



***Kidney
Cancer
UK***

The UK's leading
specialist kidney
cancer charity



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THE KIDNEY CANCER UK
PATIENT SURVEY REPORT 2018

The Kidney Cancer UK Patient Survey Report 2018

Executive summary

This survey strongly suggests that the identification of patients with a high risk of kidney cancer must be improved.

- Results show that 51% of kidney cancer cases were diagnosed as an incidental finding from an unrelated scan
- Better identification of at risk patients and the development of simple, cheap urine or blood tests are needed so that suspected cases can be referred for confirmatory scans whilst the disease is at an earlier stage when treatment is more effective.
- Laparoscopic surgery techniques have superseded traditional open surgery, but very slow uptake of newer techniques (robotics and cryoablation).
- Patients consider availability of cancer drugs an important issue to the wellbeing of kidney cancer patients.

The survey also underlines the need for better signposting to information and support that is already available for kidney cancer patients at all stages from pre-diagnosis onwards.

- Awareness of existing information and support resources needs to be improved as a priority so that patients are reassured – particularly when newly diagnosed or when identified as high risk and awaiting the results of diagnostic scans.
- Information provided through health care professionals should be subject to minimum standards that include:
 - The contact details of a specialist nurse
 - Information that patients can access whenever they need:
 - Support information specific to the patient regarding their diagnosis or treatment
 - General information on kidney cancer
 - Information that is provided through multiple channels including:
 - The Internet
 - Printed materials
 - By telephone
 - Face-to-face
 - Information that is relevant to all stages of diagnosis and treatment, including:
 - Pre-diagnosis
 - At and after diagnosis
 - Before and during treatment
 - After treatment (including successful treatment)

Design and sample

The fieldwork for the Kidney Cancer UK Patient Survey 2018 was carried out between 19 November and 14 December 2017 and was analysed in January 2018. The total number of responses was 175. This is an increase on 2016 of 64 (57%).

The profile of the 2018 sample was similar to that of the previous year. The gender split was 56% to 44% in favour of women and the split by region was relatively even. The number of responses from Scotland was proportionally higher than that of the population and there were no responses from Northern Ireland. However, no sub-group analysis by devolved country is attempted. Compared with the 2017 survey, the distribution by country is broadly similar, though there were slightly fewer responses from devolved countries in the latest survey.

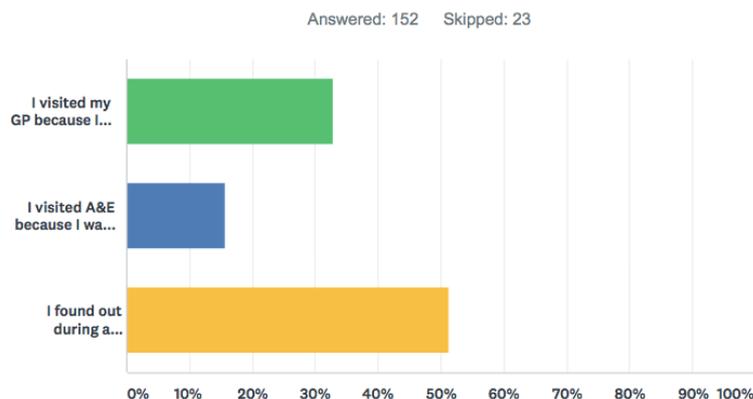
Diagnosis

The 2018 survey suggests that there has been no substantial change in the pattern of diagnosis of kidney cancer compared with the previous year.

Diagnosis most often incidental

The most concerning finding is that diagnosis most commonly takes place as an incidental finding from an unrelated scan. The 2018 survey responses suggest that this happens in the majority of cases (51.32%). This is an increase from the previous year's figure of 43.07%.

Q4 How did you find out that you had kidney cancer?



ANSWER CHOICES	RESPONSES
I visited my GP because I was feeling unwell and was sent for more tests	32.89% 50
I visited A&E because I was feeling unwell and was sent for more tests	15.79% 24
I found out during a medical scan or test that was unrelated to kidney cancer	51.32% 78
TOTAL	152

The figures above reflect the difficulties in identifying possible cases of kidney cancer, which may be symptomless. The survey shows that 46.58% of the people surveyed were symptomless when diagnosed and an additional 26.45% felt unwell but their symptoms were not associated with kidney cancer. Less than one third (30.97%) had symptoms due to kidney cancer. This is a challenge for clinicians when diagnosing kidney cancer.

Simple, cheap tests needed for high-risk patients

The survey shows that blood in the urine was the most common symptom of kidney cancer (45.70%) and this may be easily and cheaply identified through a urine test. Yet over half (55.20%) had never seen blood in urine or were only aware of blood in urine after urine tested. And in under a third of cases (31.82%) blood was obvious and/or lasted for at least a week. This illustrates the importance of developing simple tests that could be used without waiting for symptoms to appear in patients who may be at greater risk of kidney cancer. The funding of

research in to the viability of a national screening programme for kidney cancer is on-going and receiving funding from Kidney Cancer UK.

GPs need help to identify at-risk patients

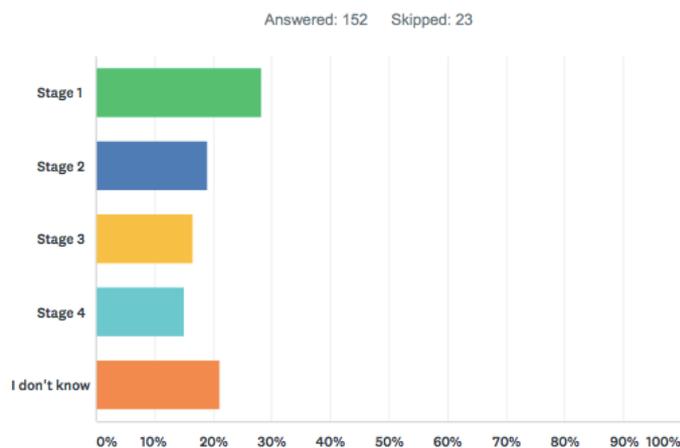
The medical history and lifestyle of the patient can indicate important risk factors. These might be accompanied by common general symptoms such as fatigue (38.41%) and pain in back/flank/side (36.42%) that, particularly in combination, should alert GPs to the need to monitor such patients more closely. Yet only one case of kidney cancer in three (32.89%) appears to have been identified following a visit to a GP. 15.79% of cases are diagnosed via an A&E consultation, which is only slightly down on the previous year. This suggests the need for an awareness and educational campaign aimed at GPs to help them identify at risk patients.

Confirmed diagnosis often not achieved until cancer at advanced stage

To first confirm diagnosis a CT scan (46.45%) and ultrasound scan (36.13%) were the most commonly used tests, which is similarly reflected in the results of the previous year's survey.

Of those survey responders who presented to a GP or an A&E Department (n=153), three quarters (78.43%) were diagnosed within 3 months and half (50.33%) in a month or less. From this it may be inferred that once the patient is identified, diagnostic services are working well. It would seem that the problems lie with the identification and testing of at risk patients.

Q12 What stage was your cancer at diagnosis?



Confirmed diagnosis is often not achieved until the cancer has reached an advanced stage. This limits treatment outcomes. 31.58% of survey responders were not diagnosed until their cancer had reached stages 3 or 4. 47.37% were diagnosed at stages 1 and 2. Here there may be tentative signs of improvement; the corresponding figures for previous year were 42.45% and 38.67%. This should be monitored in order to determine if it is a long-term trend and, if so, to identify the underlying reasons.

More than 1 in 4 patients don't know type of kidney cancer they have

The most common type of kidney cancer was clear cell renal cell carcinoma (non papillary) (56.95%). However, it is worth noting that 29.14% of responders did not know what type of kidney cancer they had (this was 18.87% in 2016). This proportion (more than one in four patients) is concerning and may be a result of issues in patient support and information, dealt with later in this report.

Surgery

Surgery remains, by far, the most likely treatment option for kidney cancer. In 90.48% of responses, the patient had had, or was due to receive, surgery; this is consistent with the year before.

Laparoscopic surgery now most common technique

As might be expected, virtually all surgery (97.04%) removed all or part of a kidney. However, there was a marked change on the technique used with laparoscopic surgery being the most common (38.52%). This is a notable increase compared with the previous year (23.66%). Traditional open surgery, which had been the most common technique in the previous year, was carried out in 25.93% of responders in the 2018 survey.

Very slow uptake of new techniques

There was also an indication that the use of robotic surgical techniques may have slightly increased (4.30% in 2018 survey compared with 2.96% in the previous year). However, the difference is very small and might only be a statistical factor. Even if it were real, this would be a disappointingly cautious increase in this new technique.

Another promising new technique, cryoablation, has shown a similarly small but inconclusive increase (2.96% in the latest survey compared with 2.15% the year before). Access to such new techniques is variable and it is important that patients who might benefit from them are able to do so, regardless of where they live.

Drug treatment

In 27.1% of responses drug treatment was used (this might have been in addition to, or instead of, surgery), which is slightly less than the year before. Of the responders who provided information on the drugs they had taken (n=50), the pattern of drugs used was similar to that in the previous year's survey. Pazopanib (Votrient) and sunitinib (Sutent) were most commonly used drugs (24.00% each).

Availability of cancer drugs important issue

The availability of cancer drugs was considered to be an important issue by 44.70% of survey responders. The use of drug therapy tends to be short term. Of the responders who had received drug therapy (n=147), the vast majority (90.24%) said they were on it for three years or less, with 51.22% taking drug therapy for less than a year. Fewer than 5% of responders said they had been on drug therapy for 5 years or longer.

Greater use of active surveillance

The use of active surveillance appeared to be higher in the 2018 survey, 27.1% of responders compared with 16.9% in the previous year. It is possible that this might relate to the higher proportion of cases identified at stages 1 and 2, but the volume of data is too small to do anything more than make a tentative suggestion at this stage.

Downturn in clinical trials

The survey results showed a downturn in the proportion of responders who were taking part in a drug trial versus the previous year. This had been 11.43%, but in the 2018 survey, the figure had fallen to 8.16%.

There are a number of possible reasons for this shift, but it is impossible to identify the cause from the results of this survey.

Patient support and information

The survey results show shortfalls in the level of support and information that patients receive. This is a concerning finding as such factors can greatly enhance the outcomes of both diagnosis and treatment.

Support was the most common issue patients felt likely to have an impact on people with kidney cancer:

Family and carer support	59.09%
Emotional support after cancer	57.58%
Support during recovery after operation	52.27%

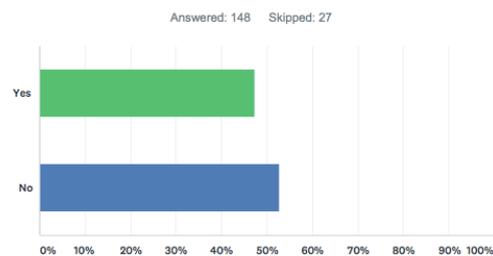
There are a number of areas that require attention and these are best broken down according to the patient pathway.

Newly diagnosed patients need more support and information

Whilst the majority of survey responders (59.73%) felt they had been told of their diagnosis in an appropriate manner, 32.21% felt that this was not done with sufficient sensitivity or that the consultation was rushed. This figure has increased from 22.86% last year.

This is coupled with a need for more information and for the provision of follow up support and information after the diagnosis is initially communicated. 53.69% of survey responders understood what they were told at diagnosis but felt they needed more information. This has also increased from the previous year's figure, which was 45.28%. 14.09% were left confused and did not fully understand the diagnosis.

Q16 Did you receive enough information about kidney cancer?



At diagnosis virtually all survey responders (95.97%) said they had had a conversation with a doctor and 37.58% had done so with a nurse.

However, the provision of follow up information is very different. In only 35.57% of cases were patients given a leaflet allowing them to gain more information after they left the consultation. Only 10.74% were given details of websites and only 25.50% were given telephone numbers to contact for further support.

In 40.14% cases the patient was not given the name of a clinical nurse specialist. This figure is significantly higher than in the survey from the previous year when it was 28.57%.

By far the greatest requirement for more information was for details about kidney cancer stage, type and what this means for the patient (42.64%). Another 20.16% wanted general information and this is a significant increase from the comparable figure last year, which was 7.23%. Both are basic requirements on which information exists. This situation could potentially be improved rapidly by better signposting to reliable sources of information.

Greater inclusion of patients' wishes before and during treatment

54.73% of responders to the 2018 survey were satisfied their views had been taken into consideration when deciding on future care, but a surprisingly high 36.49% either felt this was

only to a certain extent or that their views were not considered. These figures are very similar to those in the survey from last year, suggesting that there has been no improvement.

74.81% of survey responders said they were happy with information and support before and after surgery. 57.14% felt supported by health care professionals.

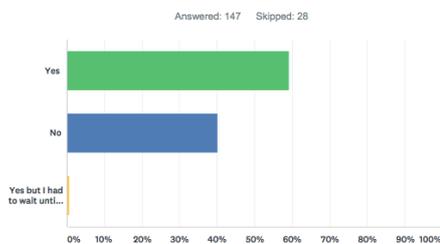
Need for patient support and information does not end after treatment

27.07% of survey responders who had surgery, felt abandoned afterwards. This is of particular concern because many of these patients are likely to have been cured. 50.38% said they were scared cancer would recur. The requirement for patient information and support does not go away after treatment – even when treatment is successful. Better signposting to existing sources of follow up support and information could lead to significant improvements in this respect. There might also be a need for some specific additions to this information.

Minimum patient information must be provided in all cases

52.70% of survey responders felt they did not receive enough information about kidney cancer. The survey results demonstrate a need for patients to be given a set of basic information as a minimum, including:

Q20 Were you given the name of a Clinical Nurse Specialist (CNS) who would be in charge of your care?



- The contact details of a specialist nurse
- General information on kidney cancer that they can access after their consultation
- Information about their diagnosis and staging and its implications for them.

Information accessible at any time via multiple channels

71.76% want to be able to access information and support at any time. This strongly suggests the need for follow up information – a consultation is often not the best time for patients to assimilate information, particularly if the consultation is their first diagnosis.

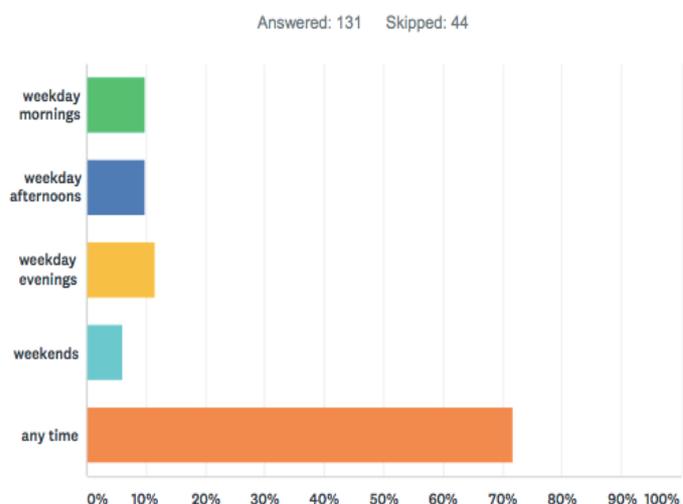
The Internet is the most likely source (48.87%) for information to which the survey responders would turn. 36.09% would contact their urology clinic or specialist nurse, but the earlier finding that in 40.14% cases the patient was not given the name of a clinical nurse specialist should be considered here.

Channels that the survey responders thought were good ways to receive information included:

Via the Internet

- Email (51.52%)
- Facebook (28.79%)
- Web Chats (14.39%)
- Telephone 35.61%
- Face-to-face education 28.72%

Q39 When would you like to access this support?



This relatively even distribution suggests that information needs to be provided through multiple channels, including some to which patients can refer at any time that suits them.

It is worth commenting that very few patients would consider contacting NHS Direct.



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