

# Kidney Cancer Patient Journey

The aim of the Kidney Cancer Patient Journey Survey 2014 was to provide information on kidney cancer care and treatment and consequently improving the quality of health services for future patients. As a result, the survey identified patient views on care they received, starting from the diagnosis through to the hospital operation and treatment.

The Survey was available through the charity's website, forum and social media platforms. Moreover, it's been shared on Macmillan and Cancer Research online community sites. More than 100 patients and carers responded.

### **The key findings include:**

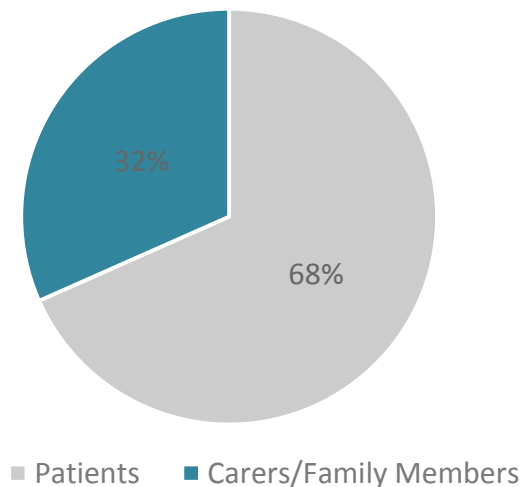
- ✓ Almost half of respondents did not have obvious symptoms of kidney cancer and consequently the cancer was discovered whilst being treated for other symptoms
- ✓ Almost 65% of respondents were not diagnosed by a GP and were referred to the hospital doctor for further tests. Most of the patients referred to see a specialist were diagnosed with kidney cancer within one to three months
- ✓ 45% were told that they have kidney cancer sensitively
- ✓ 55% felt that more attention should be paid to communicating the diagnosis
- ✓ Kidney cancer patients are increasingly positive about their care with almost 80% being satisfied with the overall cancer care. The negative comments indicate lack of communication between different departments and lack of information regarding available support
- ✓ More than half of respondent were disappointed with lack of the information received at different levels of their journey
- ✓ 71% were not given any information about James Whale Fund or Kidney Cancer Scotland.

Overall patients are reporting positively on areas including kidney cancer care (deciding the best treatment options). However, the report suggests clear areas for improvement with many patients feeling that GPs and nurses at their general practice or NHS hospital could do more during diagnosis stage and cancer treatment. What is more, many patients were a bit disappointed with the level of post treatment/operation care.

## The survey completed was by

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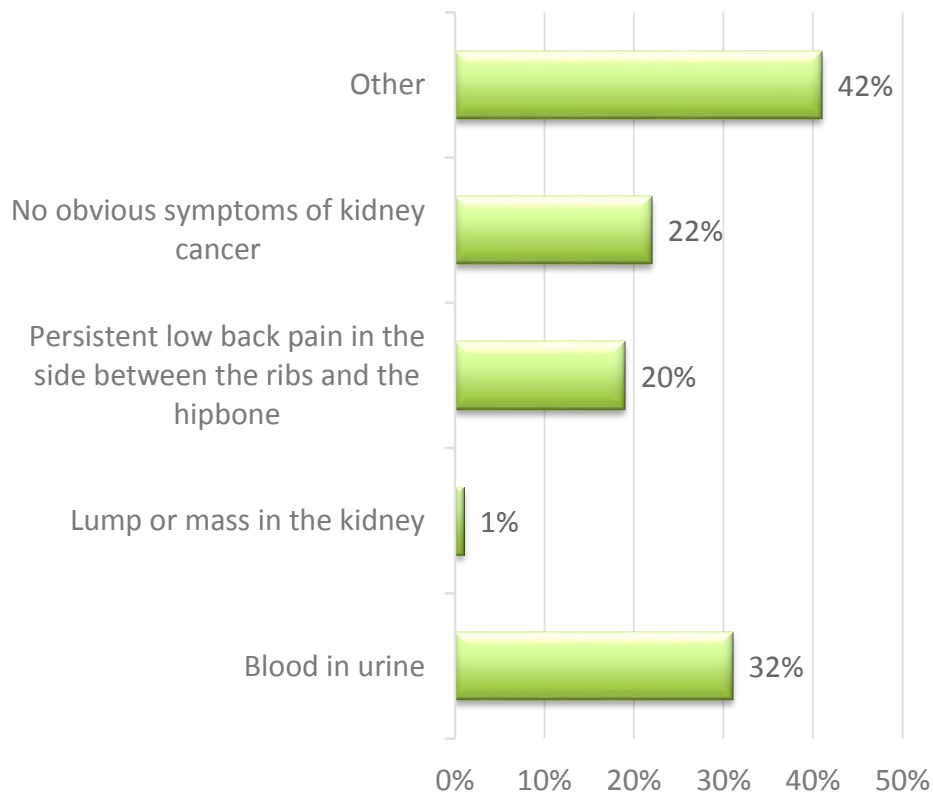
### Responses



During the research before launching the survey, we asked for feedback regarding such a questionnaire.

It has been pointed out that some of the patients may not be willing/able to complete the survey, therefore the option to complete the survey on behalf of a patient was introduced.

## The symptoms which led to the GP visit:



### Other symptoms include

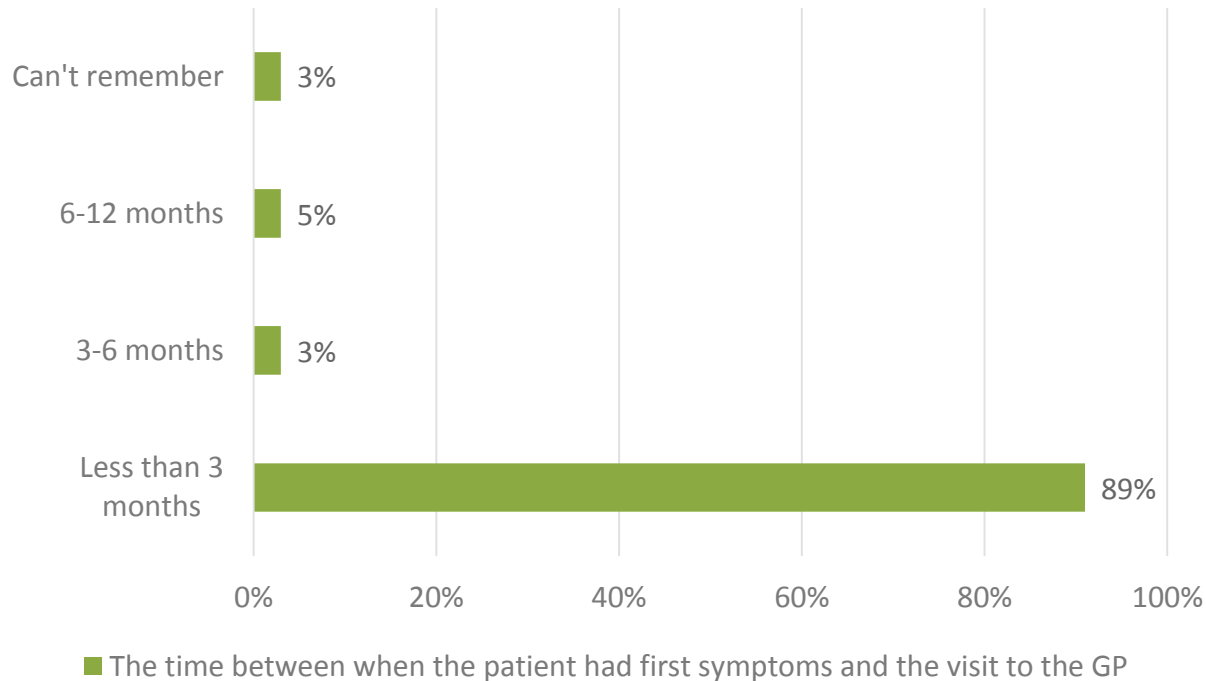
- Tiredness, fatigue (6)
- Severe and persistent cough (4)
- Breathlessness (2)
- Night sweats (4)
- Weight loss (2)
- Bad cold that wouldn't go away
- Constant migraines over a long period of time
- Ongoing stomach problems; persistent indigestion, swollen stomach, reflux, pain and discomfort when eating, Nausea not eating (5)
- Urine infection (3)
- Gallbladder issues (3)

## If there were no symptoms, the following led to the diagnosis:

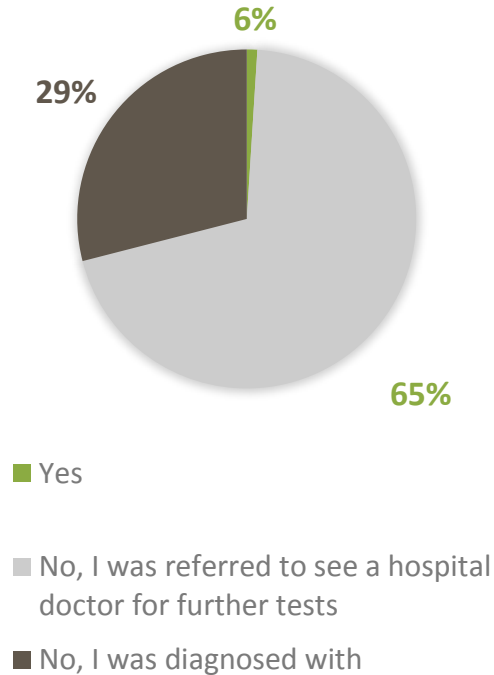
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- Being treated for a kidney disease and following a CT scan
- Found incidentally when having abdominal ultrasound
- Bladder infection UTI not clearing after series of antibiotics
- A routine ultrasound for gallstones
- Scan for kidney stones
- Treatments for asthma. CT scan to check condition of the lungs revealed an abnormality on the top of the right kidney
- Series of scans to find the cause of the persistent cough
- Sonogram on routine physical check up
- Routine ultra sound due to type 1 diabetes and blood pressure problems
- A scan for an appendicitis
- MRI scan after a back surgery revealed kidney cancer
- Clear colonoscopy/gastroscopy which prompted abdominal ultrasound
- Minor groin trauma which led to ultrasound CT
- Scan for pneumonia
- Aspirations of lymph node
- CT scan to assess blood vessel formation prior to heart transplantation showed kidney mass
- Accident went to a and e
- Simple blood test for cholesterol
- Constipation and developmental delay. A mass felt during examination
- Liver ultrasound
- Tests for myeloma then an MRI scan and a CT scan revealed the tumour on the kidney

# The time since the patient first felt unwell until the first GP (family doctor) visit?



## Were you diagnosed with kidney cancer by your GP at your first visit?



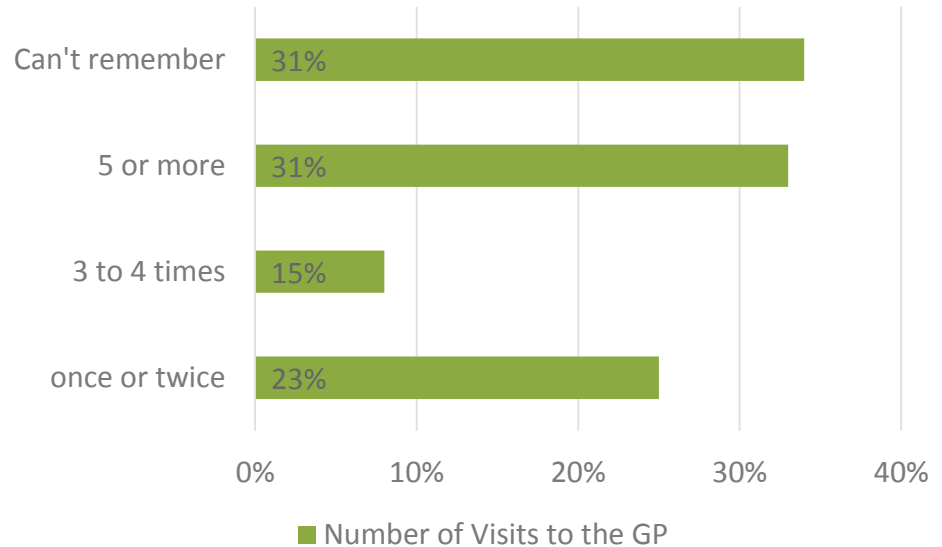
I was diagnosed with:

- *Water infection*
- *Pulled muscle*
- *UTI*
- *Kidney stones*
- *Nothing wrong , if it happens again come & see me*
- *chronic infections*
- *muscle pains, sleep apnoea, virus, "nothing" and finally pleurisy*
- *kidney infection and muscular back pain*

## Out of 29% with a different diagnosis:

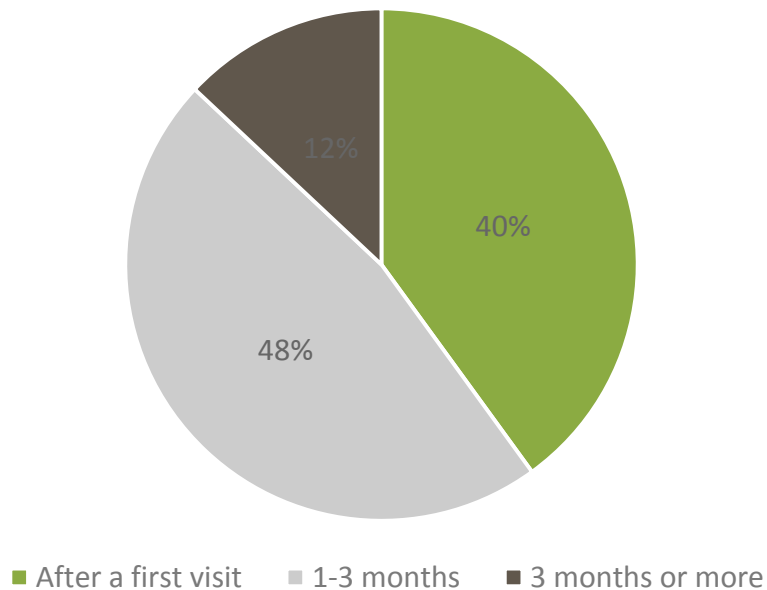
- 46% was **treated for about a month** before a kidney cancer diagnosis
- 23% was treated for about **1-3 months** before a kidney cancer diagnosis
- 31% was treated for **3 months or more** before a kidney cancer diagnosis

## Number of Visits to the GP before kidney cancer diagnosis





## How long was it until you were diagnosed with kidney cancer by a specialist? *(applies to 70% referred to see a specialist)*

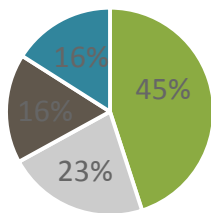


**Almost 70% of people had to wait less than a month for a visit**

**During that time their health stayed the same or got worse in over 25% of cases**

# Communicating bad news

Were you told you had kidney cancer in a way that was easily understood?



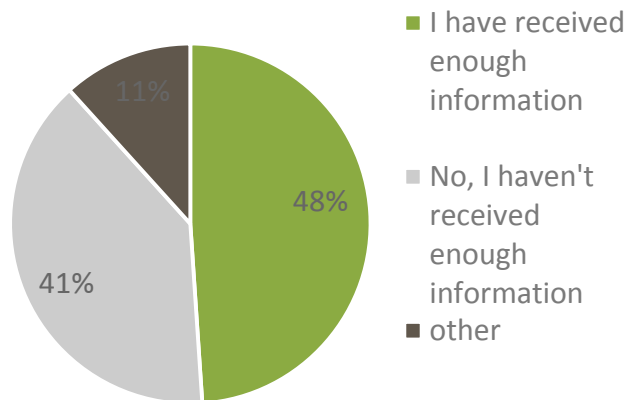
- It was told sensitively and I understood everything
- It should have been told a bit more sensitively and I needed more information
- I felt confused
- Other

## Other comments:

- It was handled very badly - just given a leaflet*
- The consultant suspected it was kidney cancer, but it wasn't until the post operative appointment that the diagnosis was confirmed by a different consultant who quite frankly was appalling in the way in which he confirmed the diagnosis, and the disrespectful and condescending manner in which my wife and I were dealt with [...] no empathy or compassion demonstrated. The appointment last about 4 minutes and when my wife tried to question the consultant about the rare form of kidney cancer she had, he dismissed her and he made it clear he wasn't willing to be questioned about the operation neither was he willing to give details!*
- Felt it was all a bit rushed*
- I was told in the open ward having been admitted the previous night, with no family support. The ward staff were not told about my diagnosis until many hours later, so I had no support at all until my husband arrived. The Dr giving me the diagnosis said he would talk to my husband when he arrived, but he didn't respond to requests from us.*
- He was told pretty coldly by a doctor on a ward with no family around and just a curtain for privacy. Had been admitted due to something unrelated and as it happened to be the day after the CT scan had been taken he asked if there was any result. It was almost literally: hand on the shoulder "sorry mate you've got advanced kidney cancer*

# Informing patients about condition and the stage of kidney cancer

Did you receive enough information about your condition and the stage of kidney cancer?



- After the operation my wife learned she had a rare form of kidney cancer and that it was a slow growing large tumour. No emotional or practical support offered and so my wife only learned about kidney cancer and the rarely of Chromophobe Renal Cell Carcinoma from her own research. Very very disappointing!
- Only when I asked. I joined a kidney cancer group and learnt about stage, grade etc My urologist was just going to say "yes it was cancer, we were right to remove it" and was shocked when I asked about cell type, grade and stage.
- Not really would have liked to have spoken to a Nurse or somebody else but was given a booklet
- I was in hospital at the time of seeing the consultant for other problems he came to see me on the ward and told me then that I had the tumour [...] I was given a booklet to take home and read. I had a follow up appointment booked for the week after. As I was in the ward for other things I didn't have the time at that moment to fully take it all in, but the follow up appointment was a lot more informative
- No. All the information I have has been as a result of my own chasing or research via the internet, and through the James Whale Fund patient forum [...] The consultant did not explain staging or the implications to me.
- Diagnosis and getting to an oncologist was a nightmare of bad communication and waiting. There were a lot of people introducing themselves, but none of them either spoke to the others or knew the status and we grew tired of explaining everything. I found out most of the information from the internet

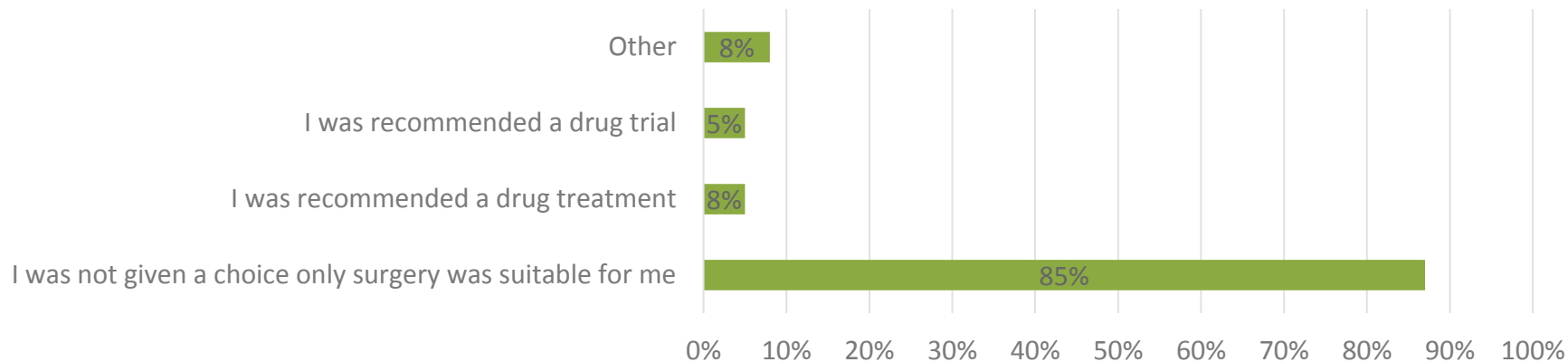
## Research after the diagnosis

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**More than 90% carried out research after the diagnosis including carers and family members**

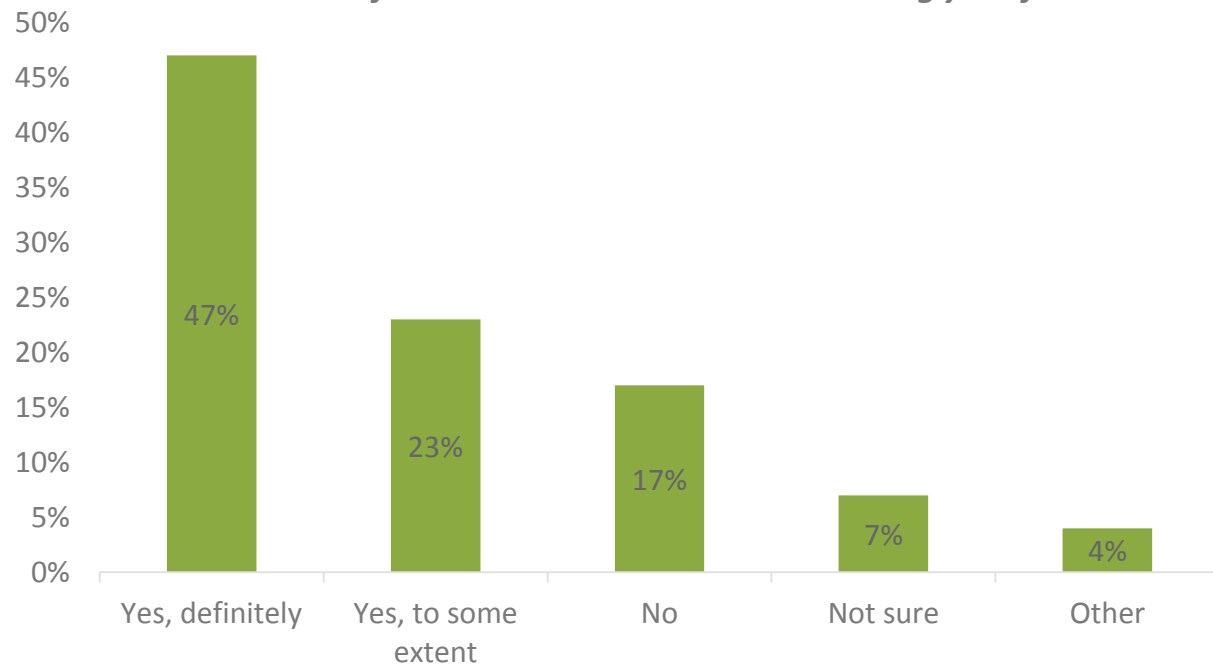
## The choice of treatment

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## Deciding the best treatment

*Do you think your views were taken into account when the team of doctors and nurses were discussing your future care?*



*Almost 80% were happy with the information received about treatment/surgery and side effects*

# Clinical Nurse Specialist

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49% were given the name of Clinical Nurse Specialist who would be in charge of care

44% were NOT given the name of Clinical Nurse Specialist

7% had to wait until a Clinical Nurse Specialist was available

# Patient Support

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**22% received information about available support, self-help groups and specialist kidney cancer charities**

**41% have not received any information on patient support but would have liked to**

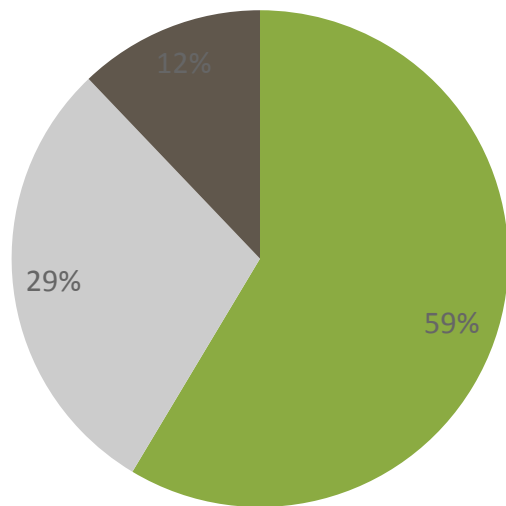
**35% have not received any information on patient support**

**71% were NOT given any information about James Whale Fund for Kidney Cancer or Kidney Cancer Scotland**

***The support information received includes mainly Macmillan Cancer Support***

## Information about financial help and benefits entitlement

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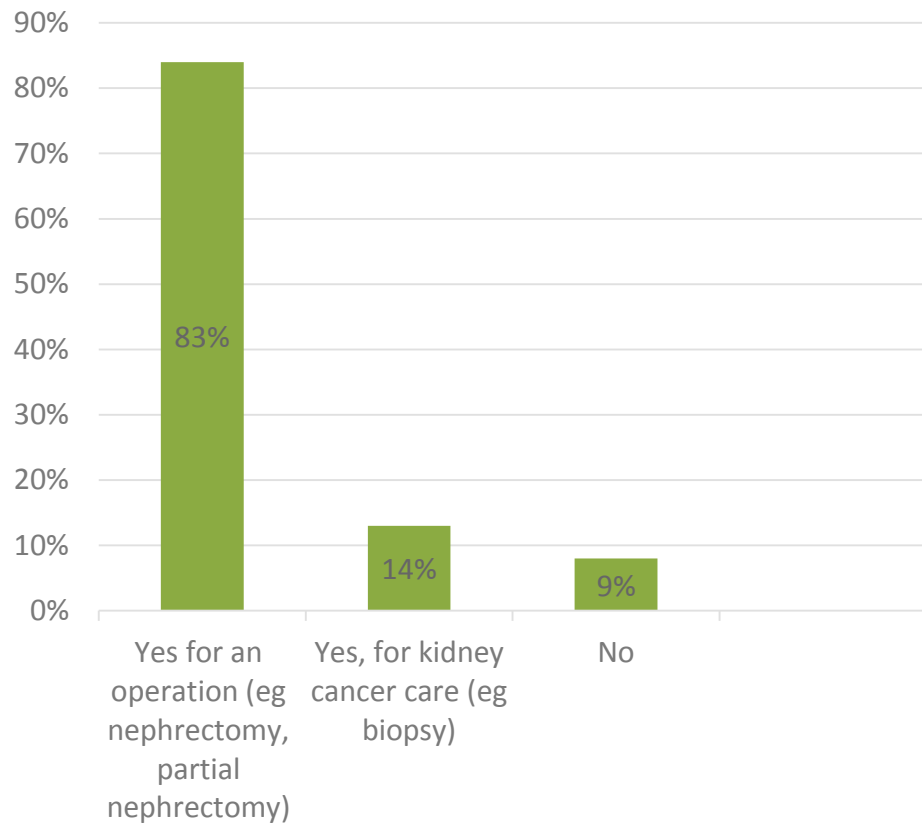
- I haven't received any information
- I haven't received any information but I would have liked to
- Yes

**Information received includes:**

- Macmillan Cancer support Leaflets**
- CLIC Sargent**
- Free prescriptions and help with travel cost leaflets**



## Hospital care & treatment



61% travelled 10 miles or less to the hospital

26% travelled 10 – 30 miles

13% travelled 30 miles or more

32% received conflicting information about the care by a medical professional

# Overall satisfaction with the hospital care & treatment

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80% satisfied with the overall care

20% not satisfied with the overall care. The comments include:

- No joined up service, lack of communication, poor after care,
- I would have liked more support
- The surgeon was excellent - however the recovering on the ward was one of the most difficult times of my life. The nursing staff were overworked and understaffed, medication was late, when I asked for anti nausea medication, it would take up to 2 hours to receive it (while being sick), it took them 24 hours to take out my drip, from the time when they said it needed to come out (by the time they did, it was starting to get infected). Many other issues.
- Mum went private for surgery then transferred back to NHS. The care received once back on the ward was horrendous
- Delays, lack of communication at the start,
- Poor level of care
- I was told I had a malignant tumour in my kidney and then I was just left to get on with things. There was no support either before or after my operation and I am disgusted with the poor after care I received, and the way I was treated by the consultant.
- I don't feel there was much communication at this hospital between the departments
- Went a couple of days with bad communication over pain meds between nurses and doctor when I reacted badly to one.
- I was treated privately, but in an NHS hospital. I had the operation (Open, Partial nephrectomy) received post op care for 3 days, then went home. No physio, no dietary advice, no oncology consultation.
- I had no after care, only after nearly having nervous breakdown! There is no joined up care, but they all write down copious notes that presumably never get read by anyone else.

## Further Comments: Positive

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- Once referred to Guys and Tim O'Brien, the care was fantastic. My mothers was a very complex case and she is one of only 32 people who have had this surgery in the UK. Saw Tim O'Brien today for her annual follow up 4 years after surgery and he is very pleased with her outcome. She is 83!
- The care at Halton haven hospice was 1st class.
- My care since diagnosis 1991 has been excellent at all times - prompt, personal, efficient, fully explained and discussed - many second opinions - specialists of my choice - BUPA is like having a second mortgage but worth every penny!
- I was very happy with the hospital and 10 year aftercare plan.
- Admitted via A&E due to the inexplicable and intense lower backpain and amount of blood in urine. 48 hours from admission to diagnosis, ten days later an elective open partial nephrectomy having been offered the choice of either open partial or radical laparoscopic. Back at work 3 weeks later. Fantastic treatment.
- Frankly I owe my life to medical staff. From the original GP who was sufficiently engaged to pursue tests, consultants, nurses, and surgeons
- Waiting to find out whether the cancer had spread was the worst - it took over 2 months to have tests and get results. It's only been 3wks since i had my kidney removed. Bournemouth hospital have been brilliant I can't thank them enough.
- The cancer team were great.

# Negative Comments

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- Diagnosis took 6 months by which point stage 4 cancer. Patient died 8 weeks later. No information on Kidney Cancer or support on offer
- I did not get my cancer diagnosis until after the partial nephrectomy as due to my age (32 at the time) they were unsure it was definitely cancer until they removed the mass
- Been at GP many times, run loads of tests, endoscopy (up & down) Barium meal etc. Results negative, no blood in urine, however, I paid for a scan and received the news I had a large tumour on my right kidney very quickly
- Not enough local groups or hospice care to help you cope with your diagnosis
- It was the most frightening time of my life. Sutent caused numerous side affects and I was very ill. My heart had to have a pacemaker, my gall bladder burst and I was admitted to hospital on several occasions [...] I can't believe I am still here writing about it. I am one lucky lady. Still afraid but alive. I only wish it had been diagnosed earlier, I knew I was ill but I had to fight hard to get the doctors to believe me in the beginning
- Was very disappointed to be told it was a suspected benign tumour which turned out to be cancer. There was no support during before or after diagnosis or operation
- Delayed diagnosis as consequently went off sick & although he asked a colleague to pick up - I was left - had surgery 3 months later by which time had spread to lymph nodes. Don't blame my surgeon but the other one was negligent. No uro mac or oncology nurse in post. Had no support - had to fight all the way through.
- There has been no support whatsoever for my husband during all of this, and he feels that he has been largely excluded/unconsidered throughout.
- I would like to see more specific advice and support for children's kidney cancers. You can find support for adult kidney cancer or general kids cancer. If my son had had neuroblastoma there would have been a much better support system

## Negative Comments Continued

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- At the time of my diagnosis (2010), I felt very alone and not well supported, I spent much time researching the options and having multiple appointments with specialists to get the information I needed. Luckily I had private health care and thank goodness for the internet! I discovered the SORCE trial and Prof Eisen!
- The consultant urologist assumed my GP had told me that it was cancer. He introduced himself by saying "all the kidney cancers in this region are referred to me, including yours". This was the first time I heard that it was cancer.  
I just feel that me as a person with emotions and needs wasn't taken in to account. I was a patient that had a tumour that needed to be removed and then since then (2013) just to be monitored. What is the point of being given a cancer nurse if you never hear from them. Where is the support? If it hadn't been for me actively seeking out support online, I would never have gotten any support. It was ME that educated myself on kidney cancer, no one from the hospital taught me. I honestly feel as though it was treated no differently than having an ingrown nail removed. I wanted to shout at them....IT WAS CANCER...IT COULD HAVE KILLED ME, TREAT IT SERIOUSLY. I was also not warned at the severity of the operation, I wasn't told how massively it would change my life for a good while. I wasn't warned that I would be in a lot of pain for a long time and that how badly a 12" scar right through your middle changes you. I wasn't told it was going to be so big. It was more or less "you will come in, we will whip it off and that will be that". I am now living in deep pain, which fair enough, it was a big operation, but no one medical warned me to be prepared for a LONG slog. I feel let down.
- It is sad that I had to go to a hospital 100 miles away for treatment a the south west only have one specialist unit.
- Awful GP, even going private she had misdiagnosis, resulting in wrong op, then left for 3 months. After follow up scans she was stage 4 with mets. Had 1 round of chemo and passed away 6 months from diagnosis. Awful all the way through!! She was always stuck in no mans land coming between kidney and bladder cancer. :-(-
- There was not an is not enough info on kidney cancer an I researched further treatments for my husband

## Patient Information

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Gender:  
55% female  
45% male

Kidney Cancer treatment for:

- Less than 1 year 28%
- 1 to 5 years 59%
- More than 5 years 13%

