

## Certificate

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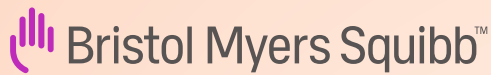
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\*only one certifier required for this option

### Part B - For completion by Medical Signatory only



# Kidney Cancer Patient Charter

This Patient Charter has been initiated and funded by Bristol-Myers Squibb and created in equal partnership with Kidney Cancer Support Network and Kidney Cancer UK.

Endorsed by



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# About this Charter



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Kidney cancer is the seventh most common cancer in the UK (the tenth most common cancer in females and the sixth most common cancer in males). Kidney cancer incidence rates have increased by more than a third (36 per cent) in the UK over the last decade.<sup>1</sup>

Being diagnosed with kidney cancer is a daunting and stressful time. Sometimes, it comes after months of investigations and appointments with healthcare professionals. For a newly diagnosed patient, there is rightly an expectation that they will be able to receive the best possible care, as well as the support that they need, throughout their subsequent journey. However, across the country, there is variation in the care that patients receive. This is reflected in the variation in patients' experiences and outcomes. There needs to be a focus on improving kidney cancer care and outcomes.<sup>2</sup>

In 2019, Bristol Myers Squibb, Kidney Cancer Support Network and Kidney Cancer UK came together to develop a report on the inequalities in access to care and support facing kidney cancer patients in the UK.\* This Patient Charter builds on that evidence by drawing together the things that patients should be able to expect when they are diagnosed with kidney cancer. This has been developed following a meeting with patient representatives. It is intended to inform policymakers about the barriers to improving kidney cancer patients' experiences and outcomes.

The '*I statements*' included in the Charter are not direct quotes from individual patients but are instead composite statements backed up by evidence-based policy insights, which have been developed with kidney cancer patients and their representatives to communicate what matters most to kidney cancer patients.

\*Kidney Research UK also provided support in the initial scoping of this report

## The intention is that this document will:



Make the case for more focus on improving kidney cancer care and outcomes.



Be ambitious for all patients but achievable within the constraints of NHS resources.



Apply to all kidney cancer patients, regardless of where they live, their tumour type, age or any other characteristic.



Apply across the UK.



Focus on principles which reflect the different points in the pathway where key challenges may overlap or be similar.

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# Getting a timely diagnosis



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*“I would value knowing my signs and symptoms will be listened to and taken seriously, so that I am referred for specialist testing quickly to get the correct diagnosis as soon as possible.”*

Early diagnosis of kidney cancer is important so that there is the best possible chance of treatment before it spreads further. Anyone with the signs or symptoms of kidney cancer should be referred for more tests in a timely way.

Kidney cancer can often present with ambiguous symptoms, such as back or flank pain, fatigue and weight loss.<sup>3</sup> This means that it is even more important that healthcare professionals, such as those in primary care, are aware of kidney cancer as a potential diagnosis.

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## Taking symptoms seriously

- Patients should be listened to and taken seriously when they express concerns about their health and should be referred in a timely way. If there is a suspicion of cancer, the guidance for suspected cancer (two-week wait) must be followed.<sup>4</sup>
- Awareness of kidney cancer among GPs and other healthcare professionals needs to improve, so they fully understand how to spot the signs and symptoms, to consider kidney cancer as a potential diagnosis and refer appropriately.

Previous research has found that more than one in four (27.5 per cent) patients reported visiting their GP about their symptoms more than twice before they were referred for specialist treatment.<sup>5</sup>

An international survey found that female patients in the UK took notably longer to be diagnosed than male patients, with 79 per cent of male patients diagnosed in three months or less compared to 67 per cent of female patients.<sup>6</sup> 16 per cent of females in the UK were diagnosed after one year, compared to only 7 per cent globally.<sup>6</sup>

Younger patients in the UK also took notably longer to be diagnosed with only 27 per cent of those aged between 30-45 diagnosed within the first month, compared to 44 per cent of those aged 46-65, and 46 per cent of people aged 66 or over.<sup>6</sup>

## Awareness of the symptoms of kidney cancer

- There should be greater awareness of kidney cancer and its signs and symptoms among members of the public and clinicians.

Evaluation of public awareness campaigns, such as NHS England's *Be Clear on Cancer* campaign, has shown that patients become more aware of symptoms (specifically blood in urine) following campaigns, resulting in a rise in referrals for kidney cancer.<sup>7</sup>

## Improving the system to detect kidney cancer

- Referral for suspected kidney cancer should happen in a timely way in line with the current 'two-week wait' guidance.
- When kidney cancer is diagnosed incidentally a review should be undertaken by all the healthcare professionals involved to identify lessons on how to ensure earlier diagnosis in future.

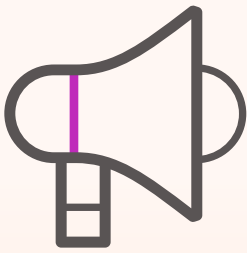
Some patients are not diagnosed with kidney cancer until their cancer has become so advanced that they become acutely unwell and present to emergency care or are diagnosed only incidentally as a result of tests for another condition.

In 2019, 59.3 per cent of kidney cancer patients surveyed by Kidney Cancer UK said their diagnosis was an incidental finding or happened while visiting an A&E Department.<sup>8</sup> This can mean that their kidney cancer is diagnosed later and so can affect their treatment options and outcomes.

More than 85 per cent of kidney cancer patients diagnosed at stage 1 survive for five years or more after their diagnosis, this falls to more than 10 per cent for those diagnosed at stage 4.<sup>9</sup>



# Being seen and heard



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*“As an expert in my own experience of kidney cancer, my voice should count in my treatment as much as I want it to, and my feedback should be considered when planning how to deliver the best possible individualised care and treatment now and in the future.”*

Everyone diagnosed with kidney cancer needs to be supported to understand what it means and to have a say in what they want from their treatment and care.

Services need to seek feedback to make sure that lessons are learned from all experiences of treatment and care – whether positive or negative – to make improvements for all kidney cancer patients.

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## Supporting patients to be involved in their care

- All kidney cancer patients should be consulted and heard as much as they would like to make a shared decision about their own care and treatment with their healthcare professional.

One in five kidney cancer patients report that they did not “definitely” feel as involved in their care as they wanted to be.<sup>5</sup> This is subject to wide regional variance, with this figure rising to one in four patients in one Cancer Alliance in England.<sup>5</sup> The National Cancer Patient Experience Survey also found that four in five kidney cancer patients reported that doctors talked about them as though they weren’t there.<sup>5</sup>

Compared to global results, considerably more patients in the UK had their treatment plans decided for them solely by their doctors. This was particularly the case for males, those with no evidence of the disease or who had been told they were cured, and patients aged 30-65.<sup>6</sup>

**38%**

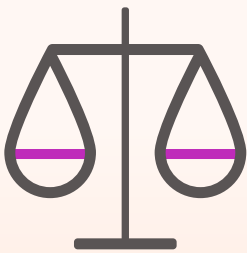
of patients in the UK had not been engaged at all in their treatment plans, in that their doctor had decided their treatment plan for them; this makes the UK an outlier compared to **29 per cent** of patients globally reporting not being engaged in their treatment plans.<sup>6</sup>

## Service design

- Kidney cancer patients should be involved in discussions and decisions about how kidney cancer services are designed and commissioned throughout the process, at all levels, including Board level.
- Decision-makers at all levels, from national government down, should seek out and respond to the views of kidney cancer patients and incorporate their experiences into service designs.

Engaging directly with patients can ensure that their needs are placed at the centre of their care. Involving patients in service (re)design can identify barriers to patients accessing care, improve patients’ experiences and ensure that services are fit for purpose for patients. This requires time and investment and involving patients from the start of a project. Previous programmes that involved cancer patients in the design of services have been found to be successful.<sup>10</sup>

# Being treated fairly



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*“I would value being able to access the best possible care and treatment, regardless of where I am treated and what type of kidney cancer I have.”*

The treatment and care options for kidney cancer depend on several factors including: how advanced the kidney cancer is and what someone with cancer says is important to them or their personal circumstances

Location should not be a barrier to accessing the best possible care and treatment; all therapeutic options and surgical techniques should be consistently available across the country, to avoid variation in experiences and outcomes.

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## Offering equal access to treatment and support

- All kidney cancer patients should be treated as an individual – their age, ethnicity, tumour type, tumour location or other characteristics should not adversely affect their treatment and care.
- Patients should have access to the latest technological advances for the treatment of kidney cancer, wherever they live in the UK.

An international survey found that overall, younger patients, males and patients with other kidney cancer sub-types in the UK experienced notably more barriers to receiving high quality care.<sup>6</sup> Younger patients (between the ages of 30-45) in the UK were affected overall by notably more barriers in receiving quality care than patients in older age groups.<sup>6</sup>

- Where patients have other conditions their support and care for all their conditions should be joined up – not dependent on them navigating multiple systems. This should be reflected in meetings of the multi-disciplinary team (MDT) that takes decisions about the patient's care. In some cases, clinical expertise will be sought from other hospitals and therefore these MDT representatives joining the meetings may not have previously seen the patient being discussed.

## Access to clinical trials

- Conversations about clinical trials should take place openly, and at an early stage. Health professionals need to make sure they are aware of the trials taking place that their patients would be eligible for, including at other institutions, and discuss the possibility of the patients being included in a trial. If appropriate, healthcare professionals should refer patients to the clinical trial team to determine whether they might be eligible. Patients should be reassured that this is a normal means of accessing treatment.

A survey of patients found that clinical trials had not been discussed with 52 per cent of patients in the UK – this makes the UK a Global outlier as the combined international figure was 33 per cent globally. In the UK, 72 per cent of patients had not been asked to participate in a clinical trial. Interestingly, UK patients are generally eager to participate in trials; of those patients who had never been asked to participate in a clinical trial, 98 per cent said it 'fairly likely' they would do so if asked compared to 89 per cent globally.<sup>6</sup>

## Consistent quality of treatment

- Patients should be offered the best possible treatment throughout the country and there should be equality of care regardless of where they live.

Innovative and less invasive approaches to treatment have been developed for use in conditions like kidney cancer. However, uptake of techniques such as stereotactic ablative radiotherapy or cryoablation is extremely slow. In a 2018 survey of kidney cancer patients, ablation therapy was offered to negligible numbers of patients who responded to the survey and robotic surgery was made available in only 9% of cases.<sup>8</sup>

Discussions about treatment options should take account of patients' quality of life and wellbeing, including how best to manage adverse effects of treatments so that this does not limit their choices. However, some kidney cancer patients in the UK report having no understanding of their treatment options, with 22 per cent of UK respondents to an international survey reporting that.<sup>6</sup>

# Evidence-based medicine



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*“My care should be based on up-to-date and evidence-based national guidance, or on international guidance where that is not available.”*

Ensuring that care is based on the latest evidence is an important way of reducing the variations in experiences and outcomes.

Where local or national guidance doesn't exist, international guidance can provide an important starting point to inform service provision.

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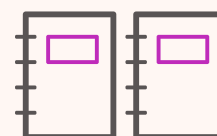
## The kidney cancer patient pathway

- A national kidney cancer pathway should be developed and adopted to set standards for optimal service delivery across the country. Implementation of guidance needs to be measured to ensure consistency across the country and to monitor progress.

Current UK guidelines date back to 2002, which pre-dates many modern treatment regimes.<sup>11</sup>

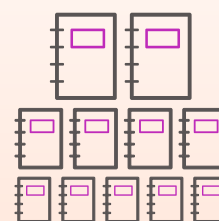
There are

**2** sets



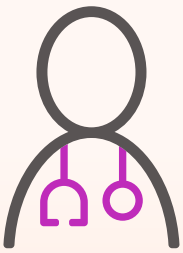
of existing guidance from Europe and

**22** pieces



of guidance in the UK from the National Institute for Health and Care Excellence (NICE) on different aspects of diagnosis, treatment and care for kidney cancer that need to be drawn together into a single definition of quality service.<sup>8</sup>

# Support throughout the journey



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*“I would value having people, such as specialist nurses and patient advocates, who will walk alongside me throughout my kidney cancer journey to advocate for me and respond to my individual circumstances.”*

The kidney cancer journey, from diagnosis through treatment and beyond, can feel uncertain.

That is why everyone with kidney cancer should have a named person to contact if they have questions about their condition or care. Clinical Nurse Specialists (CNSs) in particular, play a vital role in supporting patients with kidney cancer through this uncertainty.

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## A kidney cancer key worker

- All kidney cancer patients should have a named ‘key worker’, ideally a CNS, from the day of their diagnosis to support them and advocate on their behalf.

While this is currently the intention, almost 18 per cent of kidney cancer patients do not recall being given the name of their CNS.<sup>5</sup> Worryingly, analysis has indicated that CNSs working with kidney cancer patients have the highest caseloads of those in any area of clinical practice.<sup>12</sup>

## Waiting for results

- For those patients who have completed a course of treatment, or who have no course of treatment available, active surveillance and monitoring should be clearly explained to patients as an important part of the pathway, and they should have clarity on when scans and tests will take place.

According to an international survey of kidney cancer patients, those in the UK found waiting for tests and scans to be particularly difficult.<sup>6</sup>

## The role of Clinical Nurse Specialists

- CNSs should be able to play an active advocacy role for patients at MDT discussions – this involves ensuring they have an appropriate caseload and have the time protected to attend and contribute to meetings, in addition to the experience and knowledge of kidney cancer patients.

Ensuring that CNSs can represent patients at MDT discussions would ensure that decisions about patients better reflect their personal preferences and circumstances. However, MDT meetings can omit the perspectives of some professionals, and one study found that the mean number of people contributing in the discussion of a patient was only three.<sup>13</sup>

- CNSs should be able to make referrals to wider support services in response to patients’ individual wellbeing needs, including emotional and psychological support, nutritional support and general healthy living advice.

CNSs are well-placed to recognise and respond to patients’ needs beyond their treatment. They should be able to signpost patients to other sources of support proactively ahead of time and reactively when patients ask for support. Where the CNS role is working well, it is appreciated by patients. 39 per cent of patients surveyed by KCUK reported that their first point of call would be their specialist clinic and/or their CNS in particular.<sup>8</sup>

## Support organisations

- Information about peer support groups, patient advocacy groups and other networks should be actively and regularly shared with patients, so that they know where to turn for help.

Kidney cancer charities can provide specialist help and support for all kidney cancer patients. However, according to the National Cancer Patient Experience Survey, around a quarter of kidney cancer patients report not being given details for support or self-help groups that could support people in their position.<sup>5</sup> Services should also consider investment in local peer support networks which can provide additional help to people throughout and beyond their treatment.



# Getting the right information



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*“I would value being able to get accurate and relevant information when I need it, in a way that I can understand and in a form that is useful for me.”*

Everyone with kidney cancer needs the right information at the right time to make informed choices about their treatment and care.

This information should also be in a format that is useful and accessible to all, including those who might face barriers to accessing the internet.

## Information that patients can understand

- Information should be provided to patients when and how they need it, recognising that all patients are different. This requires information to be available in different formats, languages and styles, including verbally, written and visual aids. Information should be available at all stages of the pathway, not just at the point of diagnosis.

At present, not all kidney cancer patients receive the information they need. The National Cancer Patient Experience Survey found that one in five kidney cancer patients reported not being given the results of their tests in a way that they could understand.<sup>5</sup> More than 30 per cent of patients were not given written information about their kidney cancer diagnosis.<sup>5</sup> Worryingly, according to the IKCC survey of kidney cancer patients in the UK, 27 per cent had no understanding of their likelihood of survival.<sup>6</sup>

- Information should be provided for patients' families recognising they may have different needs to patients themselves.

Research has found that the extent to which family caregivers understand the information given around cancer care plays a crucial role in ensuring the best possible health outcome for patients.<sup>14</sup>

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## Information during diagnosis and treatment

- Patients need to be kept informed at every stage of their journey – including after their treatment – with regular follow up and clear information on what will happen to them next.
- Patients should receive correspondence between their GP and hospital team.

Having successful surgery or other treatment is not necessarily the end of the journey for some kidney cancer patients.

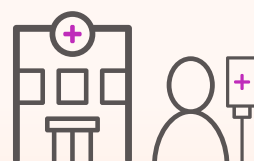
Patients with no detectable signs of kidney cancer, or those who were told they had been ‘cured’, were affected more by the fear of recurrence, and by difficulty navigating the healthcare system, according to an international survey.<sup>6</sup>

After surgery, nearly a third (32.6 per cent) of patients felt abandoned and wanted more contact with health professionals.<sup>8</sup> Providing information about when regular scans will occur and providing a facility for advance booking can support patients to feel more in control.

## Support and emotional wellbeing

- Access to emotional wellbeing support services needs to respond to individual patient needs and extend beyond traditional mental health services. This support must be offered in a timely way.

At present, the majority (62 per cent) of patients surveyed by Kidney Cancer UK said they had not been offered counselling. However, of the near 35 per cent who did receive counselling, 30 per cent said they found it beneficial.<sup>8</sup>



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Patients with kidney cancer should be able to access services quickly, for example through specialist providers such as Maggie’s centres and not face lengthy waits for counselling or other emotional wellbeing support.

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