

Written evidence submitted by Kidney Cancer UK (ECS0004)

Summary

This evidence is submitted by Kidney Cancer UK. We are a national charity set up to provide support to patients with kidney cancer, their families and their carers. We provide patient information direct to patients or via kidney cancer units; we have a Careline and also provide a free counselling service. We also have an online nurse training programme that qualifies for CPD points.

The charity has been working on kidney cancer service quality improvement since 2017. The Kidney Cancer UK Accord is a multidisciplinary steering group that includes patients and carers as well as health professionals. This group is presently carrying out a two-year retrospective quality audit through the National Disease Registry Service and what is now the Office for Health Improvements and Disparities. The results are due in April 2022 and are not included in this document. Our intention is to present the results to NHS England's National Cancer Team to support a proposal for a NICE clinical guideline on kidney cancer. The charity has also run an annual patient survey for the last seven years and the evidence provided in this document comes from the latest (2021) survey which is due for publication on 7th February. Consequently, the data are subject to an embargo until 6th February 2022 and are provided in this document in confidence.

1. Kidney Cancer UK has not seen any evidence of improvements to outcomes or to service quality as a result of the Cancer Workforce Plan.

- Access to a named clinical nurse specialist is crucial but 1 in 4 patients do not have it.
- However, during the COVID-19 pandemic less than 10% of patients said their operation had been cancelled due to the pandemic. We believe this is due to the hard work and dedication of existing NHS staff.

2. The faster diagnosis standard has had negligible impact on kidney cancer diagnostic services.

- Kidney cancer is difficult to diagnose early. A simple laboratory test has not been developed.
- Screening for kidney cancer is a research priority, as many patients would be cured if diagnosed earlier.
- Almost 65% of patients wait over a month from first presenting to diagnosis (or all clear), and 40% wait over 3 months.
- Approximately 1 in 4 patients are initially misdiagnosed.
- Just under 50% of tumours are discovered as incidental findings at the time of a scan for an unrelated condition.

3. Many kidney cancer patients do have care plans and have access to health and wellbeing information, but this is not universal.

- Over 45% of patients said they were not given enough information at diagnosis.
- However, this improves at other parts of the pathway, but remains variable.
- NHS provision of psychological support is poor. Only 12% of patients said they had received counselling on the NHS and over 60% said they had not been offered counselling at all.

4. The uptake of innovation and new technology is slow and variable.

- Ablation therapy is an alternative to surgery for some patients with small tumours. It is less invasive, which means patients are likely to recover faster. These techniques have been available for several years and are recommended by NICE technology appraisals or interventional procedures guidance. Yet only just over 1% had cryoablation and less than 1% had radiofrequency ablation.

Sources of information in this document

The Kidney Cancer UK Annual Patient Survey 2021

The following responses are based on the results of our latest patient survey. This is our 7th annual survey. Fieldwork for the survey took place in October/November of 2021. **Please note that these results have not yet been published and are subject to an embargo until 00:01 Sunday 6th February 2022.**

The survey was completed by 432 respondents of whom 333 were living in England. We do not analyse the data by devolved country. 46% said they had been diagnosed during the COVID-19 pandemic (between March 2020 the date of the survey).

COVID-19 Impact Surveys

In addition to the above, Kidney Cancer UK carried out five surveys between 3rd April 2020 to end of January 2021. The aggregated results of these are also used in our responses.

Kidney Cancer UK Service Quality Audit

We should also like to make the panel aware that we are presently carrying out a quality audit of kidney cancer services using data from the National Disease Registry Service, analysed by HDI CiC who are approved by Public Health England. The audit is ongoing and the results are not included in any of our responses below. However, we anticipate the publication of the report in April 2022.

Lack of clinical guidance on kidney cancer

It is worth noting that Cancer Research UK data show that kidney cancer in England, and throughout the UK, has some of the worst 5-year survival rates in Europe¹.

Unlike most other types of cancer, there is no evidence-based national clinical guidance for kidney cancer. This places it at a disadvantage when considering service improvements and assessing their impact, because there is no guidance framework to provide a proper basis for such things. This means, for example that there are very few local pathways or guidelines to support the work of health care professionals and any that exist are not properly evidence-based. If NHS England encourages timed pathways, this will place kidney cancer at an even greater disadvantage.

There are two separate sets of European clinical guidelines, but neither is suitable for use in this country because neither takes into consideration the funding model of the NHS, nor its definition of cost effectiveness.

As shown in the table, despite having the seventh highest incidence, according to Cancer Research UK data², there is no NICE clinical guidance specifically for kidney cancer. The only available clinical guidance that mentions it is a general document on urological cancers which is almost 20 years old and has never been updated. In the table the cancers shown in yellow all have NICE clinical guidance and/or quality standards despite have a lower incidence than kidney cancer.

1 Cancer Research UK website last accessed 24 Jan 2022 <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/kidney-cancer/survival#heading-Four>

2 Cancer Research UK website last accessed 24 Jan 2022 <https://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence/common-cancers-compared#heading-Zero>

Until this situation is rectified, every initiative intended to benefit cancer treatment as a whole, will increase the disadvantage between kidney and other types of cancer. Kidney Cancer UK has set up the Kidney Cancer UK Accord, a multi-disciplinary committee of experts covering virtually all aspects of kidney cancer. The objective of this group is to secure new NICE guidance for kidney cancer. The group has had exploratory discussions with NHS England and later this year will be making a full proposal for NHS England to commission a NICE guideline and quality standard, supported by the quality audit mentioned above and also by 3 Royal Colleges and 5 other national professional bodies.

UK ranking by incidence	Site	Guidance	Published
1	Early breast cancer Familial breast cancer Advanced breast cancer	NG101 QS12 CG164 CG81	July 2018 Sept 2011 June 2013 Feb 2009
2	Prostate cancer	NG131 QS177	May 2019 Dec 2018
3	Lung cancer	NG122 QS17	March 2019 March 2012
4	Colorectal cancer Oesophago-gastric cancer	NG151 QS20 QS176 NG83	Jan 2020 Aug 2012 Dec 2018 Jan 2018
5	Skin cancer	QS130	Sept. 2016
6	Non Hodgkin's lymphoma	NG52	July 2016
7	Urological cancers (includes kidney)	(CSG2)	(Sept 2002)
8	Head and neck cancers	QS146	March 2017
9	Brain, other CNS and intracranial tumours	No guidance	No guidance
10	Pancreatic cancer	NG85	Feb 2018
11	Bladder cancer	QS106 NG2	Dec 2015 Feb 2015
12	Haematological cancers	QS150 NG47	June 2017 May 2016
16	Ovarian cancer	QS18 CG122	May 2012 Apr 2011
??	Upper aerodigestive tract cancer	NG36	Feb 2016

Responses to selected questions

1. Workforce

The Cancer Workforce Plan committed to the expansion of capacity and skills by 2021

Did the commitment achieve a positive impact for patients?

Named clinical nurse specialist not allocated

Kidney Cancer UK has not seen any evidence of improvements to outcomes or to service quality as a result of the Cancer Workforce Plan. The latest results of our patient survey are very similar to those in previous years. For example, approximately 1 in 4 patients were not allocated a named clinical nurse specialist.

Q26. Were you given the name of a Clinical Nurse Specialist (CNS) who would be in charge of your care?

Answer	Count	Percent
Yes	297	70.05%
No	110	25.94%
Yes but I had to wait until one was available	10	2.36%
Not applicable	7	1.65%
Total	424	100%

Few operations cancelled due to COVID

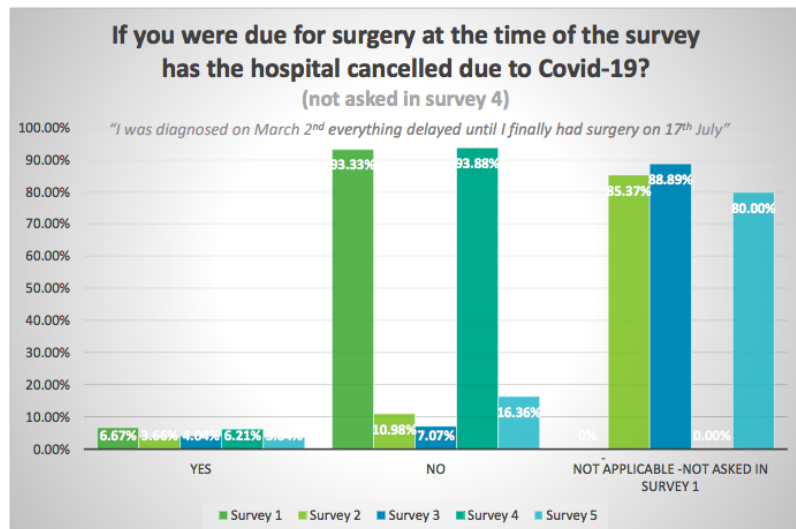
Conversely, of those respondents who had undergone surgery, very few reported that their operation had been cancelled due to the COVID-19 pandemic.

Q70-C70. If you are or were due for surgery, has the hospital cancelled it due to COVID-19?

Answer	Count	Percent
Yes	10	7.25%
No	128	92.75%
Total	138	100%

Kidney Cancer UK A

We attribute this result to the hard work and dedication of NHS staff. The result was supported by the aggregated results of the five COVID impact surveys:



Aggregated results of 5 Kidney Cancer UK Covid Impact Surveys

Few offered psychotherapy support

The annual patient survey has consistently shown that psychotherapies needed by many patients to help them cope with their cancer, are offered only occasionally. This point is dealt with under question 3.

Was it an appropriate commitment?

Unless the policy had allocated funds specifically for specified types of staff working in identified types of cancer, it is difficult to see how it could have been more specific. Doing so would have required expensive and time-consuming studies to justify the allocations. Devolving decisions on where to expand staff and skills to local level would appear to be the best way of ensuring the maximum benefit from this commitment.

The above may be true for many other cancers that are covered by NICE guidance, but in kidney cancer there is no such guidance to support funding decisions. We believe that this discourages decisions on kidney cancer funding, the decisionmakers feeling more confident to address staffing levels and skills in types of cancer that have the support of evidence-based guidance from NICE.

2. Diagnostics

A faster diagnosis standard from 2020 to ensure most patients receive a definitive diagnosis or ruling out of cancer within 28 days of referral from GP or from screening

By 2028 the proportion of cancers diagnosed at stages 1 and 2 will rise from around 50% now to 75% of cancer patients

Did the commitment achieve a positive impact for patients?

This commitment had negligible impact for kidney cancer patients and there are no signs that it will be met. Diagnosing kidney cancer is not easy: there is no quick, cheap diagnostic test to confirm diagnosis, which is generally made following ultrasound or CT scans.

The development of screening for kidney cancer is a research priority as many patients would be cured if diagnosed earlier. When the tumour is less than 4cm it rarely metastasises and should be curable by surgery; however, at its early stages it frequently causes no symptoms. Currently about 1 in 4 patients are diagnosed with metastases and are usually incurable. It is possible that screening for kidney cancer could be combined with lung cancer screening and abdominal aortic aneurysm screening. **Many patients wait 3 months and over from first presenting to diagnosis**As a result, many patients with suspected kidney cancer wait over 28 days from first feeling unwell to a confirmed diagnosis or all clear. This, we realise, is a different measure from the Faster Diagnosis Standard because it includes the time taken for the doctor to whom the patient first presented (normally a GP) to make the referral decision. However, it means that even if the Faster Diagnosis Standard is being met, the length of time before may kidney cancer patients are given a dependable answer to their concerns can be several months.

Q15. How long did it take from you first feeling unwell and seeking medical advice to receiving a diagnosis ?

Answer	Count	Percent
1 month or less	58	31.35%
Between 1 and 3 months	45	24.32%
Over 3 months.	74	40.00%
I did not visit my GP or A&E service before diagnosis	3	1.62%
Don't know	5	2.70%
Total	185	100%

Kidney Cancer UK Annual Patient Survey 2021

Many kidney tumours found incidentally

A large proportion of kidney cancer tumours are found as incidental results from scans for other, unrelated conditions. These fortuitous findings play an extremely important role in the overall diagnosis of kidney cancer, which is clearly a worrying situation.

Q12. How did you find out that you had kidney cancer?

Answer	Count	Percent
I visited my GP because I was feeling unwell and was sent for more tests	142	33.49%
I visited A&E because I was feeling unwell and was sent for more tests	56	13.21%
I found out during a medical scan or test that was unrelated to kidney cancer	203	47.88%
Other	23	5.42%
Total	424	100%

Kidney Cancer UK Annual Patient Survey 2021

Initial misdiagnosis in 1 in 4 patients In addition, the difficulties in identifying early kidney cancer led to misdiagnosis in around 25% of cases. There is no evidence that this happens in relation to diagnostic scanning. We believe it is more likely to happen before such scanning takes place and may be attributable in part to the absence of a simply diagnostic test.

Q82. Was kidney cancer your first diagnosis or were you initially misdiagnosed?

Answer	Count	Percent
It was my first diagnosis	315	74.82%
I was initially misdiagnosed	106	25.18%
Total	421	100%

Kidney Cancer UK Annual

Many kidney tumours not found until stage 3 or 4

The proportion of kidney tumours diagnosed at stages 1 and 2 is just over 40%, which is already below average. Perversely, many of these earlier findings may well be due to tumours being identified as incidental findings (mentioned earlier). There will need to be a major initiative in kidney cancer diagnosis to reach the standard of 75% of tumours being identified at stages 1 or 2.

Q19. 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?

Answer	Count	Percent
Stage 1	107	25.24%
Stage 2	67	15.80%
Stage 3	96	22.64%
Stage 4	83	19.58%
Don't know	71	16.75%
Total	424	100%

Was it an appropriate commitment?

This commitment was not specific enough to be of benefit to kidney cancer. It failed to recognise the particular difficulties in diagnosing kidney cancer. Not only is a simple diagnostic test urgently needed, but also specific, clear guidance on identifying kidney cancer that supports health professionals in referring suspected cases for diagnostic imaging more rapidly.

3. Living well with and beyond cancer By 2021 where appropriate every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support.

Did the commitment achieve a positive impact for patients?

Of course, receiving a diagnosis of cancer is a terrible shock for all patients. In kidney cancer, as we have seen a significant proportion of patients receive this diagnosis as an incidental finding from a scan they were having for another condition. For these patients the shock is even greater, and these patients may need even greater reassurance through information and supportive care to cope.

Provision of information varies throughout the pathway

Every patient is different and their needs for information and support will be individual and will vary depending on where they are in the pathway. Information on kidney cancer is provided with what seems to be a variable degree of success. At the outset, it is concerning that 46% say they were not given sufficient information to study after their initial consultation.

Q22. Were you given enough information about kidney cancer to take away to read later?

Answer	Count	Percent
Yes	196	46.23%
No	196	46.23%
I was too shocked and don't remember	17	4.01%
Don't remember	15	3.54%
Total	424	100%

Kidney Cancer UK Annual Patient Survey 2021

At the next stage of deciding on the most appropriate treatment, there appears to be less of a problem with the provision of information.

Q28. Do you feel you were given enough information about your treatment?

Answer	Count	Percent
Yes	320	75.47%
No	104	24.53%
Total	424	100%

Kidney Cancer UK Annual

Those patients who underwent surgery were generally satisfied with the information they received. However, almost a third wanted more than they received. Anecdotally, the charity is aware of cases where surgery was curative, but the patient remained anxious because they were not supported to come to terms with its success.

Q34. Were you happy with the information and support you received before and after your surgery?

Answer	Count	Percent
Yes	252	69.42%
If no, tell us what other information would have helped	111	30.58%
Total	363	n = 432.0

Kidney Cancer UK Annual

Information provision for patients undergoing systemic anti-cancer treatment is much better with only about 10% saying they would have liked more.

Q40. Were you given enough information on drug side-effects?

Answer	Count	Percent
Yes	118	89.39%
No	14	10.61%
Total	132	100%

Kidney Cancer UK Annual

Many patients want more support

The Kidney Cancer UK Annual Patient Survey asked patients who had undergone surgery how they felt afterwards. The results show a mix of positive and negative comments that indicates a need for greater support. Just over 60% of the 1171 comments made by the 432 respondents were negative

Q35. Which statements describe how you felt after surgery? (tick all that apply)

Answer	Count	Percent
I felt supported by the health professionals looking after me	173	14.77%
I felt abandoned after surgery and wished there was more contact with health professionals	136	11.61%
I didn't need or want any more support after surgery	17	1.45%
I was scared of the cancer reoccurring	178	15.20%
I was happy in the knowledge that the cancer had been removed and didn't want to think about it any more	42	3.59%
I received all the support required from cancer charities	38	3.25%
I received all the support required from friends and family	126	11.02%
I felt emotionally low	140	12.72%
I felt anxious	166	14.18%
I did not feel in control	88	7.51%
I felt pressured	8	0.68%
If you were unhappy with the support received after surgery, please let us know what type of support would have been useful	59	5.04%
Total	1171	n = 432.0

Kidney Cancer UK Annual Patient Survey 2021

NHS provision of psychological support is poor

However, as is the case with many cancers, the provision of NHS supportive psychotherapy, such as counselling, is low. The proportion of patients who relied on a charity for their counselling was greater than those who received it via the NHS and the overwhelming majority said they had not been offered it.

Q44. Were you, or have you been, offered counselling?

Answer	Count	Percent
Yes via the NHS	49	11.58%

Yes via private counsellor	19	4.49%
Yes via a charity	73	17.26%
No	263	62.17%
Rather not say	4	0.95%
Not interested	15	3.55%
Total	423	100%

Kidney Cancer UK Annual Patient Survey 2021

Was it an appropriate commitment?

In our view, the commitment is highly appropriate and identifies an important need. Clearly, in kidney cancer, there is more the NHS needs to do. However, the support offered by charities such as ours is often not sufficiently signposted by NHS staff. We believe that it would be beneficial to collaborate more closely with NHS centres to support their needs for patient information and support services.

4. Innovation and technology. Safer and more precise treatments including advanced radiotherapy techniques and immunotherapies will continue to support improvements in survival rates.

Was the commitment met overall? or (in the case of a commitment whose deadline has not yet been reached) Is the commitment on track to be met?

Did the commitment achieve a positive impact for patients?

Uptake of new treatments is slow

Kidney cancer treatment has developed rapidly over the last ten years, in terms of both surgery and of systemic treatment. Through health technology appraisals or similar processes, NICE has recommended the use of many of these. However, their uptake has been very slow. It is difficult to pin down the reasons for this. We believe that clinical guidance and a quality standard from NICE would be of significant help by providing a full and evidence-based picture of what a service should look like. It would also support investment in equipment needed to carry out some of the newer techniques. Advanced radiotherapy techniques (Stereotactic Ablative Radiotherapy, SABR) is widely used in other countries for primary kidney cancer. If approved in the UK, SABR could replace surgery as a radical treatment for patients with comorbidities. It is an outpatient procedure so hospital bed occupancy and surgical complications would be avoided, and surgical waiting lists improved.

In the 2021 Patient Survey, the use of robotic surgery remains relatively low. Cryoablation and radio frequency ablation are very poorly utilised despite being less invasive for the patients who are suitable, and probably resulting in faster recovery times in many cases.

Q33. What type of surgery have you received or are you due to have?(tick all that apply)

Answer	Count	Percent
Traditional (open) surgery was used	117	27.08%
Keyhole (laparoscopic) surgery was used	214	49.54%
Robotic techniques were used	85	19.68%
They froze the tumour (cryoablation)	6	1.39%
Radiofrequency ablation	4	0.93%
Waiting to hear what type of surgery I will have	1	0.23%
Other	6	1.39%
Total	433	n = 432.0

Was it an appropriate commitment?

Only on the last 10 – 15 years have we seen significant improvements in treatment for kidney cancer. The use of new techniques and treatments of all kinds that have been approved by NICE are vital to improving outcomes for kidney cancer patients.

The use of such treatments, within an efficient service that identifies and diagnoses patients quickly, and provides them with sufficient care and support is the ideal model of a kidney cancer service. So, whilst we need to attend to service quality in kidney cancer, doing so will have little impact on outcomes unless such services can take advantage of the latest available treatments. Once again, it must be noted that such a framework for service quality, based on evidence, has not been described for England. Having such a document will not be the sole answer to England's relatively poor survival rates for kidney cancer, but we believe it will provide the much needed basis on which to move forward.

Once again, thank you for this opportunity to share and explain our evidence. We hope that it will be of assistance.

January 2022