'Here to listen, inform & support'

Kidney Cancer UK
The UK's leading kidney cancer charity for over 20 years

Response to the Joint APPG Catch Up With Cancer summit Consultation: Solutions to the COVID induced cancer backlog

Kidney Cancer UK is grateful for the opportunity to respond to this important consultation. We are also extremely grateful for the incredible work put in by all NHS staff and particularly by those concerned with kidney cancer. Our last patient survey indicated that up to the end of 2020, kidney cancer services had been maintained at near-normal levels: only 3% (n=231) said their treatment had been delayed[1].

We appreciate the response that has been made to the COVID induced cancer backlog by the Government and NHS leaders. We should like to address three questions in this consultation and we hope our comments will be perceived not as critical but as constructive with the intention of making best use of current and any additional future resources.

What are the reforms, support and resources cancer services need to tackle the COVID induced cancer backlog?

Amidst the countless calls for additional resources, to which we also contribute in this document under the next question, there is a need to ensure that resources are carefully deployed where they can do most good. However, the current tendency to treat all services for all types of cancer in a similar way (e.g. by producing overarching cancer guidance) has led to the prioritisation of the most prevalent types of cancer (e.g. breast, prostate, lung etc.). This is supported by the argument that doing so benefits the maximum number of people and demonstrates the greatest effectiveness when overall cancer metrics are considered.

Gap in service quality

We believe that continuing this approach in tackling the COVID induced cancer backlog would be flawed. It has already begun to generate a gap in service quality between these more prevalent cancers and the rest, which can only widen if the practice continues.

Whilst there are some factors that are important to good quality services for all cancers, the diverse nature of individual types of cancer means that each has its own set of specific needs. In kidney cancer, for example, this begins at the earliest stage – diagnosis. The long term plan for cancer places great emphasis on early detection. But no matter how innovatively services are configured to do this, they will fail to do so in kidney cancer. The condition is often without symptoms until it has reached stage 3 and in any case, no test has yet been developed to detect it. So, the cancer plan has no benefit to this issue. As a consequence, a large proportion of all kidney cancer cases are detected as incidental findings when a patient is being scanned for a totally different condition – our patient survey indicated this was as high as 49% (n=278) – and this situation has remained the same over the last 3 years. Most of these cases have already reached stages 3 or 4 by the time they are diagnosed.

Kidney cancer service quality not measured

Kidney cancer is not rare. It is the seventh most common cancer in the UK[2]. Yet the quality of kidney cancer services is not measured, except where this is done as part of a broader assessment such as urological cancer services. At the time of writing Kidney Cancer UK is planning to carry out a two-year retrospective audit of kidney cancer service quality through Public Health England, which collects the data, but we are having to raise funds to pay for the analysis to be carried out as this is not routinely done.

[1] https://www.kcuk.org.uk/booklets/KCUK-patient-survey-2020/#page=1

[2] https://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence/common-cancers-compared#heading-Zero

Kidney Cancer UK
The Old Granary, Abington Park Farm, Great Abington, Cambridge, CB21 6AX
01223 870 008 hello@kcuk.org.uk www.kcuk.org.uk @kidneycanceruk

Of 12 most common cancers, kidney cancer is the only one without specific NICE guidance

Kidney Cancer UK formed the Kidney Cancer Accord, which has produced a consensus statement setting out the standards that need to be achieved in providing good quality kidney cancer services[3]. We intend this to be a stop gap until more authoritative guidance becomes available. We believe that the two-year audit will show a variable level of performance against these parameters, with the specialist centres performing best but more general centres that do not specialise in kidney cancer doing less well.

The National Institute for Health and Care Excellence (NICE) has not produced guidance on kidney cancer. At number 7 of the top 12 most common cancers, kidney cancer is the only one that has no form of guidance from NICE. This is significant because, although there are two different sets of European, evidence based clinical guidelines, neither is specific enough to guide the allocation of resources needed in a post COVID recovery of services, because they are designed to be applicable across all European countries.

England has some of worst survival rates in Europe

England (and the UK in general) has some of the worst five year survival rates in Europe[4]. This would seem to suggest that European guidelines are either not being followed or are not sufficiently applicable to the UK.

For these reasons, we recommend that:

- ***A more even balance is considered between overarching initiatives across all cancers that tend to disproportionately benefit the most common cancers and initiatives that focus on specific types of cancer that appear to be falling behind others.***
- ***NHS England refer kidney cancer to NICE to request the development of a clinical guideline and accompanying quality standard.***
- ***Quality indicators, probably based on a NICE quality standard, are measured.***

What technological or innovative solutions might be implemented long and short term to tackle the cancer crisis?

As mentioned in the previous section, a simple test to detect and/or confirm kidney cancer is urgently needed. At present, even where there are symptoms that suggest possible kidney cancer, these can only be confirmed by a CT scan, which is relatively costly. Whether a simple test would become a basis for screening (such as the Bowel Cancer Screening Programme) is not certain. GPs can already identify many patients with a higher than average risk of kidney cancer; the urgent need is for them to be able to confirm suspected kidney cancer either before, or as part of, a referral to a specialist.

Appropriate full integration of new treatment options in pathways

If identified early enough, kidney cancer surgery can often be curative. It can also be less invasive, often requiring only partial removal of a kidney. In recent years laparoscopic surgery has become the most popular surgical technique, which has reduced invasiveness markedly.

New treatment options that are even less invasive than laparoscopic surgery show great promise in treating kidney cancer. The recovery of cancer services from the impact of the COVID pandemic, is an opportunity to integrate these into treatment pathways, thus allowing their advantages not only to benefit patients but also to contribute to the recovery process. However, a NICE clinical guideline will be crucial to achieving this in kidney cancer, compared with other types of cancer which already have such guidance. Ensuring that kidney cancer is covered by a NICE guideline in the same way as other cancer

[3] https://www.kcuk.org.uk/booklets/accord-consensus-statement/#page=8

[4] https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/kidney-cancer/survival#heading-Four

types, will mean that it is able to benefit from the appropriate uptake of new treatments in the same way. If not, there is a risk that kidney cancer services will not recover as quickly, or to the same extent, as other cancers. This would be a serious concern because, as the seventh most common cancer, kidney cancer outcomes will have an impact on the overall performance of the long term plan for cancer, and we have already seen that kidney cancer 5-year survival rates are amongst the worst in Europe.

If NHS England were to commission a NICE guideline for kidney cancer, this would clearly indicate their intention to ensure that no cancer is left behind in the post-COVID recovery.

We recommend the following:

- ***The development of a rapid, inexpensive test to confirm kidney cancer should be a research priority***
- ***A review of treatment pathways for all cancer types to ensure appropriate full integration of new treatment options.***
- ***In kidney cancer specifically, the inclusion of the pathway review (mentioned above) as part of the development of a clinical guideline***

What do cancer services need to look like in the future to improve survival of cancer patients?

As already pointed out, kidney cancer survival rates in the England are amongst the worst in Europe. We believe that significant improvements could be made by concentrating services on the existing specialist units throughout England and moving treatment away from units that treat kidney cancer less frequently as part of more general services.

Anecdotally, we regularly hear reports from clinicians that suggest service quality is higher in specialist centres and that outcomes are correspondingly better. We have seen the benefits of such a model in other health conditions. However, the kidney cancer data are not analysed in such a way as to provide a definitive answer to this and unless we can raise the funding for the two-year retrospective audit mentioned earlier, that is likely to remain the same.

Identify and target cancer types that are being left behind

Overcoming the COVID induced cancer backlog is highly likely to need additional resources. However, with kidney cancer, more than just about any other in the top 12 most common types of cancer, there is potential to improve outcomes, i.e. survival rates, by improving the quality of existing services through authoritative, evidence-based guidance from NICE and greater use of less invasive therapeutic techniques. To achieve this, however, NHS England will need to focus on kidney cancer in order to narrow the gap between this, the seventh most common cancer, and other cancers in the top 12. There may be similar cases in other types of cancer. The COVID recovery is an opportunity to address these.

We recommend that in addition to looking for improvements that impact the most common cancers, NHS England use the cancer data collected by Public Health England and the National Cancer Intelligence Network to target improvement measures at specific types of cancer where service quality has not improved in line with the other more common types.

Nicholas Turkentine
Chief Operating Officer
Kidney Cancer UK