2018 IKCC PATIENT SURVEY
-United Kingdom-

Prepared for:
International Kidney Cancer Coalition
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Perception Insight
A fresh perspective you can act on

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Preface

The 2018 survey involved the preparation and distribution of surveys to patients with kidney cancer and their caregivers in 14 languages (including English UK & US, French and Canadian French, Portuguese and Brazilian Portuguese), through 30 of IKCC's Affiliate Organisations and social media, resulting in responses from 43 countries around the world.

The intent is that this year's research results will be benchmarked bi-annually against future results to identify best practices, key issues for more timely topics, and trends in key patient indicators such as shared decision making, clinical trials and quality of life both globally and by country.

Perception Insight (PI)[1], a Canadian firm specialising in global market research has assisted IKCC with all phases of this study from survey design to data collection and analysis. PI prepared reports for those countries exceeding 100 respondents, as well as a Global Report, a roll up of all responses to present a worldwide picture. As an adjunct to these reports, PI also implemented its proprietary technology to produce cross-tabulated charts for those countries in excess of 30 respondents.

For further information about this report, please contact: info@ikcc.org

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[1] https//www.perceptioninsight.ca

Reader's Notes

There are three types of tables in this report:

- Those that demonstrate Global Outliers,
- Those that demonstrate notable differences, and
- Those that report order of magnitude.

1. Global Outlier Tables

Global Outlier tables are intended to draw attention to values lying outside the normal pattern of data distribution between countries as they could indicate potential actionable differences. For example, in the case of a positive global outlier, that country could potentially be heralded as 'best practice'.

The term 'Global Outliers' is used throughout this analysis to indicate where the highest and lowest results fall outside of the pattern of values. What we deem 'outliers' are highlighted in the tables, red with white text = most negative outlier and green with black text = most positive outlier both in an enlarged font size. If the data presented in the tables is not highlighted it simply indicates the range of values in the analysis.

2. Tables of Notable Difference

These tables show differences in values between categories, e.g. males versus females and are notable to the reader as they could potentially indicate significant differences. Notable differences' are reported if they are ≤5% or ≥5%.

'Most negative' (red) and 'most positive' (green) results are indicated in the chart legends and refer to what could be construed as most positive and most negative outcomes for RCC patients. Where there is no implied positive or negative implication for patients, the colours are as in the chart legend.

3. Order of Magnitude

These tables contain similar information, however there is no implied 'most negative' or 'most positive' result; they simply bring attention to absolute differences between categories.

Country vs. Global Results

All results in this report are for the UK, unless otherwise specified as either 'Global Outliers' or 'notable differences' to global results.

INTRODUCTION

In mid-2018, the International Kidney Coalition (IKCC)[2] offered its Affiliate Organisations the opportunity to participate in its first Global Patient Survey, the over-arching goal of which is to improve our collective understanding and to contribute toward the reduction of the burden of kidney cancer around the world.

Kidney cancer (renal cell carcinoma or RCC) is the seventh most common histological type of cancer in the Western world[3] and has shown a sustained increase in its global prevalence thereby presenting an increasing burden to health systems, governments, and most of all to, individual patients and their families. Although therapies have improved for both early-stage and late-stage RCC patients, little is known about the variations in the patient experience and best practices among countries.

The 2018 survey has been specifically designed to identify geographic variations in patient education, experience and awareness, access to care, quality of life and involvement in clinical trials so that opportunities for improvement can be identified, and programs developed to better meet the needs of patients. This is achieved through examination of each of the following issues:

Knowledge and Understanding

- To what degree were patients aware of and did they have an understanding of their diagnosis, including stage, sub-type, treatment options, and expected side effects?
- Were patients made aware of advancements in the treatment of RCC?
- How successful was the healthcare profession in diagnosing RCC in a timely manner?

Clinical Trials

- To what extent were healthcare professionals proactive in discussing clinical trials with their patients?
- Of those patients who were not approached, what was the missed opportunity and how could these patients potentially be reached?

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[2] www.ikcc.org

[3] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4492569

- When was the option of a clinical trial first discussed with patients?
- Of those who were asked to participate, what sources of information about clinical trials had they been using?
- How well did patients understand the risks and benefits of enrolling?

Quality of Care

- To what extent were patients treated for their RCC, and where had they been receiving treatment?
- What specific physical and psychosocial issues were patients living with? Did these issues differ depending upon the patient’s gender or the year they were diagnosed?
- To what extent were patients communicating and reaching out for help for their issues?
- How helpful was the healthcare profession in providing support to patients who were impacted by the side effects of treatment?
- How and to what degree were patients affected during their patient timeline? Who was more notably affected?
- Which barriers stood in their way to receiving treatment? Who were more affected by these barriers?

Opportunities to Improve Care

- Are there any opportunities to improve the care, survivorship and surveillance of RCC patients?
- Are there opportunities to improve patients’ awareness of guidelines for quality kidney cancer care and follow-up?
- Who were the patients who reported that their last follow up scan was more than 3 years ago?

Shared decision making

- How engaged were patients in deciding their treatment plans?
- Did this engagement vary by factors such as place of treatment, age or gender?

KEY FINDINGS- UK

IKCC and its Affiliates can be a catalyst to enhance patient knowledge and understanding, access to quality care, shared decision making and greater participation in clinical trials, contributing to IKCC's over-arching goal of reducing the burden of kidney cancer around the world.

Specifically, there are opportunities for IKCC and its Affiliate Organisations to:

- Advocate for the early and universal diagnosis of all RCC patients;
- Provide decision aid tools to enhance sub-type knowledge for newly diagnosed patients, thereby enabling them to best participate in shared decision making with their healthcare team about treatment;
- Contribute to the advancement of kidney cancer research and potentially enhance the survivorship of patients:
  - By encouraging the healthcare community to take advantage of a virtually untapped resource of a potential pool of individuals who would be willing to participate in clinical trials, should they be asked, and by
  - Enhancing the awareness and understanding of patients about clinical trials to ensure they are equipped and comfortable in making a decision about participating.
- Contribute to improving the quality of life for RCC patients by encouraging them to share with their doctors, their experiences about how kidney cancer has impacted their lives, and by providing patients with the resources and tools to attain the psychological support they need;
- Advocate for change, and support patients who struggle with barriers standing in the way of receiving quality care;
- Bring specific attention and focus to patient sub groups who may for whatever reason go unnoticed by the healthcare community, and to their particular struggles so that they too might benefit from a better patient experience and overall quality of life;

- Improve survivorship by empowering patients through education to advocate for regular surveillance despite gender, age or stage; and

- Advocate for shared decision making for patient treatment plans through further development of decision aid tools, particularly for patient sub groups where there is evidence of notable physician directed care.

SURVEY RESULTS- UK

I. Respondent Profile

Total response rate:

- A total of 1983 individuals responded to the IKCC 2018 Global Patient Survey, including patients and caregivers from 43 countries around the world.

Respondent Demographic Profile:

- The United Kingdom had 181 respondents, or 9% of the global total.

- 79% of those responding to the survey were kidney cancer patients (71% globally) while the remaining 21% defined themselves as a carer (caregiver), family member or friend of the patient (29% globally).

- 46% of respondents were males (54% globally), 53% were females (45% globally), and 1% did not self-identify,

- Survey respondents had the following age profile:
  - Under 18 (0%),
  - 18-29 (1%),
  - 30-45 (13% compared to 20% globally),
  - 46-65 (70% compared to 57% globally), and
  - 66+ (16%).

- Survey respondents were in the following stages of kidney cancer:
  - Localised kidney cancer (8% compared to 23% globally),
  - Metastatic (56% compared to 44% globally), and
  - No evidence/told they were cured (36%).

II. Knowledge and Understanding

IKCC and its Affiliate Organisations can play an instrumental role in advocating for the early and universal diagnosis of all RCC patients, and in enhancing the knowledge and understanding of all patient subgroups, including those who fall outside the more commonly accepted definition of a typical RCC patient.

It is imperative that patients in the UK are not only aware of, but also have a solid understanding of their particular sub-type upon initial diagnosis so they can best participate in their own treatment choices.

The fundamental challenge doctors face in communicating this critical piece of information to their patients upon diagnosis must be addressed.

The IKCC has the opportunity through both patient and healthcare community education to ensure that this foundational piece of information, from which all subsequent treatment decisions flow, is shared with patients upon initial diagnosis. This will empower them to participate in any specific management strategies required for their particular sub-type, to ensure the most favourable outcome.

Younger patients (30-45 yrs.) as well as female patients in the UK took the longest to be correctly diagnosed with RCC. Since these patients fall outside the expected demographic of an RCC patient (older and male), they may therefore go unnoticed by the healthcare community.

Compared to global results, RCC patients in the UK reported similarly to their counterparts for not being told their sub-type upon initial diagnosis. Patients in the UK also had among the greatest lack of understanding of their sub-type, upon initial diagnosis, compared to their peers in other parts of the world. This is a foundational piece of information of which all RCC patients should be aware. Patients with clear cell RCC reported among the worst understanding of their sub-type, compared to clear cell patients in other countries.

In comparing RCC patients within the UK, patients with rarer forms of the disease had notably less understanding of both their stage and sub-type than clear cell patients.

Patient knowledge about certain RCC guidelines about kidney cancer care was considerably poorer compared to global averages, and there were notable gaps in understanding for certain types of treatments.

Year of Diagnosis

- UK patients who responded to this survey had been diagnosed in the following years:
  - 5% prior to 2005,
  - <1% in 2005
  - 1% in 2006,
  - 3% in 2007,
  - 4% in 2008,
  - 2% in 2009,
  - 2% in 2010,
  - 4% in 2011,
  - 6% in 2012,
  - 9% in 2013,
  - 8% in 2014,
  - 15% in 2015,
  - 11% in 2016,
  - 21% in 2017, and
  - 9% in 2018.

Success of Timely Diagnosis

- Patients in the UK were in the following stages of their kidney cancer when they were first diagnosed:
  - 52% in Stages 1 or 2 (still only within the kidney),
  - 20% in Stage 3 (cancer was still locally advanced), and
  - 27% in Stage 4 (cancer had spread).

- Following their first visit to the doctor, 42% of UK patients were correctly diagnosed in less than a month (52% globally), while
  - 31% were diagnosed in 1-3 months (26% globally),
  - 10% in 3-6 months,
  - 6% in 6 months to a year, and
  - 11% (a Global Outlier, compared to 6% globally) in more than one year.

- 15% of patients in the UK were diagnosed at a family doctor or GP's office (20% globally),
    - 14% at an emergency department,
    - 52% at a community, local or general hospital (37% globally),
    - 11% at a major cancer centre[4],
    - 4% at a private clinic (11% globally) and
    - 4% at some other facility.

- According to Table 1, females in the UK took notably longer to be diagnosed than male patients, with 79% of male patients diagnosed in 3 months or less compared to 67% of female patients (73% of females globally).

- 16% of females in the UK were diagnosed after one year (a Global Outlier, compared to 7% globally).

Table 1
Notable Differences for
Time of Diagnosis by Gender

TIME OF DIAGNOSIS	Male	Female	Notable Differences
Less than month	47%	37%	10%
1-3 months	32%	30%	
3-6 months	11%	10%	
6 months-1 year	5%	7%	
More than 1 year	5%	16%	11%
LEGEND			
Most negative			🟥
Most positive			🟩

- As shown in Table 2, younger patients in the UK took notably longer to be diagnosed with 27% of those 30-45 yrs. diagnosed within the first month, compared to 44% aged 46-65 yrs. and 46% aged 66+ yrs.

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[4] Including 8% for major cancer centres with kidney cancer specialists

Table 2
Notable Differences for
Time of Diagnosis by Age[5]

TIME OF DIAGNOSIS	30-45 yrs.	46-65 yrs.	66+ yrs.
Less than month	🟥 27%	🟩 44%	🟩 46%
1-3 months	🟥 27%	🟩 33%	🟥 25%
3-6 months	🟥 18%	🟩 8%	🟩 11%
6 months-1 year	🟥 9%	7%	🟩 4%
More than 1 year	🟥 18%	🟩 9%	🟥 14%
LEGEND			
Most negative			🟥
Most positive			🟩

Patient Knowledge and Understanding

- After their initial diagnosis 38% of patients in the UK were not told their sub-type, and
  - 28% had no understanding of their stage (20% globally),
  - 55% had no understanding of their sub-type[6] (a Global Outlier, compared to 43% globally),
  - 22% had no understanding of their treatment options,
  - 15% had no understanding of their treatment recommendations
  - 32% had no understanding of the risk of recurrence, and
  - 27% had no understanding of their likelihood of survival.

- As shown in Table 3, at the time of diagnosis:
  - Compared to clear cell patients in the UK, patients with other sub-types had notably less understanding about their sub-type than clear cell patients;
  - Patients in the UK with other sub-types had considerably less understanding about their stage than their counterparts globally (33%, a Global Outlier, compared to 21% globally);
  - Clear cell patients had notably less understanding about their likelihood of survival compared to patients with other sub-types; and

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[5] Due to insufficient sample size, data is not available for the under 30 yr. age bracket.

[6] For the purposes of analysis, sub-types have been categorized into 'clear cell RCC' and 'other' sub-types which include all other remaining sub-types reported by respondents

- Both clear cell patients and those with other sub-types had the greatest lack of understanding for sub-type (57% of those with other sub-types, and 51% of those with clear cell, a Global Outlier, compared to 43% globally).

Table 3
Lack of Patient Understanding at Time of Diagnosis by Sub-type

NO UNDERSTANDING	Clear Cell	Other Sub-types	Notable Differences
Stage	22%	33%	11%
Sub-type	51%	57%	6%
Treatment options	21%	21%	
Treatment recommendations	14%	18%	
Risk of recurrence	31%	31%	
Likelihood of survival	28%	22%	6%
LEGEND			
Most negative			🟥
Most positive			🟩

- At the time of the survey, 8% of patients in the UK were still not aware of their sub-type.

- The 92% who were aware had the following RCC sub-type:
  - Clear cell (70%, compared to 62% globally),
  - Papillary (5%),
  - Chromophobe (4%),
  - Unclassified (4%),
  - XP11 Translocation Type (1%),
  - VHL (<1%),
  - Renal Medullary (0%),
  - Collecting Duct (<1%),
  - Transitional Cell Carcinoma (<1%),
  - Renal Sarcoma (0%),
  - Wilms Tumour (0%),
  - Benign Tumour (<1%),
  - Other (6%).

- At the time of the survey, patients in the UK had no understanding of the following:
    - Biopsies for kidney cancer (22%),
    - Surgical options (12%),
    - Immunotherapy (32% compared to 26% globally),
    - Targeted therapies (30% compared to 23% globally),
    - Radiation therapies (39% compared to 29% globally),
    - Ablative therapies (67% compared to 41% globally),
    - Palliative care (36%),
    - Active surveillance (39% compared to 29% globally),
    - Nutrition/lifestyle (17%),
    - Complementary therapies (43%),
    - Guidelines for kidney cancer care (35% a Global Outlier, compared to 20% globally), or for
    - Guidelines for kidney cancer follow up (32% a Global Outlier, compared to 17% globally).

III. Clinical Trials

Every kidney cancer patient in the UK deserves access to the highest quality care AND the opportunity to participate in research thereby advancing the quality of care of patients, increasing and advancing kidney cancer research. There was a high degree of willingness amongst patients in the UK to participate should they be asked, and interest in moving this research forward through clinical trials.

There is a clear opportunity to tap more heavily into this pool of individuals who may consider participating in a trial by providing them with the necessary information at crucial stages of their treatment pathway that would both motivate them and make them feel comfortable in advocating for their own treatment decisions.

IKCC and its Affiliate Organisations, can through education and information dissemination, enhance the awareness and understanding of both RCC patients and the healthcare community so that patients have the knowledge, understanding and opportunity to participate equally in clinical trials should they wish.

Overall, the healthcare community in the UK has not been proactive in approaching RCC patients about their possible participation in clinical trials.

98% of patients who had never been approached to participate reported they would have been amenable, particularly if provided with the necessary information to make the decision. This, combined with the high rate of satisfaction of those who had participated in a trial, indicates an obvious lost opportunity to improve the quality of care and survivorship of RCC patients through research.

Patients in various stages of their treatment pathway were not being approached equally to participate in clinical trials given that the majority were asked following surgery rather than at initial diagnosis.

Patients who HAD DISCUSSIONS about clinical trials

- According to survey results, clinical trials had not been discussed with 52% of patients in the UK (a Global Outlier, compared to 33% globally).

- Of those who had discussions about clinical trials, those discussions had occurred with:
  - Another patient (11%),
  - Doctors (78%),
  - Spouses, friends or family (22% compared to 31% globally),
  - Nurses (22% a Global Outlier, compared to 10% globally),
  - Patient organisations (18%), and
  - Online groups (27% a Global Outlier, compared to 15% globally).

Patients who had NEVER BEEN ASKED to participate in a clinical trial

- 72% of patients in the UK had not been asked to participate in a clinical trial.

- Of UK patients who had never been asked to participate in a clinical trial, 98% said it said it 'fairly likely'[7] they would do so if asked (a Global Outlier, compared to 89% globally).

- Of the patients in the UK who said they would be fairly likely[8] to do so, they were being treated at:
  - Community/ local /general hospitals (52% a Global Outlier, compared to 37% globally),
  - Major cancer centres[9] (34% compared to 45% globally),
  - 3% at private clinics, and
  - 2% at 'other' (5% globally).

- Of the 98% of UK patients who said it would be 'fairly likely' they would participate in a clinical trial:
  - 41% said they would be 'likely' to participate, while
  - 59% would require more information to make a decision of whether or not to do so.

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[7] 'Fairly likely is the combined result of 'Likely' and 'Maybe; would need more information".

[8] 'Fairly likely' is the combined result of 'Likely' and 'Maybe; would need more information'.

[9] Including major cancer centres with kidney cancer specialists (21% compared to 30% globally).

- Of patients in the UK who said they would need more information before they agreed to participate in a clinical trial, these patients were being treated at:
    - Community/ local /general hospitals (53% compared to 38% globally),
    - Major cancer centres[10] (34% compared to 44% globally), and
    - Private clinics (4%).

- Of those patients in the UK who would be 'fairly likely' to participate in a clinical trial if asked, this would be the case for:
    - 98% of those with metastatic RCC[11] (92% globally), and
    - 98% of those with no evidence of the disease, or were told they were cured (a Global Outlier, compared to 91% globally).

- 58% of patients in the UK with clear cell RCC (67% globally) and 69% of those with other sub-types (77% globally) had never been asked to participate in a clinical trial.

- Patients being treated for other sub-types who had never been approached to participate in a clinical trial were being treated at:
    - Community/local or general hospitals (54% a Global Outlier, compared to 28% globally),
    - Major cancer centres[12] (23% compared to 47% globally),
    - Private clinics (4% compared to 9% globally).

Patients who HAD BEEN ASKED to participate in a clinical trial

- Of the patients in the UK who had been asked to participate in a clinical trial:
    - 9% of their initial discussions were with another patient,
    - 91% with doctors,
    - 17% with spouses, family or friends (31% globally),
    - 23% with nurses (15% globally),
    - 19% with patient organisations,
    - 26% with online groups (a Global Outlier, compared to 16% globally), and
    - 4% had no previous discussion with anyone.

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[10] Including major cancer centres with kidney cancer specialists (19%, a Global Outlier compared to 30% globally)

[11] Due to insufficient sample size, data is not reported for patients with localised RCC

[12] Including major cancer centres with kidney cancer specialists (19% compared to 30% globally),

- The option of a clinical trial was first been discussed with:
  - 35% upon diagnosis (24% globally),
  - 59% of patients after surgery (a Global Outlier, compared to 49% globally),
  - 4% after other treatments (a Global Outlier, compared to 21% globally), and
  - 2% who were left with no other treatment options.

- For patients in the UK who had the option of a clinical trial first discussed with them after surgery:
  - 15% were being treated at community/local or general hospitals,
  - 77% at major cancer centres[13] (72% globally), and
  - 0% at private clinics.

- When the option of a clinical trial was discussed with patients:
  - 62% understood very well the risks and benefits of participating (a Global Outlier, compared to 47% globally),
  - 30% had at least some understanding (41% globally), and
  - 9% had a very limited understanding.

- Of those in the UK who were asked to participate in a clinical trial, 89% agreed.

- Those who agreed to participate did so because:
  - Their doctor recommended it (60% as compared to 55% globally),
  - They thought it might offer better care (60%),
  - They wanted a specific type of treatment (5% compared to 13% globally),
  - It was their only option for treatment (5% a Global Outlier, compared to 22% globally),
  - They wanted to help kidney cancer research (60% compared to 39% globally), and
  - Affordability, financial reasons (0% compared to 13% globally).

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[13] Including major cancer centres with kidney cancer specialists (70% compared to 72% globally),

- 97% of patients in the UK who participated in a clinical trial were either ‘very satisfied’ or ‘satisfied’, and of those:
  - 64% were ‘very satisfied’ (44% globally),
  - 33% ‘satisfied’ (46% globally) and
  - 3% were very dissatisfied (10% globally).

IV. Quality of Care

Kidney cancer has a profound effect on the lives of patients in the UK as demonstrated by the impact of both physical and psychosocial issues, and the barriers standing in the way of receiving quality care.

There is strong evidence to suggest that RCC patients in the UK are choosing to 'suffer in silence' from the effects of their disease, not reaching out to their healthcare teams for the support they need to improve the quality of their lives. This constitutes a clear call to both IKCC and the healthcare community to encourage conversations with patients about how kidney cancer has affected their lives, particular attention paid to more heavily impacted patient sub groups that may often go unnoticed, such as females, and those who had no evidence of the disease, or who had been told they were cured, thereby ensuring universal psychosocial support for all patients.

There is also a role for IKCC and its Affiliate Organisations to play in the UK to advocate for change and to provide support for patients who struggle with barriers standing in the way to receiving quality care. Unfortunately, younger patients, males, and those with rarer sub-types are bearing the brunt of these barriers, preventing them from attaining a better quality of life.

Patients in the UK were impacted by the greatest number of physical conditions per patient compared to other RCC patients globally. They were also impacted by a number of psychosocial issues and were most affected with disease related anxiety.

Although male and female RCC patients have a similar biological experience with kidney cancer, patients in the UK reported notable differences between males and females for both physical and psychosocial impacts. While males tended to be impacted mostly by stress related to employment and financial issues, female patients were most affected by anxiety related to their disease including the fear of recurrence.

Surprisingly, patients in the UK with no evidence of the disease or who had been told they were cured were impacted by the greatest number of *physical conditions per patient compared to their counterparts in other countries.*

Although 98% of patients in the UK were affected by psychosocial issues, and a high percentage were finding their doctors to be helpful when they did reach out, as many as half were not fully communicating their emotional issues to their healthcare team.
Overall, younger patients, males and patients with other sub-types in the UK experienced notably more barriers to receiving quality care.

Treatment for Kidney Cancer

- According to survey results, 3% of UK patients had not had any treatment for their kidney cancer after their first diagnosis.

- At the time of the survey, 8% of patients in the UK had not been receiving any treatments at all.

- As shown in Table 4, for their first treatment,
  - 64% had received them from community/local or general hospitals (47% globally),
  - 29% at major cancer centres[14] (38% globally), and
  - 4% from private clinics.

- Of those patients in the UK who had been receiving treatments since that time:
  - 42% had been receiving them from community/local or general hospitals (a Global Outlier, compared to 31% globally),
  - 46% from major cancer centres[15] (51% globally), and
  - 2% from private clinics (7% globally).

- As can be seen in Table 4, there was a notable migration of patients initially treated at community/local or general hospitals to major cancer centres, as evidenced by a decline of 22% in community/local or general hospitals, and an increase of 17% to major cancer centres.

Table 4
Notable Differences between Place of Treatment for Patient Initial and Subsequent Treatments in the UK

PLACE OF TREATMENT	First Treatment	Subsequent Treatments	Notable Differences
Community/local/general hospitals	**64%**	**42%**	**-22%**
Major cancer centres	**29%**	**46%**	**17%**
Private clinics	**4%**	**2%**	

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[14] Including major cancer centres with kidney cancer specialists (21% compared to 26% globally),

[15] Including major cancer centres with kidney cancer specialists (32%)

Physical Conditions

- As can be seen in Table 5, 7% of UK patients were not impacted by any conditions affecting their physical well-being since their initial diagnosis.

- Of those who were impacted, fatigue was the condition that affected them the most, followed by:
  - Bowel changes and by
  - Sleeplessness.

- Patients in the UK were impacted considerably more than patients globally by:
  - Fatigue,
  - Changes in taste and smell,
  - Sleeplessness,
  - Change of hair colour,
  - Memory loss, and by
  - Aching joints.

- They were affected notably more than patients globally by:
  - Trouble concentrating,
  - Bowel changes,
  - Pain related to surgery,
  - Itching, and by
  - Nausea and vomiting.

- They were impacted considerably less than patients globally by weight loss, and notably less by skin reactions.

- Patients in the UK were affected by the greatest number of physical conditions per patient compared to other RCC patients globally[16].

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[16] Further detail is available in the IKCC Global Report

Table 5
Notable Differences between UK and Global Results for Physical Conditions

PHYSICAL CONDITIONS	Global	UK	Notable Differences
NOT AFFECTED	8%	7%	
Fatigue	66%	78%	12%
Trouble concentrating	24%	34%	10%
Mucositis/mouth ulcers	17%	15%	
Muscle weakness	32%	29%	
Pain related to surgery	29%	34%	5%
Bowel changes	33%	43%	10%
Loss of appetite	25%	28%	
Changes in taste and smell	25%	31%	6%
Sleeplessness	31%	43%	12%
Itching	17%	23%	6%
Hair loss	13%	12%	
Change of hair colour	17%	24%	7%
Memory loss	13%	21%	8%
Changes in sexual function	15%	16%	
Aching joints	22%	36%	14%
Sore feet and hands	23%	27%	
Weight loss	24%	16%	8%
Cramps	11%	15%	
Fluid retention	12%	12%	
Skin reactions	17%	12%	5%
Nausea and vomiting	22%	31%	9%

LEGEND	
Negative (white font = Global Outlier)	🟥
Positive (enlarged font= Global Outlier)	🟩

- As can be seen in Table 6, males were impacted notably more than females by:
  - Bowel changes,
  - Changes in taste and smell
  - Sore feet and hands
  - Loss of appetite,
  - Nausea and vomiting,
  - Changes in sexual function, and by
  - Itching.

- Females were impacted notably more than males by:
  - Fatigue,
  - Trouble concentrating,
  - Aching joints,
  - Sleeplessness,
  - Hair loss,
  - Memory loss,
  - Muscle weakness, and by
  - Pain related to surgery.

Table 6
Notable Differences in the UK for Physical Conditions by Gender

PHYSICAL CONDITION	Males	Females	Notable Differences
NOT AFFECTED	8%	5%	
Fatigue	71%	83%	12%
Trouble concentrating	28%	40%	12%
Mucositis/mouth ulcers	14%	16%	
Muscle weakness	25%	33%	8%
Pain related to surgery	32%	37%	5%
Bowel changes	50%	37%	13%
Loss of appetite	34%	23%	11%
Changes in taste and smell	38%	25%	13%
Sleeplessness	37%	48%	11%
Itching	28%	20%	8%
Hair loss	7%	17%	10%
Change of hair colour	25%	24%	
Memory loss	17%	25%	8%
Changes in sexual function	21%	12%	9%
Aching joints	29%	40%	11%
Sore feet and hands	33%	22%	11%
Weight loss	18%	14%	
Cramps	14%	15%	
Fluid retention	12%	13%	
Skin reactions	14%	11%	
Nausea and vomiting	36%	26%	10%

LEGEND	
Most negative	🟥
Most positive	🟩

- Table 7 illustrates Global Outliers for physical conditions affecting patients' well-being in the UK by gender.

- For example, in the UK both male and female patients were considerably more affected by trouble concentrating than male and female patients in other countries.

- Both male and female patients in the UK were impacted by among the greatest number of physical conditions per patient compared to their counterparts in other countries.[17]

Table 7
Global Outliers for UK results
Physical Conditions by Gender

PHYSICAL CONDITION	Males	Females
Trouble concentrating	28%	40%
Muscle weakness	25%	
Pain related to surgery	32%	
Sleeplessness		48%
Itching		20%
Change of hair colour	25%	24%
Memory loss		25%
Weight Loss	18%	14%
Sore feet and hands	33%	
Nausea and vomiting	36%	
LEGEND		
Negative Global Outlier for the UK		🟥
Positive Global Outlier for the UK		🟩

- As Table 8 shows, patients diagnosed prior to 2014 were notably more affected than patients diagnosed in 2014 and later by:
    - Trouble concentrating,
    - Muscle weakness,
    - Bowel changes,
    - Hair loss,
    - Mucositis/mouth ulcers,
    - Skin reactions,
    - Change of hair colour,
    - Sore feet and hands,
    - Cramps,

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[17] For further detail, see the IKCC Global Report

  - Memory loss,
  - Itching, and by
  - Fluid retention.

- Patients diagnosed after 2014 were more notably affected by:
  - Pain related to surgery, and by
  - Sleeplessness.

Table 8
Notable Differences in the UK for
Physical Conditions by Year of Diagnosis

PHYSICAL CONDITION	Prior to 2014	2014-2018	Notable Differences
NOT AFFECTED	10%	5%	5%
Fatigue	76%	78%	
Trouble concentrating	47%	27%	20%
Mucositis/mouth ulcers	24%	11%	13%
Muscle weakness	41%	23%	18%
Pain related to surgery	25%	39%	14%
Bowel changes	53%	37%	16%
Loss of appetite	29%	27%	
Changes in taste and smell	34%	30%	
Sleeplessness	39%	45%	6%
Itching	29%	20%	9%
Hair loss	22%	7%	15%
Change of hair colour	32%	20%	12%
Memory loss	27%	18%	9%
Changes in sexual function	19%	15%	
Aching joints	36%	35%	
Sore feet and hands	34%	23%	11%
Weight loss	17%	15%	
Cramps	22%	12%	10%
Fluid retention	17%	10%	7%
Skin reactions	20%	8%	12%
Nausea and vomiting	31%	31%	
LEGEND			
Most negative			🟥
Most positive			🟩

- Table 9 illustrates Global Outliers for physical conditions affecting patients' well-being in the UK by year of diagnosis.

- For example, UK patients diagnosed in 2014 and later were considerably more affected by pain related to surgery than patients diagnosed at that time in other countries.

- Patients diagnosed prior to 2014 were impacted by the greatest number of physical conditions per patient compared to patients diagnosed at that time in other countries.[18]

Table 9
Global Outliers for UK results
Physical Conditions by Year of Diagnosis

PHYSICAL CONDITION	Prior to 2014	2014 and Later
Muscle weakness	🟥 41%	🟩 23%
Trouble concentrating	🟥 47%	
Pain related to surgery		🟥 39%
Bowel changes	🟥 53%	
Changes in taste and smell	🟥 34%	
Sleeplessness	🟥 39%	🟥 45%
Itching	🟥 29%	
Hair loss		🟩 7%
Aching joints		🟥 35%
Sore feet and hands	🟥 34%	
Cramps	🟥 22%	
LEGEND		
Negative Global Outlier for the UK		🟥
Positive Global Outlier for the UK		🟩

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[18] For further detail, see the IKCC Global Report

- As shown in Table 10, metastatic RCC patients were more notably affected by every physical condition than patients with no evidence of the disease, or who had been told they were cured, with the exception of pain related to surgery and sleeplessness.

Table 10
Notable Differences in the UK for
Physical Conditions by Stage[19]

PHYSICAL CONDITION	Metastatic RCC	No Evidence/ Cured	Notable Differences
NOT AFFECTED	1%	17%	16%
Fatigue	84%	57%	27%
Trouble concentrating	42%	17%	25%
Mucositis/mouth ulcers	23%	4%	19%
Muscle weakness	33%	17%	16%
Pain related to surgery	30%	41%	11%
Bowel changes	60%	15%	45%
Loss of appetite	43%	6%	37%
Changes in taste and smell	52%	4%	48%
Sleeplessness	39%	44%	5%
Itching	30%	13%	17%
Hair loss	19%	9%	10%
Change of hair colour	48%	0%	48%
Memory loss	23%	17%	6%
Changes in sexual function	20%	9%	11%
Aching joints	42%	22%	20%
Sore feet and hands	37%	7%	30%
Weight loss	18%	11%	7%
Cramps	22%	9%	13%
Fluid retention	18%	7%	11%
Skin reactions	17%	2%	15%
Nausea and vomiting	43%	11%	32%

LEGEND	
Most negative	🟥
Most positive	🟩

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[19] Due to insufficient sample size, data is not reported for patients with localised RCC

- Table 11 illustrates Global Outliers for physical conditions that affected patients' well-being in the UK by Stage of RCC.

- For example, patients with metastatic RCC were considerably less affected by weight loss than metastatic patients in other countries.

- Patients in the UK who had no evidence of RCC, or who had been told they were cured, were impacted by the greatest number of physical conditions per patient compared to their counterparts in other countries.[20]

Table 11
Global Outliers for UK results
Conditions Affecting Physical Well-being by Stage

PHYSICAL CONDITION	Metastatic RCC	No Evidence/ cured
Sleeplessness		44%
Memory loss		17%
Itching	30%	
Changes in taste and smell	52%	
Change of hair colour	48%	
Sore feet and hands	37%	
Weight loss	18%	
Nausea and vomiting	43%	

LEGEND	
Negative Global Outlier for the UK	🟥
Positive Global Outlier for the UK	🟩

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[20] For further detail, see the IKCC Global Report

Psychosocial Issues

- As can be seen in Table 12, 2% of UK patients had not had their sense of emotional well-being impacted by psychosocial issues since their initial diagnosis.

- Of those who were impacted, disease related anxiety affected them the most followed by the fear of recurrence.

- Compared to global results, patients in the UK were considerably more impacted by problems getting life or health insurance (21% a Global Outlier, compared to 13% globally).

- They were affected notably more than patients globally by:
    - Disease related anxiety,
    - Depression,
    - Isolation,
    - Changes in relationships, and by
    - Loss or reduction in employment.

Table 12
Notable Differences between UK and Global Results for Psychosocial Issues

PSYCHOSOCIAL ISSUE	Global	UK	Notable Differences
NOT AFFECTED	4%	2%	
General anxiety	31%	35%	
Disease-related anxiety	60%	67%	7%
Fear of dying	44%	48%	
Fear of recurrence	50%	50%	
Depression	27%	33%	6%
Isolation	16%	21%	5%
Changes in relationships	28%	33%	5%
Difficulty on the job or in school	19%	22%	
Stress related to financial issues	28%	25%	
Loss or reduction in employment	20%	29%	9%
Difficulty navigating the healthcare system	14%	15%	
Problems getting life or health insurance	13%	21%	8%
Concerns about body image/physical appearance	22%	24%	
Relationships with friends/others	18%	19%	
Sexuality	14%	13%	

LEGEND	
•Negative (white font = Global Outlier)	🟥
Positive (enlarged font= Global Outlier)	🟩

- According to Table 13, males in the UK were impacted notably more than females by:
  - Stress related to financial issues, and by
  - Difficulty on the job or in school.

- Females were impacted notably more than males by:
  - The fear of recurrence,
  - Disease-related anxiety, and by
  - Isolation.

Table 13
Notable Differences in the UK for
Psychosocial Issues by Gender

PSYCHOSOCIAL ISSUE	Males	Females	Notable Differences
NOT AFFECTED	4%	1%	
General anxiety	34%	36%	
Disease-related anxiety	62%	72%	10%
Fear of dying	49%	48%	
Fear of recurrence	41%	58%	17%
Depression	36%	32%	
Isolation	17%	24%	7%
Changes in relationships	33%	33%	
Difficulty on the job or in school	28%	18%	10%
Stress related to financial issues	33%	18%	15%
Loss or reduction in employment	30%	28%	
Difficulty navigating the healthcare system	14%	15%	
Problems getting life or health insurance	20%	23%	
Concerns about body image/physical appearance	24%	25%	
Relationships with friends/others	20%	18%	
Sexuality	13%	13%	
LEGEND			
Most negative			🟥
Most positive			🟩

- Table 14 illustrates Global Outliers for psychosocial issues that impacted patients' emotional well-being in the UK by gender.

- For example, both males and females were considerably more impacted trying to get life/health insurance than male and female patients in other countries.

Table 14
Global Outliers for UK results
Psychosocial Issues by Gender

PSYCHOSOCIAL ISSUE	Males	Females
Problems getting life/health insurance	20%	23%
Loss/reduction in employment	30%	

LEGEND	
Negative Global Outlier for the UK	🟥
Positive Global Outlier for the UK	🟩

- As shown in Table 15, patients diagnosed in 2014 and later were impacted more notably than those diagnosed prior to 2014 by:
    - Stress related to financial issues,
    - Fear of dying,
    - Depression,
    - Difficulty navigating the healthcare system,
    - Disease related anxiety,
    - Changes in relationships, and by
    - General anxiety.

- Those diagnosed prior to 2014 were affected more notably by:
    - Problems getting life/health insurance, and by
    - Relationships with friends/other.

Table 15
Notable Differences in the UK for Psychosocial Issues by Year of Diagnosis

PSYCHOSOCIAL ISSUE	Prior to 2014	2014 and Later	Notable Differences
NOT AFFECTED	2%	3%	
General anxiety	29%	38%	9%
Disease-related anxiety	61%	71%	10%
Fear of dying	39%	53%	14%
Fear of recurrence	51%	49%	
Depression	24%	38%	14%
Isolation	19%	22%	
Changes in relationships	29%	35%	6%
Difficulty on the job or in school	22%	23%	
Stress related to financial issues	15%	31%	16%
Loss or reduction in employment	31%	28%	
Difficulty navigating the healthcare system	8%	19%	11%
Problems getting life or health insurance	27%	18%	9%
Concerns about body image/physical appearance	27%	23%	
Relationships with friends/others	25%	15%	10%
Sexuality	14%	13%	

LEGEND	
Most negative	🟥
Most positive	🟩

- Table 16 shows Global Outliers for psychosocial issues that impacted patients' emotional well-being in the UK by year of diagnosis.

- For example, UK patients diagnosed in 2014 and later were considerably more affected by the fear of dying, isolation and problems getting life/health insurance than patients diagnosed at the same time in other countries.

Table 16
Global Outliers for UK results
Psychosocial Issues by Year of Diagnosis

PSYCHOSOCIAL ISSUE	Prior to 2014	2014 and later
Fear of dying		53%
Isolation		22%
Problems getting life/health insurance		18%
Loss/reduction in employment	31%	
Concerns about body image/physical appearance	27%	
LEGEND		
Negative Global Outlier for the UK		🟥
Positive Global Outlier for the UK		🟩

- As shown in Table 17, patients in the metastatic stage of their RCC were impacted notably more than those who had no evidence of the disease, or who had been told they were cured, for:
  - Disease related anxiety,
  - Fear of dying,
  - Changes in relationships,
  - Depression,
  - Stress related to financial issues,
  - Concerns about body image/physical appearance,
  - Isolation, and by
  - Sexuality.

- Those with no evidence of RCC or who had been told they were cured were affected more by the fear of recurrence, and by difficulty navigating the healthcare system.

Table 17
Notable Differences between Stage of RCC for Psychosocial Issues in the UK[21]

PSYCHOSOCIAL ISSUE	Metastatic RCC	No Evidence/ cured	Notable Differences
NOT AFFECTED	4%	0%	
General anxiety	30%	33%	
Disease-related anxiety	72%	59%	13%
Fear of dying	57%	31%	26%
Fear of recurrence	24%	91%	67%
Depression	39%	20%	19%
Isolation	23%	11%	12%
Changes in relationships	37%	24%	13%
Difficulty on the job or in school	24%	20%	
Stress related to financial issues	30%	15%	15%
Loss or reduction in employment	39%	22%	17%
Difficulty navigating the healthcare system	11%	17%	6%
Problems getting life or health insurance	23%	20%	
Concerns about body image/physical appearance	30%	13%	17%
Relationships with friends/others	20%	11%	9%
Sexuality	16%	11%	5%

LEGEND	
Most negative	🟥
Most positive	🟩

- Table 18 illustrates Global Outliers for psychosocial issues that impacted patient’s emotional well-being in the UK by stage.

- For example, those with no evidence of the disease, or who had been told they were cured, in the UK were considerably more affected by the fear of recurrence than their peers in other countries.

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[21] Due to insufficient sample size, data is not available for patients with localised RCC

Table 18
Global Outliers for UK results
Psychosocial Issues by Stage

PSYCHOSOCIAL ISSUE	Metastatic RCC	No Evidence/ cured
Fear of recurrence	24%	91%
Problems getting life/health insurance	23%	
LEGEND		
Negative Global Outlier for the UK		🟥
Positive Global Outlier for the UK		🟩

Patient Timeline- Most Difficult Times

- According to Table 19, UK patients experienced their most difficult times during their experience with kidney cancer:
    - Waiting for surgery or scan results, and
    - During the process of diagnosis.

- Compared to global results, they were affected considerably more waiting for surgery or scan results (56% a Global Outlier, compared to 37% globally).

- They were affected notably more than patients globally by long term adjustment and survivorship.

- They were affected notably less than patients globally during the surveillance period and with treatment for recurrence.

Table 19
Notable Differences between UK and Global Results for Most Difficult Times for RCC Patients

MOST DIFFICULT TIME	Global	UK	Notable Differences
NOT AFFECTED	2%	4%	
During the process of diagnosis	51%	52%	
Surveillance period	19%	14%	5%
Surgery & recovery afterwards	38%	36%	
Follow up scans	17%	17%	
Waiting for surgery or scan results	37%	56%	19%
Diagnosis of recurrence	21%	18%	
Treatment for recurrence	10%	3%	7%
Diagnosis of further disease progression	23%	20%	
Dealing with side effects of treatment	29%	33%	
Transition to palliative care	4%	4%	
Long term adjustment, survivorship	12%	19%	7%
LEGEND			
Negative (white font = Global Outlier)			🟥
Positive (enlarged font= Global Outlier)			🟩

- As shown in Table 20, female patients in the UK were affected notably more than male patients for surgery and recovery afterwards, while males were affected notably more than females for dealing with the side effects of treatment.

Table 20
Notable Differences in the UK for
Most Difficult Times by Gender

MOST DIFFICULT TIME	Males	Females	Notable Differences
NOT AFFECTED	4%	3%	
During the process of diagnosis	54%	51%	
Surveillance period	13%	15%	
Surgery and recovery afterwards	22%	47%	25%
Follow up scans	14%	18%	
Waiting for surgery or scan results	54%	57%	
Diagnosis of recurrence	18%	17%	
Treatment for recurrence	5%	1%	
Diagnosis of further disease progression	21%	20%	
Dealing with side effects of treatment	38%	28%	10%
Transition to palliative care	5%	3%	
Long term adjustment, survivorship	20%	18%	
LEGEND			
Most negative			🟥
Most positive			🟩

- Table 21 illustrates Global Outliers for patients’ most difficult times in the UK by gender.

- For example, both male and female UK patients were considerably more affected waiting for surgery or scan results than male and female patients in other countries.

Table 21
Global Outliers UK results
Most Difficult Times by Gender

MOST DIFFICULT TIME	Males	Females
Surgery and recovery afterwards	22%	
Waiting for surgery or scan results	54%	57%
Long term adjustment, survivorship	20%	
LEGEND		
Negative Global Outlier for the UK		🟥
Positive Global Outlier for the UK		🟩

Communication and Support from Healthcare Professionals

- Of those patients in the UK who experienced psychosocial issues, 49% said they communicated them to a healthcare professional while 51% had not.

- In the UK:
  - 45% were very open and told the doctor everything in great detail,
  - 27% shared some of their issues, but not to the full extent,
  - 18% held back some details and minimized their symptoms and side effects or chose not to communicate their issues at all, and
  - 10% had not had the opportunity to communicate their issues at all.

- Of patients in the UK who chose to tell the doctor or everything in great detail about their psychosocial issues, this was the case for:
  - 55% of male patients,
  - 37% of female patients,

  - 32% of patients[22] who were 30-45 yrs. (39% globally),
  - 45% who were middle aged (46-65 yrs.), and
  - 58% who were senior patients (66+ yrs.).

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[22] Due to insufficient sample sizes, data was not reported for the Under 18-29 age bracket.

- For those who communicated their issues 88% of patients found their doctors to be helpful, while this had not been the case for the remaining 12%.

Barriers to Receiving Quality Care

- Patients in the UK had the following types of healthcare coverage:
    - Government healthcare (95% compared to 73% globally),
    - Private insurance (7%, compared to 39% globally),
    - Self-coverage (1%, compared to 14% globally), and
    - Family coverage (1%, compared to 6% globally).

- As Table 22 shows, 48% of patients in the UK had not experienced any barriers to receiving quality care.

- They were most affected by wait times to treatment.

- Compared to patients globally, patients in the UK were affected more notably by:
    - Wait times to treatment,
    - Lack of personal support, and by
    - Lack of a locally available specialty doctor.

Table 22
Notable Differences between UK and Global Results for Barriers to Receiving Quality Care

BARRIER TO RECEIVING QUALITY CARE	Global	UK	Notable Differences
NOT AFFECTED	39%	🟩 48%	9%
Lack of affordability, cost of treatment	21%	🟩 2%	19%
Lack of access to treatment centre (travel)	13%	🟩 5%	8%
Inability to understand the treatment	6%	🟩 1%	5%
Lack of access to up-to-date treatment/equipment	14%	13%	
Wait time to treatment was longer than necessary	14%	🟥 22%	8%
Lack of personal support	13%	🟥 19%	6%
No specialty doctor available locally	9%	🟥 14%	5%
Difficulty managing career/caregiver role while in treatment	9%	5%	
Fear of discrimination by my employer/ friends/ family	5%	5%	
No available treatments	5%	1%	
LEGEND			
Negative (white font = Global Outlier)			🟥
Positive (enlarged font= Global Outlier)			🟩

- According to Table 23, younger patients (30-45 yrs.) in the UK were affected overall by notably more barriers in receiving quality care than patients in older age groups.

Table 23
Notable Differences in the UK for Barriers to Receiving Quality Care by Age[23]

BARRIER TO RECEIVING QUALITY CARE	30-45 yrs.	46-65 yrs.	66+ yrs.
NOT AFFECTED	🟥 41%	🟩 50%	46%
Lack of affordability, cost of treatment	0%	2%	4%
Lack of access to treatment centre (travel)	🟩 0%	🟩 4%	🟥 14%
Inability to understand the treatment	0%	0%	4%
Lack of access to up-to-date treatment/equipment	14%	13%	14%
Wait time to treatment was longer than necessary	🟥 27%	🟩 22%	🟩 21%
Lack of personal support	🟥 23%	🟥 21%	🟩 7%
No specialty doctor available locally	🟩 9%	🟥 15%	🟥 18%
Difficulty managing career/caregiver role while in treatment	🟥 18%	🟩 3%	🟩 0%
Fear of discrimination by my employer/ friends/ family	🟥 9%	🟩 4%	🟩 0%
No available treatments	0%	2%	0%
LEGEND			
Most negative			🟥
Most positive			🟩

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[23] Due to insufficient sample size, data is not reported for under 30 yrs.

- Table 24 shows Global Outliers for barriers to receiving quality care in the UK by age.

- For example, UK patients aged 30-65 yrs. experienced considerably fewer barriers in having access to available treatments than their peers in other countries.

Table 24
Global Outliers UK results for
Barriers to Receiving Quality Care by Age

BARRIER TO RECEIVING QUALITY CARE	30-45 yrs.	46-65 yrs.	66+ yrs.
No available treatments	0%	2%	
Lack of access to available treatment centre (travel)		4%	
Fear of discrimination by employer/ friends/ family		4%	
LEGEND			
Negative Global Outlier for the UK			🟥
Positive Global Outlier for the UK			🟩

- As Table 25 indicates, overall, males were notably more affected by barriers to receiving quality care than females.

- Male patients were also more notably affected by:
  - Lack of access to the most up to date treatments/equipment, and by
  - The lack of locally available specialty physicians.

- Females were considerably more affected by a lack of personal support than were females in other countries (21%, a Global Outlier, compared to 15% globally).

Table 25
Notable Differences in the UK for
Barriers to Receiving Quality Care by Gender

BARRIER TO RECEIVING QUALITY CARE	Males	Females	Notable Differences
NOT AFFECTED	45%	51%	6%
Lack of affordability, cost of treatment	3%	1%	
Lack of access to treatment centre (travel)	7%	4%	
Inability to understand the treatment	1%	0%	
Lack of access to up-to-date treatment/equipment	19%	9%	10%
Wait time to treatment was longer than necessary	23%	22%	
Lack of personal support	16%	21%	5%
No specialty doctor available locally	17%	12%	5%
Difficulty managing career/caregiver role while in treatment	4%	7%	
Fear of discrimination by my employer/ friends/ family	4%	5%	
No available treatments	1%	1%	

LEGEND	
Most negative	🟥
Most positive	🟩

- As shown in Table 26, overall, patients with other sub-types experienced notably more barriers receiving quality care than patients with clear cell RCC and for:
    - Local availability of a specialty physician,
    - Access to the most up to date treatment/equipment, and for
    - Fear of discrimination.

Table 26
Notable Differences in the UK for
Barriers to Receiving Quality Care by Sub-Type

BARRIER TO RECEIVING QUALITY CARE	Clear Cell	Other sub-types	Notable Differences
NOT AFFECTED	50%	42%	8%
Lack of affordability, cost of treatment	2%	0%	
Lack of access to treatment centre (travel)	5%	3%	
Inability to understand the treatment	0%	0%	
Lack of access to up-to-date treatment/equipment	12%	17%	5%
Wait time to treatment was longer than necessary	21%	22%	
Lack of personal support	19%	19%	
No specialty doctor available locally	12%	19%	7%
Difficulty managing career/caregiver role while in treatment	5%	8%	
Fear of discrimination by my employer/ friends/ family	3%	8%	5%
No available treatments	1%	3%	

LEGEND	
Most negative	🟥
Most positive	🟩

- Clear cell patients in the UK experienced considerably more issues with a lack of personal support than clear cell patients in other countries (19%, a Global Outlier, compared to 13% globally).

- They experienced considerably fewer issues with the fear of discrimination by employer/friends/family than patients in other countries (3% a Global Outlier, compared to 7% globally).

V. Opportunities to Improve Care

There is an opportunity for IKCC and its Affiliate Organisations to improve survivorship of patients in the UK by empowering patients through education to advocate for regular surveillance despite gender, age or stage. Particular attention should be paid to those with no evidence of the disease, or who had been told they were cured, and older patients (66+ yrs).

Surveillance

- At the time of the survey, patients in the UK were in the following stages of their RCC:
  - 5% were in Stage 1 or 2 (13% globally),
  - 2% in Stage 3 (8% globally),
  - 49% in Stage 4 (40% globally),
  - 29% had no evidence of the disease (19% globally),
  - 3% had been told they were cured (10% globally), and
  - 4% had died.

- Their last follow up scan occurred:
  - Less than one year ago (86%),
  - 1-3 years ago (7%), and
  - More than 3 years ago (6%).

- Most recent follow up scans had occurred more than three years ago for:
  - 1% of those in Stage 4[24],
  - 11% of those who had no evidence of the disease or had been told they were cured (a Global Outlier, compared to 5% globally),

  - 0% of those aged 30-45 yrs[25],
  - 5% of those aged 46-65,
  - 14% of those aged 66+ yrs. (a Global Outlier, compared to 6% globally),

  - 5% of males,
  - 7% of females,

  - 4% of those with no understanding of kidney cancer guidelines, and

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[24] Due to insufficient data, results are not reported for Stages 1, 2 or 3 or for patients who have died.

[25] Due to insufficient data, results are not reported for under 30 yr. age brackets

  - 4% of those with no understanding of the guidelines for kidney cancer follow up.

VI. Shared decision making

As shared decision making becomes increasingly recognized as a pillar of patient-centered healthcare, IKCC and its Affiliate Organisations have the opportunity to play a key role in the UK to advocate for and support shared decision making for patient treatment plans through further development of decision aid tools particularly for patient sub groups where there is evidence of notable physician directed care.

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 yrs.

There is a possibility that shared decision making in the UK has decreased notably for patients diagnosed since 2016, this being the worst result of any other country surveyed.

- 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 (a Global Outlier, compared to 29% globally),

- Of those patients who were involved in their treatment decision:
  - 4% made the decision by themselves,
  - 42% made a joint decision with their doctors (51% globally), and
  - 14% were asked for input from their doctors.

- The following helped UK patients with their treatment plans:
  - Partner/spouse (69% compared to 56% globally),
  - Parents (5%, compared to 13% globally),
  - Children (23%),
  - Friends/other family members (14% compared to 20% globally),
  - Local family doctor (8% compared to 22% globally), and
  - A patient organisation (9%).

- 19% of patients made the decision by themselves, and for 1%, the decision rested on their personal financial situation.

- Of those patients in the UK where their treatment plans were decided for them by their doctors:
    - 42% were being treated in community centres/local or general hospitals (34% globally),
    - 42% at major cancer centres[26], and
    - 3% at private clinics (9% globally).

- In the case where treatment plans were decided solely by the doctor without any input from the patient this affected[27]:
    - 41% of those aged 30-45 yrs. (a Global Outlier, compared to 28% globally),
    - 38% of those aged 46-65 yrs. (a Global Outlier, compared to 30% globally),
    - 35% of those aged 66+ yrs. (27% globally),

    - 39% of those in Stage 4[28] (30% globally),
    - 39% of those who had no evidence of the disease or who were told they were cured (a Global Outlier, compared to 31% globally),

    - 42% of male patients (a Global Outlier, compared to 28% globally),
    - 34% of female patients.

    - 35% of those diagnosed prior to 2016 (a Global Outlier, compared to 28% globally), and for
    - 43% of those diagnosed in 2016 and later (a Global Outlier, compared to 21% globally).

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[26] Including major cancer centres with kidney cancer specialists (23%, a Global Outlier compared to 30% globally),

[27] Due to insufficient sample size, data is not reported for the under 30 age brackets.

[28] Due to insufficient sample sizes, data is not available for Stages 1, 2 or 3 or for patients who had died.

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Most importantly, the IKCC wishes to thank every kidney cancer patient and caregiver who took the time to complete our survey. This report, and our work going forward to address these results, is dedicated to you all with our sincere appreciation.

APPENDIX

Methodology

Data Collection

The survey was mounted using the QuestionPro platform. It opened live August 23rd, 2018 and closed October 31st, 2018.

Since this survey was conducted, the platform has remained open and available for patients to provide information that can be used in future analysis.

At cut-off on October 31st, the raw data was downloaded for processing. The responses were then loaded into a relational database during which extraneous data elements were ignored and not loaded, including those with a:

- Submission date prior to going live (August 23rd, 2018);
- Submission date later than the cut-off date (October 31st, 2018);
- Country designation of 24 (Afghanistan) which was used to test/verify the survey after the go live date; and where
- The respondent left the survey without answering Question 6, being the first non-demographic question.

Also during this process the following ‘associated data’ was recorded for each response and is available for inclusion in further analysis:

- Language used by the respondent,
- Status, i.e. complete or incomplete,
- Time it took to take the survey,
- The time of day the survey was done
- Country where the survey was done, and
- Number of the last question answered.

Other data elements that could be added for future analysis include:

- The browser used,
- The device used (Computer, Mobile or Tablet), and
- The operating system.

All responses to ‘Don’t know’ were segregated from the analysis except where requested.

Derived Questions

A ‘derived question’ is a question with its own identifier, and is associated with responses from a survey question that:

- Has had the responses grouped in some way, i.e. responses to age or ‘Under 18’ and ‘19-29’ combined as response value ‘Under 30’ as well as ‘80+’ and ‘66-80’ combined as response ‘Over 65’,
- Has had only a subset of the survey responses included because one or more of the question choices lacked sufficient numbers to be included in the analysis. (In such case those responses have been excluded.), or that
- Have, for the efficiency of processing, had only a subset of the survey responses included based on some criteria, e.g. Patients that had their first treatment at a private clinic were males and were aged 30-45. None of this type of question was necessary in this analysis.

Outliers

Outliers were used in two ways in the analysis:

- To highlight where an analytical value (e.g. the percentage age of males who face financial difficulties in France) is different enough to be worthy of noting. The standard outlier equation was modified to use a multiplier of .5 rather than the standard multiplier of 1.5, resulting in the following:
    - Lower fence = 1st quartile – (interquartile range * .5)
    - Upper fence = 3rd quartile + (interquartile range * .5)

  Some discretion has been used where an analytic value was very near + or - to either of the fences.

- To exclude countries because they lacked sufficient responses to be comparable to the responses from other countries. The lower fence formula, as above, was used on the range of the number of responses from each country in each analysis. Regardless of the value of the lower fence, if a country had less than 10 responses it was excluded from the analysis.

List of Tables