

How your support is changing the face of kidney cancer diagnosis & treatments in the UK

Impact Report



www.kcuk.org.uk

Summer 2021

A message from Nick Turkentine — CEO, Kidney Cancer UK

Dear friend

We are delighted to be able to send you this Impact Report on how your donations are helping Kidney Cancer UK & Kidney Cancer Scotland to build a better world for kidney cancer patients across the UK.

The projects that your donations enable us to work on have a direct effect on the lives of patients, carers and their families and through your support we are working to improve diagnosis times, create clear aligned treatment pathways, reduce the burden of kidney cancer to the patient and support the NHS through the service we are uniquely able to provide.



At the root of all we do is ensuring kidney cancer is on everyone's radar, from those who have no diagnosis through to GP's, to the devolved NHS services in England, Scotland, Wales and Northern Ireland and the UK Government. We work tirelessly to raise the awareness of kidney cancer at all points because if you are a member of the public or the highest office in the land, knowledge is everything.

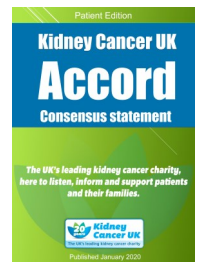
Since 2016 we have been working on a project titled 'The Kidney Cancer UK Accord' in which we are aiming to establish with the NHS a set of Quality Performance Indicators (QPIs), which is essentially a recognised pathway for kidney cancer patients, for which there is none for England, Wales and Northern Ireland. We expand further in this Impact Report.

We would not be able to do this important work if it were not for your kind support and we hope this Impact Report goes some way to let you know you enable us to deliver these services.

On behalf of the team here and every person in the UK touched by kidney cancer, I sincerely thank you for your support.

Nick

A handwritten signature in black ink that reads 'Nick Turkentine'. The signature is written in a cursive, slightly slanted style.



Working for better kidney cancer services

Our commitment to supporting patients and carers is most often seen through our Careline, our counselling service and the information we provide through our booklets and online support groups. However, we believe that it is also important to engage with the Government and the NHS on behalf of patients and carers in order to influence the services they provide.



Setting out what good kidney cancer services should provide

This is not about criticising the care provided by health professionals in the NHS, but about helping them to be more effective in treating patients. It is important to remember that these dedicated individuals are often held back by the limited resources and time they have. Kidney cancer has to compete against every other type of cancer and every other medical condition to secure the trained medics, equipment and medicines that are needed to diagnose and treat it. Kidney Cancer UK plays a crucial role in doing this – the voice of patients is often more powerful than that of the health professionals.

This is why in 2017, Kidney Cancer UK set up a committee bringing together health professionals, patients and carers called the Kidney Cancer UK Accord. This group has produced a document that sets out the standards of what good kidney cancer services should provide to the patient in the form of a Consensus Statement. The development of the statement was widely welcomed, representing as it did, the opinion of the experts on the Kidney Cancer Accord Committee. However, the consensus was intended to be the start of a much bigger programme, that would improve standards of service throughout the kidney cancer pathway.

No existing kidney cancer guidelines.

We are amongst the worst outcomes in Europe

Why is all this needed? The simple answer is because it does not exist. The public body that produces definitive guidance to health professionals in England and



Wales is the National Institute for Health and Care Excellence (NICE). Unlike most other cancers (including many that are less common than kidney cancer), NICE has not produced any guidance specifically on kidney cancer. The last time it looked at kidney cancer was over 20 years ago as part of work looking at a whole group of (urological?) cancers.

So, there is no single set of guidelines, specific to England, Wales or Northern Ireland that covers all aspects of diagnosis, treatment and care at all stages of kidney cancer. Added to this, and despite the incredibly hard work and dedication of health professionals across the country, the UK has some of the lowest kidney cancer survival rates in Europe.

Building health professional support for a NICE guideline

These two factors brought together the Kidney Cancer UK Accord and led to the Consensus Statement. It is now driving our work that we believe will lead to comprehensive guidelines and standards for kidney cancer from NICE, something we have never seen in England, Wales and Northern Ireland.

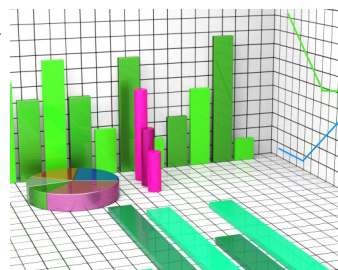




At present, Kidney Cancer UK Accord is contacting all professional bodies and Royal Colleges that have members working within kidney cancer. The aim is to galvanise these bodies to support Kidney Cancer UK when it formally calls for the development by NICE of guidelines and standards for kidney cancer. This process is at an early stage, but there have already been several rapid and constructive responses to Kidney Cancer UK's call to action.

Largest and most detailed study of kidney cancer services

In a closely related, important piece of work, Kidney Cancer UK is commissioning a study that will measure how well kidney cancer services have been performing up to now. This is a major investment for the charity and is being overseen by the Kidney Cancer UK Accord: we believe it will be the largest and most detailed study of kidney cancer services ever carried out in England. The charity is working with the National Cancer Registration and Analysis Service and the National Disease Registration Service. The preparations are almost complete, and work is due to start by the beginning of September and deliver final data by Spring 2022.



Improvements in services, and access to latest techniques in diagnosis and treatment

What does all this mean for people with kidney cancer and their carers?

It means better diagnosis, treatment and care. Along the pathway of kidney cancer, many different kinds of health professional are involved, and they provide the best care they can within their speciality. A guideline that covers the entire pathway will help individual specialists to work together more effectively; from GPs who often first see risk factors that could lead to kidney cancer, to expert surgeons and oncologists, supported by specialist nurses and other professionals. Unlike now, once our Accord is adopted by NICE and the NHS, all of these people will work to the same set of guidelines. As well as that, patients and carers will be able to see these guidelines and the extent to which they are being met in their personal journey.



With the guidelines will come a set of standards that kidney cancer services will be expected to meet. These will most likely take over from the Consensus Statement that Kidney Cancer UK Accord produced. These guidelines and standards will drive improvements in services, including appropriate access to the latest techniques in diagnosis and treatment for patients.

This also gives rise to the possibility of measuring performance against these standards. To date, the NHS in England and Wales has not widely adopted such measures (often called quality performance indicators or QPIs). The study of current services that Kidney Cancer UK is about to carry out will show the value in doing so.

Measurement of services in this way is not new. The NHS in Scotland has a set of QPIs that it operates and updates regularly. Kidney Cancer UK's sister charity, Kidney Cancer Scotland successfully took part of their last review in 2019 and is preparing to take part in the forthcoming review due to be announced at any time.

After 20 years, put kidney cancer on a par with other cancers

NICE guidelines cover England and Wales and may be adopted in Northern Ireland. Whether or not they are used as performance measures, having authoritative, up-to-date guidelines and standards for kidney cancer will, after 20 years, bring it onto a par with other cancers; it will also bring it more fully to the attention of senior NHS officials at regional and national level who decide how budgets are divided across all diseases.

Your support will help change the face of kidney cancer treatments forever

Kidney Cancer UK exists to help people with kidney cancer and their carers. We believe that this is not only about providing support services in addition to the NHS, but that it is also about being the representative of patients and carers in ensuring the NHS provides them with the best care possible. So perhaps most important of all, NICE guidelines and standards will provide kidney cancer patients and carers with a long overdue framework with which they, and we, can hold the NHS to account.



To download a copy of the Kidney Cancer UK Accord—Consensus Statement go to www.kcuk.org.uk/library and scroll down the page.

Here to listen, inform and support

Your support helps provide our Careline and Counselling Service, thank you.

0800 002 9002
KIDNEY CANCER CARELINE
Here to help

0300 102 0101
KIDNEY CANCER COUNSELLING
Here to support

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

Kidney Cancer Scotland
Scotland's leading kidney cancer charity

© 2014 - 2019 Kidney Cancer Care Ltd.
Kidney Cancer UK, Kidney Cancer Care and Kidney Cancer Scotland are trading titles of Kidney Cancer Care Ltd.
Postal Address: Kidney Cancer UK, The Old Granary, Park Farm, Great Abington, Cambridge, CB21 6AX
Kidney Cancer Care Ltd is a registered charity in England and Wales (1120146) and Scotland (SC043642)
Registered Office: The Old Granary, Park Farm, Great Abington, Cambridge, CB21 6AX. Company Number England and Wales (05937304)