2018 IKCC PATIENT SURVEY
-India-

Prepared for:
International Kidney Cancer Coalition
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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:

- 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 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- India

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 females who fall outside the typical patient demographic;

- Provide decision aid tools to enhance sub-type knowledge for newly diagnosed patients, particularly for those with clear cell RCC, thereby enabling them to best participate in shared decision making with their healthcare team about future 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 of RCC patients by encouraging male and middle aged patients in particular to share with their doctors their experiences about how kidney cancer has impacted their lives especially for physical conditions. Provide patients with the resources and tools for the psychological support they need;

- Explore best practices pertaining to the unique experience of patients in India, and their relative lack of impact from psychological issues;

- Advocate for change and provide support to patients who struggle with barriers standing in the way of receiving quality care, paying particular attention to sub groups such as clear cell and older patients;

- 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 where there is evidence of physician directed care.

SURVEY RESULTS- India

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:
- India had 140 respondents, or 7% of the global total.

- 35% of those responding to the survey were kidney cancer patients (a Global Outlier compared to 71% globally) while the remaining 65% defined themselves as a caregiver, family member or friend of the patient (a Global Outlier compared to 29% globally).

- 56% of respondents were males, and 42% were females, while 2% did not self-identify,

- Survey respondents had the following age profile:
  - Under 18 (2%),
  - 18-29 (6%),
  - 30-45 (32% compared to 20% globally),
  - 46-65 (50% compared to 57% globally), and
  - 66+ (9% compared to 20% globally).

- Survey respondents were in the following stages of kidney cancer:
  - Localised kidney cancer (73% a Global Outlier compared to 23% globally),
  - Metastatic (17% a Global Outlier compared to 44% globally), and
  - No evidence/told they were cured (10% a Global Outlier compared to 33% globally).

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 India 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.

61% of patients in India were not told their sub-type upon initial diagnosis, the highest lack of patient awareness for any country. Globally, patients also reported among the greatest lack of understanding of this foundational piece of information of which all RCC patients should be aware. Patients in India with clear cell RCC reported among the worst understanding of their sub-type compared to patients with rarer sub-types.

Compared to patients in other countries, patients in India also reported the greatest lack of understanding per patient of kidney cancer treatments and guidelines.

Older patients (66+ yrs.) as well as female patients in India took the longest to be correctly diagnosed, with females falling outside the expected demographic of an RCC patient (profiled as being typically older and male).

Year of Diagnosis

- Patients from India who responded to this survey had been diagnosed in the following years:
  - 1% prior to 2005,
  - 0% in 2005
  - 0% in 2006,
  - 0% in 2007,
  - 3% in 2008,
  - 1% in 2009,
  - 4% in 2010,
  - 1% in 2011,
  - 2% in 2012,
  - 4% in 2013,
  - 5% in 2014,
  - 10% in 2015,
  - 23% in 2016,
  - 28% in 2017, and
  - 17% in 2018.

Success of Timely Diagnosis

- Patients in India were in the following stages of their kidney cancer when they were first diagnosed:
  - 41% were in Stages 1 or 2 (still only within the kidney) compared to 53% globally,
  - 41% were in Stage 3 (cancer was still locally advanced), a Global Outlier, compared to 20% globally, and
  - 17% were in Stage 4 (the cancer had spread) compared to 26% globally.

- Following their first visit to the doctor, 35% of patients from India were correctly diagnosed in less than a month (compared to 52% globally), while
  - 54% were diagnosed in 1-3 months (a Global Outlier, compared to 26% globally),
  - 7% in 3-6 months,
  - 3% in 6 months to a year, and
  - 2% in more than one year.

- 9% of patients in India were diagnosed at a family doctor or GP's office (20% globally),
  - 4% were diagnosed in at an emergency department (12% globally),
  - 37% were diagnosed in at a community, local or general hospital,
  - 24% were diagnosed in at a major cancer centre[4] (13% globally),
  - 26% were diagnosed in at a private clinic (a Global Outlier, compared to 11% globally), and
  - 0% were diagnosed in at some other facility (7% globally).

- According to Table 1, females in India took notably longer to be diagnosed than male patients, with 91% of male patients diagnosed in less than three months compared to 83% of females (82% of males and 73% of females globally).

Table 1
Notable Differences for
Time of Diagnosis by Gender

TIME OF DIAGNOSIS	Male	Female	Notable Differences
Less than month	33%	36%	
1-3 months	58%	47%	11%
3-6 months	4%	11%	7%
6 months-1 year	3%	4%	
More than 1 year	1%	2%	
LEGEND			
Most negative			
Most positive			

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[4] Including 10% for major cancer centres with kidney cancer specialists

- As shown in Table 2, older patients in India took notably longer to be diagnosed with 100% of those under 30 yrs. diagnosed within the first three months (82% globally), compared to 75% of those aged 66+ yrs. (83% globally).

Table 2
Notable Differences for
Time of Diagnosis by Age

TIME OF DIAGNOSIS	Under 30 yrs.	30-45 yrs.	46-65 yrs.	66+ yrs.
Less than month	60%	45%	24%	33%
1-3 months	40%	45%	64%	42%
3-6 months	0%	5%	8%	17%
6 months-1 year	0%	2%	3%	8%
More than 1 year	0%	2%	2%	0%
LEGEND				
Most negative				
Most positive				

Patient Knowledge and Understanding

- After their initial diagnosis 61% of patients in India were not told their sub-type (a Global Outlier, compared to 38% globally), and
  - o 27% had no understanding of their stage (20% globally),
  - o 41% had no understanding of their sub-type[5],
  - o 21% had no understanding of their treatment options,
  - o 39% had no understanding of their treatment recommendations (a Global Outlier, compared to 19% globally),
  - o 31% had no understanding of the risk of recurrence, and
  - o 35% had no understanding of their likelihood of survival (a Global Outlier, compared to 25% globally).

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[5] 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.

- As shown in Table 3, at the time of diagnosis:
  - Notably more patients in India with clear cell RCC had less understanding about critical aspects of their disease than patients with other sub-types, and
  - Both clear cell patients and those with other sub-types had the greatest lack of understanding for treatment recommendations and sub-type.

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

NO UNDERSTANDING	Clear Cell	Other Sub-types	Notable Differences
Stage	29%	23%	6%
Sub-type	46%	32%	14%
Treatment options	27%	10%	17%
Treatment recommendations	48%	32%	16%
Risk of recurrence	37%	29%	8%
Likelihood of survival	39%	27%	12%
LEGEND			
Most negative			
Most positive			

- At the time of the survey, 32% of patients in India were still not aware of their sub-type (a Global Outlier, compared to 11% globally).

- The 68% who were aware reported the following RCC sub-types:
  - Clear cell (45% a Global Outlier, compared to 62% globally),
  - Papillary (6%),
  - Chromophobe (1%),
  - Unclassified (1%),
  - XP11 Translocation Type (0%),
  - VHL (1%),
  - Renal Medullary (1%),

- o Collecting Duct (0%),
- o Transitional Cell Carcinoma (0%),
- o Renal Sarcoma (2%),
- o Wilms Tumour (3%),
- o Benign Tumour (1%),
- o Other (6%).

- At the time of the survey, patients in India also had no understanding of the following:
  - o Biopsies for kidney cancer (29% compared to 20% globally),
  - o Surgical options (19% compared to 8% globally),
  - o Immunotherapy (61% a Global Outlier, compared to 26% globally),
  - o Targeted therapies (48% a Global Outlier, compared to 23% globally),
  - o Radiation therapies (36% compared to 29% globally),
  - o Ablative therapies (53% compared to 41% globally),
  - o Palliative care (52% a Global Outlier, compared to 33% globally),
  - o Active surveillance (38% compared to 29% globally),
  - o Nutrition/lifestyle (15%),
  - o Complementary therapies (43%),
  - o Guidelines for kidney cancer care (22%), or for
  - o Guidelines for kidney cancer follow up (11% compared to 17% globally).

- Patients in India reported the greatest lack of understanding per patient of the treatments and guidelines for kidney cancer listed above compared to patients in other countries.[6]

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

III. Clinical Trials

Every kidney cancer patient in India 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 India 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 India has not been proactive in approaching RCC patients about their possible participation in clinical trials, as evidenced by the majority who were asked only after they had been left with no other treatment options.

The fact that 75% of patients who had never been approached to participate reported they would be fairly likely to do so if asked, particularly if provided with the necessary information to make the decision, and the high satisfaction experienced by those who had actually participated, indicates an obvious lost opportunity to improve the quality of care and survivorship of RCC patients through research.

Compared to global results, considerably more patients in India had the option of a clinical trial discussed with them upon diagnosis. Even so, there is room for more patients to have this initial discussion earlier in the patient timeline. It is notable that half were approached after surgery rather than upon initial diagnosis.

Patients who HAD DISCUSSIONS about clinical trials

- According to survey results, clinical trials were not discussed with 22% of patients in India (33% globally).

- Of those who had discussions about clinical trials, those discussions had occurred with:
  - Another patient (16%),
  - Doctors (94% compared to 75% globally),
  - Spouses, friends or family (12% compared to 31% globally),
  - Nurses (8%),
  - Patient organisations (13% compared to 19% globally), and
  - Online groups (1% a Global Outlier compared to 15% globally).

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

- 65% of patients in India had never been asked to participate in a clinical trial (70% globally).

- Of patients in India who had never been asked to participate in a clinical trial[7], 75% said it said it 'fairly likely'[8] they would do so if asked.

- Of the patients in India who said they would be fairly likely[9] to do so, they were being treated[10] at:
  - Community/ local /general hospitals (19%),
  - Major cancer centres[11] (73%),
  - Private clinics (6%), and
  - 0% at 'other'.

- Of the 75% of patients in India who said it would be 'fairly likely' they would participate in a clinical trial[12]:
  - 10% said they would be 'likely' to participate, and
  - 90% said they would require more information to make a decision of whether or not to do so.

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[7] Due to insufficient sample size, data is reported for India but cannot be compared to global results (n=64)
[8] 'Fairly likely is the combined result of 'Likely' and 'Maybe; would need more information".
[9] 'Fairly likely' is the combined result of 'Likely' and 'Maybe; would need more information'.
[10] Due to insufficient sample size, data is reported for India but cannot be compared to global results (n=48)
[11] Including major cancer centres with kidney cancer specialists (48%).
[12] Due to insufficient sample size, data is reported for India but cannot be compared to global results (n=48)

- Of patients in India who said they would need more information before they agreed to participate in a clinical trial, these patients were being treated at[13]:
  o Community/ local /general hospitals (21%),
  o Major cancer centres[14] (70%), and
  o Private clinics (7%).

- Of those patients in India who would be 'fairly likely' to participate in a clinical trial if asked[15], this would be the case for 78% of patients with localised RCC (87% globally).

- In India compared to other countries, notably more clear cell RCC patients had never been asked to participate in a clinical trial (70% compared to 50% of those with other sub-types, a Global Outlier, compared to 77% globally).

  Patients who HAD BEEN ASKED to participate in a clinical trial
- Of the patients in India who were asked to participate in a clinical trial:
  o 6% of their initial discussions were with another patient ,
  o 97% with doctors (88% globally),
  o 3% with spouses, family or friends (31% globally),
  o 3% with nurses (15% globally),
  o 6% with patient organisations (18% globally),
  o 0% with online groups (16% globally), and
  o 0% had no previous discussion with anyone.

- Compared to patients globally, when asked to participate in a clinical trial, patients in India consulted the fewest number of sources available to educate themselves about this possibility[16].

- The option of a clinical trial had first been discussed with:
  o 48% upon diagnosis (a Global Outlier, compared to 24% globally),
  o 48% of patients after surgery,

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[13] Due to insufficient sample size, data is reported for India but cannot be compared to global results (n=43)
[14] Including major cancer centres with kidney cancer specialists (49%)
[15] Due to insufficient sample size data is not reported for either metastatic RCC patients or for those who had no evidence of the disease or had been told they were cured.
[16] Further details are available in the IKCC Global Report

- o 3% after other treatments (a Global Outlier, compared to 21% globally), and
- o 0% who were left with no other treatment options (6% globally).

- For patients in India who had the option of a clinical trial first discussed with them after surgery:
  - o 27% were being treated at community/local or general hospitals (18% globally),
  - o 40% at major cancer centres[17] (72% globally), and
  - o 33% at private clinics (a Global Outlier compared to 3% globally).

- When the option of a clinical trial was discussed with patients:
  - o 21% understood very well the risks and benefits of participating (47% globally),
  - o 76% had at least some understanding (a Global Outlier, compared to 41% globally), and
  - o 3% had a very limited understanding (12% globally).

- Of those in India who were asked to participate in a clinical trial, 94% agreed (86% globally).

- Those who agreed to participate did so because:
  - o Their doctor recommended it (19% a Global Outlier, compared to 55% globally),
  - o They thought it might offer better care (23% a Global Outlier, compared to 61% globally),
  - o They wanted a specific type of treatment (6% compared to 13% globally),
  - o It was their only option for treatment (58% a Global Outlier, compared to 22% globally),
  - o They wanted to help kidney cancer research (3% a Global Outlier, compared to 39% globally), and
  - o Affordability, financial reasons (3% compared to 13% globally).

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[17] Including major cancer centres with kidney cancer specialists (13% a Global Outlier compared to 57% globally),

- 96% of patients in India were either 'very satisfied' or 'satisfied' (90% globally) with the experience, and of those:
    - 23% were 'very satisfied' (44% globally),
    - 73% were 'satisfied' (46% globally), and
    - 3% were very dissatisfied (10% globally).

- 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:
    - Lack of enough information to make a decision (7% compared to 19% globally),
    - Not eligible for the trial (7% compared to 21% globally),
    - Distrust of clinical trials (21%),
    - Fear of placebo (14%),
    - Fear of uncertainty (36% a Global Outlier, compared to 26% globally),
    - Extra tests or interventions required (7% compared to 18% globally),
    - Geographic distance (7% compared to 16% globally),
    - Affordability, financial costs (7%),
    - Not available at my hospital (14%),
    - Toxicity of treatment (21%), and
    - Other (7% compared to 16% globally).

IV. Quality of Care

Kidney cancer has a profound effect on the lives of patients in India 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 India 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 is particularly relevant given the evidence in this report suggesting that compared to global results, physical conditions per patient are greatest in India, and patients are most reticent to fully communicate their psychosocial issues. 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 should be paid to more heavily impacted patient sub groups who often go unnoticed by the healthcare community, to ensure universal psychosocial support for all patients.

The unique experience of patients in India related to their relative lack of impact from psychological issues presents an opportunity for the IKCC to explore best practices.

There is a role for IKCC and its Affiliate Organisations to play in India to advocate for change and to provide support for patients who struggle with barriers to quality care. This is particularly relevant given that patients in India experienced notably more barriers than patients in other countries. Middle aged patients and those with clear cell RCC experienced the greatest number of barriers per patient than their counterparts in other countries.

Overall, RCC patients in India were impacted considerably more than patients globally by conditions affecting their physical well-being.

Compared to patients in other countries, patients in India were affected by the least number of psychosocial issues and difficult times per patient.

Female patients and those with localised RCC in India were also affected by the least number of psychosocial issues per patient.

Despite the fact that 96% of patients in India suffered from psychosocial issues and a high percentage were finding their doctors to be helpful when they did reach out, compared to global results, patients were considerably less open in communicating their psychosocial issues to their doctors. This was particularly the case for male and middle aged patients.

RCC patients in India experienced notably more barriers to receiving quality care per patient compared to patients in other countries. Patients aged 46+ yrs. and those with clear cell RCC in India experienced the greatest number of barriers to care per patient than their counterparts in other countries.

Treatment for Kidney Cancer

- According to survey results, 2% of patients from India had not had any treatment for their kidney cancer after their first diagnosis.

- At the time of the survey, 1% of patients in India were not receiving any treatments at all (7% globally).

- As shown in Table 4, for their first treatment,
  o 26% received them from community/local or general hospitals (47% globally),
  o 61% at major cancer centres[18] (38% globally), and
  o 11% from private clinics.

- Of those patients in India who had been receiving treatments since that time:
  o 19% had been receiving them from community/local or general hospitals (31% globally),
  o 62% from major cancer centres[19] (51% globally), and
  o 18% from private clinics (a Global Outlier compared to 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 7% in community/local or general hospitals , and an increase of 7% to major cancer centres.

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

PLACE OF TREATMENT	First Treatment	Subsequent Treatments	Notable Differences
Community/local/general hospitals	26%	19%	-7%
Major cancer centres	61%	62%	
Private clinics	11%	18%	7%

[18] Including major cancer centres with kidney cancer specialists (34% compared to 26% globally),
[19] Including major cancer centres with kidney cancer specialists (33%)

Physical Conditions

- As can be seen in Table 5, 2% of patients from India 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 affecting them the most, followed by muscle weakness.

- Patients in India were impacted considerably more than patients globally by:
  o Mucositis/mouth ulcers,
  o Muscle weakness,
  o Sore feet and hands,
  o Weight loss, and by
  o Skin reactions.

- They were considerably less impacted than patients globally by:
  o Pain related to surgery, and by
  o Bowel changes.

- Compared to global results, they were notably less impacted by memory loss and changes in sexual function, and notably more by nausea and vomiting.

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

PHYSICAL CONDITIONS	Global	India	Notable Differences
NOT AFFECTED	8%	**2%**	6%
Fatigue	66%	64%	
Trouble concentrating	24%	24%	
Mucositis/mouth ulcers	17%	**40%**	23%
Muscle weakness	32%	**56%**	24%
Pain related to surgery	29%	**22%**	7%
Bowel changes	33%	**11%**	22%
Loss of appetite	25%	28%	
Changes in taste and smell	25%	21%	
Sleeplessness	31%	35%	
Itching	17%	21%	
Hair loss	13%	16%	
Change of hair colour	17%	20%	
Memory loss	13%	**5%**	8%
Changes in sexual function	15%	**2%**	13%
Aching joints	22%	26%	
Sore feet and hands	23%	**30%**	7%
Weight loss	24%	**31%**	7%
Cramps	11%	10%	
Fluid retention	12%	15%	
Skin reactions	17%	**31%**	14%
Nausea and vomiting	22%	**33%**	11%
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:
  - Fatigue,
  - Pain related to surgery,
  - Sleeplessness,
  - Itching,

- o   Aching joints and by
- o   Weight loss.

- Females were impacted notably more than males by:
  - o   Trouble concentrating,
  - o   Mucositis/mouth ulcers,
  - o   Muscle weakness,
  - o   Bowel changes,
  - o   Changes in taste and smell, and by
  - o   Hair loss.

Table 6
Notable Differences in India for
Physical Conditions by Gender

PHYSICAL CONDITION	Males	Females	Notable Differences
NOT AFFECTED	3%	0%	
Fatigue	70%	54%	16%
Trouble concentrating	21%	27%	6%
Mucositis/mouth ulcers	36%	44%	8%
Muscle weakness	53%	63%	10%
Pain related to surgery	27%	17%	10%
Bowel changes	6%	15%	9%
Loss of appetite	29%	25%	
Changes in taste and smell	20%	25%	5%
Sleeplessness	41%	27%	14%
Itching	24%	19%	5%
Hair loss	14%	19%	5%
Change of hair colour	21%	17%	
Memory loss	6%	4%	
Changes in sexual function	1%	4%	
Aching joints	30%	21%	9%
Sore feet and hands	27%	31%	
Weight loss	37%	25%	12%
Cramps	10%	10%	
Fluid retention	13%	17%	
Skin reactions	33%	31%	
Nausea and vomiting	29%	38%	9%
LEGEND			
Most negative			
Most positive			

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

- For example, in India both male and female patients were considerably worse off for mucositis/mouth ulcers and with muscle weakness than male and female patients in other countries.

Table 7
Global Outliers for India
Physical Conditions by Gender

PHYSICAL CONDITION	Males	Females
Mucositis/mouth ulcers	36%	44%
Muscle weakness	53%	63%
Bowel changes	6%	15%
Pain related to surgery		17%
Sore feet and hands		31%
Nausea and vomiting		38%
Memory loss		4%
Weight Loss	37%	
Skin reactions	33%	31%
LEGEND		
Negative Global Outlier for India		
Positive Global Outlier for India		

- As Table 8 shows, patients diagnosed in 2014 and later were most negatively affected by fatigue and muscle weakness.

- They were considerably more affected than patients globally diagnosed at that time by:
  o Mucositis/mouth ulcers,
  o Muscle weakness,
  o Sore feet and hands, and by
  o Weight loss.

- And considerably less affected than those diagnosed at the same time globally by:
  - Pain related to surgery and by
  - Bowel changes.

- They were notably less affected than patients globally by:
  - Fatigue,
  - Changes in taste and smell,
  - Memory loss, and by
  - Changes in sexual function,

- And notably more affected by:
  - Change of hair colour,
  - Skin reactions, and by
  - Nausea and vomiting.

Table 8
Notable Differences between India and Global Results
Physical Conditions for Patients Diagnosed 2014 and Later[20]

PHYSICAL CONDITION	Global	2014 and Later	Notable Differences
NOT AFFECTED	6%	2%	
Fatigue	67%	59%	8%
Trouble concentrating	24%	24%	
Mucositis/mouth ulcers	16%	36%	20%
Muscle weakness	33%	57%	24%
Pain related to surgery	30%	20%	10%
Bowel changes	30%	6%	24%
Loss of appetite	26%	24%	
Changes in taste and smell	24%	19%	5%
Sleeplessness	33%	37%	
Itching	17%	20%	
Hair loss	12%	13%	
Change of hair colour	16%	21%	5%
Memory loss	12%	5%	7%
Changes in sexual function	12%	1%	11%
Aching joints	22%	27%	5%
Sore feet and hands	22%	31%	9%
Weight loss	23%	35%	12%
Cramps	9%	11%	
Fluid retention	10%	14%	
Skin reactions	16%	27%	11%
Nausea and vomiting	21%	30%	9%
LEGEND			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			

- As shown in Table 9, patients with localised RCC were most affected by fatigue and muscle weakness.

- Patients in India with localised RCC were considerably more affected than patients globally by:
  - Trouble concentrating,
  - Mucositis/mouth ulcers,

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[20] Due to insufficient sample size, data is not reported for patients diagnosed prior to 2014.

    o Muscle weakness,

    o Change of hair colour and by

    o Nausea and vomiting.

- And considerably less affected than localised RCC patients globally by pain related to surgery.

- They notably less affected than localised patients globally by:
  - o Bowel changes,
  - o Memory loss, and by
  - o Changes in sexual function.

Table 9
Notable Differences between India and Global Results
Physical Conditions for Patients with Localised RCC[21]

PHYSICAL CONDITION	Global	Localised RCC	Notable Differences
NOT AFFECTED	6%	0%	6%
Fatigue	56%	65%	9%
Trouble concentrating	19%	25%	6%
Mucositis/mouth ulcers	16%	39%	23%
Muscle weakness	31%	61%	30%
Pain related to surgery	28%	14%	14%
Bowel changes	20%	14%	6%
Loss of appetite	22%	22%	
Changes in taste and smell	19%	20%	
Sleeplessness	29%	30%	
Itching	15%	22%	7%
Hair loss	11%	14%	
Change of hair colour	10%	19%	9%
Memory loss	10%	3%	7%
Changes in sexual function	12%	3%	9%
Aching joints	18%	25%	7%
Sore feet and hands	17%	26%	9%
Weight loss	22%	29%	7%
Cramps	11%	12%	
Fluid retention	12%	17%	5%
Skin reactions	18%	33%	15%
Nausea and vomiting	22%	33%	11%
LEGEND			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			

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[21] Due to insufficient sample size, data is not reported for patients with metastatic RCC or for patients with no evidence of the disease or who had been told they were cured.

Psychosocial Issues

- As can be seen in Table 10, 4% of patients in India had not had their sense of emotional well-being impacted by psychosocial issues since their initial diagnosis.

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

- Compared to patients globally, patients in India were considerably less impacted by:
  o Fear of recurrence,
  o Changes in relationships,
  o Difficulty on the job or in school,
  o Concerns about body image, and by
  o Relationships with friends/others.

- They were more notably impacted than patients globally by stress related to financial issues and less notably by:
  o Loss or reduction in employment, and by their
  o Sexuality.

- Patients in India were affected by the least number of psychosocial issues per patient compared to those in other countries.[22]

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

Table 10
Notable Differences between India and Global Results for
Psychosocial Issues

PSYCHOSOCIAL ISSUE	Global	India	Notable Differences
NOT AFFECTED	4%	4%	
General anxiety	31%	35%	
Disease-related anxiety	60%	58%	
Fear of dying	44%	48%	
Fear of recurrence	50%	**26%**	24%
Depression	27%	26%	
Isolation	16%	13%	
Changes in relationships	28%	**13%**	15%
Difficulty on the job or in school	19%	**10%**	9%
Stress related to financial issues	28%	**39%**	11%
Loss or reduction in employment	20%	**10%**	10%
Difficulty navigating the healthcare system	14%	10%	
Problems getting life or health insurance	13%	9%	
Concerns about body image/physical appearance	22%	**14%**	8%
Relationships with friends/others	18%	**10%**	8%
Sexuality	14%	**6%**	8%
LEGEND			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			

- According to Table 11, males in India were affected notably more than females by:
  - o Financial issues,
  - o Difficulty on the job or in school,
  - o Stress related to financial issues, and by
  - o Loss or reduction in employment.

- Females were more notably affected than males by both general and disease-related anxiety.

Table 11
Notable Differences in India for
Psychosocial Issues by Gender

PSYCHOSOCIAL ISSUE	Males	Females	Notable Differences
NOT AFFECTED	4%	4%	
General anxiety	32%	39%	7%
Disease-related anxiety	51%	69%	18%
Fear of dying	49%	47%	
Fear of recurrence	24%	27%	
Depression	25%	24%	
Isolation	13%	14%	
Changes in relationships	14%	12%	
Difficulty on the job or in school	13%	4%	9%
Stress related to financial issues	42%	33%	9%
Loss or reduction in employment	13%	8%	5%
Difficulty navigating the healthcare system	11%	8%	
Problems getting life or health insurance	7%	8%	
Concerns about body image/physical appearance	13%	16%	
Relationships with friends/others	10%	12%	
Sexuality	6%	2%	
LEGEND			
Most negative			
Most positive			

- Table 12 illustrates Global Outliers for psychosocial issues affecting patients' emotional well-being in India by gender.

- For example, both males and females were considerably better off for the fear of recurrence and changes in relationships than male and female patients in other countries.

- Female patients in India were impacted by the least number of psychosocial issues per patient compared to female patients in other countries.[23]

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

Table 12
Global Outliers for India
Psychosocial Issues by Gender

PSYCHOSOCIAL ISSUE	Males	Females
Fear of recurrence	24%	27%
Changes in relationships	14%	12%
Concerns about body image	13%	
Relationships with friends/others	10%	
Difficulty on the job or in school		4%
Loss/reduction in employment		8%
LEGEND		
Negative Global Outlier for India		
Positive Global Outlier for India		

- As shown in Table 13, patients in India who were diagnosed in 2014 and later were mostly affected by disease related anxiety and by the fear of dying.

- Compared to patients globally who were diagnosed in 2014 and later, patients in India were considerably less affected by:
  - Fear of recurrence,
  - Changes in relationships,
  - Concerns about body image, and by
  - Relationships with friends/others.

- Patients in India were affected notably more by stress related to financial issues than patients also diagnosed at that time, and notably less by:
  - Difficulty on the job or in school,
  - Loss or reduction in employment, and by
  - Sexuality.

- Patients in India diagnosed 2014 and later were impacted by the least number of psychosocial issues per patient compared patients diagnosed at the same time in other countries.[24]

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

Table 13
Notable Differences between India and Global Results
Psychosocial Issues for Patients Diagnosed Prior to 2014[25]

PSYCHOSOCIAL ISSUE	Global	2014 and Later	Notable Differences
NOT AFFECTED	3%	3%	
General anxiety	34%	32%	
Disease-related anxiety	62%	58%	
Fear of dying	48%	49%	
Fear of recurrence	51%	**25%**	26%
Depression	30%	31%	
Isolation	16%	15%	
Changes in relationships	28%	**10%**	18%
Difficulty on the job or in school	18%	**11%**	7%
Stress related to financial issues	33%	**39%**	6%
Loss or reduction in employment	19%	**12%**	7%
Difficulty navigating the healthcare system	16%	12%	
Problems getting life or health insurance	12%	9%	
Concerns about body image/physical appearance	22%	**11%**	11%
Relationships with friends/others	18%	**11%**	7%
Sexuality	12%	**5%**	7%
LEGEND			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			

- As shown in Table 14, patients with localised RCC were most impacted by disease related anxiety and by the fear of dying.

- They were considerably less impacted than patients globally by:
  - Fear of recurrence,
  - Changes in relationships,
  - Concerns about body image, and by
  - Relationships with friends/others.

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[25] Due to insufficient sample size data is not available for patients diagnosed prior to 2014.

- They were notably more affected by disease related and general anxiety, the fear of dying and depression than patients globally, and notably less by:
    - Difficulty navigating the healthcare system, and by
    - Problems getting life or health insurance.

- Patients in India with localised RCC were impacted by the least number of psychosocial issues per patient compared to localised RCC patients in other countries.[26]

Table 14
Notable Differences between India and Global Results
Psychosocial Issues for Patients with Localised RCC[27]

PSYCHOSOCIAL ISSUE	Global	Localised RCC	Notable Differences
NOT AFFECTED	4%	4%	
General anxiety	32%	40%	8%
Disease-related anxiety	53%	58%	5%
Fear of dying	43%	51%	8%
Fear of recurrence	50%	26%	24%
Depression	28%	33%	5%
Isolation	14%	15%	
Changes in relationships	26%	8%	18%
Difficulty on the job or in school	17%	8%	9%
Stress related to financial issues	33%	36%	
Loss or reduction in employment	16%	13%	
Difficulty navigating the healthcare system	17%	10%	7%
Problems getting life or health insurance	17%	11%	6%
Concerns about body image/physical appearance	21%	15%	6%
Relationships with friends/others	17%	10%	7%
Sexuality	8%	8%	
LEGEND			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			

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[26] For further detail, see the IKCC Global Report
[27] Due to insufficient sample size, data is not available for patients with metastatic RCC or who had no evidence of the disease or who had been told they were cured.

Patient Timeline- Most Difficult Times

- According to Table 15, compared to patients globally, patients from India were affected considerably more during the process of diagnosis.

- Compared to patients globally, patients in India were considerably less affected by difficult times overall and by:
    - Surgery and recovery afterwards,
    - Waiting for surgery or scan results, and by
    - Diagnosis of recurrence.

- They were less notably impacted than patients globally during the surveillance period.

- Patients in India were affected by among the least number of difficult times per patient compared to patients in other countries.[28]

Table 15
Notable Differences between India and Global Results for
Most Difficult Times for RCC Patients

MOST DIFFICULT TIME	Global	India	Notable Differences
NOT AFFECTED	2%	**7%**	5%
During the process of diagnosis	51%	**63%**	12%
Surveillance period	19%	**13%**	6%
Surgery & recovery afterwards	38%	**27%**	11%
Follow up scans	17%	15%	
Waiting for surgery or scan results	37%	**11%**	26%
Diagnosis of recurrence	21%	**14%**	7%
Treatment for recurrence	10%	11%	
Diagnosis of further disease progression	23%	20%	
Dealing with side effects of treatment	29%	25%	
Transition to palliative care	4%	5%	
Long term adjustment, survivorship	12%	15%	
LEGEND			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			

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

- As shown in Table 16, overall, female patients in India were affected notably more by difficult times than male patients.

- Females were more notably affected than males by:
  o The process of diagnosis,
  o Surveillance period,
  o Follow up scans, and by
  o Long term adjustment, survivorship.

- Males were more notably affected than females by:
  o Waiting for surgery or scan results,
  o Diagnosis of recurrence,
  o Treatment for recurrence, and by
  o Transition to palliative care.

Table 16
Notable Differences in India for
Most Difficult Times by Gender

MOST DIFFICULT TIME	Males	Females	Notable Differences
NOT AFFECTED	11%	2%	9%
During the process of diagnosis	59%	69%	10%
Surveillance period	10%	17%	7%
Surgery and recovery afterwards	27%	29%	
Follow up scans	10%	19%	9%
Waiting for surgery or scan results	13%	8%	5%
Diagnosis of recurrence	17%	10%	7%
Treatment for recurrence	13%	8%	5%
Diagnosis of further disease progression	23%	19%	
Dealing with side effects of treatment	25%	25%	
Transition to palliative care	7%	2%	5%
Long term adjustment, survivorship	8%	23%	15%
LEGEND			
Most negative			
Most positive			

- Table 17 illustrates Global Outliers for patients' most difficult times in India by gender.

- For example, female patients were considerably worse off during the process of diagnosis than female patients in other countries.

- Both male and female patients in India were affected by the least number of difficult times per patient compared to male and female patients in other countries.[29]

Table 17
Global Outliers for India
Most Difficult Times by Gender

MOST DIFFICULT TIME	Males	Females
NOT AFFECTED	11%	
Surveillance period	10%	
Waiting for surgery or scan results	13%	8%
Transition to palliative care	7%	
During the process of diagnosis		69%
Surgery and recovery afterwards		29%
Diagnosis of recurrence		10%
Long term adjustment, survivorship		23%
LEGEND		
Negative Global Outlier for India		
Positive Global Outlier for India		

Communication and Support from Healthcare Professionals

- Of those patients in India who experienced psychosocial issues 60% said they communicated the issues to a healthcare professional (50% globally), while 40% had not done so (50% globally).

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

- In India:
    - 25% were very open and told the doctor everything in great detail (a Global Outlier, compared to 47% globally),
    - 42% shared some of their issues, but not to the full extent (a Global Outlier, compared to 31% globally),
    - 20% held back some details and minimized their symptoms and side effects or chose not to communicate their issues at all (a Global Outlier, compared to 15% globally), and
    - 13% had not had the opportunity to communicate their issues at all (a Global Outlier, compared to 6% globally),

- Of patients in India who chose to tell the doctor or everything in great detail about their psychosocial issues this was the case for:
    - 25% of male patients (a Global Outlier, compared to 52% globally),
    - 25% of female patients (42% globally),
    - 29%[30] of those 30-45 yrs. (39% globally),
    - 20% of those 46-65 yrs. (a Global Outlier, compared to 49% globally), and
    - 36% of those 66+ yrs. (a Global Outlier, compared to 54% globally),

- For those who communicated their issues, 95% of patients found their doctors to be helpful, while this had not been the case for the remaining 5%.

Barriers to Receiving Quality Care
- Patients in India had the following types of healthcare coverage:
    - Government healthcare (13% a Global Outlier, compared to 73% globally),
    - Private insurance (9%, compared to 39% globally),
    - Self-coverage (63% a Global Outlier, compared to 14% globally), and
    - Family coverage (47% a Global Outlier, compared to 6% globally).

- As Table 18 shows, 5% of patients in India had not experienced any barriers to receiving quality care, a notably poorer result compared to patients globally.

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

- They were most affected by lack of affordability and the cost of treatment.

- Patients in India were affected considerably more than patients globally by:
  - Lack of affordability/cost of treatment,
  - Lack of access to a treatment centre, and by
  - Inability to understand the treatment.

- Compared to patients globally, they were more notably affected by:
  - Overall impacts from barriers to receiving quality care,
  - Lack of personal support, and by
  - Lack of an available specialty doctor.

Table 18
Notable Differences between India and Global Results for
Barriers to Receiving Quality Care

BARRIER TO RECEIVING QUALITY CARE	Global	India	Notable Differences
NOT AFFECTED	39%	5%	34%
Lack of affordability, cost of treatment	21%	72%	51%
Lack of access to treatment centre (travel)	13%	26%	13%
Inability to understand the treatment	6%	28%	22%
Lack of access to up-to-date treatment/equipment	14%	12%	
Wait time to treatment was longer than necessary	14%	18%	
Lack of personal support	13%	20%	7%
No specialty doctor available locally	9%	20%	11%
Difficulty managing career/caregiver role while in treatment	9%	6%	
Fear of discrimination by my employer/ friends/ family	5%	6%	
No available treatments	5%	8%	
LEGEND			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			

- As can be seen to in Table 19, patients under 30 yrs. in India were affected by notably fewer barriers compared to older patients.

- However, they were notably more affected by lack of affordability and the cost of their treatment and by a lack of personal support.

Table 19
Notable Differences in India for
Barriers to Receiving Quality Care by Age

BARRIER TO RECEIVING QUALITY CARE	Under 30 yrs.	30-45 yrs.	46-65 yrs.	66+ yrs.
NOT AFFECTED	10%	6%	3%	8%
Lack of affordability, cost of treatment	90%	67%	71%	75%
Lack of access to treatment centre (travel)	10%	28%	27%	25%
Inability to understand the treatment	10%	19%	35%	33%
Lack of access to up-to-date treatment/equipment	10%	14%	10%	17%
Wait time to treatment was longer than necessary	10%	14%	23%	17%
Lack of personal support	20%	31%	16%	8%
No specialty doctor available locally	10%	14%	24%	25%
Difficulty managing career/caregiver role while in treatment	0%	11%	3%	8%
Fear of discrimination by my employer/ friends/ family	0%	8%	3%	17%
No available treatments	0%	14%	5%	8%
LEGEND				
Most negative				
Most positive				

- Table 20 shows Global Outliers for barriers to receiving quality care in India by age[31].

- For example, patients from India 46-65 yrs. were considerably better off for the fear of discrimination than their peers in other countries.

- Patients aged 46+ yrs. in India suffered from the greatest number of barriers to receiving quality care per patient compared patients in that age bracket in other countries.[32]

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[31] Due to a small sample size, results for the under 30 yr. age bracket are not compared to global results (n=10)

Table 20
Global Outliers for India for
Barriers to Receiving Quality Care by Age[33]

BARRIER TO RECEIVING QUALITY CARE	30-45 yrs.	46-65 yrs.	66+ yrs.
NOT AFFECTED			8%
Lack of affordability, cost of treatment		71%	75%
Lack of access to treatment centre (travel)		27%	
Inability to understand the treatment	19%	35%	33%
Lack of access to up-to-date treatment/equipment			
Wait time to treatment was longer than necessary			
Lack of personal support	31%		
No specialty doctor available locally		24%	
Difficulty managing career/caregiver role while in treatment			8%
Fear of discrimination by my employer/ friends/ family		3%	17%
No available treatments			
LEGEND			
Negative Global Outlier for India			
Positive Global Outlier for India			

- As Table 21 indicates, overall, males were notably more affected than females by a lack of access to the most up to date treatments/equipment, and by the fear of discrimination.

- Females were notably more affected than males by lack of access to a treatment centre, and by difficulty managing their career/caregiver role while in treatment.

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[32] For further detail, see the IKCC Global Report
[33] Due tp insufficient data, results are not reported for under 30 yrs.

Table 21
Notable Differences in India for
Barriers to Receiving Quality Care by Gender

BARRIER TO RECEIVING QUALITY CARE	Males	Females	Notable Differences
NOT AFFECTED	4%	6%	
Lack of affordability, cost of treatment	71%	70%	
Lack of access to treatment centre (travel)	23%	32%	9%
Inability to understand the treatment	30%	28%	
Lack of access to up-to-date treatment/equipment	16%	6%	10%
Wait time to treatment was longer than necessary	20%	17%	
Lack of personal support	19%	17%	
No specialty doctor available locally	21%	19%	
Difficulty managing career/caregiver role while in treatment	1%	13%	12%
Fear of discrimination by my employer/ friends/ family	9%	0%	9%
No available treatments	9%	6%	
LEGEND			
Most negative			
Most positive			

- Table 22 illustrates Global Outliers for barriers to receiving quality care in India by gender.

- For example, in India both male and female patients were considerably worse off for being able to understand their treatment than male and female patients in other countries.

Table 22
Global Outliers for India
Barriers to Receiving Quality Care by Gender

PHYSICAL CONDITION	Males	Females
Lack of affordability, cost of treatment	71%	70%
Lack of access to treatment centre (travel)		32%
Inability to understand the treatment	30%	28%
No specialty doctor available locally	21%	
Difficulty managing career/caregiver role while in treatment	1%	
Fear of discrimination by my employer/ friends/ family		0%
LEGEND		
Negative Global Outlier for India		
Positive Global Outlier for India		

- As shown in Table 23, overall, patients with clear cell were notably more affected overall than patients with other sub-types.

- They experienced notably more barriers than patients with other sub-types for:
    - Lack of affordability/cost of treatment,
    - Inability to understand the treatment,
    - Wait times to treatment, and for
    - Lack of a locally available specialty doctor.

- Patients with other sub-types experienced notably more barriers than patients with clear cell RCC for:
    - Lack of access to a treatment centre,
    - Lack of personal support, and for
    - Lack of available treatments.

Table 23
Notable Differences in India for
Barriers to Receiving Quality Care by Sub-Type

BARRIER TO RECEIVING QUALITY CARE	Clear Cell	Other sub-types	Notable Differences
NOT AFFECTED	0%	7%	7%
Lack of affordability, cost of treatment	73%	66%	7%
Lack of access to treatment centre (travel)	18%	34%	16%
Inability to understand the treatment	36%	28%	8%
Lack of access to up-to-date treatment/equipment	14%	17%	
Wait time to treatment was longer than necessary	30%	14%	16%
Lack of personal support	9%	24%	15%
No specialty doctor available locally	30%	10%	20%
Difficulty managing career/caregiver role while in treatment	5%	7%	
Fear of discrimination by my employer/ friends/ family	7%	7%	
No available treatments	2%	21%	19%
LEGEND			
Most negative			
Most positive			

- Table 24 illustrates Global Outliers for barriers to receiving quality care in India by sub-type.

- Compared to clear cell patients globally, clear cell patients in India were considerably worse off experiencing barriers to receiving quality care.

- Clear cell patients in India experienced the greatest number of barriers to receiving quality care per patient compared to clear cell patients globally[34].

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

Table 24
Global Outliers for India
Barriers to Receiving Quality Care by Sub-type

BARRIER TO RECEIVING QUALITY CARE	Clear Cell RCC	Other Sub-types
NOT AFFECTED	**0%**	
Lack of affordability, cost of treatment	**73%**	**66%**
Lack of access to treatment centre (travel)		**34%**
Inability to understand the treatment	**36%**	**28%**
No specialty doctor available locally	**30%**	
Wait time to treatment	**30%**	
Lack of personal support		**24%**
No available treatments		**21%**
LEGEND		
Negative Global Outlier for India		
Positive Global Outlier for India		

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

Surveillance
- At the time of the survey, patients in India were in the following stages of their RCC:
  - 36% were in Stage 1 or 2 (a Global Outlier, compared to 13% globally),
  - 36% in Stage 3 (a Global Outlier, compared to 8% globally),
  - 17% in Stage 4 (a Global Outlier, compared to 40% globally),
  - 1% had no evidence of the disease (19% globally),
  - 8% had been told they were cured (10% globally), and
  - 2% had died.

- Their last follow up scan occurred:
  - Less than one year ago (89%),
  - 1-3 years ago (8%), 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,
  - 3% of those in Stage 3[35],

  - 0% of those 30 yrs. and under,
  - 2% of those aged 30-45 yrs.[36],
  - 0% of those aged 46-65 yrs.,
  - 0% of those aged 66+ yrs. (a Global Outlier, compared to 6% globally),

  - 1% of males,
  - 0% of females, and for

  - 9% of those with no understanding of the guidelines for kidney cancer follow up (a Global Outlier compared to 5% globally).

[35] Due to insufficient data, results are not reported for Stage 4, for a patient who had no evidence of the disease or who had been told they were cured, or for patients who had died.
[36] Due to insufficient data results are not reported for under 30 yrs.

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 India 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 India had their treatment plans decided for them solely by their doctors. This was particularly the case for those being treated in major cancer centres.

Patients in India in the 30-65 yr. age bracket, in Stage 1 or 2 of their disease, and those diagnosed in 2016 and later engaged in considerably less shared decision making with their doctors compared to global results.

- 42% of patients in India 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,
  - 38% made a joint decision with their doctors (51% globally), and
  - 15% were asked for input from their doctors.

- The following helped patients with their treatment plans[37]:
  - Partner/spouse (51%),
  - Parents (23%),
  - Children (23%),
  - Friends/other family members (29%),
  - Local family doctor (27%), and
  - A patient organisation (23%).

- 3% of patients in India made the decision by themselves, and for 11%, the decision rested on their personal financial situation.

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[37] Data available for under 30 yrs. is limited but is not compared to global results (n=75)

- Of those patients in India where their treatment plans were decided for them by their doctors:
    - o 10% were being treated in community centres/local or general hospitals (a Global Outlier, compared to 34% globally),
    - o 66% at major cancer centres[38] (45% globally), and
    - o 24% at private clinics (a Global Outlier, compared to 9% globally).

- In the case where treatment plans were decided solely by the doctor without any input from the patient, this affected[39]:
    - o 36% of those aged 30-45 yrs. (a Global Outlier, compared to 28% globally),
    - o 46% of those aged 46-65 yrs. (a Global Outlier, compared to 30% globally),
    - o 38% of those aged 66+ yrs. (27% globally).

    - o 39% of those in Stage 1 or 2[40] (a Global Outlier, compared to 25% globally),
    - o 35% of those in Stage 3 (20% globally),

    - o 43% of male patients (a Global Outlier, compared to 28% globally),
    - o 42% of female patients (a Global Outlier, compared to 30% globally), and

    - o 41% of those diagnosed in 2016 and later[41] (30% globally).

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[38] Including major cancer centres with kidney cancer specialists (37%, compared to 30% globally),
[39] Due to insufficient sample size, data is not reported for the under 30 age bracket.
[40] Due to insufficient sample sizes, data is not available for Stage 4, for those with no evidence of the disease or who had been told they were cured, or for patients who had died.
[41] Due to insufficient sample sizes, data is not available for patients diagnosed prior to 2016.

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