



# **2018 IKCC PATIENT SURVEY**

## **-Japan-**

**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 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)<sup>1</sup>, 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](mailto:info@ikcc.org)

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<sup>1</sup> <https://www.perceptioninsight.ca>

## Reader's Notes

There are three types of tables in this report:

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

### 1. Global Outlier Tables

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

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

### 2. Tables of Notable Difference

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

'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)<sup>2</sup> 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<sup>3</sup> 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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<sup>2</sup> [www.ikcc.org](http://www.ikcc.org)

<sup>3</sup> <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- Japan

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 and younger patients for example who fall outside the typical patient demographic;
- Provide decision aid tools to enhance patient awareness and understanding for sub-type upon initial diagnosis 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 them to share with their doctors their experiences about how kidney cancer has impacted their lives, and provide patients with the resources and tools for the psychological support they need, particularly for those with localised RCC, or who had no evidence of the disease, or who had been told they were cured;
- Explore best practices pertaining to the unique experience of patients in Japan; their relative lack of impact from physical conditions, and the lack of psychosocial issues on the part of metastatic patients;

- Advocate for change and support patients who struggle with barriers standing in their way of receiving quality care;
- Bring specific attention and focus to the particular struggles of patient sub groups that may for whatever reason go unnoticed by the healthcare community such as younger patients, females, and clear cell patients, 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- Japan**

### **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:**

- Japan had 195 respondents, or 10% of the global total.
- 85% of those responding to the survey were kidney cancer patients (71% globally) while the remaining 15% defined themselves as a caregiver, family member or friend of the patient (29% globally).
- 52% of respondents were males, and 48% were females.
- Survey respondents had the following age profile:
  - Under 18 (0%),
  - 18-29 (2%),
  - 30-45 (25%),
  - 46-65 (63%), and
  - 66+ (11%).
- Survey respondents were in the following stages of kidney cancer:
  - Localised kidney cancer (25%),
  - Metastatic (37% compared to 44% globally), and
  - No evidence/told they were cured (38% 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 Japan 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.***

*41% of patients in Japan were not told their sub-type upon initial diagnosis. Patients in Japan had the greatest lack of understanding about their sub-type, a foundational piece of information of which all RCC patients should be aware. Clear cell RCC patients in Japan also had a more notable lack of understanding of various aspects of their disease than patients with other sub-types.*

*Compared to global results, although notably more RCC patients in Japan were diagnosed in 3 months or less, female patients and younger patients (30-45 yrs.), took notably longer to be correctly diagnosed.*

### **Year of Diagnosis**

- Japanese patients had been diagnosed in the following years:
  - 5% prior to 2005,
  - 2% in 2005
  - 1% in 2006,
  - 1% in 2007,
  - 1% in 2008,
  - 1% in 2009,
  - 3% in 2010,
  - 2% in 2011,
  - 5% in 2012,
  - 6% in 2013,
  - 7% in 2014,
  - 15% in 2015 (10% globally),
  - 19% in 2016 (13% globally),
  - 24% in 2017, and
  - 11% in 2018.

### **Success of Timely Diagnosis**

- Patients in Japan were in the following stages of their kidney cancer when they were first diagnosed:
  - 64% in Stages 1 or 2 , still only within the kidney (53% globally),
  - 16% in Stage 3, cancer was still locally advanced, and
  - 20% in Stage 4, cancer had spread (26% globally).
- Following their first visit to the doctor, 62% of Japanese patients were correctly diagnosed in less than a month (52% globally), while
  - 28% were diagnosed in 1-3 months,
  - 6% in 3-6 months,
  - 3% in 6 months to a year, and
  - 1% in more than one year.
- 19% of patients in Japan were diagnosed at a family doctor or GP's office,
  - 4% at an emergency department (12% globally),
  - 54% at a community, local or general hospital (37% globally),

- 11% at a major cancer centre<sup>4</sup>,
  - 10% at a private clinic, and
  - 3% at some other facility.
- According to Table 1, females in Japan took notably longer to be diagnosed than male patients, with 66% of male patients diagnosed in less than a month compared to 57% of females (55% of males and 48% of females globally).
  - 87% of females were diagnosed in three months or less, compared to 92% of males (73% for females and 82% of males globally).

**Table 1**  
**Notable Differences for**  
**Time of Diagnosis by Gender**

<b>TIME OF DIAGNOSIS</b>	<b>Male</b>	<b>Female</b>	<b>Notable Differences</b>
<b>Less than month</b>	<b>66%</b>	<b>57%</b>	<b>9%</b>
<b>1-3 months</b>	<b>26%</b>	<b>30%</b>	
<b>3-6 months</b>	<b>4%</b>	<b>8%</b>	
<b>6 months-1 year</b>	<b>3%</b>	<b>3%</b>	
<b>More than 1 year</b>	<b>1%</b>	<b>1%</b>	
<b>LEGEND</b>			
<b>Most negative</b>			
<b>Most positive</b>			

- As shown in Table 2, younger patients in Japan took notably longer to be diagnosed with 87% of those 30-45 yrs. diagnosed within the first 3 months (73% globally), compared to 95% aged 66+ yrs. (83% globally).

<sup>4</sup> Including 8% for major cancer centres with kidney cancer specialists

**Table 2**  
**Notable Differences between for**  
**Time of Diagnosis by Age<sup>5</sup>**

TIME OF DIAGNOSIS	30-45 yrs.	46-65 yrs.	66+ yrs.
Less than month	57%	62%	80%
1-3 months	30%	29%	15%
3-6 months	7%	5%	5%
6 months-1 year	4%	3%	0%
More than 1 year	2%	1%	0%
LEGEND			
Most negative			
Most positive			

### **Patient Knowledge and Understanding**

- After their initial diagnosis 41% of Japanese patients were not told their sub-type, and:
  - 17% had no understanding of their stage,
  - 42% had no understanding of their sub-type<sup>6</sup>,
  - 18% had no understanding of their treatment options,
  - 16% had no understanding of their treatment recommendations,
  - 22% had no understanding of the risk of recurrence, and
  - 21% had no understanding of their likelihood of survival.
  
- As shown in Table 3, at the time of diagnosis:
  - Clear cell RCC patients in Japan had a more notable lack of understanding about stage, treatment recommendations, risk of recurrence and the likelihood of survival than patients with other sub-types;
  - Patients with other sub-types had a more notable lack of understanding about their sub-type than clear cell patients; and
  - Both clear cell patients and those with other sub-types had the greatest lack of understanding for sub-type (40% of those with clear cell and 46% of those with other sub-types).

<sup>5</sup> Due to insufficient sample size, data is not available for the under 30 yr. age bracket.

<sup>6</sup> 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	18%	13%	5%
Sub-type	40%	46%	6%
Treatment options	19%	15%	
Treatment recommendations	17%	12%	5%
Risk of recurrence	22%	16%	6%
Likelihood of survival	21%	16%	5%
LEGEND			
Most negative			
Most positive			

- At the time of the survey, 8% of patients in Japan were still not aware of their sub-type.
- The 92% who were aware reported the following RCC sub-types:
  - Clear cell (75% a Global Outlier, compared to 62% globally),
  - Papillary (2%),
  - Chromophobe (8%),
  - Unclassified (2%),
  - XP11 Translocation Type (0%),
  - VHL (0%),
  - Renal Medullary (0%),
  - Collecting Duct (1%),
  - Transitional Cell Carcinoma (2%),
  - Renal Sarcoma (0%),
  - Wilms Tumour (0%),
  - Benign Tumour (1%),
  - Other (4%).

- At the time of the survey, patients in Japan also had no understanding of the following:
  - Biopsies for kidney cancer (24%),
  - Surgical options (4%).
  - Immunotherapy (24%),
  - Targeted therapies (17% compared to 23% globally),
  - Radiation therapies (28%),
  - Ablative therapies (4% compared to 41% globally),
  - Palliative care (40% compared to 33% globally),
  - Active surveillance (58% a Global Outlier, compared to 29% globally),
  - Nutrition/lifestyle (17%),
  - Complementary therapies (75% a Global Outlier, compared to 39% globally),
  - Guidelines for kidney cancer care (16%), or for
  - Guidelines for kidney cancer follow up (27% compared to 17% globally).

### III. Clinical Trials

***Every kidney cancer patient in Japan 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 Japan to participate should they be asked.***

***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.***

*With 91% of patients never having been asked to participate in a clinical trial, there is evidence to suggest that the healthcare community in Japan has not been proactive in approaching RCC patients about their possible participation in this type of research.*

*The fact that 90% of patients who had never been approached to participate in a clinical trial reported they would be fairly likely to do so if asked, particularly if provided with the necessary information to make the decision, along with the very high rates of participation and satisfaction of those who had been asked and participated, indicates an obvious lost opportunity to improve the quality of care and survivorship of RCC patients through research.*

*The majority of patients in Japan had the option of a clinical trial discussed with them after surgery or other treatments rather than upon initial diagnosis. Compared to global results, when the option was discussed with patients, notably fewer patients had a very good understanding about the risks and benefits of participating.*



### **Patients who HAD DISCUSSIONS about clinical trials**

- According to survey results, clinical trials had not been discussed with 50% of patients in Japan (33% globally).
- Of those who had discussions about clinical trials, those discussions had occurred with:
  - Another patient (6% a Global Outlier, compared to 12% globally),
  - Doctors (63% compared to 75% globally),
  - Spouses, friends or family (51% a Global Outlier, compared to 31% globally),
  - Nurses (5% compared to 10% globally),
  - Patient organisations (16%), and
  - Online groups (9% compared to 15% globally).

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

- 91% of patients in Japan had never been asked to participate in a clinical trial (70% globally).
- Of Japanese patients who had never been asked to participate in a clinical trial, 90% said it said it 'fairly likely'<sup>7</sup> they would do so if asked.
- Of the patients in Japan who said they would be fairly likely<sup>8</sup> to do so, they were being treated at:
  - Community/ local /general hospitals (57% a Global Outlier, compared to 37% globally),
  - Major cancer centres<sup>9</sup> (35% compared to 45% globally),
  - 1% at private clinics (6% globally), and
  - 4% at 'other'.
- Of the 90% of Japanese patients who said it would be 'fairly likely' they would participate in a clinical trial:
  - 37% said they would be 'likely' to participate, while
  - 63% 'would require more information to make a decision of whether or not to do so'.

<sup>7</sup> 'Fairly likely' is the combined result of 'Likely' and 'Maybe; would need more information'.

<sup>8</sup> 'Fairly likely' is the combined result of 'Likely' and 'Maybe; would need more information'.

<sup>9</sup> Including major cancer centres with kidney cancer specialists (22% compared to 30% globally).

- Of patients in Japan who said they would need more information before they agreed to participate in a clinical trial, those patients were being treated at:
  - Community/ local /general hospitals (59% a Global Outlier, compared to 38% globally),
  - Major cancer centres<sup>10</sup> (34% compared to 44% globally), and
  - Private clinics (0% compared to 7% globally).
  
- Of those patients in Japan who would be 'fairly likely' to participate in a clinical trial if asked, this would be the case for:
  - 82% of patients with localised RCC (87% globally),
  - 94% of those with metastatic RCC, and
  - 89% of those with no evidence of the disease or were told they were cured.
  
- 89% of patients in Japan with clear cell RCC (a Global Outlier, compared to 67% globally) and 97% 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 (64% a Global Outlier, compared to 28% globally),
  - Major cancer centres<sup>11</sup> (22% compared to 47% globally),
  - Private clinics (0% compared to 9% globally), and
  - Other (11%).

#### **Patients who HAD BEEN ASKED to participate in a clinical trial**

- Of the patients in Japan who were asked to participate in a clinical trial:
  - 0% of their initial discussions had been with another patient (a Global Outlier, compared to 9% globally),
  - 81% with doctors (88% globally),
  - 50% with spouses, family or friends (a Global Outlier, compared to 31% globally),
  - 6% with nurses (15% globally),

<sup>10</sup> Including major cancer centres with kidney cancer specialists (25% compared to 30% globally)

<sup>11</sup> Including major cancer centres with kidney cancer specialists (20% compared to 30% globally),

- 13% with patient organisations (18% globally),
- 6% with online groups (16% globally), and
- 6% had no previous discussion with anyone.
  
- The option of a clinical trial had first been discussed with:
  - 38% upon diagnosis (24% globally),
  - 50% of patients after surgery,
  - 13% after other treatments (21% globally), and
  - 0% who had been left with no other treatment options (6% globally).
  
- When the option of a clinical trial was discussed with patients:
  - 33% understood very well the risks and benefits of participating (47% globally),
  - 60% had at least some understanding (41% globally), and
  - 7% had a very limited understanding (12% globally).
  
- Of those in Japan who had been asked to participate in a clinical trial, 100% had agreed (a Global Outlier, compared to 86% globally).
  
- Those who had agreed to participate did so because:
  - Their doctor recommended it (43% compared to 55% globally),
  - They thought it might offer better care (79% compared to 61% globally),
  - They wanted a specific type of treatment (7% compared to 13% globally),
  - It was their only option for treatment (14% compared to 22% globally),
  - They wanted to help kidney cancer research (36%), and
  - Affordability, financial reasons (50% a Global Outlier compared to 13% globally).
  
- 86% of patients in Japan who participated in a clinical trial were either 'very satisfied' or 'satisfied', and of those:
  - 50% were 'very satisfied' (44% globally),
  - 36% 'satisfied' (46% globally), and
  - 14% 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:
  - Lack of enough information to make a decision (27% compared to 19% globally),
  - Not eligible for the trial (18%),
  - Distrust of clinical trials (9% compared to 21% globally),
  - Fear of placebo (0% a Global Outlier, compared to 18% globally),
  - Fear of uncertainty (27%),
  - Extra tests or interventions required (9% compared to 18% globally),
  - Geographic distance (0% compared to 16% globally),
  - Affordability, financial costs (0% compared to 7% globally),
  - Not available at my hospital (18%),
  - Toxicity of treatment (9% a Global Outlier, compared to 22% globally), and
  - Other (0% a Global Outlier, compared to 16% globally).
  
- Patients in Japan had the least number of reasons per patient for not wanting to participate in a clinical trial compared to patients globally.<sup>12</sup>

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<sup>12</sup> Further detail is available in the IKCC Global Report

#### **IV. Quality of Care**

***Kidney cancer has a profound effect on the lives of patients in Japan as demonstrated by the impact of both physical and psychosocial issues, and the barriers standing in the way of receiving quality care. Given the considerably positive results in Japan for the relative lack of physical conditions impacting patients, there is potential to explore best practices. However, it is notable that these conditions may be worsening for patients diagnosed since 2014.***

***There is strong evidence to suggest that RCC patients in Japan 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, and those in the localised stage of the disease who often go unnoticed by the healthcare community, to ensure universal psychosocial support for all patients.***

***There is a role for IKCC and its Affiliate Organisations to play in Japan to advocate for change and to provide support for patients who struggle with barriers to quality care, and to pay particular attention to younger patients, females, and clear cell RCC patients who may often go unnoticed by the healthcare community.***

***Patients in Japan were impacted by the least number of physical conditions per patient compared to patients globally. However, given that patients diagnosed in 2014 and later in Japan were notably more negatively affected overall by physical conditions than those diagnosed prior to that time, it is possible that physical conditions are worsening.***

***Metastatic patients in Japan were impacted by the least number of psychosocial issues per patient compared to global results. In fact, patients with localised RCC, and who had no evidence of the disease, or who had been told they were cured, were impacted notably more than metastatic patients for a number of psychosocial issues.***

*Even though 99% of patients in Japan reported being affected by psychosocial issues, compared to patients globally, patients in Japan were affected by among the least number of difficult times per patient.*

*Although male and female patients have a similar biological experience with RCC, they experienced very different physical conditions, psychosocial issues and difficult times as a result of the disease.*

*Despite the fact that 99% of patients in Japan were impacted by psychosocial issues and a very high percentage were finding their doctors to be helpful when they did reach out, compared to global results, considerably more patients were not communicating their emotional issues to their healthcare team. Compared to global results, notably fewer female and middle aged patients were being very open with their doctors.*

*RCC patients in Japan faced notably more barriers to receiving quality care per patient compared to patients in other countries. Younger patients (30-45 yrs.), females, and clear cell RCC patients experienced notably more barriers to care.*

### Treatment for Kidney Cancer

- According to survey results, 0% of Japanese patients had not had any treatment for their kidney cancer after their first diagnosis.
- At the time of the survey, 2% of patients in Japan had not been receiving any treatments at all (7% globally).
- As shown in Table 4, for their first treatment,
  - 64% received them from community/local or general hospitals (47% globally),
  - 30% at major cancer centres<sup>13</sup> (38% globally),
  - 2% from private clinics (7% globally), and
  - 4% from other treatment centres.
- Of those patients in Japan who had been receiving treatments since that time:
  - 59% had been receiving them from community/local or general hospitals (a Global Outlier, compared to 31% globally),
  - 35% from major cancer centres<sup>14</sup> (51% globally)
  - 1% from private clinics (7% globally), and
  - 3% at other treatment centres.
- 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 5% in community/local or general hospitals , and an increase of 5% to major cancer centres.

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

PLACE OF TREATMENT	First Treatment	Subsequent Treatments	Notable Differences
Community/local/general hospitals	64%	59%	-5%
Major cancer centres	30%	35%	5%
Private clinics	2%	1%	
Other	4%	3%	

<sup>13</sup> Including major cancer centres with kidney cancer specialists (22%).

<sup>14</sup> Including major cancer centres with kidney cancer specialists (23% compared to 36% globally)

### **Physical Conditions**

- As can be seen in Table 5, 6% of Japanese 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 affecting them the most, followed by pain related to surgery.
- Compared to patients globally, patients in Japan were impacted notably more by pain related to surgery, and notably less by:
  - Fatigue,
  - Trouble concentrating,
  - Bowel changes,
  - Changes in taste and smell,
  - Changes in sexual function, and by
  - Skin reactions.
- Compared to global results, patients in Japan were impacted considerably less by a number of physical conditions as indicated by the Global Outliers in the Table.
- Japanese patients were impacted by the least number of physical conditions per patient compared to patients globally.<sup>15</sup>

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<sup>15</sup> Further details are available in the IKCC Global Report



**Table 5**  
**Notable Differences between Japan and Global Results for**  
**Physical Conditions**

PHYSICAL CONDITIONS	Global	Japan	Notable Differences
NOT AFFECTED	8%	6%	
Fatigue	66%	60%	6%
Trouble concentrating	24%	13%	11%
Mucositis/mouth ulcers	17%	7%	10%
Muscle weakness	32%	19%	13%
Pain related to surgery	29%	36%	7%
Bowel changes	33%	22%	11%
Loss of appetite	25%	11%	14%
Changes in taste and smell	25%	20%	5%
Sleeplessness	31%	22%	9%
Itching	17%	6%	11%
Hair loss	13%	11%	
Change of hair colour	17%	11%	6%
Memory loss	13%	1%	12%
Changes in sexual function	15%	2%	13%
Aching joints	22%	6%	16%
Sore feet and hands	23%	21%	
Weight loss	24%	12%	12%
Cramps	11%	1%	10%
Fluid retention	12%	5%	7%
Skin reactions	17%	12%	5%
Nausea and vomiting	22%	8%	14%
LEGEND			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			

- As can be seen in Table 6, males were affected notably more than females by changes in taste and smell and by sore feet and hands.
- Females were impacted more notably than males by:
  - Fatigue,
  - Trouble concentrating,
  - Sleeplessness,
  - Hair loss, and by
  - Fluid retention.

**Table 6**  
**Notable Differences in Japan for**  
**Physical Conditions by Gender**

PHYSICAL CONDITION	Males	Females	Notable Differences
NOT AFFECTED	8%	5%	
Fatigue	54%	65%	11%
• Trouble concentrating	11%	16%	5%
• Mucositis/mouth ulcers	9%	5%	
• Muscle weakness	17%	21%	
• Pain related to surgery	38%	35%	
• Bowel changes	23%	20%	
• Loss of appetite	12%	10%	
• Changes in taste and smell	24%	16%	8%
• Sleeplessness	20%	25%	5%
• Itching	8%	5%	
• Hair loss	8%	14%	6%
• Change of hair colour	10%	12%	
• Memory loss	0%	2%	
• Changes in sexual function	3%	1%	
• Aching joints	7%	6%	
• Sore feet and hands	27%	15%	12%
• Weight loss	11%	12%	
• Cramps	2%	0%	
• Fluid retention	2%	9%	7%
• Skin reactions	13%	10%	
• Nausea and vomiting	10%	6%	
LEGEND			
Most negative			
Most positive			

- Table 7 illustrates Global Outliers for physical conditions affecting patients' well-being in Japan by gender.
- For example, in Japan male patients were considerably worse off with pain related to surgery than male patients in other countries.
- Both male and female patients in Japan were impacted by the least number of physical conditions per patient compared to male and female patients in other countries.<sup>16</sup>

<sup>16</sup> For further details see the IKCC Global Report

**Table 7**  
**Global Outliers for Japan**  
**Physical Conditions by Gender**

PHYSICAL CONDITION	Males	Females
Trouble concentrating	11%	
Mucositis/mouth ulcers		5%
Muscle weakness	17%	21%
Pain related to surgery	38%	
Bowel changes		20%
Loss of appetite	12%	10%
Itching	8%	5%
Change of hair colour	10%	
Memory loss	0%	2%
Aching joints	7%	6%
Weight loss	11%	12%
Cramps	2%	0%
Fluid retention	2%	
Nausea and vomiting	10%	6%
LEGEND		
Negative Global Outlier for Japan		
Positive Global Outlier for Japan		

- Table 8 shows notable differences between patients diagnosed prior to 2014, and those diagnosed 2014 and later for physical conditions.
- Those diagnosed prior to 2014 were impacted notably more than those diagnosed 2014 and later by:
  - Loss of appetite,
  - Change of hair colour, and by
  - Weight loss.
- Those diagnosed 2014 and later reported notably more impacts than patients diagnosed prior to 2014 for:
  - Fatigue,
  - Trouble concentrating,
  - Hair loss,
  - Aching joints, and for
  - Skin reactions.

**Table 8**  
**Notable Differences in Japan for**  
**Physical Conditions by Year of Diagnosis**

PHYSICAL CONDITION	Prior to 2014	2014 and Later	Notable Differences
NOT AFFECTED	10%	5%	5%
Fatigue	51%	62%	11%
Trouble concentrating	10%	15%	5%
Mucositis/mouth ulcers	10%	6%	
Muscle weakness	20%	18%	
Pain related to surgery	34%	37%	
Bowel changes	24%	21%	
Loss of appetite	15%	10%	5%
Changes in taste and smell	22%	20%	
Sleeplessness	20%	23%	
Itching	5%	7%	
Hair loss	2%	13%	11%
Change of hair colour	15%	10%	5%
Memory loss	0%	2%	
Changes in sexual function	5%	2%	
Aching joints	2%	8%	6%
Sore feet and hands	24%	20%	
Weight loss	17%	10%	7%
Cramps	0%	2%	
Fluid retention	2%	6%	
Skin reactions	7%	13%	6%
Nausea and vomiting	5%	9%	
<b>LEGEND</b>			
Most negative			
Most positive			

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

- For example, Japanese patients diagnosed prior to 2014 were considerably worse off with pain related to surgery than patients diagnosed prior to 2014 in other countries.
- Patients in Japan diagnosed both prior to and later than 2014 were impacted by the least number of physical conditions per patient compared to patients diagnosed at those times globally.<sup>17</sup>

**Table 9**  
**Global Outliers for Japan**  
**Physical Conditions by Year of Diagnosis**

PHYSICAL CONDITION	Prior to 2014	2014 and Later
Trouble concentrating	10%	15%
Mucositis/mouth ulcers	10%	
Muscle weakness	20%	18%
Pain related to surgery	34%	
Loss of appetite		10%
Itching	5%	7%
Sleeplessness		23%
Change of hair colour		10%
Hair loss	2%	
Memory loss	0%	2%
Changes in sexual function	5%	
Aching joints	2%	8%
Weight loss		10%
Cramps	0%	2%
Fluid retention	2%	
Skin reactions	7%	
Nausea and vomiting	5%	9%
LEGEND		
Negative Global Outlier for Japan		
Positive Global Outlier for Japan		

- Table 10 shows notable differences between patients in various stages of RCC by physical conditions affecting their well-being. For example,

<sup>17</sup> Further detail is available in the IKCC Global Report

patients both with localised and metastatic RCC were impacted notably more by weight loss compared to those who had no evidence of the disease, or who had been told they were cured.

**Table 10**  
**Notable Differences in Japan for**  
**Physical Conditions by Stage**

PHYSICAL CONDITION	Localised RCC	Metastatic RCC	No Evidence/ Cured
NOT AFFECTED	8%	0%	12%
Fatigue	58%	62%	54%
Trouble concentrating	14%	9%	19%
Mucositis/mouth ulcers	3%	12%	3%
Muscle weakness	14%	22%	15%
Pain related to surgery	47%	28%	39%
Bowel changes	11%	33%	15%
Loss of appetite	11%	19%	2%
Changes in taste and smell	8%	40%	12%
Sleeplessness	25%	24%	22%
Itching	0%	10%	5%
Hair loss	8%	16%	5%
Change of hair colour	6%	22%	7%
Memory loss	0%	2%	0%
Changes in sexual function	0%	3%	3%
Aching joints	8%	9%	5%
Sore feet and hands	8%	47%	5%
Weight loss	14%	16%	3%
Cramps	0%	2%	2%
Fluid retention	6%	5%	5%
Skin reactions	3%	26%	3%
Nausea and vomiting	3%	16%	3%
<b>LEGEND</b>			
Most negative			
Most positive			

- Table 11 illustrates Global Outliers for physical conditions affecting patients' well-being in Japan by stage.

- For example, Japanese patients with localised RCC were considerably worse off with pain related to surgery than localised RCC patients in other countries.
- Patients diagnosed in all stages of RCC were impacted by the least number of physical conditions per patient compared to their counterparts in other countries.<sup>18</sup>

**Table 11**  
**Global Outliers for Japan**  
**Physical Conditions by Stage**

PHYSICAL CONDITION	Localised RCC	Metastatic RCC	No Evidence/ cured
NOT AFFECTED		0%	
Mucositis/mouth ulcers		12%	
Muscle weakness		22%	
Pain related to surgery	47%		
Loss of appetite	11%	19%	2%
Itching	0%	10%	
Sleeplessness		24%	
Change of hair colour			
Hair loss			
Memory loss		2%	
Changes in sexual function		3%	
Aching joints		9%	5%
Weight loss		16%	3%
Sore feet and hands		47%	5%
Cramps		2%	
Nausea and vomiting		16%	
LEGEND			
Negative Global Outlier for Japan			
Positive Global Outlier for Japan			

## Psychosocial Issues

<sup>18</sup> For further detail, see the IKCC Global Report

- As can be seen in Table 12, 1% of Japanese patients 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 fear of recurrence.
- Compared to patients globally, patients in Japan were affected considerably more by the fear of dying and the fear of recurrence.
- They were also impacted notably more by disease related anxiety, and stress related to financial issues.

**Table 12**  
**Notable Differences between Japan and Global Results for**  
**Psychosocial Issues**

PSYCHOSOCIAL ISSUE	Global	Japan	Notable Differences
NOT AFFECTED	4%	1%	
General anxiety	31%	34%	
Disease-related anxiety	60%	70%	10%
Fear of dying	44%	59%	15%
Fear of recurrence	50%	67%	17%
Depression	27%	10%	17%
Isolation	16%	10%	6%
Changes in relationships	28%	13%	15%
Difficulty on the job or in school	19%	20%	
Stress related to financial issues	28%	37%	9%
Loss or reduction in employment	20%	19%	
Difficulty navigating the healthcare system	14%	2%	12%
Problems getting life or health insurance	13%	6%	7%
Concerns about body image/physical appearance	22%	12%	10%
Relationships with friends/others	18%	14%	
Sexuality	14%	1%	13%
<b>LEGEND</b>			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			



- According to Table 13, males in Japan were impacted notably more than females by the fear of dying, stress related to financial issues and by loss/reduction in employment.
- Females were affected notably more than males by the fear of recurrence, isolation, and with concerns about body image/appearance.

**Table 13**  
**Notable Differences in Japan for**  
**Psychosocial Issues by Gender**

PSYCHOSOCIAL ISSUE	Males	Females	Notable Differences
NOT AFFECTED	0%	2%	
General anxiety	32%	35%	
Disease-related anxiety	70%	71%	
Fear of dying	69%	48%	21%
Fear of recurrence	62%	72%	10%
Depression	9%	12%	
Isolation	6%	13%	7%
Changes in relationships	12%	14%	
Difficulty on the job or in school	20%	19%	
Stress related to financial issues	40%	34%	6%
Loss or reduction in employment	22%	16%	6%
Difficulty navigating the healthcare system	1%	2%	
Problems getting life or health insurance	6%	5%	
Concerns about body image/physical appearance	8%	17%	9%
Relationships with friends/others	14%	13%	
Sexuality	1%	1%	
LEGEND			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			

- Table 14 illustrates Global Outliers for psychosocial issues affecting patients' emotional well-being in Japan by gender.

- For example, overall Japanese male patients were impacted considerably more by the fear of dying and the fear of recurrence compared to male patients in other countries.

**Table 14**  
**Global Outliers for Japan**  
**Psychosocial Issues by Gender**

PSYCHOSOCIAL ISSUE	Males	Females
Fear of dying	69%	
Fear of recurrence	62%	72%
Changes in relationships	12%	14%
Difficulty navigating the healthcare system	1%	2%
Concerns about body image/appearance	8%	
Depression		12%
LEGEND		
Negative Global Outlier for Japan		
Positive Global Outlier for Japan		

- As shown in Table 15, patients diagnosed in 2014 and later were affected more notably than those diagnosed prior to 2014 by:
  - General anxiety,
  - Fear of dying,
  - Changes in relationships,
  - Stress related to financial issues, and by
  - Concerns about body image appearance.
- Patients diagnosed prior to 2014 were impacted notably more than those diagnosed 2014 or later by:
  - Disease related anxiety, and by
  - Difficulty on the job or in school.

**Table 15**  
**Notable Differences in Japan for**  
**Psychosocial Issues by Year of Diagnosis**

PSYCHOSOCIAL ISSUE	Prior to 2014	2014 and Later	Notable Differences
NOT AFFECTED	2%	1%	
General anxiety	26%	36%	10%
Disease-related anxiety	74%	69%	5%
Fear of dying	52%	61%	9%
Fear of recurrence	64%	68%	
Depression	10%	10%	
Isolation	7%	10%	
Changes in relationships	7%	15%	8%
Difficulty on the job or in school	24%	19%	5%
Stress related to financial issues	33%	38%	5%
Loss/reduction in employment	19%	19%	
Difficulty navigating the health care system	2%	1%	
Problems getting life or health insurance	7%	5%	
Concerns about body image/physical appearance	5%	14%	9%
Relationships with friends/other	12%	14%	
Sexuality	0%	1%	
<b>LEGEND</b>			
Most negative			
Most positive			

- Table 16 shows Global Outliers for psychosocial issues affecting patients' emotional well-being in Japan by year of diagnosis.
- For example, Japanese patients diagnosed before 2014 were considerably worse off with disease related anxiety than patients diagnosed 2014 and later in other countries.

**Table 16**  
**Global Outliers for Japan**  
**Psychosocial Issues by Year of Diagnosis**

PSYCHOSOCIAL ISSUE	Prior to 2014	2014 and Later
Disease-related anxiety	74%	
Fear of dying	52%	61%
Fear of recurrence	64%	68%
Depression	10%	10%
Isolation		10%
Changes in relationships	7%	15%
Difficulty navigating the health care system	2%	1%
Problems getting life or health insurance		5%
Concerns about body image/physical appearance	5%	
Relationships with friends/other	12%	
Sexuality	0%	
LEGEND		
Negative Global Outlier for Japan		
Positive Global Outlier for Japan		

- Table 17 details specific psychosocial issues affecting Japanese patients' well-being in their various stages of RCC.
- For example, patients in both the localised and metastatic stages were impacted notably more by stress related to financial issues than patients who had no evidence of the disease, or who had been told they were cured.

**Table 17**  
**Notable Differences between Stage of RCC for**  
**Psychosocial Issues in Japan**

PSYCHOSOCIAL ISSUE	Localised RCC	Metastatic RCC	No Evidence/ cured
NOT AFFECTED	0%	2%	2%
General anxiety	35%	36%	32%
Disease-related anxiety	68%	69%	67%
Fear of dying	49%	61%	62%
Fear of recurrence	84%	48%	73%
Depression	11%	7%	15%
Isolation	5%	7%	13%
Changes in relationships	16%	11%	13%
Difficulty on the job or in school	14%	26%	17%
Stress related to financial issues	41%	46%	23%
Loss or reduction in employment	32%	11%	22%
Difficulty navigating the healthcare system	5%	0%	2%
Problems getting life or health insurance	5%	3%	5%
Concerns about body image/physical appearance	19%	13%	7%
Relationships with friends/others	16%	7%	20%
Sexuality	3%	2%	0%
LEGEND			
Most negative			
Most positive			

- Table 18 illustrates Global Outliers for patients' psychosocial issues by RCC stage.
- For example, metastatic patients were impacted considerably less by isolation than metastatic patients in other countries.
- Metastatic RCC patients were affected by the least number of psychosocial issues per patient compared to metastatic patients in other countries.<sup>19</sup>

<sup>19</sup> For further details see the IKCC Global Report

**Table 18**  
**Global Outliers for Japan**  
**Psychosocial Issues by Stage**

PSYCHOSOCIAL ISSUE	Localised RCC	Metastatic RCC	No Evidence/ cured
Fear of dying			62%
Fear of recurrence	84%	48%	
Isolation		7%	
Depression	11%		15%
Loss/reduction in employment	32%		
Changes in relationships		11%	13%
Stress related to financial issues		46%	
Difficulty navigating the health care system		0%	
Concerns about body image/physical appearance		13%	7%
Relationships with friends/other		7%	20%
Sexuality		2%	
LEGEND			
Negative Global Outlier for Japan			
Positive Global Outlier for Japan			

### **Patient Timeline- Most Difficult Times**

- According to Table 19, Japanese patients experienced their most difficult time during their experience with surgery and recovery afterwards. They were affected considerably more than patients globally.
- Compared to patients globally, Japanese patients were affected:
  - Considerably more by the diagnosis of recurrence; and
  - Notably more by the surveillance period, and by treatment for recurrence.

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

<b>MOST DIFFICULT TIME</b>	<b>Global</b>	<b>Japan</b>	<b>Notable Differences</b>
NOT AFFECTED	2%	2%	
During the process of diagnosis	51%	40%	11%
Surveillance period	19%	31%	12%
Surgery & recovery afterwards	38%	46%	8%
Follow up scans	17%	6%	11%
Waiting for surgery or scan results	37%	31%	6%
Diagnosis of recurrence	21%	29%	8%
Treatment for recurrence	10%	16%	6%
Diagnosis of further disease progression	23%	16%	7%
Dealing with side effects of treatment	29%	21%	8%
Transition to palliative care	4%	2%	
Long term adjustment, survivorship	12%	3%	9%
<b>LEGEND</b>			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			

- As shown in Table 20, females in Japan were affected most during the process of diagnosis.
- They were affected more notably than male patients during the process of diagnosis and waiting for surgery or scan results.
- Male patients were affected most by surgery and recovery afterwards, and more notably than females by:
  - Surgery and recovery,
  - Diagnosis of recurrence,
  - Treatment for recurrence,
  - Diagnosis of further disease progression, and in
  - Dealing with the side effects of treatment.

**Table 20**  
**Notable Differences in Japan for**  
**Most Difficult Times by Gender**

MOST DIFFICULT TIME	Males	Females	Notable Differences
NOT AFFECTED	2%	2%	
During the process of diagnosis	33%	48%	15%
Surveillance period	31%	30%	
Surgery and recovery afterwards	48%	43%	5%
Follow up scans	7%	5%	
Waiting for surgery or scan results	26%	37%	11%
Diagnosis of recurrence	32%	26%	6%
Treatment for recurrence	19%	13%	6%
Diagnosis of further disease progression	21%	10%	11%
Dealing with side effects of treatment	24%	18%	6%
Transition to palliative care	3%	1%	
Long term adjustment, survivorship	2%	4%	
LEGEND			
Most negative			
Most positive			

- Table 21 illustrates Global Outliers for patients' most difficult times in Japan by gender.
- For example, both male and female Japanese patients were considerably worse off dealing with diagnosis of recurrence than male and female patients in other countries.
- Female patients in Japan reported among the lowest number of 'most difficult times' per patient than other female patients globally<sup>20</sup>.

<sup>20</sup> For further details see the IKCC Global Report



**Table 21**  
**Global Outliers for Japan**  
**Most Difficult Times by Gender**

<b>MOST DIFFICULT TIME</b>	<b>Males</b>	<b>Females</b>
Surveillance period	31%	
Surgery and recovery afterwards	48%	
Follow up scans		5%
Diagnosis of recurrence	32%	26%
Diagnosis of further disease progression		10%
Dealing with side effects of treatment		18%
Long term adjustment, survivorship	2%	4%
<b>LEGEND</b>		
Negative Global Outlier for Japan		
Positive Global Outlier for Japan		

### **Communication and Support from Healthcare Professionals**

- Of those patients in Japan who experienced psychosocial issues, 34% said they communicated their issues to a healthcare professional (a Global Outlier compared to 50% globally), while 66% had not done so (a Global Outlier compared to 50% globally).
- In Japan:
  - 44% were very open and told the doctor everything in great detail,
  - 36% shared some of their issues, but not to the full extent (31% globally),
  - 14% held back some details and minimized their symptoms and side effects or chose not to communicate their issues at all, and
  - 6% had not had the opportunity to communicate their issues at all.
- Of patients in Japan who chose to tell the doctor or everything in great detail about their psychosocial issues this was the case for:
  - 52% of male patients, and 36% of female patients (42% globally),
  - 48% of those aged 30-45 yrs. (39% globally),
  - 42% of patients<sup>21</sup> aged 46-65 yrs. (49% globally), and
  - 53% aged 66+ yrs.

<sup>21</sup> Due to insufficient sample sizes, data was not reported for the under 30 yr. age brackets.

- For those who communicated their issues 91% of patients found their doctors to be helpful, while this had not been the case for the remaining 9%.
- Of those, 39% found them to be very helpful (50% globally), and 52% found them to be somewhat helpful (42% globally).

### **Barriers to Receiving Quality Care**

- Patients in Japan had the following types of healthcare coverage:
  - Government healthcare (76%),
  - Private insurance (51%, compared to 39% globally),
  - Self-coverage (21%, compared to 14% globally), and
  - Family coverage (7%).
- As Table 22 shows, 32% of patients in Japan had not experienced any barriers to receiving quality care (39% globally).
- Lack of affordability and the cost of treatment was the number one barrier reported.
- Compared to patients globally, patients in Japan were more notably affected overall by barriers to receiving quality care.

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

BARRIER TO RECEIVING QUALITY CARE	Global	Japan	Notable Differences
NOT AFFECTED	39%	32%	7%
Lack of affordability, cost of treatment	21%	34%	13%
Lack of access to treatment centre (travel)	13%	12%	
Inability to understand the treatment	6%	4%	
Lack of access to up-to-date treatment/equipment	14%	15%	
Wait time to treatment was longer than necessary	18%	22%	
Lack of personal support	14%	7%	7%
No specialty doctor available locally	13%	7%	6%
Difficulty managing career/caregiver role while in treatment	9%	14%	5%
Fear of discrimination by my employer/ friends/ family	9%	8%	
No available treatments	5%	6%	
LEGEND			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			

- According to Table 23, younger patients (30-45 yrs.) in Japan were affected overall by notably more barriers than older age groups, while those 46-65 yrs. experienced relatively fewer barriers.
- Compared to patients globally in their age group, patients aged 66+ yrs. were impacted considerably more by wait times to treatment, and by lack of available treatment.

**Table 23**  
**Notable Differences in Japan for**  
**Barriers to Receiving Quality Care by Age<sup>22</sup>**

BARRIER TO RECEIVING QUALITY CARE	30-45 yrs.	46-65 yrs.	66+ yrs.
NOT AFFECTED	21%	36%	37%
Lack of affordability, cost of treatment	49%	29%	21%
Lack of access to treatment centre (travel)	14%	10%	21%
Inability to understand the treatment	0%	5%	5%
Lack of access to up-to-date treatment/equipment	14%	16%	11%
Wait time to treatment was longer than necessary	21%	22%	32%
Lack of personal support	7%	7%	11%
No specialty doctor available locally	9%	6%	5%
Difficulty managing career/caregiver role while in treatment	28%	9%	0%
Fear of discrimination by my employer/ friends/ family	14%	6%	5%
No available treatments	9%	4%	11%
LEGEND			
Negative (white font = Global Outlier)			
Positive (enlarged font= Global Outlier)			

- Table 24 shows notable differences for barriers to receiving quality care in Japan by gender.
- For example, males were less notably affected by barriers overall than female patients.

<sup>22</sup> Due to insufficient sample size, data is not reported for the under 30 yr. age bracket.

**Table 24**  
**Notable Differences in Japan for**  
**Barriers to Receiving Quality Care by Gender**

BARRIER TO RECEIVING QUALITY CARE	Males	Females	Notable Differences
NOT AFFECTED	34%	29%	5%
Lack of affordability, cost of treatment	30%	39%	9%
Lack of access to treatment centre (travel)	14%	10%	
Inability to understand the treatment	3%	4%	
Lack of access to up-to-date treatment/equipment	16%	14%	
Wait time to treatment was longer than necessary	23%	21%	
Lack of personal support	7%	8%	
No specialty doctor available locally	8%	6%	
Difficulty managing career/caregiver role while in treatment	6%	23%	17%
Fear of discrimination by my employer/ friends/ family	10%	5%	5%
No available treatments	10%	1%	9%
LEGEND			
Most negative			
Most positive			

- As shown in Table 25, overall, patients with clear cell RCC experienced notably more barriers to receiving quality care than patients with other sub-types.
- Clear cell patients experienced notably more barriers than patients with other sub-types for:
  - Lack of affordability,
  - Lack of access to treatment,
  - Inability to understand the treatment, and for
  - Lack of access to up to date treatment/equipment.
- Patients with other sub-types experienced notably more barriers than patients with other sub-types for:
  - Wait times to treatment, and for
  - Difficulty managing career/caregiver roles during treatment.

**Table 25**  
**Notable Differences in Japan for**  
**Barriers to Receiving Quality Care by Sub-Type**

BARRIER TO RECEIVING QUALITY CARE	Clear Cell	Other Sub-types	Notable Differences
NOT AFFECTED	31%	39%	8%
Lack of affordability, cost of treatment	40%	7%	33%
Lack of access to treatment centre (travel)	15%	4%	11%
Inability to understand the treatment	5%	0%	5%
Lack of access to up-to-date treatment/equipment	16%	11%	5%
Wait time to treatment was longer than necessary	19%	39%	20%
Lack of personal support	6%	7%	
No specialty doctor available locally	8%	4%	
Difficulty managing career/caregiver role while in treatment	13%	18%	5%
Fear of discrimination by my employer/ friends/ family	8%	4%	
No available treatments	6%	7%	
LEGEND			
Most negative			
Most positive			

- Table 26 shows the Global Outliers for barriers Japanese patients experienced to receiving quality care by sub-type.
- For example, patients with other sub-types experienced considerably fewer barriers than patients globally for a lack of personal support and for the fear of discrimination.

**Table 26**  
**Global Outliers for Japan**  
**Most Difficult Times by Sub-type**

MOST DIFFICULT TIME	Clear Cell	Other Sub-types
Lack of personal support		7%
Difficulty managing career/caregiver role while in treatment	13%	18%
Fear of discrimination by my employer/ friends/ family		4%
LEGEND		
Negative Global Outlier for Japan		
Positive Global Outlier for Japan		

## V. Opportunities to Improve Care

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

### Surveillance

- At the time of the survey, patients in Japan were in the following stages of their RCC:
  - 18% were in Stage 1 or 2 (13% globally),
  - 5% in Stage 3,
  - 34% in Stage 4 (40% globally),
  - 32% had no evidence of the disease (19% globally), and
  - 3% had been told they were cured (10% globally), and
  - 3% had died.
- Their last follow up scan had occurred:
  - Less than one year ago (95% compared to 85% globally),
  - 1-3 years ago (3% a Global Outlier compared to 9% globally), and
  - More than 3 years ago (2%).
- Most recent follow up scans had occurred more than three years ago for:
  - 0% of those in Stage 1 or 2<sup>23</sup>,
  - 2% of those in Stage 4,
  - 2% of those who had no evidence of the disease or had been told they were cured,
  - 2% of those aged 30-45 yrs.<sup>24</sup>,
  - 2% of those aged 46-65,
  - 5% of those aged 66+ yrs.,
  - 2% of males,
  - 2% of females,
  - 4% of those with no understanding of kidney cancer guidelines, and
  - 2% of those with no understanding of the guidelines for kidney cancer follow up.

<sup>23</sup> Due to insufficient data, results are not reported for Stage 3 or for patients who have died

<sup>24</sup> Due to insufficient data, results are not reported for 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 Japan 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.***

*30% of Japanese patients had their treatment plans decided for them solely by their doctors. This was particularly the case for those being treated at community centres/local or general hospitals, the greatest result reported for any other country. Compared to global results, patients in the 66+ yr. age bracket, and those in Stage 1 or 2 of their disease engaged in considerably less shared decision making with their doctors.*

- 30% of patients in Japan had not been engaged at all in their treatment plans, in that their doctor had decided their treatment plan for them.
- Of those patients who were involved in their treatment decision:
  - 3% made the decision by themselves,
  - 59% made a joint decision with their doctors (51% globally), and
  - 8% were asked for input from their doctors.
- The following helped Japanese patients with their treatment plans:
  - Partner/spouse (54%),
  - Parents (13%),
  - Children (13% compared to 21% globally),
  - Friends/other family members (15% compared to 20% globally),
  - Local family doctor (10% compared to 22% globally), and
  - A patient organisation (11%).
- 29% of patients made the decision by themselves (a Global Outlier, compared to 18% globally), and for 2%, the decision had rested on their personal financial situation.



- Of those patients in Japan where their treatment plans had been decided for them by their doctors:
  - 65% were being treated in community centres/local or general hospitals (a Global Outlier, compared to 34% globally),
  - 31% at major cancer centres<sup>25</sup>, and
  - 2% 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:
  - 20% of those aged 30-45 yrs.<sup>26</sup>,
  - 31% of those aged 46-65 yrs.,
  - 35% of those aged 66+ yrs. (27% globally),
  
  - 32% of those in Stage 1 or 2<sup>27</sup> (25% globally),
  - 31% of those in Stage 4,
  - 25% of those who had no evidence of the disease, or who had been told they were cured (31% globally),
  
  - 31% of males,
  - 28% of females,
  
  - 25% of those diagnosed prior to 2016, and
  - 33% of those diagnosed 2016 and after.

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<sup>25</sup> Including major cancer centres with kidney cancer specialists (18%, a Global Outlier compared to 30% globally),

<sup>26</sup> Due to insufficient sample size, data is not reported for the under 30 age brackets.

<sup>27</sup> Due to insufficient sample sizes, data is not available for patients in Stage 3 or who had died.

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

## APPENDIX

### Methodology

#### Data Collection

The survey was mounted using the QuestionPro platform. It opened live August 23<sup>rd</sup>, 2018 and closed October 31<sup>st</sup>, 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 31<sup>st</sup>, 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 23<sup>rd</sup>, 2018);
- Submission date later than the cut-off date (October 31<sup>st</sup>, 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 = 1<sup>st</sup> quartile – (interquartile range \* .5)
  - Upper fence = 3<sup>rd</sup> 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.

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