2018 IKCC PATIENT SURVEY
-UNITED STATES-

Prepared for:
International Kidney Cancer Coalition
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TABLE OF CONTENTS

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 Mexican 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 Mexican 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:

- o Those that demonstrate Global Outliers,
- o Those that demonstrate notable differences, and
- o 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 India, 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?
- When was the option of a clinical trial first discussed with patients?

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

- Of those who were asked to participate, what sources of information were they using for clinical trials?
- 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- United States

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 including younger patients who fall outside the typical patient demographic;

- Provide decision aid tools to enhance sub-type understanding for newly diagnosed patients, thereby enabling them to best participate in shared decision making with their healthcare team about future treatment;

- Explore best practices in the United States related to healthcare communication with patients upon diagnosis, for enhanced patient awareness of their sub-type and greater understanding about their disease, treatments and guidelines;

- 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 particularly upon initial diagnosis to ensure they are equipped and comfortable in making their decision about participating. This is of particular importance in the United States, given the considerable need for information on the part of patients who seek to educate themselves before making an informed decision;

- 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 affected their lives, and provide patients with the resources and tools for the psychological and physical support they need. Particular attention should be paid to patients who may be often overlooked including for example those with localised RCC and with no evidence of the disease, or who had been told they were cured;

- Advocate for change, and support patients who struggle with barriers standing in the way of receiving quality care;

- Bring specific attention and focus to the particular struggles of patient sub groups who may for whatever reason go unnoticed by the healthcare community, including for example younger patients, females, and those with rarer sub-types, so 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- United States

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 States had 233 respondents, or 12% of the global total.

- 74% of those responding to the survey were kidney cancer patients while the remaining 26% defined themselves as a caregiver, family member or friend of the patient.

- 48% of respondents were males (54% globally), and 52% females (45% globally).

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

- Survey respondents were in the following stages of kidney cancer:
  - Localised kidney cancer (9% compared to 23% globally),
  - Metastatic (58% compared to 44% globally), and
  - No evidence/told they were cured (34%).

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 United States 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.

Healthcare teams in the United States are among the best globally at communicating with patients about their sub-type upon original diagnosis, and treatments and guidelines available to them. There is the possibility of exploring best practices related to healthcare communication with patients during this crucial period on the patient timeline.

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 favorable outcome.

Knowledge of sub-type upon initial diagnosis is a foundational piece of information of which all patients should be aware. Although 22% of patients in the United States were not told their sub-type, this was a considerably better result compared to results globally.

Upon initial diagnosis, patients in the United States had the greatest lack of understanding about their sub-type compared to their understanding of other aspects of their disease.

Although patients in the United States were diagnosed notably earlier than those globally, younger patients (30-45 yrs.) took the longest to be correctly diagnosed.

Year of Diagnosis

- American patients who responded to this survey were diagnosed in the following years:
  o 7% prior to 2005,
  o 1% in 2005,
  o 1% in 2006,
  o 2% in 2007,
  o 5% in 2008,
  o 2% in 2009,
  o 3% in 2010,
  o 5% in 2011,
  o 4% in 2012,
  o 3% in 2013,
  o 8% in 2014,
  o 11% in 2015,
  o 11% in 2016,
  o 22% in 2017, and
  o 12% in 2018.

Success of Timely Diagnosis

- Patients in the United States were in the following stages of their kidney cancer when they were first diagnosed:
  o 44% in Stages 1 or 2 (53% globally),
  o 20% in Stage 3, and
  o 34% in Stage 4 (26% globally).

- Following their first visit to the doctor, 67% of patients in the United States were correctly diagnosed in less than a month (52% globally), while
  o 13% were diagnosed in 1-3 months (a Global Outlier compared to 26% globally),
  o 9% in 3-6 months,
  o 6% in 6 months to a year, and
  o 4% in more than one year.

- Patients in the United States were diagnosed at:
  - A family doctor or GP's office (36% compared to 20% globally),
  - An emergency department (29% a Global Outlier, compared to 12% globally),
  - A community, local or general hospital (13% compared to 37% globally),
  - A major cancer centre[4] (9%),
  - A private clinic (7%), and
  - Some other facility (7%).

- According to Table 1, there was no notable difference in the length of time taken to diagnose male versus female patients in the United States, with 80% of males diagnosed in less than 3 months compared to 82% of females.

Table 1
Notable Differences for
Time of Diagnosis by Gender

TIME OF DIAGNOSIS	Male	Female	Notable Differences
Less than month	67%	68%	
1-3 months	13%	14%	
3-6 months	11%	8%	
6 months-1 year	3%	9%	6%
More than 1 year	6%	3%	
LEGEND			
Most negative			
Most positive			

- As shown in Table 2, younger patients in the United States took notably longer to be diagnosed, with 66% of those 30-45 yrs. diagnosed within the first three months, compared to 84% of those 46-65 yrs., and 85% of those aged 66+ yrs.

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[4] Including 7% 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	45%	71%	74%
1-3 months	21%	13%	11%
3-6 months	10%	8%	9%
6 months-1 year	14%	4%	7%
More than 1 year	10%	4%	0%
LEGEND			
Most negative			
Most positive			

Patient Knowledge and Understanding

- After their initial diagnosis 22% of patients in the United States were not told their sub-type (a Global Outlier, compared to 38% globally), and
  - 16% had no understanding of their stage,
  - 44% had no understanding of their sub-type[6],
  - 22% had no understanding of their treatment options,
  - 13% had no understanding of their treatment recommendations (19% globally),
  - 26% had no understanding of the risk of recurrence, and
  - 22% had no understanding of their likelihood of survival.

- As shown in Table 3, at the time of diagnosis:
  - Compared to clear cell patients, notably more patients with other sub-types had less understanding about their stage or sub-type,
  - Clear cell patients had notably less understanding about their risk of recurrence and likelihood of survival than patients with other sub-types; and
  - Both clear cell patients and those with other sub-types had the greatest lack of understanding about their sub-type (41% of those with clear cell and 54% of those with other sub-types).

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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

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

NO UNDERSTANDING	Clear Cell	Other Sub-types	Notable Differences
Stage	15%	22%	7%
Sub-type	41%	54%	13%
Treatment options	23%	20%	
Treatment recommendations	13%	13%	
Risk of recurrence	28%	19%	9%
Likelihood of survival	23%	16%	7%
LEGEND			
Most negative			
Most positive			

- At the time of the survey, 2% of patients in the United States were still not aware of their sub-type (11% globally).

- The 98% who were aware reported the following RCC sub-types:
  - Clear cell (76%, a Global Outlier, compared to 62% globally)
  - Papillary (7%),
  - Chromophobe (4%),
  - Unclassified (3%),
  - XP11 Translocation Type (1%),
  - VHL (3%),
  - Renal Medullary (0%),
  - Collecting Duct (0%),
  - Transitional Cell Carcinoma (0%),
  - Renal Sarcoma (0%),
  - Wilms Tumour (0%),
  - Benign Tumour (1%),
  - Other (2%).

- At the time of the survey, patients in the United States also had no understanding of the following:
  - Biopsies for kidney cancer (11% compared to 20% globally),
  - Surgical options (4%).
  - Immunotherapy (17% a Global Outlier, compared to 26% globally),
  - Targeted therapies (19%),
  - Radiation therapies (27%),
  - Ablative therapies (42%),
  - Palliative care (28% compared to 33% globally),
  - Active surveillance (15% a Global Outlier, compared to 29% globally),
  - Nutrition/lifestyle (7% a Global Outlier, compared to 14% globally),
  - Complementary therapies (32% compared to 39% globally),
  - Guidelines for kidney cancer care (15% compared to 20% globally), or for
  - Guidelines for kidney cancer follow up (10% compared to 17% globally).

III. **Clinical Trials**

Every kidney cancer patient in the United States 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 United States 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.

Compared to global results, although the healthcare community in the United States has been notably more proactive in approaching RCC patients about their participation, there is still untapped potential for the recruitment of individuals who would be willing to participate in a clinical trial. This would not only improve the quality of care and survivorship of RCC patients but also serve as a vehicle to advance cancer research.

89% of patients who had never been approached to participate in a clinical trial reported they would have been amenable had they been asked to do so. This combined with the high rate of willingness of patients to help with kidney cancer research through their participation, along with the positive experience of those who had actually participated indicates an obvious opportunity to improve the quality of care and survivorship of patients through research.

American patients who were asked to participate in a clinical trial needed notably more information than other patients globally, as evidenced by the fact that they consulted the greatest number of sources available to them.

Compared to patients globally, although notably more patients were asked to participate in clinical trials in the United States, 74% were asked after surgery, after other treatments, or once they were left with no other treatment options.

Patients who HAD DISCUSSIONS about clinical trials

- According to survey results, clinical trials had not been discussed with 32% of patients in the United States.

- Of those who had discussions about clinical trials, those discussions had occurred with:
  o Another patient (22% a Global Outlier, compared to 12% globally),
  o Doctors (85%, compared to 75% globally),
  o Spouses, friends or family (28%),
  o Nurses (17%, compared to 10% globally),
  o Patient organisations (20%), and
  o Online groups (40% a Global Outlier, compared to 15% globally).

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

- 60% of patients in the United States had never been asked to participate in a clinical trial (70% globally).

- Of American patients who had never been asked to participate in a clinical trial, 89% said it said it was 'fairly likely'[7] they would do so if asked.

- Of the patients in the United States who said they would be fairly likely[8] to do so, they were being treated at:
  o Community/ local /general hospitals (27% compared to 37% globally),
  o Major cancer centres[9] (54% compared to 45% globally),
  o 13% at private clinics (6% globally), and
  o 2% at 'other'.

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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 (35% compared to 30% globally).

- Of the 89% of American patients who said it would be 'fairly likely' they would participate in a clinical trial:
  - 28% said they would be 'likely' to participate (a Global Outlier, compared to 38% globally), while
  - 72% would require more information to make a decision of whether or not to do so (a Global Outlier, compared to 62% globally).

- Of patients in the United States 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 (26% compared to 38% globally),
  - Major cancer centres[10] (48%), and
  - Private clinics (18% a Global Outlier, compared to 7% globally), and
  - 3% at 'other'.

- Patients in the United States who would be fairly likely to participate in a clinical trial consisted of:
  - 91% of those with localised RCC,
  - 89% of those with metastatic RCC, and
  - 91% of those with no evidence of the disease, or who had been told they were cured.

- 58% of patients in the United States 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 (19% compared to 28% globally),
  - Major cancer centres[11] (55% compared to 47% globally),
  - Private clinics (13% a Global Outlier, compared to 9% globally).

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[10] Including major cancer centres with kidney cancer specialists (29%)
[11] Including major cancer centres with kidney Cancer specialists (52% compared to 30% globally),

Patients who HAD BEEN ASKED to participate in a clinical trial

- Of the patients in the United States who were asked to participate in a clinical trial[12]:
  - 23% of their initial discussions were with another patient (a Global Outlier, compared to 9% globally),
  - 95% with doctors (88% globally),
  - 37% with spouses, family or friends (31% globally),
  - 25% with nurses (15% globally),
  - 15% with patient organisations,
  - 35% with online groups (a Global Outlier, compared to 16% globally), and
  - 1% had no previous discussion with anyone.

- Compared to patients globally, when asked to participate in a clinical trial, patients in the United States consulted the highest number of sources available to educate themselves about the possibility of doing so[13].

- The option of a clinical trial was first discussed with:
  - 26% upon diagnosis,
  - 52% of patients after surgery,
  - 18% after other treatments, and
  - 4% left with no other treatment options.

- For patients in the United States who had the option of a clinical trial first discussed with them after surgery:
  - 9% were being treated at community/local or general hospitals (18% globally),
  - 84% at major cancer centres[14] (72% globally), and
  - 2% at private clinics., and
  - 0% at 'other'.

- When the option of a clinical trial was discussed with patients:
  - 44% understood very well the risks and benefits of participating,
  - 43% had at least some understanding, and

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[12] Of those patients asked to participate in a clinical trial in the United States, these trials were discussed with the highest number of different sources than in any other country.
[13] Further details are available in the IKCC Global Report
[14] Including major cancer centres with kidney cancer specialists (68% compared to 57% globally),

- o   13% had a very limited understanding.

- Of those in the United States who were asked to participate in a clinical trial, 83% agreed.

- Those who agreed to participate did so because:
  - o   Their doctor recommended it (64% compared to 55% globally),
  - o   They thought it might offer better care (70% compared to 61% globally),
  - o   They wanted a specific type of treatment (20% compared to 13% globally),
  - o   It was their only option for treatment (17% compared to 22% globally),
  - o   They wanted to help kidney cancer research (52% compared to 39% globally), and
  - o   Affordability, financial reasons (14%).

- 91% of patients in the United States who participated in a clinical trial were either 'very satisfied' or 'satisfied', and of those:
  - o   58% were 'very satisfied' (44% globally),
  - o   33% 'satisfied' (46% globally), and
  - o   10% were very dissatisfied.

- Those patients who had either never been asked to participate in a clinical trial or who had declined their participation provided the following reasons for their unwillingness to participate:
  - o   Lack of enough information to make a decision (31% compared to 19% globally),
  - o   Not eligible for the trial (23%),
  - o   Distrust of clinical trials (12% compared to 21% globally),
  - o   Fear of placebo (15%),
  - o   Fear of uncertainty (31% compared to 26% globally),
  - o   Extra tests or interventions required (27% compared to 18% globally),
  - o   Geographic distance (19%),
  - o   Affordability, financial costs (12% compared to 7% globally),
  - o   Not available at my hospital (8% compared to 14% globally),
  - o   Toxicity of treatment (23%), and
  - o   Other (19%).

IV. **Quality of Care**

Kidney cancer has a profound effect on the lives of patients in the United States 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 United States 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 must be paid to more heavily impacted patient sub groups such as females, those in the localised stage of the disease, or who had no evidence of the disease, or who had been told they were cured, as they often go unnoticed by the healthcare community, thus ensuring universal psychosocial support for all patients.

There is a role for IKCC and its Affiliate Organisations to play in the United States to advocate for change and to provide support for patients who struggle with barriers to quality care. Compared to global results, although American patients experienced notably fewer barriers, special attention should be given to younger patients, females and those with rarer sub-types who are bearing the brunt of these barriers, preventing them from attaining a better quality of life.

Metastatic patients, male patients, and those diagnosed in 2014 and later in the United States experienced the greatest number of physical conditions per patient compared to their counterparts in other countries. However, there is evidence to suggest that physical conditions may be improving.

Although male and female patients have a similar biological experience with RCC, male patients in the United States were more notably impacted than female patients by a number of physical conditions.

Compared to patients globally, patients in the United States were impacted by the greatest number of psychosocial issues, and reported the greatest number of 'difficult times' per patient. Female patients were impacted by the greatest number of psychosocial issues per patient than female patients in other countries

Surprisingly, patients with localised RCC, and those who had no evidence of the disease, or been told they were cured, were impacted notably more than metastatic patients by a number of psychosocial issues. In fact, they were impacted considerably more than their peers worldwide for a number of these issues.

Despite the fact that 96% of patients in the United States were impacted by psychosocial issues, and a high percentage were finding their doctors to be helpful when they did reach out, 41% of patients in the United States were not communicating their emotional issues to their healthcare team.

Compared to patients globally, RCC patients in the United States faced notably fewer barriers to receiving quality care. However, within the United States, overall, younger patients (30-45 yrs.), females and those with rarer sub-types were experienced notably more barriers.

Treatment for Kidney Cancer

- According to survey results, 4% of American patients had not had any treatment for their kidney cancer after their first diagnosis.

- At the time of the survey, 6% of patients in the United States had not been receiving any treatments at all.

- As shown in Table 4, for their first treatment,
    o 44% had received them from community/local or general hospitals,
    o 46% at major cancer centres[15] (38% globally), and
    o 3% from private clinics.

- Of those patients in the United States who had been receiving treatments since that time:
    o 18% had been receiving them from community/local or general hospitals (31% globally),
    o 65% from major cancer centres[16] (51% globally), and
    o 9% from private clinics.

- As can be seen in Table 4, there was a notable migration of patients initially treated at community/local or general hospitals particularly to major cancer centres, as evidenced by a decline of 26% in community/local or general hospitals, and an increase of 19% at major cancer centres.

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

PLACE OF TREATMENT	First Treatment	Subsequent Treatments	Notable Differences
Community/local/general hospitals	44%	18%	-26%
Major cancer centres	46%	65%	19%
Private clinics	3%	9%	6%

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[15] Including major cancer centres with kidney cancer specialists (28%),
[16] Including major cancer centres with kidney cancer specialists (47%)

Physical Conditions

- As can be seen in Table 5, 8% of American patients had not been 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,
  - Sleeplessness,
  - Aching joints, and by
  - Muscle weakness.

- Patients in the United States were affected considerably more by changes in taste and smell and by hair colour change than patients globally.

- They were also more notably affected by a number of other physical conditions listed in the Table.

Table 5
Notable Differences between the United States and Global Results for
Physical Conditions

PHYSICAL CONDITIONS	Global	United States	Notable Differences
NOT AFFECTED	8%	8%	
Fatigue	66%	76%	10%
Trouble concentrating	24%	29%	5%
Mucositis/mouth ulcers	17%	11%	6%
Muscle weakness	32%	35%	
Pain related to surgery	29%	26%	
Bowel changes	33%	43%	10%
Loss of appetite	25%	32%	7%
Changes in taste and smell	25%	34%	9%
Sleeplessness	31%	36%	5%
Itching	17%	20%	
Hair loss	13%	17%	
Change of hair colour	17%	25%	8%
Memory loss	13%	16%	
Changes in sexual function	15%	20%	5%
Aching joints	22%	35%	13%
Sore feet and hands	23%	25%	
Weight loss	24%	26%	
Cramps	11%	10%	
Fluid retention	12%	10%	
Skin reactions	17%	16%	
Nausea and vomiting	22%	24%	
LEGEND			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			

- As shown in Table 6, males were impacted notably more than females by a number of physical conditions that affected their physical well-being.

**Table 6
Notable Differences in the United States for
Physical Conditions by Gender**

PHYSICAL CONDITION	Males	Females	Notable Differences
NOT AFFECTED	3%	13%	10%
Fatigue	83%	69%	14%
Trouble concentrating	28%	30%	
Mucositis/mouth ulcers	14%	9%	5%
Muscle weakness	38%	31%	7%
Pain related to surgery	28%	24%	
Bowel changes	46%	41%	5%
Loss of appetite	40%	25%	15%
Changes in taste and smell	42%	26%	16%
Sleeplessness	36%	36%	
Itching	23%	17%	6%
Hair loss	6%	27%	21%
Change of hair colour	32%	19%	13%
Memory loss	16%	16%	
Changes in sexual function	34%	6%	28%
Aching joints	32%	38%	6%
Sore feet and hands	25%	25%	
Weight loss	33%	19%	14%
Cramps	12%	7%	5%
Fluid retention	10%	11%	
Skin reactions	22%	10%	12%
Nausea and vomiting	25%	23%	
LEGEND			
Most negative			
Most positive			

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

- For example, in the United States female patients were considerably more affected by hair loss than female patients in other countries.

- Male patients in the United States were impacted by the greatest number of physical conditions per patient compared to male patients globally[17].

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[17] Further details are available in the IKCC Global Report

Table 7
Global Outliers for the United States
Physical Conditions by Gender

PHYSICAL CONDITION	Males	Females
Fatigue	83%	
Trouble concentrating	28%	
Loss of appetite	40%	
Change of hair colour	32%	
Hair loss		27%
LEGEND		
Negative Global Outlier for the United States		
Positive Global Outlier for the United States		

- Table 8 shows physical conditions affecting patients in the United States depending on their year of diagnosis.

- For example, patients diagnosed in 2014 or later were affected notably more by:
  o Changes in taste and smell,
  o Muscle weakness, and by
  o Sleeplessness.

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

PHYSICAL CONDITION	Prior to 2014	2014 and Later	Notable Differences
NOT AFFECTED	11%	7%	
Fatigue	74%	78%	
Trouble concentrating	28%	30%	
Mucositis/mouth ulcers	17%	9%	8%
Muscle weakness	31%	37%	6%
Pain related to surgery	24%	28%	
Bowel changes	44%	43%	
Loss of appetite	31%	33%	
Changes in taste and smell	29%	36%	7%
Sleeplessness	33%	38%	5%
Itching	22%	18%	
Hair loss	22%	14%	8%
Change of hair colour	29%	23%	6%
Memory loss	22%	12%	10%
Changes in sexual function	22%	18%	
Aching joints	38%	34%	
Sore feet and hands	24%	25%	
Weight loss	25%	27%	
Cramps	10%	9%	
Fluid retention	14%	9%	5%
Skin reactions	24%	12%	12%
Nausea and vomiting	29%	21%	8%
LEGEND			
Most negative			
Most positive			

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

- For example, American patients diagnosed in 2014 and later were considerably more affected by bowel changes than patients diagnosed at that time in other countries.

- Patients diagnosed in 2014 and later in the United States 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 the United States
Physical Conditions by Year of Diagnosis

PHYSICAL CONDITION	Prior to 2014	2014 and Later
NOT AFFECTED		7%
Bowel changes		43%
Changes in taste and smell		36%
Aching joints		34%
LEGEND		
Negative Global Outlier for the United States		
Positive Global Outlier for the United States		

- As shown in Table 10, metastatic RCC patients in the United States were notably more impacted by physical conditions than patients in other stages of the disease.

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

Table 10
Notable Differences in the United States for
Physical Conditions by Stage

PHYSICAL CONDITION	Localised RCC	Metastatic RCC	No Evidence/ Cured
NOT AFFECTED	29%	3%	11%
Fatigue	57%	91%	59%
Trouble concentrating	14%	43%	11%
Mucositis/mouth ulcers	0%	18%	3%
Muscle weakness	14%	47%	20%
Pain related to surgery	21%	28%	24%
Bowel changes	14%	60%	26%
Loss of appetite	29%	48%	6%
Changes in taste and smell	7%	55%	5%
Sleeplessness	36%	43%	29%
Itching	7%	22%	15%
Hair loss	0%	21%	11%
Change of hair colour	7%	43%	3%
Memory loss	0%	24%	8%
Changes in sexual function	21%	21%	12%
Aching joints	14%	43%	24%
Sore feet and hands	7%	34%	12%
Weight loss	14%	39%	8%
Cramps	0%	16%	2%
Fluid retention	7%	12%	9%
Skin reactions	7%	24%	6%
Nausea and vomiting	7%	33%	11%
LEGEND			
Most negative			
Most positive			

- Table 11 illustrates Global Outliers for physical conditions that affected patients' well-being in the United States by stage.

- For example, patients with metastatic RCC were considerably more affected by changes in taste and smell than metastatic patients in other countries.

- Metastatic patients in the United States were impacted by the greatest number of physical conditions per patient compared to metastatic patients in other countries.[19]

Table 11
Global Outliers for the United States
Conditions Affecting Physical Well-being by Stage

PHYSICAL CONDITION	Localised RCC	Metastatic RCC	No Evidence/ cured
NOT AFFECTED	29%		
Hair loss	0%		
Changes in taste and smell		55%	
Trouble concentrating			11%
Muscle weakness			20%
Pain related to surgery			24%
Hair loss			11%
Aching joints			24%
Sore feet and hands			12%
LEGEND			
Negative Global Outlier for the United States			
Positive Global Outlier for the United States			

Psychosocial Issues

- As can be seen in Table 12, since their initial diagnosis, 4% of American patients were not affected by psychosocial issues.

- Of those impacted, disease related anxiety was the issue that affected them the most followed by the fear of recurrence.

- Patients in the United States were impacted considerably more than patients globally by:
  - Depression,
  - Isolation, and by
  - Difficulty on the job or in school.

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

- They were affected notably more than patients globally by:
  - General and disease related anxiety,
  - Sexuality,
  - Relationships with friends/others, and by
  - Loss or reduction in employment.

- Patients in the United States were impacted by the greatest number of psychosocial issues per patient compared to patients in other countries.[20]

Table 12
Notable Differences between the United States and Global Results for
Psychosocial Issues

PSYCHOSOCIAL ISSUE	Global	United States	Notable Differences
NOT AFFECTED	4%	4%	
General anxiety	31%	37%	6%
Disease-related anxiety	60%	70%	10%
Fear of dying	44%	44%	
Fear of recurrence	50%	52%	
Depression	27%	42%	15%
Isolation	16%	25%	9%
Changes in relationships	28%	30%	
Difficulty on the job or in school	19%	26%	7%
Stress related to financial issues	28%	32%	
Loss or reduction in employment	20%	26%	6%
Difficulty navigating the healthcare system	14%	18%	
Problems getting life or health insurance	13%	13%	
Concerns about body image/physical appearance	22%	26%	
Relationships with friends/others	18%	23%	5%
Sexuality	14%	22%	8%
LEGEND			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			

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

- According to Table 13, females in the United States were affected notably more overall than males by psychosocial issues.

- Female patients were also affected more notably than male patients by:
  - General anxiety, and by
  - Fear of recurrence.

- Males were affected notably more than females by:
  - Fear of dying
  - Difficulty on the job or in school,
  - Relationships with friends/others, and by
  - Sexuality.

Table 13
Notable Differences in the United States for
Psychosocial Issues by Gender

PSYCHOSOCIAL ISSUE	Males	Females	Notable Differences
NOT AFFECTED	8%	1%	7%
General anxiety	34%	40%	6%
Disease-related anxiety	71%	69%	
Fear of dying	51%	38%	13%
Fear of recurrence	40%	63%	23%
Depression	41%	43%	
Isolation	23%	27%	
Changes in relationships	31%	29%	
Difficulty on the job or in school	29%	23%	6%
Stress related to financial issues	30%	33%	
Loss or reduction in employment	27%	25%	
Difficulty navigating the healthcare system	18%	18%	
Problems getting life or health insurance	13%	13%	
Concerns about body image/physical appearance	27%	25%	
Relationships with friends/others	26%	19%	7%
Sexuality	30%	14%	16%
LEGEND			
Most negative			
Most positive			

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

- For example, both males and females were considerably more impacted by isolation than male and female patients in other countries.

- Both male and female patients in the United States were impacted the most by the number of psychosocial issues per patient compared to male and female patients in other countries[21].

Table 14
Global Outliers for the United States
Psychosocial Issues by Gender

PSYCHOSOCIAL ISSUE	Males	Females
Depression		43%
Isolation	23%	27%
Concerns about body image	27%	
Relationships with friends/others	26%	
LEGEND		
Negative Global Outlier for the United States		
Positive Global Outlier for the United States		

- As shown in Table 15, patients in the United States diagnosed prior to 2014 were impacted notably more than those diagnosed in 2014 and later by:
  o Fear of recurrence,
  o Problems getting life/health insurance, and by
  o Sexuality.

- Those diagnosed in 2014 and later were impacted more notably by:
  o General anxiety,
  o Fear of dying,
  o Depression, and by
  o Concerns about body image/physical appearance.

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[21] Further details is available in the IKCC Global Report

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

PSYCHOSOCIAL ISSUE	Prior to 2014	2014 and Later	Notable Differences
NOT AFFECTED	4%	4%	
General anxiety	32%	40%	8%
Disease-related anxiety	68%	71%	
Fear of dying	32%	51%	19%
Fear of recurrence	57%	49%	8%
Depression	31%	48%	17%
Isolation	24%	25%	
Changes in relationships	31%	30%	
Difficulty on the job or in school	26%	26%	
Stress related to financial issues	34%	30%	
Loss or reduction in employment	24%	27%	
Difficulty navigating the healthcare system	18%	18%	
Problems getting life or health insurance	20%	9%	11%
Concerns about body image/physical appearance	20%	29%	9%
Relationships with friends/others	24%	22%	
Sexuality	26%	20%	6%
LEGEND			
Most negative			
Most positive			

- Table 16 shows Global Outliers for psychosocial issues affecting patients' emotional well-being in the United States by year of diagnosis.

- For example, American patients diagnosed in 2014 and later were considerably more affected by depression, isolation, and concerns about body image than patients diagnosed at the same time in other countries.

- Patients in the United States diagnosed both prior to and after 2014 were impacted by the greatest number of physical conditions per patient compared to patients diagnosed during those times in other countries.[22]

Table 16
Global Outliers for the United States
Psychosocial Issues by Year of Diagnosis

PSYCHOSOCIAL ISSUE	Prior to 2014	2014 and Later
Depression	31%	48%
Difficulty on the job or in school	26%	
Difficulty navigating the healthcare system	18%	
Isolation		25%
Concerns about body image/physical appearance		29%
LEGEND		
Negative Global Outlier for the United States		
Positive Global Outlier for the United States		

- Table 17 illustrates psychosocial issues that affected patients in the United States by stage.

- For example, those with localised or metastatic RCC were most impacted by disease related anxiety, while those with no evidence of RCC, or who had been told they were cured, were most impacted by the fear of recurrence.

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

Table 17
Notable Differences between Stages of RCC for
Psychosocial Issues in the United States

PSYCHOSOCIAL ISSUE	Localised RCC	Metastatic RCC	No Evidence/ cured
NOT AFFECTED	0%	5%	5%
General anxiety	36%	32%	45%
Disease-related anxiety	64%	72%	68%
Fear of dying	43%	48%	39%
Fear of recurrence	50%	30%	85%
Depression	43%	43%	41%
Isolation	7%	31%	20%
Changes in relationships	36%	36%	20%
Difficulty on the job or in school	7%	32%	18%
Stress related to financial issues	43%	32%	27%
Loss or reduction in employment	14%	33%	14%
Difficulty navigating the healthcare system	29%	18%	15%
Problems getting life or health insurance	7%	11%	17%
Concerns about body image/physical appearance	21%	31%	18%
Relationships with friends/others	29%	27%	15%
Sexuality	21%	25%	14%
LEGEND			
Most negative			
Most positive			

- Table 18 illustrates Global Outliers for psychosocial issues that affected patient emotional well-being in the United States by stage.

- For example, those in all stages of RCC in the United States were considerably more impacted by depression than their peers in other countries.

- Patients in all stages of RCC in the United States were impacted by the greatest number of psychosocial per patient compared to patients in other countries.[23]

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

Table 18
Global Outliers for the United States
Psychosocial Issues by Stage

PSYCHOSOCIAL ISSUE	Localised RCC	Metastatic RCC	No Evidence/ cured
NOT AFFECTED		5%	
Depression	43%	43%	41%
Difficulty navigating the healthcare system	29%		
Relationships with friends/others	29%		
Sexuality	21%		
Isolation		31%	20%
Difficulty on the job or in school		32%	
General anxiety			45%
Concerns about body image			18%
LEGEND			
Negative Global Outlier for the United States			
Positive Global Outlier for the United States			

Patient Timeline- Most Difficult Times

- According to Table 19, American patients experienced the most difficult times during the process of diagnosis, waiting for surgery or scan results and for surgery and recovery afterwards.

- They were affected more notably than patients globally:
  - During the surveillance period and by
  - Follow up scans.

- Compared to patients globally, patients in the United States were affected by the gretest number of difficult times per patient compared to patients globally.[24]

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

Table 19
Notable Differences between the United States and Global Results for
Most Difficult Times for RCC Patients

MOST DIFFICULT TIME	Global	United States	Notable Differences
NOT AFFECTED	2%	0%	
During the process of diagnosis	51%	52%	
Surveillance period	19%	26%	7%
Surgery & recovery afterwards	38%	40%	
Follow up scans	17%	23%	6%
Waiting for surgery or scan results	37%	40%	
Diagnosis of recurrence	21%	19%	
Treatment for recurrence	10%	10%	
Diagnosis of further disease progression	23%	22%	
Dealing with side effects of treatment	29%	33%	
Transition to palliative care	4%	2%	
Long term adjustment, survivorship	12%	10%	
LEGEND			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			

- As shown in Table 20, compared to male patients, female patients in the United States were more notably impacted:
  - During the process of diagnosis,
  - During the surveillance period,
  - Surgery and recovery afterwards,
  - Follow up scans,
  - Waiting for surgery or scan results, and by
  - Long term adjustment/survivorship.

- Male patients in the United States were more notably impacted by:
  - Treatment for recurrence,
  - Diagnosis of further disease progression, and in
  - Dealing with the side effects of treatment.

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

MOST DIFFICULT TIME	Males	Females	Notable Differences
NOT AFFECTED	0%	1%	
During the process of diagnosis	48%	55%	7%
Surveillance period	17%	35%	18%
Surgery and recovery afterwards	32%	47%	15%
Follow up scans	20%	26%	6%
Waiting for surgery or scan results	37%	43%	6%
Diagnosis of recurrence	21%	17%	
Treatment for recurrence	13%	8%	5%
Diagnosis of further disease progression	28%	15%	13%
Dealing with side effects of treatment	45%	23%	22%
Transition to palliative care	4%	0%	
Long term adjustment, survivorship	7%	14%	7%
LEGEND			
Most negative			
Most positive			

- Table 21 illustrates Global Outliers for patients' most difficult times in the United States by gender.

- For example, male American patients were considerably more affected in dealing with the side effects of treatment than male patients in other countries.

- Female patients in the United States were affected by the greatest number of difficult times per patient than female patients in other countries.[25]

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

Table 21
Global Outliers for the United States for
Most Difficult Times by Gender

MOST DIFFICULT TIME	Males	Females
NOT AFFECTED	0%	
Surveillance period		35%
Dealing with side effects of treatment	45%	
LEGEND		
Negative Global Outlier for the United States		
Positive Global Outlier for the United States		

Communication and Support from Healthcare Professionals

- Of those patients in the United States who experienced psychosocial issues 59% said they communicated the issues to a healthcare professional (50% globally), while 41% had not done so (50% globally).

- In the United States:
  - 53% were very open and told the doctor everything in great detail (47% globally),
  - 31% shared some of their issues, but not to the full extent,
  - 14% held back some details and minimized their symptoms and side effects or chose not to communicate their issues at all, and
  - 1% had not had the opportunity to communicate their issues at all (6% globally).

- Of patients in the United States who chose to tell the doctor or everything in great detail about their psychosocial issues this was the case for:
  - 55% of male patients and 52% of female patients,
  - 48% of patients[26] 30-45 yrs. (39% globally),
  - 55% of those 46-65 yrs. (49% globally), and
  - 52% of those 66+ yrs.

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[26] Due to insufficient sample sizes, data was not reported for the Under 30 age bracket.

- For those who communicated their issues 94% of patients found their doctors to be helpful, while this had not been the case for the remaining 6%.

- 58% found them to be 'very helpful' (a Global Outlier, compared to 50% globally) and 36% 'somewhat helpful' (42% globally).

Barriers to Receiving Quality Care

- Patients in the United States had the following types of healthcare coverage:
  o Government healthcare (31% a Global Outlier, compared to 73% globally),
  o Private insurance (81% a Global Outlier, compared to 39% globally),
  o Self-coverage (6%, compared to 14% globally), and
  o Family coverage (4%).

- As Table 22 shows, compared to global results, patients in the United States were notably less affected overall by barriers to receiving quality care (53% compared to 39% globally).

- They were affected most by the lack of a locally available specialty doctor.

- They were affected notably more than patients globally by the lack of a locally available specialty doctor.

Table 22
Notable Differences between the United States and Global Results for
Barriers to Receiving Quality Care

BARRIER TO RECEIVING QUALITY CARE	Global	United States	Notable Differences
NOT AFFECTED	39%	53%	14%
Lack of affordability, cost of treatment	21%	9%	12%
Lack of access to treatment centre (travel)	13%	10%	
Inability to understand the treatment	6%	0%	6%
Lack of access to up-to-date treatment/equipment	14%	7%	7%
Wait time to treatment was longer than necessary	14%	10%	
Lack of personal support	13%	10%	
No specialty doctor available locally	9%	22%	13%
Difficulty managing career/caregiver role while in treatment	9%	7%	
Fear of discrimination by my employer/ friends/ family	5%	7%	
No available treatments	5%	4%	
LEGEND			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			

- According to Table 23, younger patients (30-45 yrs.) in the United States were affected overall by notably more barriers than older age groups, particularly those 66+ yrs.

Table 23
Notable Differences in the United States for
Barriers to Receiving Quality Care by Age[27]

BARRIER TO RECEIVING QUALITY CARE	30-45 yrs.	46-65 yrs.	66+ yrs.
NOT AFFECTED	41%	53%	60%
Lack of affordability, cost of treatment	21%	8%	4%
Lack of access to treatment centre (travel)	10%	13%	2%
Inability to understand the treatment	0%	0%	0%
Lack of access to up-to-date treatment/equipment	0%	9%	7%
Wait time to treatment was longer than necessary	10%	11%	7%
Lack of personal support	14%	10%	9%
No specialty doctor available locally	17%	23%	24%
Difficulty managing career/caregiver role while in treatment	17%	7%	0%
Fear of discrimination by my employer/ friends/ family	7%	8%	0%
No available treatments	0%	4%	7%
LEGEND			
Most negative			
Most positive			

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

- For example, American patients aged 46-65 yrs. were considerably more negatively affected by lack of access to a locally available specialty doctor than patients of the same age in other countries.

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

Table 24
Global Outliers for the United States for
Barriers to Receiving Quality Care by Age[28]

BARRIER TO RECEIVING QUALITY CARE	30-45 yrs.	46-65 yrs.	66+ yrs.
No available treatments	0%		
Lack of access to up to date treatment/equipment	0%		
Lack of locally available specialty doctor		23%	
LEGEND			
Negative Global Outlier for the United States			
Positive Global Outlier for the United States			

- As Table 25 indicates female patients in the United States overall were notably more affected by barriers to receiving quality care than were male patients.

- They were also more notably affected by:
  - Lack of affordability/cost of treatment,
  - Difficulty managing career/caregiver role during treatment, and by
  - Fear of discrimination.

- Female patients were considerably more negatively affected in not having a specialty doctor locally available than female patients in other countries.

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

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

BARRIER TO RECEIVING QUALITY CARE	Male	Female	Notable Differences
NOT AFFECTED	62%	44%	18%
Lack of affordability, cost of treatment	5%	13%	8%
Lack of access to treatment centre (travel)	8%	12%	
Inability to understand the treatment	0%	0%	
Lack of access to up-to-date treatment/equipment	8%	6%	
Wait time to treatment was longer than necessary	11%	9%	
Lack of personal support	10%	10%	
No specialty doctor available locally	12%	32%	20%
Difficulty managing career/caregiver role while in treatment	4%	9%	5%
Fear of discrimination by my employer/ friends/ family	3%	10%	7%
No available treatments	5%	4%	
LEGEND			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			

- As shown in Table 26, patients in the United States with other sub-types experienced notably more barriers overall in receiving quality care than patients with clear cell RCC.

- Patients with other sub-types were affected notably more than clear cell patients for the fear of discrimination.

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

BARRIER TO RECEIVING QUALITY CARE	Clear Cell	Other sub-types	Notable Differences
NOT AFFECTED	**55%**	**44%**	11%
Lack of affordability, cost of treatment	10%	7%	
Lack of access to treatment centre (travel)	10%	11%	
Inability to understand the treatment	0%	0%	
Lack of access to up-to-date treatment/equipment	7%	7%	
Wait time to treatment was longer than necessary	10%	11%	
Lack of personal support	9%	13%	
No specialty doctor available locally	22%	22%	
Difficulty managing career/caregiver role while in treatment	7%	7%	
Fear of discrimination by my employer/ friends/ family	**5%**	**13%**	8%
No available treatments	4%	7%	
LEGEND			
Most negative			
Most positive			

- Table 27 shows Global Outliers for barriers to receiving quality care in the United States by sub-type.

- For example, patients with other sub-types in the United States were affected considerably more by the fear of discrimination than their peers in other countries.

Table 27
Global Outliers for the United States for
Barriers to Receiving Quality Care by Sub-type[29]

BARRIER TO RECEIVING QUALITY CARE	Clear cell	Other Sub-type
Lack of access to up to date treatment/equipment		**7%**
Fear of discrimination		**13%**
LEGEND		
Negative Global Outlier for the United States		
Positive Global Outlier for the United States		

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[29] Due to insufficient data results are not reported for under 30rs.

V. **Opportunities to Improve Care**
There is an opportunity for IKCC and its Affiliate Organisations to improve survivorship of patients in the United States by empowering patients through education to advocate for regular surveillance despite gender, age or stage.

Surveillance

- At the time of the survey, patients in the United States were in the following stages of their RCC:
  - 7% were in Stage 1 or 2 (13% globally),
  - 1% in Stage 3 (8% globally),
  - 53% in Stage 4 (40% globally),
  - 28% had no evidence of the disease (19% globally),
  - 3% had been told they were cured (10% globally), and
  - 1% had died.

- Their last follow up scan occurred:
  - Less than one year ago (93% compared to 85% globally),
  - 1-3 years ago (6%), and
  - More than 3 years ago (1%).

- Most recent follow up scans had occurred more than three years ago for:
  - 0% of those in Stage 1 or 2[30],
  - 0% of those in Stage 4,
  - 3% of those who had no evidence of the disease or had been told they were cured,

  - 0% of those aged 30-45 yrs.[31],
  - 1% of those aged 46-65,
  - 2% of those aged 66+ yrs.,

  - 1% of males,
  - 1% of females,

  - 0% of those with no understanding of kidney cancer guidelines (5% globally), and
  - 0% of those with no understanding of the guidelines for kidney cancer follow up (5% globally).

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[30] Due to insufficient data, results are not reported for Stage 3 or for patients who had died.
[31] Due to insufficient data, results are not reported for the under 30 yr. age brackets

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 United States 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. There is urgency required as evidenced by a possible decline in shared decision making for patients diagnosed in recent years.

22% of RCC patients in the United States had their treatment plans decided for them solely by their doctors. This was particularly the case for those being treated in major cancer centres and for younger patients.

There is a possibility that shared decision making in the United States has declined for patients diagnosed since 2016.

- 22% of patients in the United States were not engaged at all in their treatment plans, in that their doctor had decided their treatment plan solely for them (a Global Outlier, compared to 29% globally),

- Of those patients who were involved in their treatment decision:
    - 6% made the decision by themselves,
    - 63% made a joint decision with their doctors (51% globally), and
    - 8% were asked for input from their doctors.

- The following helped American patients with their treatment plans:
    - Partner/spouse (68% compared to 56% globally),
    - Parents (13%),
    - Children (22%),
    - Friends/other family members (21%),
    - Local family doctor (21%), and
    - A patient organisation (10%).

- 14% of patients made the decision by themselves, and for 2%, the decision rested on their personal financial situation.

- Of those patients in the United States where their treatment plans were decided for them by their doctors:
  - 26% were being treated in community centres/local or general hospitals (34% globally),
  - 51% at major cancer centres[32] (45% globally), and
  - 15% 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:[33]
  - 25% of those aged 30-45 yrs.,
  - 23% of those aged 46-65 yrs. (30% globally),
  - 17% of those aged 66+ yrs. (27% globally),

  - 21% of those in Stage 1 or 2,
  - 20% of those in Stage 4[34] (a Global Outlier, compared to 30% globally),
  - 22% of those who had no evidence of the disease or who were told they were cured (a Global Outlier, compared to 31% globally),

  - 22% of male patients (28% globally),
  - 22% of female patients (a Global Outlier, compared to 30% globally)

  - 18% of those diagnosed prior to 2016 (28% globally) and
  - 27% of those diagnosed 2016 and later.

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[32] Including major cancer centres with kidney cancer specialists (34%),
[33] Due to insufficient sample size, data is not reported for the under 30 age brackets.
[34] Due to insufficient sample sizes, data is not available for Stage 3 or for patients who had died.

Acknowledgements

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