and was analysed in late September 2018. The total number of responses was 270. This is an increase of 95 (54%) over the previous survey in which fieldwork was carried out in late 2017¹. This is a very strong increase in response rate.

The gender split has changed in favour of women who now represent 61% of responders compared with 39% men².

The distribution of responses was similar to the previous survey, although the proportion from devolved countries had increased. Despite this, devolved country responses accounted for only 15% of the total and no sub-group analysis is possible³.

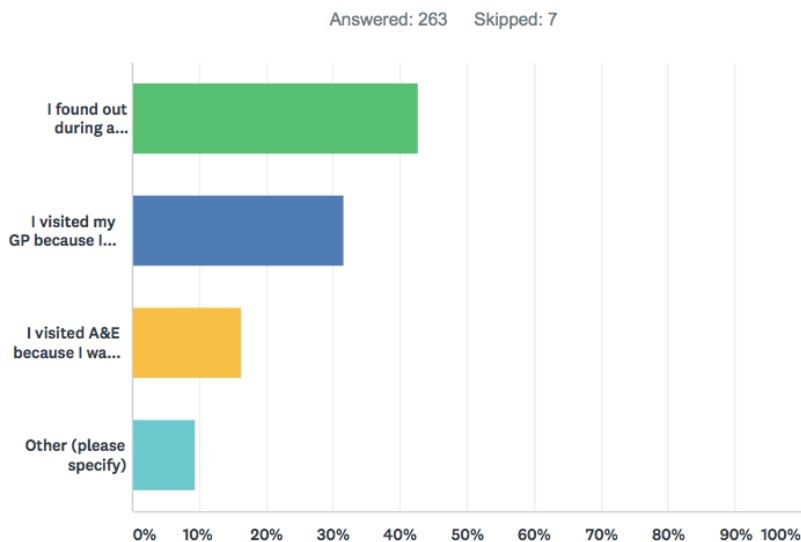
Diagnosis

In line with previous patient surveys, the difficulties in diagnosing kidney cancer are highlighted by the findings. 43% of patients were symptomless when diagnosed⁴.

Discovered as an incidental finding

A high proportion of patients (43%) say their cancer was discovered as an incidental finding from a scan or test for another, unrelated condition⁵. This is broadly consistent with the findings of previous surveys.

Q8 Where did you find out that you had kidney cancer?



There are some common symptoms that, considered as a pattern, could suggest kidney cancer as one of several potential diagnoses. The survey indicated that the following are the most common⁶:

Fatigue	39% of patients
Pain in back/flank or side	39% of patients
Blood in urine	36% of patients
Night sweats	28% of patients
Weight loss	18% of patients

Kidney cancer often not considered as a potential diagnosis

However, despite being the seventh most common form of cancer, kidney cancer is often not considered when two or more of these symptoms is seen. The absence of specific clinical guidelines and patient pathways for kidney cancer from the National Institute for Health and Care Excellence (NICE) means there is little advice and support to help doctors (particularly GPs) in England and Wales to identify possible cases of kidney cancer. The same is true in Scotland and Northern Ireland.

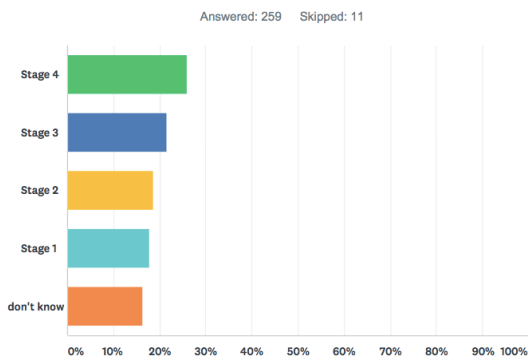
The survey results suggest that better evidence-based guidance on early identification and diagnosis of kidney cancer is needed urgently. Even in Scotland, which has a set of Quality Performance Indicators for kidney cancer, there is no indicator looking at early identification and referral of possible kidney cancer cases⁷.

Almost half of patients initially misdiagnosed

It is, perhaps, not surprising that the survey shows that 47% of patients were not diagnosed until their cancer had reached an advanced stage (3 or 4)⁸.

Related to this, but of greater concern is that a high proportion of patients were initially misdiagnosed. Of 242 patients who responded, almost half (45%) were initially misdiagnosed⁹.

Q16 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 ?



Kidney cancer was commonly mistaken for conditions such as a urine infection (11%) or kidney stones (6%) with a wide variety of other conditions being diagnosed incorrectly⁹.

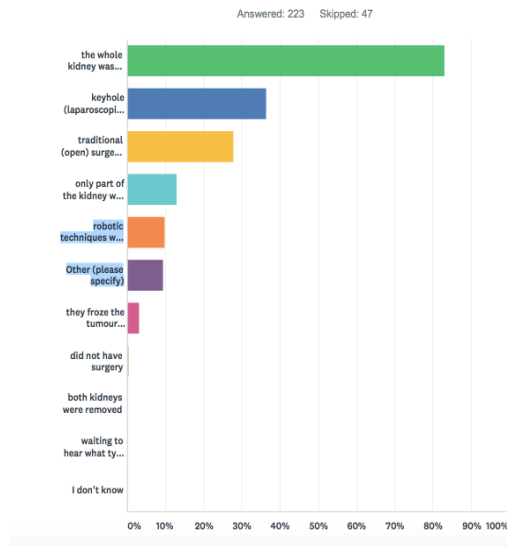
Need for diagnostic tools paramount

This is not a failure of individual doctors; it is a systemic failure that must be addressed as a priority. We have known for some time that kidney cancer is difficult to diagnose. A simple blood test to detect it needs to be developed, but until such a test is available, the need for evidence-based diagnostic tools is paramount.

Surgery

Surgery is the most likely treatment for kidney cancer; of 252 patients who responded to this question, 88% said they had had surgery¹⁰. In 83% of cases, the whole kidney was removed¹.

Q28 What type of surgery have you received or are due you to have? (tick all that apply)



Less invasive laparoscopic surgery was carried out in 36% of cases, compared with traditional (open) surgery (28%)¹¹. This is consistent with the previous survey.

Newer less invasive techniques such as robotic surgery appear to have increased slowly. Robotic surgery was carried out in 10% of cases and the tumour was frozen (cryoablation) in 3%¹¹; both are slightly increased compared with the previous survey, although the increase is not marked. These newer techniques have greater recovery benefits whilst easing pressure on NHS services, yet these results strongly suggest that they are not offered to all who might benefit.

Drug treatment

Of 248 responses, 41% said they had received drug treatment in tablet or intravenous form¹². This is much higher than indicated by the results of the previous survey. The reasons for this are not clear and without further confirmation, it would be risky to draw any firm conclusions.

Amongst the 101 responders who gave information on the drugs they had taken, sunitinib (47%), pazopanib (43%) and nivolumab (27%) were the most frequently mentioned¹³, sunitinib and pazopanib were also the most frequently mentioned as first line treatments¹⁴.

94 responders gave details of the length of time they were on medication and the majority (72%) said they took it for two years or less (47% said they took it for less than a year)¹⁵.

100 responders provided details on their participation in clinical trials¹⁶. Of these 56% said they had never been involved in a clinical trial. Only one person stated they had been offered the chance to participate in a trial but were not interested. A significant proportion of patients have previously reported that they have not had an opportunity to take part in clinical studies and these results would appear to be consistent.

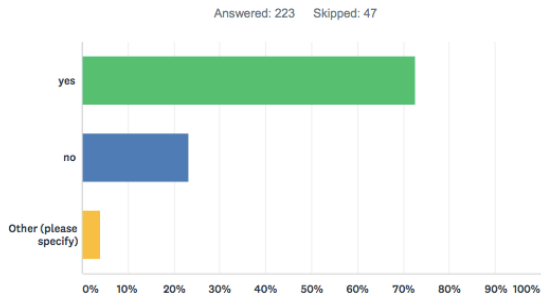
Patient support and information

Information and support for patients is clearly vital. Ensuring patients have sufficient information when they need it is challenging because individuals require information at different times, depending on their personal preferences. It is very important to ensure patients have support and information throughout their care pathway from first diagnosis onwards and not forgetting their importance even after a successful surgical procedure.

Good information and support at diagnosis

60% of 257 responders said they had been told they had kidney cancer in an appropriate way¹⁷ and 48% of 254 responders said they had been told in a way that they easily understood¹⁸. This suggests that information and support at the point of diagnosis is good, though there is still room for improvement.

Q29 Were you happy with the information and support you received before and after your surgery?



It is very important to ensure patients have support and information throughout their care pathway from first diagnosis onwards and not forgetting the need even after a successful surgical procedure. Patient charities provide effective support and information programmes that help many patients and it is

important that health care professionals make new patients aware of them from diagnosis onwards. From 223 responses in the survey, 73% said they were satisfied with the level of information and support they had received before and after surgery¹⁹. However it is also worth noting that 45% of 222 responders said they felt anxious following surgery and 45% said they were scared the cancer would reoccur²⁰.

Clinic and Clinical Nurse Specialist first port of call for support

Of 245 responses in this survey, 41% said they would turn to their specialist clinic and/or their Clinical Nurse Specialist for support in the first instant²¹. This underlines the important role of specialist nurses. However, 25% of 256 responses showed the patient had not been given the name of their Clinical Nurse Specialist²².

24% of 245 responders said they would go to the Kidney Cancer UK website as their first choice for support²¹.

There was a strong preference in favour of accessing information and support via a website (45% of 239 responses)²³. Local support groups (16%) and telephone contact (14%) were also popular²³.

It is very hard to interpret these results but one way of looking at them may be that support via a website is always available, whenever the patient needs it. They can access the information at any time they wish and can assimilate it at their own individual speed. Some patients have previously said that receiving a large pack of information at the time they are given their diagnosis makes them feel overwhelmed. Getting the quantity and timing of information right is difficult because individual needs are different. In this survey, 51% of 257 responders said that at diagnosis they were not given enough information to take away to read later²⁴. One solution may be to provide access to a

library of information that can be obtained as and when each patient needs it, for example downloaded from a website.

Peer support through local groups can be reassuring as well as providing a source of practical information. And telephone contact when needed (e.g. with a Clinical Nurse Specialist) allows patients to check their understanding and ask any specific questions that have relating to their own situation.

Flexible approach

As an overall approach, these findings seem to indicate that a flexible approach to information and support is needed and that this should be provided by other patients, or patient organisations, as well as health care professionals.

The report showed how faith in email communication has plummeted as just 3% of those surveyed said they would like to receive information via email²³ compared to over 73% last year².

About Kidney Cancer:

In 2014, kidney cancer was the seventh most common cancer in adults in the UK, there were around 12,500 new cases of kidney cancer in the UK in 2014, that's 34 cases diagnosed every day²⁵.

There were 4,400 kidney cancer deaths in the UK in 2014, that's 12 deaths every day; this accounts for about 4% of all cancer deaths in the UK²⁵.

In UK men, it is the fifth most common cancer, with 7,500 cases diagnosed in 2013, and in UK women it ranked tenth most common cancer, with around 4,400 cases diagnosed in 2013²⁵.

It has been estimated that the lifetime risk of developing kidney cancer is 1 in 52 men and 1 in 87 women will be diagnosed with kidney cancer during their lifetime²⁵

References

- 1 Kidney Cancer UK Patient Survey 2018. Data on file. Report published February 2018
- 2 Kidney Cancer UK Patient Survey Autumn 2018. Question 2. Data on file Kidney Cancer UK
- 3 Kidney Cancer UK Patient Survey Autumn 2018. Question 4. Data on file Kidney Cancer UK
- 4 Kidney Cancer UK Patient Survey Autumn 2018. Question 11. Data on file Kidney Cancer UK
- 5 Kidney Cancer UK Patient Survey Autumn 2018. Question 8. Data on file Kidney Cancer UK
- 6 Kidney Cancer UK Patient Survey Autumn 2018. Question 10. Data on file Kidney Cancer UK
- 7 Renal Cancer Quality Performance Indicators Patients diagnosed during January 2012 to December 2014
Publication date – 23 August 2016. Available at <http://www.isdscotland.org/Health-Topics/Quality-Indicators/Publications/2016-08-23/2016-08-23-Renal-QPI-Report.pdf>
- 8 Kidney Cancer UK Patient Survey Autumn 2018. Question 16. Data on file Kidney Cancer UK
- 9 Kidney Cancer UK Patient Survey Autumn 2018. Question 13. Data on file Kidney Cancer UK
- 10 Kidney Cancer UK Patient Survey Autumn 2018. Question 27. Data on file Kidney Cancer UK
- 11 Kidney Cancer UK Patient Survey Autumn 2018. Question 28. Data on file Kidney Cancer UK
- 12 Kidney Cancer UK Patient Survey Autumn 2018. Question 31. Data on file Kidney Cancer UK
- 13 Kidney Cancer UK Patient Survey Autumn 2018. Question 32. Data on file Kidney Cancer UK
- 14 Kidney Cancer UK Patient Survey Autumn 2018. Question 33. Data on file Kidney Cancer UK
- 15 Kidney Cancer UK Patient Survey Autumn 2018. Question 34. Data on file Kidney Cancer UK
- 16 Kidney Cancer UK Patient Survey Autumn 2018. Question 36. Data on file Kidney Cancer UK
- 17 Kidney Cancer UK Patient Survey Autumn 2018. Question 17. Data on file Kidney Cancer UK
- 18 Kidney Cancer UK Patient Survey Autumn 2018. Question 18. Data on file Kidney Cancer UK
- 19 Kidney Cancer UK Patient Survey Autumn 2018. Question 29. Data on file Kidney Cancer UK
- 20 Kidney Cancer UK Patient Survey Autumn 2018. Question 30. Data on file Kidney Cancer UK
- 21 Kidney Cancer UK Patient Survey Autumn 2018. Question 37. Data on file Kidney Cancer UK
- 22 Kidney Cancer UK Patient Survey Autumn 2018. Question 23. Data on file Kidney Cancer UK
- 23 Kidney Cancer UK Patient Survey Autumn 2018. Question 38. Data on file Kidney Cancer UK
- 24 Kidney Cancer UK Patient Survey Autumn 2018. Question 19. Data on file Kidney Cancer UK
- 25 Cancer Research UK. Kidney cancer statistics <http://ow.ly/7K1130m5SNO>



*The service is free to call though some networks may charge. Please check with your service provider if in doubt.

Kidney Cancer UK

The Old Coach House
High Street
Harston
Cambridge
CB22 7PZ
T: 01223-870008
(Mon-Fri 9am-5pm)
E: Office1@kcuk.org.uk

Kidney Cancer Scotland

Spiersbridge House
Spiersbridge Business Park
Thornliebank
Glasgow
G46 8NG
T: 0141 428 3494
(Mon-Fri 9am – 5:30pm)
E: contact@kidneycancerscot.org