



Bristol-Myers Squibb

# Overcoming Inequality:

Achieving better outcomes for kidney cancer patients

Endorsed by



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## Overcoming Inequality:

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# Executive summary

Since the early 1990s, the incidence of kidney cancer has risen by 87 per cent, and it is now the seventh most common cancer in the UK.<sup>1</sup>

Despite that, there is not the public awareness of kidney cancer that there is of other, less common conditions. Alongside this, the UK is one of the poorest performing developed nations for kidney cancer mortality, and Scotland and England have the third and fourth worst rates of five-year survival for the disease in Europe according to the latest systematic international comparison.<sup>2</sup>

Recent five-year survival data from the Office for National Statistics also indicate significant variation by region, more than is the case with any other cancer for which data were available.<sup>3</sup>

Several issues can affect the identification and management of kidney cancer. Following desk research and engagement with the kidney cancer community, we have identified three key areas for consideration:

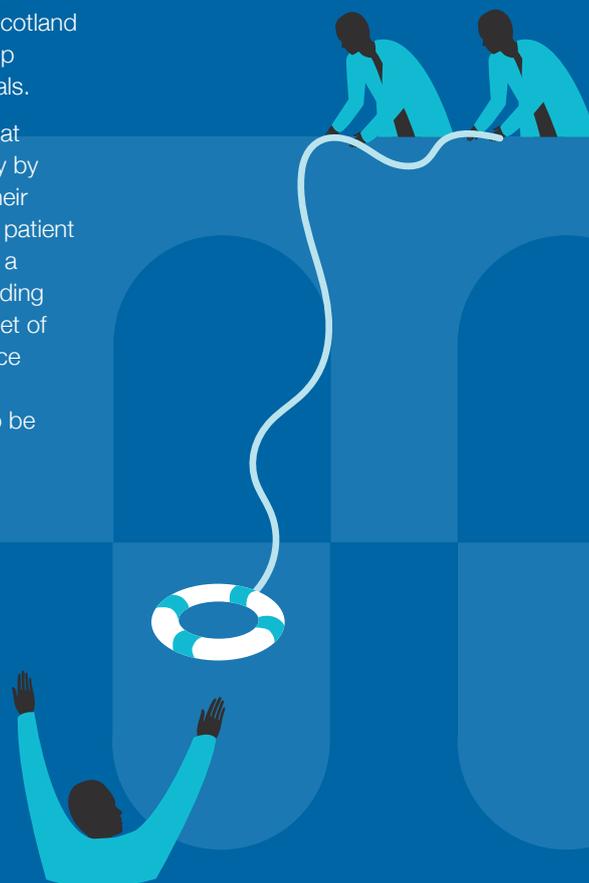
- Ensuring timely diagnosis of kidney cancer
- Workforce challenges
- Access to treatment and follow up

Across the UK, policymakers are focusing on the challenge of meeting the needs of a growing population of cancer patients, delivering treatment faster and more effectively and ensuring patients have the right support throughout. To deliver on that ambition, inequalities in the diagnosis, treatment and care of kidney cancer must be a point of focus. This report sets out those inequalities and makes a number of recommendations as to how they can be tackled.

## Background information

This report has been developed following extensive research on the kidney cancer patient experience, as well as diagnostic and treatment pathways in the UK. It brings together insights gained from a series of interviews and two roundtable meetings in Scotland and England with the patient group community and health professionals.

This report coincides with work that has been underway independently by Kidney Cancer UK since 2017. Their work reflects a deep focus on the patient journey through the publication of a Consensus Statement recommending the implementation of a broader set of Kidney Cancer Quality Performance Indicators (KCQPIs) for patients in England and Wales. This is due to be published in December 2019.



# Introduction

## About kidney cancer

Kidney cancers are a group of malignancies that begin in the kidney and collectively make up one of the most common cancers in the UK.<sup>1,4,5</sup> Different types of kidney cancer are defined by the type of cells that form the cancer and where it starts. The most common of these in adults is renal cell carcinoma (RCC), accounting for approximately 80 per cent of cases.<sup>6</sup>

The disease particularly affects people in their 60s or 70s, but can affect younger people, and is more common in men than in women.<sup>1</sup> Other risk factors, in addition to age include smoking, high blood pressure and working in some professions.

There is evidence to suggest that those at risk include workers exposed to specific types of dust and those working in agriculture.<sup>7,8</sup> One in three cases of kidney cancer (33.5 per cent in men and women in the UK) is estimated to be preventable.<sup>9</sup>

The survival rate for those diagnosed with kidney cancer in the UK is markedly lower than the average across Europe. Data from 2000-07 shows that for England, Scotland and Wales the five-year survival rates are 47 per cent, 46 per cent and 50 per cent respectively, compared to the European average of 60 per cent.<sup>2</sup>

This means that Scotland and England have the third and fourth poorest survival rates respectively for kidney cancer of the European countries for which data are available. By contrast, the best performing country in Europe, Austria, has a 71 per cent survival rate.<sup>2</sup>

## Kidney cancer and mortality:



87%

Over the past 20 years, the incidence rate for kidney cancer has increased by around **87 per cent**, with more than 12,000 new cases now being diagnosed on average each year<sup>1</sup>



25%

The proportion of people diagnosed with kidney cancer is expected to rise by **more than a quarter** between 2014 and 2035<sup>1</sup>



74%

In 2016, 4,619 people died from kidney cancer, and the rate of mortality has risen by more than **74 per cent** since the early 1970s<sup>10</sup>



33%

In the most deprived areas of England, the rate of incidence for kidney cancer is 19 per cent higher in men and **33 per cent higher** in women than in the least deprived areas<sup>1</sup>

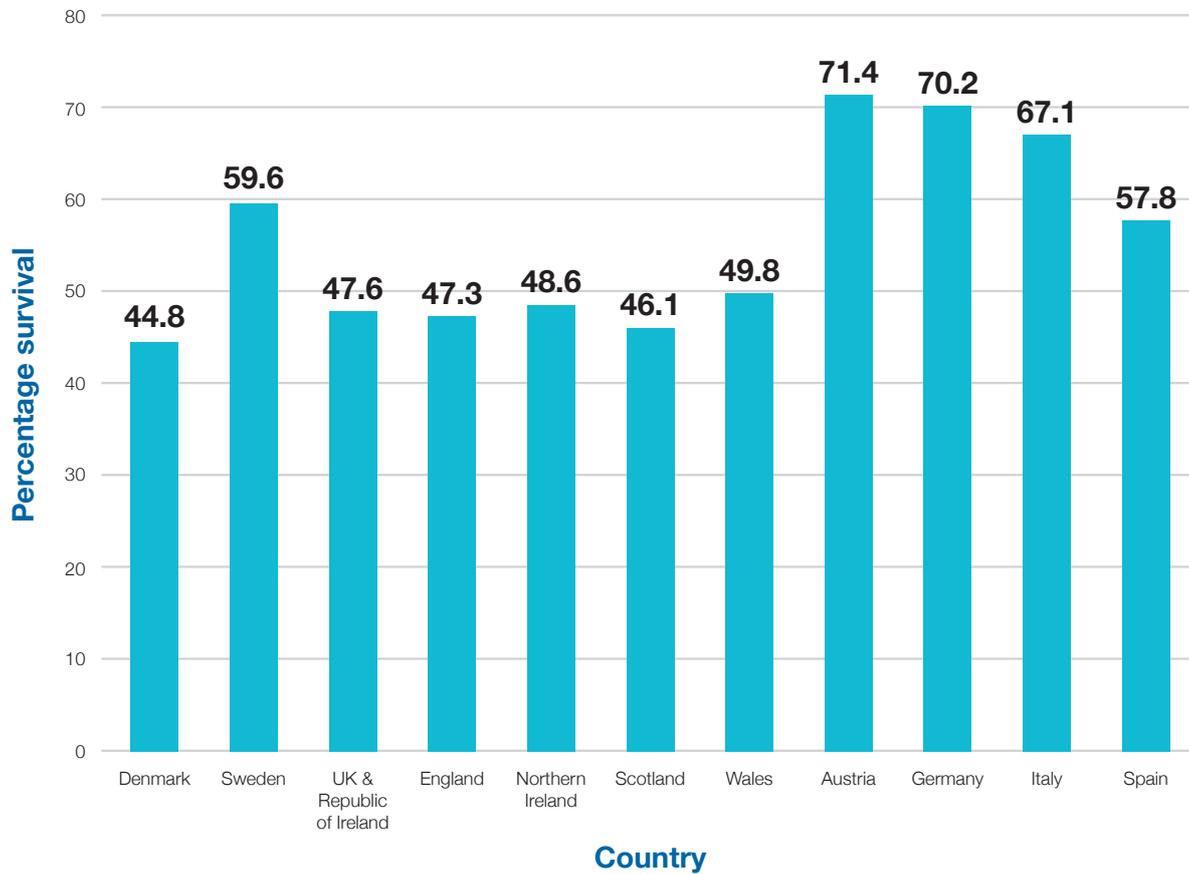
## Overcoming Inequality:

Achieving better outcomes for kidney cancer patients

Figure 1:

### Relative survival of kidney cancer patients in selected European countries.

(Figure adapted from De Angelis et al., 2014)<sup>2</sup>



Kidney cancer affects a large and growing number of patients. This report sets out a number of areas where focus from policymakers is required to ensure kidney cancer patients receive the high-quality care that they deserve, no matter where they are being treated.

If the UK is to improve patient outcomes and patient experience in kidney cancer, action must be taken at points throughout the patient pathway, from diagnosis and treatment to follow up care. Otherwise, UK patients will continue to be at a disadvantage compared to those from other comparable countries.



# The UK policy context for kidney cancer

Across the UK, the funding spent on cancer care has risen progressively, and is predicted to rise to more than £15 billion by 2021.<sup>11</sup> Cancer has been a primary focus for the health service for many years, and as a result survival rates are improving for many tumour types and are at an all-time high across all cancers. Over the past 40 years, the survival index for all cancers has more than doubled from 24 per cent in 1971-72 to 50 per cent in 2010-11.<sup>12</sup>

## England

In England, much of the focus on cancer is now being driven by *The NHS Long Term Plan*, which introduced an ambition to increase the proportion of all cancers diagnosed at stages I and II from around half (54-55 per cent in 2010-14) to three quarters by 2028.<sup>13,14</sup> Only around 56 per cent of kidney cancers are diagnosed at these stages, so this represents an opportunity to improve early diagnosis in England.<sup>1</sup>

*The Plan* sets out a number of ways in which this will be achieved, including the roll out of rapid diagnostic centres, upgraded diagnostic equipment and a focus on referring patients presenting with non-specific symptoms. This could be of particular benefit to kidney cancer patients, as the clearest signs of kidney cancer, such as flank pain or palpable abdominal mass are not always present at diagnosis and laboratory tests are required to confirm the disease.<sup>6</sup>

But delivering the commitments in *The Plan* will also require additional workforce reforms. To do that, the *NHS People Plan* is expected to be published in late 2019 and set out the required levels of staffing to meet these goals. Workforce challenges affecting the identification and management of kidney cancer are discussed later in this report.

## Scotland

Scotland's reforms to cancer care are primarily driven by the Scottish Government's 2016 strategy, *Beating Cancer: Ambition and Action*.<sup>15</sup> This draws together pledges across diagnosis, survival, access to treatment and workforce requirements for the health service.

There is a particular focus on early diagnosis of cancers, as well as on ensuring that primary care physicians feel supported to refer patients who are worried that their cancer may have returned, which is an issue in kidney cancer. It also builds on the £39 million spent on diagnostic equipment and processes since the 2012 Detect Cancer Early programme.<sup>15</sup>

## Wales

In recent years, much has been done to develop the cancer infrastructure in Wales, including improving rates of early diagnosis and building awareness of cancer symptoms.<sup>17</sup> However, issues such as diagnostic capacity and workforce continue to require improvement, with the Royal College of Radiologists warning that only three full-time equivalent consultant clinical radiologist posts have been added to NHS Wales in the past five years, despite the increasing number of patients.<sup>16</sup>

The *Cancer Delivery Plan for Wales*, which included commitments aimed at improving early diagnosis and mortality rates, is due for renewal after 2020, providing an opportunity to ensure that Wales is offering the best possible care to patients with kidney cancer.<sup>17</sup>

## Northern Ireland

Northern Ireland's cancer care infrastructure is also in need of improvement, with only 43.7 per cent of patients diagnosed with a urological cancer in September 2018 starting their first treatment within the 62-day waiting time target.<sup>18</sup>

In March 2019, the Department of Health in Northern Ireland announced that it would seek to develop a new Cancer Strategy in conjunction with the clinical and patient community.<sup>19</sup> This is intended to build on existing initiatives to improve cancer survival and could be an opportunity to address areas of inequality, such as in kidney cancer.<sup>19</sup>

This Strategy will be developed in the absence of a Northern Ireland Executive, which has not been in place since the power-sharing agreement between parties fell through in 2017. However, the Strategy cannot be implemented until the Executive is restored and a Minister is in place.

## Overcoming Inequality:

Achieving better outcomes for kidney cancer patients



# Diagnosis of kidney cancer

One of the most significant factors in the success of cancer treatment is how early the cancer is detected and diagnosed. Kidney cancer is often diagnosed at a later stage, with only around 56 per cent of patients diagnosed at stages I or II in England and Northern Ireland.<sup>1</sup> In Scotland there are no differences between the proportion of patients diagnosed at an early or late stage.<sup>1</sup> By contrast, studies have shown that the proportion of prostate cancer patients diagnosed at these stages ranges from 57-63 per cent.<sup>20</sup>

In a global survey of kidney cancer patients, the UK had an above-average proportion of patients diagnosed within three months of first presenting – 31 per cent, compared to the global average of 26 per cent.<sup>21</sup> However, the UK also had a substantially higher proportion of patients who waited more than a year for diagnosis, accounting for 11 per cent of patients, compared to the global average of 6 per cent.<sup>21</sup>

### Incidental and opportunistic diagnosis of kidney cancer

Kidney cancer can involve non-specific symptoms, such as flank pain and abdominal swelling.<sup>6</sup> In a 2018 survey of kidney cancer patients, 43 per cent reported being diagnosed incidentally as a result of unrelated tests and just over 15 per cent reported only being diagnosed after presenting at an emergency department.<sup>22</sup>

### Referral as an obstacle for early diagnosis

The non-specific symptoms of kidney cancer can also lead to difficulties in primary care clinicians recognising it as a potential diagnosis or attributing the symptoms to another disease – in one survey of UK patients, 45 per cent reported being initially misdiagnosed with another, non-malignant condition and therefore not referred for appropriate tests.<sup>22</sup>

## What are patients saying?

Our analysis of the 2017 National Cancer Patient Experience Survey in England found that...

**27.5%**

More than one in four kidney cancer (**27.5 per cent**) patients visited their GP about their symptoms more than twice before being referred.<sup>23</sup>

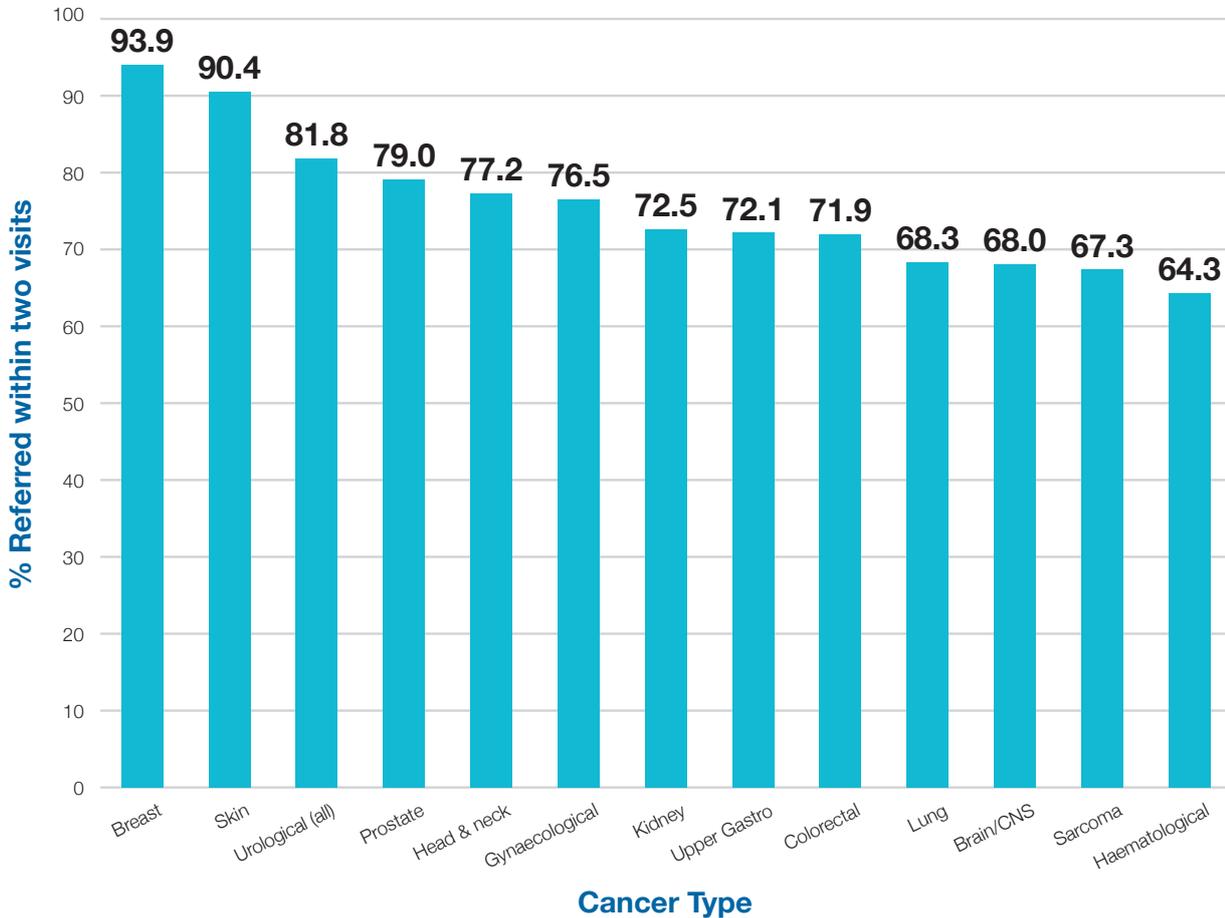
**20%**

By contrast, only around **one in five** prostate cancer patients reported that many visits before a referral was made.<sup>24</sup>

**93.9%**

In breast cancer, where there is a high awareness of symptoms, **93.9 per cent** of patients reported being referred within one or two appointments with their doctor.<sup>24</sup>

**Figure 2:**  
**Proportion of patients in England reporting being referred to a specialist within two visits to their GP by cancer type.**<sup>23,24</sup>  
(Adapted from the National Cancer Patient Experience Survey 2017)



The speed with which kidney cancer patients are referred from primary care varies widely across England. In the Cancer Alliance that performed worst against this indicator, 38 per cent of patients reported visiting their GP more than twice, compared to only 19 per cent in the best performing Cancer Alliance.<sup>23</sup>

Once referred, many patients still experience a wait to see a specialist. At present, all four nations in the UK are falling short of their stated '31-day wait' targets for urological cancers, which requires patients to receive their first treatment within a month of a decision being taken to treat them.<sup>18,25,26,27,28</sup> In England, there is a significant variation in the proportion of kidney cancer patients who felt that they should have been seen by a specialist sooner; in one

Cancer Alliance, approximately 27 per cent of patients said the process took too long, compared to only around 8 per cent in another.<sup>23</sup>

### Diagnostic capacity in kidney cancer

The incidence of kidney cancer has risen rapidly in the UK over the past two decades and the number of people diagnosed is predicted to continue to grow.<sup>29</sup> However, investment in the workforce and equipment required to offer ultrasound and computerised-tomography scans to a growing number of patients has failed to keep pace.

In 2018, nearly one in ten consultant radiology posts (9 per cent) in NHS England and 18 per cent in Northern Ireland were unfilled, including those that play a vital role in the kidney cancer

diagnostic pathway.<sup>16</sup> A 2018 report from the Royal College of Radiologists notes that six in ten consultant clinical radiologist roles remain unfilled for 12 months or more.<sup>16</sup> Scotland also has a specific issue with diagnostic staff retention, with a net 6 per cent of radiologists who train in Scotland going to work in other UK nations and almost one in five Scottish radiologists expected to retire before 2023.<sup>30</sup>

Lengthy waits for diagnosis have a detrimental impact. Kidney cancer patients in the UK were 19 per cent more likely than the international average to have reported that waiting for surgery or scan results was the most difficult time in their experience of the disease, and were the most affected by wait times to start treatment compared to other countries analysed.<sup>21</sup>

## Overcoming Inequality:

Achieving better outcomes for kidney cancer patients

## Recommendations: Improving rates of early diagnosis

To meet the growing numbers of patients requiring investigations for kidney cancer and to ensure timely referral, we have identified a number of steps that must be taken by policymakers.

### Improving awareness of kidney cancer:

Recognition of the signs and symptoms of kidney cancer among the general public and clinicians is a clear barrier to patients seeking and receiving help earlier. In the past, public campaigns such as Be Clear on Cancer have successfully raised awareness and led to more referrals to specialists following symptoms such as blood in urine<sup>31</sup>

- National policymakers such as **Public Health England, NHS Scotland, Public Health Wales and the Public Health Agency in Northern Ireland** should consider the impact of public awareness campaigns on the rate of early diagnosis.

- **Health Education England and devolved bodies** responsible for medical education and ongoing professional development should also present plans to increase the level of clinical understanding and recognition of kidney cancer, including encouraging primary care physicians to consider kidney cancer as a potential diagnosis.

### Investing in the diagnostic workforce:

It is clear from our research that the number of healthcare professionals working in cancer diagnosis is insufficient to meet the demands of a growing number of patients. This continues to be an issue across the UK

- **The UK Government** must make available funding to NHS England and to the devolved administrations for investment in the diagnostic workforce.
- **NHS England, NHS Scotland, NHS Wales and the Department of Health in Northern Ireland** must set out clearly how they plan to invest sustainably in growing diagnostic capacity.
- **NHS England, NHS Scotland, NHS Wales and Department of Health in Northern Ireland** should publish plans to improve the recruitment and retention of staff involved in the diagnosis of kidney cancer.

### Improving referral pathways:

The delays that are experienced by kidney cancer patients in being referred to a specialist are a potential source of poorer outcomes. To improve the time taken from presentation to diagnosis and treatment, referral pathways must be streamlined and better understood

- The National Institute for Health and Care Excellence (NICE), the Scottish Intercollegiate Guidelines Network (SIGN) and other devolved equivalents should act to ensure that clear guidelines for referral to a specialist urologist are in place, regardless of whether a patient first presents to their GP, in an acute setting or through an unrelated investigation.
- NICE and devolved nations' equivalents should also publish updated clinical guidance on the treatment of kidney cancer, to reflect advances in diagnostic and treatment approaches.





# The kidney cancer workforce

Because the diagnosis and management of kidney cancer falls between a number of specialties, patients require the input of a range of clinicians in different roles. Our research has found a number of ways in which this could be potentially more effectively managed in practice and identified issues with ensuring patients are supported throughout their journey.<sup>32</sup>

## Improving multi-disciplinary team care for kidney cancer patients

Once a patient is under the care of a specialist and there are decisions to be made around their diagnosis or course of treatment, the patient will usually be discussed at a meeting of the multi-disciplinary team (MDT).

**Our research has highlighted that the key attendees at a kidney cancer MDT meeting should include the following professionals where possible to ensure access to a full range of skills and perspectives:**

**Urologists**

**Medical Oncologists**

**Clinical Oncologists**

**Clinical Nurse Specialists**

**Radiologists**

**Pathologists**

**Dietitians**

**Physiotherapists**

**Occupational Therapists**

**Psychologists**

**Counsellors**

**Representatives of any clinical trials, such as co-ordinators or research nurses**

To consider the full range of treatment options, it is important that all patients are discussed by the full MDT. However, there are indications that this is not always the case, with the number of attendees at MDTs ranging from 7-27 clinicians and an average of 14.<sup>33</sup> One study found that the most common number of participants in the discussion of a patient was only three.<sup>33</sup>

This means that there is a risk that the full range of treatment options may not be considered, or decisions may need to be delayed while additional input is sought.

It is important that the MDT making a decision about a patient has input from the clinician or clinicians who have examined the patient and discussed their wishes with them.

Although this can present a logistical challenge, without this, decisions about the best way forward for a patient could be deferred, which could lead to delays in starting treatment.<sup>33</sup>

We have heard that, in some cases, the only clinician who has examined the patient is at a distant referring hospital and is not able to physically attend the MDT meeting.<sup>32</sup> This was highlighted in relation to rural areas, particularly in Scotland.<sup>32</sup>

It is important that colleagues from different specialisms can reliably join via telephone or video link to provide their perspective on the patient.<sup>32</sup>

## Clinical Nurse Specialists in kidney cancer

A CNS is a member of the multidisciplinary team working in a hospital, with specialised training in cancer nursing. The CNS is the primary link between the patient and the treatment centre, intended to be a point of contact and to help patients navigate the healthcare system.

In the case of many cancers, a CNS will only see patients with that tumour type. Frequently, however, CNSs responsible for kidney cancer are also responsible for supporting patients with other urological tumours, such as prostate, testicular and other genitourinary cancers. One study shows that of selected adult cancers, urology has the highest ratio of cases per CNS, as well as the highest ratio of patients living two-years post diagnosis per CNS.<sup>34</sup> This means CNSs working in urological cancers, including kidney cancer, likely have the highest case load of any CNSs, and potentially the least time to support patients.

## Overcoming Inequality:

Achieving better outcomes for kidney cancer patients

### What are patients saying?



**41%**  
Where the CNS role is working well, it is appreciated by patients. **41 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>22</sup>

However, patients with kidney cancer are less likely to know who their CNS is than patients with any other major type of cancer.<sup>23, 24</sup>

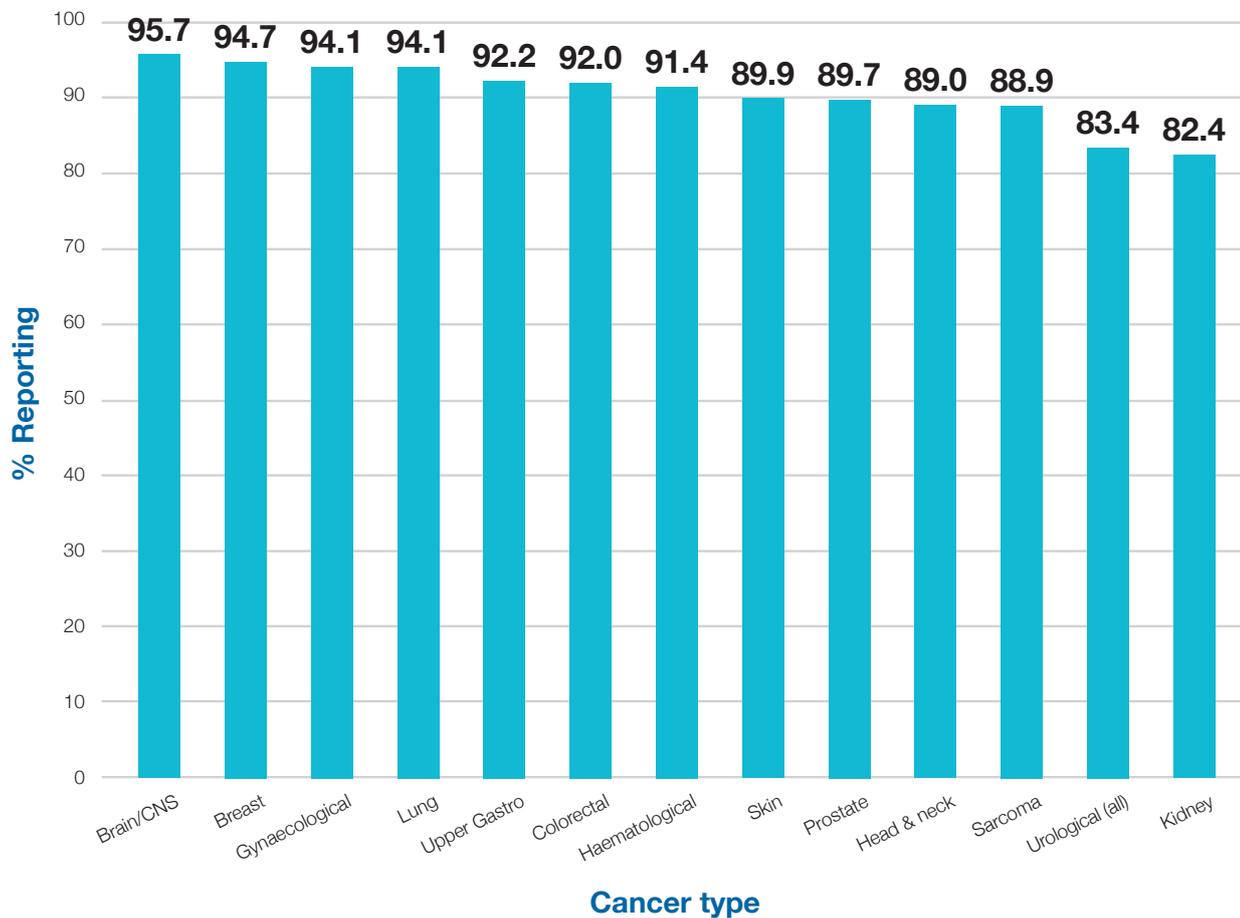
**82%**  
On average, **82 per cent** of patients with kidney cancer reported being given the name of their CNS.<sup>23</sup>

By contrast, more than **90 per cent** of patients with cancers including brain, breast, colorectal and cervical cancer all reported being assigned a named CNS.<sup>24</sup>

Figure 3:

### Proportion of patients who report being given the name and details of their CNS by cancer type.<sup>23,24</sup>

(Graph adapted from National Cancer Patient Experience Survey Data 2017)



In addition, there is a significant geographical variation in the proportion of kidney cancer patients who reported being told the name of their CNS, ranging from only 66.7 per cent in the poorest performing Cancer Alliance to 91.4 per cent in the best.<sup>23</sup>

Along with the fact that kidney cancer CNSs often work across multiple cancers, there is the added pressure of insufficient numbers of CNSs overall. Although specific data are not available for urological CNSs, across nursing, there have been more than 35,000 unfilled posts in the 12 month period from March 2018 to March 2019.<sup>35</sup> The result is likely a continued impact on the capacity of CNSs.

Given the importance of CNSs to kidney cancer patients, and the particular pressures on those working in kidney cancer, there must be a focus on improving the numbers of staff available and ensuring they have time to provide appropriate care.

## Recommendations: Alleviating the impact of workforce issues in kidney cancer

**To ensure that every kidney cancer patient has the right team around them, our research has identified a number of recommendations for policymakers.**

**Improving the effectiveness of the MDT meeting:** Our research has highlighted the importance of ensuring that all relevant professionals can be present at meetings of the MDT

- **Clinical leaders, hospital managers and those responsible for service design** should ensure that staff of all levels and all roles have the time to attend the MDT meetings and this is recognised as a valuable part of their role
- Where geography or other barriers prevent all MDT members attending the meeting in person, **NHS trusts** must invest in technology such as teleconferencing and videoconferencing, to ensure that the necessary expertise can be shared in a timely way to avoid delays for patients

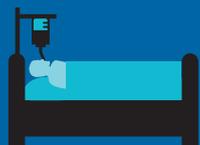
**Expansion of the CNS kidney cancer workforce:** It has been demonstrated that CNSs working in urology have the highest caseload of patients per nurse

- To meet the needs of kidney cancer patients, **NHS England, NHS Scotland, NHS Wales and the Department of Health in Northern Ireland** must invest in expanding the CNS workforce and maintaining caseloads at manageable numbers



## Overcoming Inequality:

Achieving better outcomes for kidney cancer patients



# Access to treatment and follow up

The most common treatment for kidney cancer is surgery; 88 per cent of patients surveyed by KCUK reported having undergone surgery, with the vast majority of them receiving a radical nephrectomy to remove the affected kidney.<sup>22</sup> Increasingly, new surgical approaches such as minimally invasive procedures and cryo-ablation of the affected tissue are being considered.<sup>22</sup>

In addition to, or instead of surgery there are several other treatments including radiotherapy and systemic therapies, such as immunotherapies, that can be used to treat or palliate kidney cancer patients. However, our research has highlighted potential issues with access to some therapies and how management of kidney cancer is approached.

## Inequalities in access to treatment

The UK has among the poorest rates of survival for kidney cancer, with only 48 per cent of patients surviving for five years after diagnosis, compared to the Northern, Central and Southern European averages of 55.8 per cent, 64.6 per cent and 64.4 per cent.<sup>2</sup>

In an analysis of estimated five-year survival rates across different Cancer Alliances in England, kidney and urinary tract cancers were found to have one of the largest variations between the best and worst performing.<sup>3</sup> Survivability varied between 55.5 per cent in the worst performing Cancer Alliance to 70.5 per cent in the best performing.<sup>3</sup>

## Shared decision making

It is vital that patients are involved in decisions about their treatment. This can include having a choice between different therapeutic approaches, balancing the impact of these against personal and well-being priorities. The process of shared-decision making involves conversations between a patient and the professionals caring for them around personal preferences, options, benefits, risk and consequences leading to an informed decision.

Kidney Cancer Support Network has highlighted findings from the *Adult Inpatient Survey* conducted by the Care Quality Commission (CQC) that found 46 per cent of cancer patients did not feel that they had “definitely” been as involved in their treatment as they wanted to be.<sup>36</sup>

Analysis of the data from the *National Cancer Patient Experience Survey* shows that approximately one in five kidney cancer patients were not definitely as involved in their treatment as they could have been.<sup>23</sup> This varies nationally, with some areas performing better than others. In one Cancer Alliance, 25.8 per cent of patients said that they weren’t definitely involved to the degree they wanted to be, compared to only 4.2 per cent in another.<sup>23</sup>

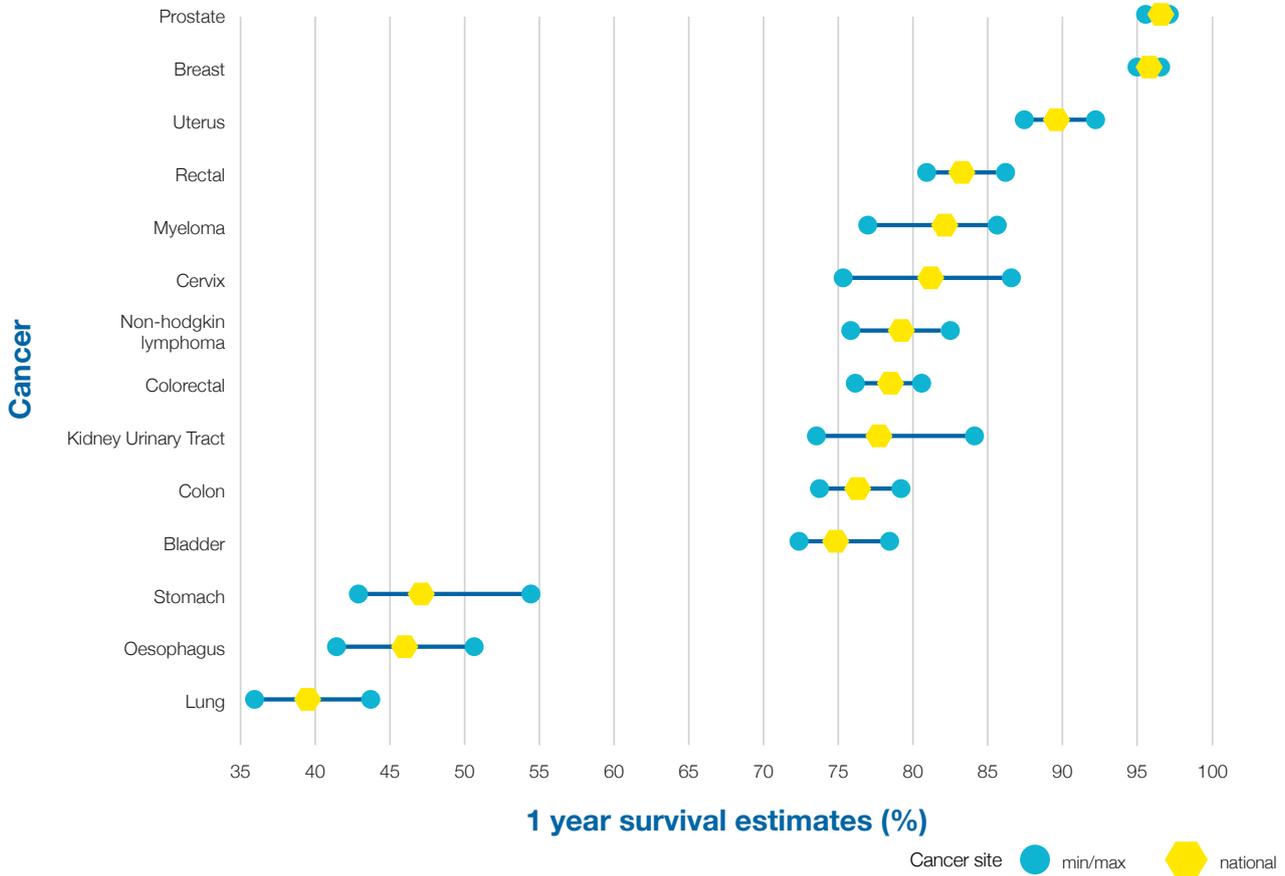
## Surgery

Access to innovative therapeutic surgery appears to be a potential barrier to better treatment outcomes in some places. A KCUK survey of kidney cancer patients found that while the majority of patients had undergone surgery, only 10 per cent of surgeries were performed with minimally invasive robotic technologies.<sup>22</sup> These have been shown to have greater recovery benefits while easing pressure on NHS services, but may not be being offered to all of those who could benefit.<sup>22</sup> Similarly, only 3 per cent of kidney cancer patients responding to the survey had undergone cryo-ablative surgeries.<sup>22</sup> Although the prevalence of these approaches has increased in recent years, these results suggest they are not being made available to all patients who could benefit.<sup>22</sup>

Figure 4:

**Age-standardised one-year net survival rate for adults with cancer in England, including range of survival rates.<sup>3</sup>**

(Graph taken from Office for National Statistics (May 2019) Geographic patterns of cancer survival in England: adults diagnosed 2012 to 2016 and followed up to 2017.)



**Access to innovative systemic therapies**

The use of second-line treatments also varies across the UK, with 19.5 per cent of patients in England receiving these treatments, compared to 8.5 per cent in Scotland and 7.5 per cent in Wales.<sup>37</sup>

While not all patients will be eligible for these treatments it is not clear whether there are sufficient differences in the patient populations of each country to explain these variations. It is vital that all treatment options are discussed with all patients so that they can agree with their health professionals which one is most appropriate for them.

There have been a large number of new clinical trials in the area of kidney cancer over the past few years, particularly for systemic therapies. However, a

recent survey of kidney cancer patients indicated that relatively few patients had participated, with 56 per cent of patients reporting not having taken part in this kind of research, and many indicating that they had not had the possibility discussed with them.<sup>22</sup>

Taken together, these findings suggest that there is variation in access to different types of treatment dependent on where patients are receiving treatment. This is a potential driver of inequality and variability in treatment outcomes and must be addressed by policymakers.

**Information and support for patients making decisions about their treatment**

It is important that patients are informed about all their treatment options. The

majority of kidney cancer patients, 88 per cent, felt that their options had been explained to them fully before starting treatment.<sup>23</sup> 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, compared to only 3 per cent in France.<sup>21, 38</sup>

Along with information, patients need to be supported to take part in decisions about their care. The majority of kidney cancer patients surveyed, 81 per cent, reported that they were as involved in decisions about their care and treatment as they had wanted to be, although this varies from 96 per cent in the best performing Cancer Alliance to 74 per cent in the worst.<sup>23</sup>

## Overcoming Inequality:

Achieving better outcomes for kidney cancer patients

### What are patients saying?

Currently, only around a quarter (**26.4 per cent**) of kidney cancer patients in England report receiving a written care plan that outlines their course of treatment.<sup>23</sup>

This is lower than in many other cancers including brain, breast, colorectal, cervical, lung and prostate in which more than **30 per cent** of patients have a care plan.<sup>24</sup> This also appears to be an issue across the UK.

In Wales, **88 per cent** of patients with urological cancers did not report being offered a written care plan.<sup>39</sup>

### Follow up for kidney cancer patients

Because kidney cancer often presents with ambiguous symptoms, it is of particular importance that patients who have undergone treatment are monitored for signs that their cancer is returning. At present, kidney cancer patients receive regular scans, usually on a six-monthly basis for up to five years after their treatment ends.

However, we have heard that there is a wide geographical variation around the way in which follow up scans are organised and scheduled. Previously, a number of different booking processes have been identified as a possible cause of delays when designing new systems.<sup>40</sup> In some areas, a patient's next appointment is booked on the spot each time they have a scan. In other treatment centres, patients must wait to receive a letter at home before a follow up scan can be booked. This can lead to worry and confusion, particularly if people move to another area. It is important that follow up pathways are standardised and consistent across the country, so that patients have certainty about what will happen when their treatment ends.

In England, *The NHS Long Term Plan* commits the NHS to introduce follow up pathways for people who are worried that their cancer may have come back by 2023. However, these will be rolled out initially only for selected cancers. They will first be available for patients with breast cancer in 2019 and then for patients

with prostate and colorectal cancers in 2020. This presents an opportunity to address the kidney cancer mortality rate, and these pathways should be available to kidney cancer patients at the earliest possible opportunity.

Given the commitments in *The Plan* are primarily focused on England, it is vital that kidney cancer patients in Scotland, Wales and Northern Ireland have equal access to standardised and comprehensive follow up. As a result, NHS Scotland, NHS Wales and the Department of Health in Northern Ireland should assess their existing processes and look to replicate the model being adopted in England.

### Recommendations: Improving treatment and follow up for kidney cancer patients

**To ensure kidney cancer patients are able to access high quality treatment and aftercare wherever they live, we have highlighted a number of recommendations that have arisen from our research below:**

#### Increasing the use of care plans:

A high proportion of kidney cancer patients report not receiving written information on their condition or treatment. Kidney cancer patients also are among the most likely to report not receiving a care plan

- **NHS England, NHS Scotland, NHS Wales and the Department of Health in Northern Ireland** should commit to ensuring all patients receive a care plan and receive written information on their treatment in a format that they can understand

#### Access to improved follow up pathways:

Because the symptoms of kidney cancer can be ambiguous, patients can be understandably concerned about the risk of their cancer returning

- **NHS England, NHS Scotland, NHS Wales and the Department of Health in Northern Ireland** should ensure that follow up pathways are well designed and communicated to patients, so they have confidence that they are being effectively monitored
- Policymakers should act to ensure compliance with all international standards and guidelines

#### Greater investment in innovative interventions:

While a range of new and innovative surgical approaches and systemic therapies are available, it is clear that access to them is inconsistent and unequal

- **NHS England, NHS Scotland, NHS Wales and the Department of Health in Northern Ireland** must commit to investing in equipment and medicines. This must be done with a focus on offering patients all the treatments they are eligible for based on their own needs and preferences



## Summary of recommendations

Kidney cancer is a disease affecting more people every year. However, this report has highlighted several areas across diagnosis, workforce and access to treatment in which improvements are needed to ensure that patients are able to access high quality care wherever they live, and to achieve equity with other cancer types.

### Improving awareness of kidney cancer:

Recognition of the signs and symptoms of kidney cancer among the general public and clinicians is a clear barrier to patients seeking and receiving help earlier. In the past, public campaigns such as Be Clear on Cancer have successfully raised awareness and led to more referrals to specialists following symptoms such as blood in urine<sup>31</sup>

- National policymakers such as **Public Health England, NHS Scotland, Public Health Wales and the Public Health Agency in Northern Ireland** should consider the potential impact of public awareness campaigns on the rate of early diagnosis
- **Health Education England and devolved bodies** responsible for medical education and ongoing professional development should also present plans to increase the level of clinical understanding and recognition of kidney cancer, including encouraging primary care physicians to consider kidney cancer as a potential diagnosis

### Investing in the diagnostic workforce:

It is clear from our research that the number of healthcare professionals working in cancer diagnosis is insufficient to meet the demands of a growing number of patients. This continues to be an issue across the UK

- **The UK Government** must make available funding to NHS England and to the devolved administrations for investment in the diagnostic workforce
- **NHS England, NHS Scotland, NHS Wales and the Department of Health in Northern Ireland** must set out clearly how they plan to invest sustainably in growing diagnostic capacity
- **NHS England, NHS Scotland, NHS Wales and Department of Health in Northern Ireland** should publish plans to improve the recruitment and retention of staff involved in the diagnosis of kidney cancer

### Improving referral pathways:

The delays that are experienced by kidney cancer patients in being referred to a specialist are a potential source of poorer outcomes. To improve the time taken from presentation to diagnosis and treatment, referral pathways must be streamlined and better understood

- The National Institute for Health and Care Excellence (NICE), the Scottish Intercollegiate Guidelines Network (SIGN) and other devolved equivalents should act to ensure that clear guidelines for referral to a specialist urologist are in place, regardless of whether a patient first presents to their GP, in an acute setting or through an unrelated investigation

- NICE and devolved nations' equivalents should also publish updated clinical guidance on the treatment of kidney cancer, to reflect advances in diagnostic and treatment approaches

### Improving the effectiveness of the MDT:

Our research has highlighted the importance of ensuring that all relevant professionals can be present at meetings of the MDT

- **Clinical leaders, hospital managers and those responsible for service design** should ensure that staff at all levels and in all relevant roles have the time to attend the MDT and this is recognised as a valuable part of their role
- Where geography or other barriers prevent all MDT members attending in person, **NHS trusts** must invest in technology, such as teleconferencing and videoconferencing to ensure that the necessary expertise can be shared in a timely way to avoid delays for patients

## Overcoming Inequality:

Achieving better outcomes for kidney cancer patients

# Summary of recommendations

### **Expansion of the CNS kidney cancer workforce:**

It has been demonstrated that CNSs working in urology have the highest caseload of patients per nurse

- **To meet the needs of kidney cancer patients, NHS England, NHS Scotland, NHS Wales and the Department of Health in Northern Ireland** must invest in expanding the CNS workforce and maintaining caseloads at manageable numbers

### **Increasing the use of care plans:**

High proportions of kidney cancer patients report not receiving written information on their condition or treatment. Kidney cancer patients also are among the most likely to report not receiving a care plan

- **NHS England, NHS Scotland, NHS Wales and the Department of Health in Northern Ireland** should commit to ensuring all patients receive a care plan and receive written information on their treatment in a format that they can understand
- **Access to improved follow up pathways:** Because the symptoms of kidney cancer can be ambiguous, patients can be understandably concerned about the risk of their cancer returning

- **NHS England, NHS Scotland, NHS Wales and the Department of Health in Northern Ireland** should ensure that follow up pathways are well designed and communicated to patients, so they have confidence that they are being effectively monitored
- Policymakers should act to ensure compliance with all international standards and guidelines, such as the European Association of Urology's guidelines on kidney cancer

### **Greater investment in innovative interventions:**

While a range of new and innovative surgical approaches and systemic therapies are available, it is clear that access to them is inconsistent and unequal

- **NHS England, NHS Scotland, NHS Wales and the Department of Health in Northern Ireland** must commit to investing in equipment and medicines. This must be done with a focus on offering patients all the treatments they are eligible for based on their own needs and preferences



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## Overcoming Inequality:

Achieving better outcomes for kidney cancer patients

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