



# **2018 IKCC PATIENT SURVEY**

## **-South Korea-**

**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- South Korea

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

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

- Advocate for the early and universal diagnosis of all RCC patients including younger patients for example, who fall outside the typical patient demographic;
- Provide decision aid tools to enhance sub-type knowledge for newly diagnosed patients, thereby enabling them to best participate in shared decision making with their healthcare team about 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 in light of the fact that psychosocial issues may be worsening over time;
- Advocate for change, and support 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 particularly for patient sub groups where there is evidence of notable physician directed care.



## **SURVEY RESULTS- South Korea**

### **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:**

- South Korea had 228 respondents, or 12% of the global total.
- 58% of those responding to the survey were kidney cancer patients (71% globally) while the remaining 42% defined themselves as a caregiver, family member or friend of the patient (29% globally).
- 71% of respondents were males (a Global Outlier, compared to 54% globally), and 29% were females (a Global Outlier, compared to 45% globally).
- Survey respondents had the following age profile:
  - Under 18 (0%),
  - 18-29 (1%),
  - 30-45 (35% compared to 20% globally),
  - 46-65 (53% compared to 57% globally), and
  - 66+ (11% compared to 20% globally).
- Survey respondents were in the following stages of kidney cancer:
  - Localised kidney cancer (25%),
  - Metastatic (52% compared to 44% globally), and
  - No evidence/told they were cured (23% 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 South Korea 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 South Korea were not told their sub-type upon initial diagnosis and 45% lacked an understanding of this foundational piece of information, of which all RCC patients should be aware.*

*Patients within South Korea, upon diagnosis, with rarer forms of RCC had notably less understanding of their treatment options and risk of recurrence than did clear cell patients.*

*Compared to global results, although patients in South Korea took notably less time to be correctly diagnosed (within in one month or less), this was not the case for younger patients (30-45 yrs.), who fell outside the expected demographic of an RCC patient, who is profiled as being typically older and male. That being said, there was no notable difference between age groups for a correct diagnosis in 3 months or less.*

### **Year of Diagnosis**

- South Korean patients who responded to this survey had been diagnosed in the following years:
  - 2% prior to 2005,
  - 2% in 2005
  - 1% in 2006,
  - 1% in 2007,
  - 2% in 2008,
  - 1% in 2009,
  - 1% in 2010,
  - 2% in 2011,
  - 2% in 2012,
  - 4% in 2013,
  - 8% in 2014,
  - 4% in 2015,
  - 13% in 2016,
  - 31% in 2017 (a Global Outlier, compared to 20% globally), and
  - 27% in 2018 (a Global Outlier, compared to 12% globally).

### **Success of Timely Diagnosis**

- Patients in South Korea were in the following stages of their kidney cancer when they were first diagnosed:
  - 50% in Stages 1 or 2,
  - 16% in Stage 3, and
  - 33% in Stage 4 (26% globally).
  
- Following their first visit to the doctor, 67% of South Korean patients were correctly diagnosed in less than a month (52% globally), while
  - 27% were diagnosed in 1-3 months,
  - 3% in 3-6 months (a Global Outlier, compared to 10% globally),
  - 1% in 6 months to a year (a Global Outlier, compared to 6% globally), and
  - 0% (6% globally) in more than one year.

- 0% of patients in South Korea were diagnosed at a family doctor or GP's office (a Global Outlier, compared to 20% globally),
  - 6% at an emergency department (12% globally),
  - 54% at a community, local or general hospital (37% globally),
  - 23% at a major cancer centre<sup>4</sup> (13% globally),
  - 16% at a private clinic (11% globally) and
  - 1% at some other facility.
- According to Table 1, there were no notable differences in the length of time it took for a correct diagnosis between males and females in South Korea.

**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>68%</b>  | <b>65%</b>    |                            |
| <b>1-3 months</b>        | <b>28%</b>  | <b>27%</b>    |                            |
| <b>3-6 months</b>        | <b>2%</b>   | <b>6%</b>     |                            |
| <b>6 months-1 year</b>   | <b>1%</b>   | <b>2%</b>     |                            |
| <b>More than 1 year</b>  | <b>1%</b>   | <b>0%</b>     |                            |
| <b>LEGEND</b>            |             |               |                            |
| <b>Most negative</b>     |             |               |                            |
| <b>Most positive</b>     |             |               |                            |

<sup>4</sup> Including 19% for major cancer centres with kidney cancer specialists, a Global Outlier compared to 8% globally.

- As shown in Table 2, there were no notable differences in the time taken to diagnose patients of different ages in South Korea given that 96% aged 30-45 yrs., 94% of those aged 46-65 yrs. and 96% of those 66+ yrs. were all diagnosed within 3 months. The only notable difference concerned 30-45 year olds where fewer of them were diagnosed in less than a month compared to those in other age brackets.

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

| TIME OF DIAGNOSIS | 30-45 yrs. | 46-65 yrs. | 66+ yrs. |
|-------------------|------------|------------|----------|
| Less than month   | 64%        | 69%        | 72%      |
| 1-3 months        | 32%        | 25%        | 24%      |
| 3-6 months        | 4%         | 4%         | 0%       |
| 6 months-1 year   | 0%         | 2%         | 4%       |
| More than 1 year  | 0%         | 1%         | 0%       |
| LEGEND            |            |            |          |
| Most negative     |            |            |          |
| Most positive     |            |            |          |

### Patient Knowledge and Understanding

- After their initial diagnosis 41% of patients in South Korea were not told their sub-type, and
  - 13% had no understanding of their stage (20% globally),
  - 45% had no understanding of their sub-type<sup>6</sup>,
  - 31% had no understanding of their treatment options (a Global Outlier, compared to 21% globally),
  - 24% had no understanding of their treatment recommendations (19% globally),
  - 33% had no understanding of the risk of recurrence (28% globally), and
  - 25% had no understanding of their likelihood of survival.

<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

- As shown in Table 3, at the time of diagnosis:
  - Notably more patients in South Korea with other sub-types had less understanding about their treatment options or risk of recurrence than patients with clear cell RCC; and
  - Both clear cell patients and those with other sub-types had the greatest lack of understanding for sub-type (42% of those with clear cell and 46% of those with other sub-types).

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

| <b>NO UNDERSTANDING</b>          | <b>Clear Cell</b> | <b>Other Sub-types</b> | <b>Notable Differences</b> |
|----------------------------------|-------------------|------------------------|----------------------------|
| <b>Stage</b>                     | 13%               | 12%                    |                            |
| <b>Sub-type</b>                  | 42%               | 46%                    |                            |
| <b>Treatment options</b>         | 29%               | 35%                    | 6%                         |
| <b>Treatment recommendations</b> | 24%               | 24%                    |                            |
| <b>Risk of recurrence</b>        | 30%               | 43%                    | 13%                        |
| <b>Likelihood of survival</b>    | 23%               | 26%                    |                            |
| <b>LEGEND</b>                    |                   |                        |                            |
| <b>Most negative</b>             |                   |                        |                            |
| <b>Most positive</b>             |                   |                        |                            |

- At the time of the survey, 7% of patients in South Korea were still not aware of their sub-type.
- The 93% who were aware reported the following RCC sub-types:
  - Clear cell (70%, compared to 62% globally),
  - Papillary (4%),
  - Chromophobe (4%),
  - Unclassified (3%),
  - XP11 Translocation Type (3%),
  - VHL (0%),
  - Renal Medullary (0%),
  - Collecting Duct (0%),

- Transitional Cell Carcinoma (1%),
  - Renal Sarcoma (1%),
  - Wilms Tumour (0%),
  - Benign Tumour (1%),
  - Other (5%).
- 
- At the time of the survey, patients in South Korea also had no understanding of the following:
    - Biopsies for kidney cancer (32% compared to 20% globally),
    - Surgical options (7%),
    - Immunotherapy (24%),
    - Targeted therapies (21%),
    - Radiation therapies (33%),
    - Ablative therapies (48% compared to 41% globally),
    - Palliative care (42% compared to 33% globally),
    - Active surveillance (31%),
    - Nutrition/lifestyle (14%),
    - Complementary therapies (34% compared to 39% globally),
    - Guidelines for kidney cancer care (17%), or for
    - Guidelines for kidney cancer follow up (23% compared to 17% globally).

### III. Clinical Trials

***Every kidney cancer patient in South Korea 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 South Korea 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.***

*Compared to global results, the healthcare community in South Korea has been relatively more proactive in approaching patients to participate in clinical trials.*

*However, the fact that 97% of patients who had never been approached to participate reported they would be fairly likely to do so, particularly if provided with the necessary information to make the decision, and the high satisfaction experienced by those who actually participated, indicates an obvious lost opportunity to improve the quality of care and survivorship of RCC patients through research.*

*Patients in various stages of their treatment pathway were not being approached equally to participate in clinical trials. Rather than upon initial diagnosis, the majority were asked either following surgery, after other treatments, or after they had been left with no other treatment options.*



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

- According to survey results, clinical trials were not discussed with 13% of patients in South Korea (33% globally).
- Of those who had discussions about clinical trials, those discussions had occurred with:
  - Another patient (12%),
  - Doctors (61% compared to 75% globally),
  - Spouses, friends or family (52% a Global Outlier, compared to 31% globally),
  - Nurses (4% compared to 10% globally),
  - Patient organisations (40% a Global Outlier, compared to 19% globally), and
  - Online groups (15%).

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

- 61% of patients in South Korea had never been asked to participate in a clinical trial (70% globally).
- Of South Korean patients who had never been asked to participate in a clinical trial, 97% said it said it 'fairly likely'<sup>7</sup> they would do so if asked (a Global Outlier, compared to 89% globally).
- Of the patients in South Korea who said they would be fairly likely<sup>8</sup> to do so, they were being treated at:
  - Community/local/general hospitals (34%),
  - Major cancer centres<sup>9</sup> (66% compared to 45% globally),
  - 0% at private clinics, and
  - 0% at 'other' (5% globally).
- Of the 97% of South Korean patients who said it would be 'fairly likely' they would participate in a clinical trial:
  - 40% said they would be 'likely' to participate, while
  - 60% '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 (a Global Outlier 60% compared to 30% globally).

- Of patients in South Korea who said they would need more information before they agreed to participate in a clinical trial, these patients were being treated at:
  - Community/ local /general hospitals (37%),
  - Major cancer centres<sup>10</sup> (63% a Global Outlier, compared to 44% globally), and
  - Private clinics (0%).
- Patients who would be fairly likely to participate in a clinical trial if asked consisted of:
  - 97% of those with metastatic RCC<sup>11</sup> (92% globally), and
  - 95% of those with no evidence of the disease or had been told they were cured.
- 59% of patients in South Korea with clear cell RCC (67% globally) and 69% of those with other sub-types (77% globally) had never been asked to participate in a clinical trial.
- Patients being treated for other sub-types who had never been approached to participate in a clinical trial were being treated at:
  - Community/local or general hospitals (23% compared to 28% globally),
  - Major cancer centres<sup>12</sup> (78% compared to 47% globally),
  - Private clinics (0% compared to 9% globally).

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

- Of the patients in South Korea who had been asked to participate in a clinical trial:
  - 9% of their initial discussions were with another patient,
  - 77% with doctors (compared to 88% globally),
  - 56% with spouses, family or friends (a Global Outlier, compared to 31% globally),
  - 9% with nurses (15% globally),
  - 49% with patient organisations (a Global Outlier, compared to 18% globally),

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<sup>10</sup> Including major cancer centres with kidney cancer specialists (59%, a Global Outlier compared to 30% globally)

<sup>11</sup> Due to insufficient sample size, data is not reported for patients with localised RCC

<sup>12</sup> Including major cancer centres with kidney cancer specialists (19% compared to 30% globally),

- 15% with online groups, and
- 0% had no previous discussion with anyone.
  
- The option of a clinical trial was first discussed with:
  - 15% upon diagnosis (24% globally),
  - 44% of patients after surgery (49% globally),
  - 29% after other treatments (21% globally), and
  - 12% who were left with no other treatment options (6% globally).
  
- For patients in South Korea who had the option of a clinical trial first discussed with them after surgery:
  - 24% were being treated at community/local or general hospitals (18% globally),
  - 71% at major cancer centres<sup>13</sup>, and
  - 0% at private clinics.
  
- When the option of a clinical trial was discussed with patients:
  - 42% understood very well the risks and benefits of participating (47% globally),
  - 40% had at least some understanding, and
  - 18% had a very limited understanding (12% globally).
  
- Of those in South Korea who were asked to participate in a clinical trial, 91% agreed (86% globally).
  
- Those who agreed to participate did so because:
  - Their doctor recommended it (59%),
  - 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 (27% compared to 22% globally),
  - They wanted to help kidney cancer research (4% a Global Outlier, compared to 39% globally), and
  - Affordability, financial reasons (30% compared to 13% globally).

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<sup>13</sup> Including major cancer centres with kidney cancer specialists (62% compared to 57% globally),

- 93% of patients in South Korea who participated in a clinical trial were either 'very satisfied' or 'satisfied', and of those:
  - 23% were 'very satisfied' (44% globally),
  - 70% 'satisfied' (46% globally), and
  - 7% 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 (36% a Global Outlier, compared to 21% globally),
  - Distrust of clinical trials (27% compared to 21% globally),
  - Fear of placebo (18%),
  - Fear of uncertainty (36% a Global Outlier, compared to 26% globally),
  - Extra tests or interventions required (9% compared to 18% globally),
  - Geographic distance (0% compared to 16% globally),
  - Affordability, financial costs (9%),
  - Not available at my hospital (9% compared to 14% globally),
  - Toxicity of treatment (18%), and
  - Other (9% compared to 16% globally).

#### IV. Quality of Care

***Kidney cancer has a profound effect on the lives of patients in South Korea 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 South Korea 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 evidence in this report suggesting that patients in South Korea were notably worse off than patients globally for psychosocial issues that may be worsening over time. 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 female patients and those with localised RCC or who had no evidence of the disease, or who had been told they were cured, as they often go unnoticed by the healthcare community.***

***Given that patients in South Korea experienced notably more barriers to receiving quality care than patients globally, there is an opportunity for IKCC and its Affiliate Organisations to play a role in advocating for change and providing support for patients who struggle with these barriers.***

*RCC patients in South Korea were generally comparable overall to patients globally for the degree to which they experienced physical conditions. Compared to global results, overall, patients diagnosed in 2014 and later in South Korea were less negatively affected by physical conditions than those diagnosed prior to that time, introducing the possibility that physical conditions for patients may have improved over time.*

*Compared to patients globally, patients in South Korea were notably worse off for a number of psychosocial issues. Impacted by a number of*

*psychosocial issues, which were reported to have been notably worse for those diagnosed in more recent years, suggests that psychosocial issues may be worsening over time.*

*Although males and females have a similar biological experience with RCC, they experienced very different physical conditions and psychosocial issues as a result of the disease. For example, female patients in South Korea were more notably impacted than male patients by a number of psychosocial issues, particularly related to anxiety, while males were more troubled by financial issues and their jobs or school.*

*It is surprising that patients with localised RCC, or who had no evidence of the disease, or who had been told they were cured, were more notably impacted by certain physical conditions and psychosocial issues than metastatic patients. In fact, some of the psychosocial issues for these patients were among the worst when compared to patients globally.*

*Despite the fact that 100% of patients in South Korea were impacted by psychosocial issues, and a high percentage were finding their doctors to be helpful when they did reach out, 28% were not communicating their emotional issues to their doctors. Female patients and those 66+ yrs. in South Korea were notably less open with their doctors compared to patients globally.*

*RCC patients in South Korea were notably more affected by barriers to receiving quality care per patient than patients in other countries. Older patients (66+ yrs.), and patients with clear cell were most affected by barriers to receiving quality care. In fact, patients with clear cell experienced the greatest number of barriers per patient compared to their peers in other countries.*

### Treatment for Kidney Cancer

- According to survey results, 0% of South Korean patients had not had any treatment for their kidney cancer after their first diagnosis.
- At the time of the survey, 2% of patients in South Korea had not been receiving any treatments at all (7% globally).
- As shown in Table 4, for their first treatment,
  - 42% had received them from community/local or general hospitals (47% globally),
  - 56% at major cancer centres<sup>14</sup> (38% globally), and
  - 2% from private clinics (7% globally).
- Of those patients in South Korea who had been receiving treatments since that time:
  - 29% had been receiving them from community/local or general hospitals,
  - 70% from major cancer centres<sup>15</sup> (51% globally), and
  - 0% from private clinics (7% globally).
- As can be seen in the table, 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 13% in community/local or general hospitals, and an increase of 14% to major cancer centres.

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

| PLACE OF TREATMENT                | First Treatment | Subsequent Treatments | Notable Differences |
|-----------------------------------|-----------------|-----------------------|---------------------|
| Community/local/general hospitals | 42%             | 29%                   | -13%                |
| Major cancer centres              | 56%             | 70%                   | 14%                 |
| Private clinics                   | 2%              | 0%                    |                     |

<sup>14</sup> Including major cancer centres with kidney cancer specialists (50% a Global Outlier compared to 26% globally),

<sup>15</sup> Including major cancer centres with kidney cancer specialists (63% a Global Outlier compared to 36% globally)

### **Physical Conditions**

- As can be seen in Table 5, 5% of South Korean 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 number one condition affecting them the most.
- Patients in South Korea were impacted considerably more than patients globally by weight loss, and considerably less by:
  - Changes in taste and smell, and
  - Sleeplessness,
  - Cramps, and by
  - Fluid retention.
- They were affected notably more than patients globally by:
  - Mucositis/mouth ulcers,
  - Loss of appetite, and by
  - Skin reactions
- And notably less than patients globally by:
  - Trouble concentrating,
  - Bowel changes,
  - Memory loss,
  - Changes in sexual function,
  - Aching joints, and by
  - Sore feet and hands.



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

| PHYSICAL CONDITIONS                      | Global | South Korea | Notable Differences |
|--|--------|-------------|---------------------|
| NOT AFFECTED                             | 8%     | 5%          |                     |
| Fatigue                                  | 66%    | 69%         |                     |
| Trouble concentrating                    | 24%    | 15%         | 9%                  |
| Mucositis/mouth ulcers                   | 17%    | 22%         | 5%                  |
| Muscle weakness                          | 32%    | 32%         |                     |
| Pain related to surgery                  | 29%    | 30%         |                     |
| Bowel changes                            | 33%    | 28%         | 5%                  |
| Loss of appetite                         | 25%    | 31%         | 6%                  |
| Changes in taste and smell               | 25%    | 19%         | 6%                  |
| Sleeplessness                            | 31%    | 26%         | 5%                  |
| Itching                                  | 17%    | 19%         |                     |
| Hair loss                                | 13%    | 13%         |                     |
| Change of hair colour                    | 17%    | 16%         |                     |
| Memory loss                              | 13%    | 8%          | 5%                  |
| Changes in sexual function               | 15%    | 8%          | 7%                  |
| Aching joints                            | 22%    | 15%         | 7%                  |
| Sore feet and hands                      | 23%    | 18%         | 5%                  |
| Weight loss                              | 24%    | 31%         | 7%                  |
| Cramps                                   | 11%    | 3%          | 8%                  |
| Fluid retention                          | 12%    | 2%          | 10%                 |
| Skin reactions                           | 17%    | 23%         | 6%                  |
| Nausea and vomiting                      | 22%    | 18%         |                     |
| LEGEND                                   |        |             |                     |
| Negative (white font = Global Outlier)   |        |             |                     |
| Positive (enlarged font= Global Outlier) |        |             |                     |

- As can be seen in Table 6, males were more notably impacted than females by:
  - Mucositis/mouth ulcers,
  - Muscle weakness,
  - Changes in sexual function,
  - Sore feet and hands,
  - Weight loss, and by
  - Skin reactions.

- Females were impacted more notably than males by:
  - Fatigue,
  - Pain related to surgery,
  - Bowel changes,
  - Change of hair colour, and by
  - Memory loss.

**Table 6**  
**Notable Differences in South Korea for**  
**Physical Conditions by Gender**

| PHYSICAL CONDITION         | Males | Females | Notable Differences |
|----------------------------|-------|---------|---------------------|
| NOT AFFECTED               | 6%    | 2%      |                     |
| Fatigue                    | 67%   | 73%     | 6%                  |
| Trouble concentrating      | 16%   | 12%     |                     |
| Mucositis/mouth ulcers     | 26%   | 12%     | 14%                 |
| Muscle weakness            | 34%   | 27%     | 7%                  |
| Pain related to surgery    | 26%   | 39%     | 13%                 |
| Bowel changes              | 26%   | 34%     | 8%                  |
| Loss of appetite           | 30%   | 34%     |                     |
| Changes in taste and smell | 20%   | 17%     |                     |
| Sleeplessness              | 25%   | 27%     |                     |
| Itching                    | 20%   | 17%     |                     |
| Hair loss                  | 14%   | 10%     |                     |
| Change of hair colour      | 15%   | 20%     | 5%                  |
| Memory loss                | 7%    | 12%     | 5%                  |
| Changes in sexual function | 9%    | 3%      | 6%                  |
| Aching joints              | 14%   | 17%     |                     |
| Sore feet and hands        | 21%   | 12%     | 9%                  |
| Weight loss                | 33%   | 25%     | 8%                  |
| Cramps                     | 3%    | 3%      |                     |
| Fluid retention            | 2%    | 3%      |                     |
| Skin reactions             | 26%   | 15%     | 11%                 |
| Nausea and vomiting        | 18%   | 19%     |                     |
| <b>LEGEND</b>              |       |         |                     |
| Most negative              |       |         |                     |
| Most positive              |       |         |                     |

- Table 7 illustrates Global Outliers for physical conditions affecting patients' well-being in South Korea by gender.
- For example, in South Korea male patients were considerably better off for having trouble concentrating than male patients in other countries.

**Table 7**  
**Global Outliers for South Korea**  
**Physical Conditions by Gender**

| PHYSICAL CONDITION                      | Males | Females |
|---|-------|---------|
| Trouble concentrating                   | 16%   |         |
| Cramps                                  | 3%    | 3%      |
| Fluid retention                         | 2%    | 3%      |
| Skin reactions                          | 26%   |         |
| Loss of appetite                        |       | 34%     |
| Hair loss                               |       | 10%     |
| LEGEND                                  |       |         |
| Negative Global Outlier for South Korea |       |         |
| Positive Global Outlier for South Korea |       |         |

- As Table 8 shows, patients diagnosed prior to 2014 were notably more negatively affected by a number of conditions affecting their physical well-being than patients diagnosed in 2014 and later including:
  - Trouble concentrating,
  - Bowel changes,
  - Loss of appetite,
  - Sleeplessness,
  - Hair loss,
  - Change of hair colour,
  - Changes in sexual function,
  - Aching joints,
  - Sore feet and hands,
  - Weight loss,
  - Cramps,
  - Fluid retention, and by

- Nausea and vomiting.
- Patients diagnosed after 2014 were more notably affected by:
  - Muscle weakness,
  - Pain related to surgery, and by
  - Skin reactions.

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

| PHYSICAL CONDITION         | Prior to 2014 | 2014 and Later | Notable Differences |
|----------------------------|---------------|----------------|---------------------|
| NOT AFFECTED               | 6%            | 5%             |                     |
| Fatigue                    | 71%           | 68%            |                     |
| Trouble concentrating      | 20%           | 14%            | 6%                  |
| Mucositis/mouth ulcers     | 23%           | 22%            |                     |
| Muscle weakness            | 29%           | 34%            | 5%                  |
| Pain related to surgery    | 26%           | 31%            | 5%                  |
| Bowel changes              | 37%           | 26%            | 11%                 |
| Loss of appetite           | 37%           | 31%            | 6%                  |
| Changes in taste and smell | 20%           | 19%            |                     |
| Sleeplessness              | 31%           | 25%            | 6%                  |
| Itching                    | 17%           | 19%            |                     |
| Hair loss                  | 20%           | 12%            | 8%                  |
| Change of hair colour      | 23%           | 15%            | 8%                  |
| Memory loss                | 11%           | 8%             |                     |
| Changes in sexual function | 20%           | 5%             | 15%                 |
| Aching joints              | 26%           | 13%            | 13%                 |
| Sore feet and hands        | 26%           | 17%            | 9%                  |
| Weight loss                | 37%           | 29%            | 8%                  |
| Cramps                     | 9%            | 2%             | 7%                  |
| Fluid retention            | 9%            | 1%             | 8%                  |
| Skin reactions             | 17%           | 24%            | 7%                  |
| Nausea and vomiting        | 31%           | 16%            | 15%                 |
| <b>LEGEND</b>              |               |                |                     |
| Most negative              |               |                |                     |
| Most positive              |               |                |                     |

- Table 9 illustrates Global Outliers for physical conditions affecting patients' well-being in South Korea by year of diagnosis.
- For example, South Korean patients diagnosed in 2014 and later were considerably worse off for sleeplessness than patients diagnosed at that time in other countries.
- Patients diagnosed 2014 and later were affected by among the least number of physical conditions per patient compared to their peers in other countries.<sup>16</sup>

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

| PHYSICAL CONDITION                      | Prior to 2014 | 2014 and Later |
|---|---------------|----------------|
| NOT AFFECTED                            | 6%            |                |
| Trouble concentrating                   |               | 14%            |
| Fluid retention                         |               | 1%             |
| Sleeplessness                           |               | 25%            |
| Aching joints                           |               | 13%            |
| Cramps                                  |               | 2%             |
| LEGEND                                  |               |                |
| Negative Global Outlier for South Korea |               |                |
| Positive Global Outlier for South Korea |               |                |

- As shown in Table 10, metastatic RCC patients appear to be more notably affected by a number of specific physical conditions affecting their well-being than patients with localised RCC, or who had no evidence of the disease, or who had been told they were cured.
- Localised patients were more notably affected by fatigue and trouble concentrating, while patients with no evidence of the disease or who had been told they were cured were more notably affected by pain related to surgery and weight loss.

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

**Table 10**  
**Notable Differences in South Korea for**  
**Physical Conditions by Stage**

| PHYSICAL CONDITION         | Localised RCC | Metastatic RCC | No Evidence/ Cured |
|----------------------------|---------------|----------------|--------------------|
| NOT AFFECTED               | 7%            | 2%             | 5%                 |
| Fatigue                    | 81%           | 65%            | 65%                |
| Trouble concentrating      | 19%           | 12%            | 14%                |
| Mucositis/mouth ulcers     | 0%            | 44%            | 5%                 |
| Muscle weakness            | 21%           | 45%            | 26%                |
| Pain related to surgery    | 30%           | 15%            | 56%                |
| Bowel changes              | 21%           | 44%            | 12%                |
| Loss of appetite           | 19%           | 51%            | 7%                 |
| Changes in taste and smell | 9%            | 33%            | 5%                 |
| Sleeplessness              | 23%           | 26%            | 21%                |
| Itching                    | 14%           | 26%            | 9%                 |
| Hair loss                  | 9%            | 21%            | 2%                 |
| Change of hair colour      | 2%            | 31%            | 5%                 |
| Memory loss                | 7%            | 11%            | 5%                 |
| Changes in sexual function | 2%            | 11%            | 2%                 |
| Aching joints              | 9%            | 21%            | 9%                 |
| Sore feet and hands        | 7%            | 30%            | 7%                 |
| Weight loss                | 23%           | 34%            | 35%                |
| Cramps                     | 2%            | 4%             | 2%                 |
| Fluid retention            | 2%            | 3%             | 0%                 |
| Skin reactions             | 2%            | 41%            | 7%                 |
| Nausea and vomiting        | 12%           | 33%            | 2%                 |
| <b>LEGEND</b>              |               |                |                    |
| Most negative              |               |                |                    |
| Most positive              |               |                |                    |

- Table 11 illustrates Global Outliers for physical conditions affecting patients' well-being in South Korea by stage.
- For example, patients in South Korea with localised RCC were impacted considerably more by fatigue than localised RCC patients globally.

**Table 11**  
**Global Outliers for South Korea**  
**Physical Conditions by Stage**

| PHYSICAL CONDITION                      | Localised RCC | Metastatic RCC | No Evidence/ cured |
|---|---------------|----------------|--------------------|
| NOT AFFECTED                            |               |                | 5%                 |
| Fatigue                                 | 81%           |                |                    |
| Fluid retention                         | 2%            | 3%             | 0%                 |
| Mucositis/mouth ulcers                  |               | 44%            |                    |
| Pain related to surgery                 |               | 15%            | 56%                |
| Sleeplessness                           |               | 26%            |                    |
| Memory loss                             |               | 11%            |                    |
| Cramps                                  |               | 4%             |                    |
| Muscle weakness                         |               |                | 26%                |
| Hair loss                               |               |                | 2%                 |
| Changes in sexual function              |               |                | 2%                 |
| Weight loss                             |               |                | 35%                |
| Skin reactions                          |               | 41%            | 7%                 |
| LEGEND                                  |               |                |                    |
| Negative Global Outlier for South Korea |               |                |                    |
| Positive Global Outlier for South Korea |               |                |                    |

### **Psychosocial Issues**

- As can be seen in Table 12, 0% of South Korean 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 the fear of recurrence.
- Patients in South Korea were impacted considerably more than patients globally by:

- Fear of recurrence, and by
- Stress related to financial issues.
- Compared to patients globally, they were more notably impacted by:
  - General anxiety, and by
  - Disease related anxiety,
- And less notably by:
  - Loss or reduction in employment, and by
  - Sexuality.

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

| PSYCHOSOCIAL ISSUE                            | Global | South Korea | Notable Differences |
|---|--------|-------------|---------------------|
| NOT AFFECTED                                  | 4%     | 0%          |                     |
| General anxiety                               | 31%    | 37%         | 6%                  |
| Disease-related anxiety                       | 60%    | 69%         | 9%                  |
| Fear of dying                                 | 44%    | 47%         |                     |
| Fear of recurrence                            | 50%    | 58%         | 8%                  |
| Depression                                    | 27%    | 29%         |                     |
| Isolation                                     | 16%    | 16%         |                     |
| Changes in relationships                      | 28%    | 31%         |                     |
| Difficulty on the job or in school            | 19%    | 21%         |                     |
| Stress related to financial issues            | 28%    | 49%         | 21%                 |
| Loss or reduction in employment               | 20%    | 9%          | 11%                 |
| Difficulty navigating the healthcare system   | 14%    | 12%         |                     |
| Problems getting life or health insurance     | 13%    | 12%         |                     |
| Concerns about body image/physical appearance | 22%    | 24%         |                     |
| Relationships with friends/others             | 18%    | 21%         |                     |
| Sexuality                                     | 14%    | 3%          | 11%                 |
| <b>LEGEND</b>                                 |        |             |                     |
| Negative (white font = Global Outlier)        |        |             |                     |
| Positive (enlarged font= Global Outlier)      |        |             |                     |



- According to Table 13, males in South Korea were affected notably more than females by:
  - General anxiety,
  - Changes in relationships,
  - Difficulty on the job or in school, and by
  - Stress related to financial issues.
  
- Females were affected notably more than males by:
  - Disease-related anxiety
  - Fear of dying,
  - Fear of recurrence,
  - Depression,
  - Problems getting life/health insurance, and by
  - Relationships with friends/others.

**Table 13**  
**Notable Differences in South Korea for**  
**Psychosocial Issues by Gender**

| PSYCHOSOCIAL ISSUE                            | Males | Females | Notable Differences |
|---|-------|---------|---------------------|
| NOT AFFECTED                                  | 1%    | 0%      |                     |
| General anxiety                               | 40%   | 29%     | 11%                 |
| Disease-related anxiety                       | 65%   | 78%     | 13%                 |
| Fear of dying                                 | 44%   | 54%     | 10%                 |
| Fear of recurrence                            | 55%   | 64%     | 9%                  |
| Depression                                    | 27%   | 32%     | 5%                  |
| Isolation                                     | 16%   | 17%     |                     |
| Changes in relationships                      | 33%   | 27%     | 6%                  |
| Difficulty on the job or in school            | 24%   | 14%     | 10%                 |
| Stress related to financial issues            | 51%   | 44%     | 7%                  |
| Loss or reduction in employment               | 8%    | 12%     |                     |
| Difficulty navigating the healthcare system   | 11%   | 15%     |                     |
| Problems getting life or health insurance     | 10%   | 17%     | 7%                  |
| Concerns about body image/physical appearance | 23%   | 27%     |                     |
| Relationships with friends/others             | 19%   | 25%     | 6%                  |
| Sexuality                                     | 3%    | 3%      |                     |
| <b>LEGEND</b>                                 |       |         |                     |
| Most negative                                 |       |         |                     |
| Most positive                                 |       |         |                     |

- Table 14 illustrates Global Outliers for psychosocial issues affecting patients' emotional well-being in South Korea by gender.
- For example, both males and females were considerably worse off for having to deal with stress related to financial issues than male and female patients in other countries.

**Table 14**  
**Global Outliers for South Korea**  
**Psychosocial Issues by Gender**

| PSYCHOSOCIAL ISSUE                      | Males | Females |
|---|-------|---------|
| General anxiety                         | 40%   |         |
| Fear of recurrence                      | 55%   |         |
| Stress related to financial issues      | 51%   | 44%     |
| Fear of dying                           |       | 54%     |
| Relationships with friends/others       |       | 25%     |
| LEGEND                                  |       |         |
| Negative Global Outlier for South Korea |       |         |
| Positive Global Outlier for South Korea |       |         |

- As shown in Table 15, patients diagnosed in 2014 and later were more notably affected than those diagnosed prior to 2014 by:
  - General and disease related anxiety,
  - Fear of recurrence,
  - Changes in relationships,
  - Difficulty on the job or in school,
  - Stress related to financial issues, and by
  - Concerns about body image/physical appearance.
- Those who were diagnosed prior to 2014 were affected more notably by:
  - Fear of dying,
  - Isolation,
  - Loss or reduction in employment, and by
  - Problems getting life/health insurance.

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

| PSYCHOSOCIAL ISSUE                            | Prior to 2014 | 2014-2018 | Notable Differences |
|---|---------------|-----------|---------------------|
| NOT AFFECTED                                  | 3%            | 0%        |                     |
| General anxiety                               | 26%           | 39%       | 13%                 |
| Disease-related anxiety                       | 63%           | 70%       | 7%                  |
| Fear of dying                                 | 54%           | 46%       | 8%                  |
| Fear of recurrence                            | 54%           | 59%       | 5%                  |
| Depression                                    | 29%           | 29%       |                     |
| Isolation                                     | 29%           | 14%       | 15%                 |
| Changes in relationships                      | 20%           | 34%       | 14%                 |
| Difficulty on the job or in school            | 17%           | 22%       | 5%                  |
| Stress related to financial issues            | 43%           | 51%       | 8%                  |
| Loss or reduction in employment               | 20%           | 7%        | 13%                 |
| Difficulty navigating the healthcare system   | 11%           | 12%       |                     |
| Problems getting life or health insurance     | 17%           | 11%       | 6%                  |
| Concerns about body image/physical appearance | 20%           | 25%       | 5%                  |
| Relationships with friends/others             | 23%           | 21%       |                     |
| Sexuality                                     | 6%            | 2%        |                     |
| <b>LEGEND</b>                                 |               |           |                     |
| Most negative                                 |               |           |                     |
| Most positive                                 |               |           |                     |

- Table 16 shows Global Outliers for psychosocial issues affecting patients' emotional well-being in South Korea by year of diagnosis.
- For example, South Korean patients diagnosed in 2014 and later were considerably worse off in dealing with stress related to financial issues than patients diagnosed at that time in other countries.

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

| PSYCHOSOCIAL ISSUE                      | Prior to 2014 | 2014 and Later |
|---|---------------|----------------|
| Fear of dying                           | 54%           |                |
| Depression                              | 29%           |                |
| Stress related to financial issues      |               | 51%            |
| Loss/reduction in employment            |               | 7%             |
| LEGEND                                  |               |                |
| Negative Global Outlier for South Korea |               |                |
| Positive Global Outlier for South Korea |               |                |

- As shown in Table 17, patients in the metastatic stage of their RCC were notably more affected than those with localised RCC, or who had no evidence of the disease, or had been told they were cured, for a number of psychosocial issues affecting their well-being.
- Patients with localised RCC and those with no evidence of the disease, or who had been told they were cured, were affected most by the fear of recurrence, while those in the metastatic stage were most impacted by the fear of dying.

**Table 17**  
**Notable Differences between Stage for**  
**Psychosocial Issues in South Korea**

| PSYCHOSOCIAL ISSUE                            | Localised RCC | Metastatic RCC | No Evidence/ cured |
|---|---------------|----------------|--------------------|
| NOT AFFECTED                                  | 0%            | 1%             | 0%                 |
| General anxiety                               | 39%           | 34%            | 42%                |
| Disease-related anxiety                       | 70%           | 68%            | 74%                |
| Fear of dying                                 | 41%           | 62%            | 28%                |
| Fear of recurrence                            | 80%           | 31%            | 81%                |
| Depression                                    | 30%           | 31%            | 23%                |
| Isolation                                     | 7%            | 19%            | 23%                |
| Changes in relationships                      | 23%           | 42%            | 23%                |
| Difficulty on the job or in school            | 25%           | 23%            | 21%                |
| Stress related to financial issues            | 50%           | 59%            | 33%                |
| Loss or reduction in employment               | 7%            | 7%             | 14%                |
| Difficulty navigating the healthcare system   | 16%           | 13%            | 7%                 |
| Problems getting life or health insurance     | 18%           | 6%             | 23%                |
| Concerns about body image/physical appearance | 7%            | 40%            | 12%                |
| Relationships with friends/others             | 16%           | 26%            | 14%                |
| Sexuality                                     | 2%            | 5%             | 0%                 |
| LEGEND  |               |                |                    |
| Most negative                                 |               |                |                    |
| Most positive                                 |               |                |                    |

- Table 18 illustrates Global Outliers for psychosocial issues affecting patient's emotional well-being in South Korea by stage.
- For example, those in all stages of RCC were considerably worse off in having to deal with stress related to financial issues than their peers in other countries.

**Table 18**  
**Global Outliers for South Korea**  
**Psychosocial Issues by Stage**

| PSYCHOSOCIAL ISSUE                      | Localised RCC | Metastatic RCC | No Evidence/ cured |
|---|---------------|----------------|--------------------|
| Fear of recurrence                      | 80%           |                |                    |
| Difficulty on the job or in school      | 25%           |                |                    |
| Stress related to financial issues      | 50%           | 59%            | 33%                |
| Concerns about body image               | 7%            | 40%            |                    |
| Changes in relationships                |               | 42%            |                    |
| Sexuality                               |               | 5%             |                    |
| General anxiety                         |               |                | 42%                |
| Fear of dying                           |               |                | 28%                |
| Depression                              |               |                | 23%                |
| Isolation                               |               |                | 23%                |
| LEGEND                                  |               |                |                    |
| Negative Global Outlier for South Korea |               |                |                    |
| Positive Global Outlier for South Korea |               |                |                    |

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

- According to Table 19, South Korean patients experienced the most difficult times during the process of diagnosis.
- They were affected considerably more than patients globally during the process of diagnosis, and considerably less by follow up scans.
- Compared to patients globally, they were more notably impacted during the surveillance period and treatment for recurrence.

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

| <b>MOST DIFFICULT TIME</b>               | <b>Global</b> | <b>South Korea</b> | <b>Notable Differences</b> |
|--|---------------|--------------------|----------------------------|
| NOT AFFECTED                             | 2%            | 1%                 |                            |
| During the process of diagnosis          | 51%           | <b>65%</b>         | 14%                        |
| Surveillance period                      | 19%           | <b>28%</b>         | 9%                         |
| Surgery & recovery afterwards            | 38%           | 35%                |                            |
| Follow up scans                          | 17%           | <b>6%</b>          | 11%                        |
| Waiting for surgery or scan results      | 37%           | 37%                |                            |
| Diagnosis of recurrence                  | 21%           | 25%                |                            |
| Treatment for recurrence                 | 10%           | <b>15%</b>         | 5%                         |
| Diagnosis of further disease progression | 23%           | 20%                |                            |
| Dealing with side effects of treatment   | 29%           | 26%                |                            |
| Transition to palliative care            | 4%            | 1%                 |                            |
| Long term adjustment, survivorship       | 12%           | 16%                |                            |
| <b>LEGEND</b>                            |               |                    |                            |
| Negative (white font = Global Outlier)   |               |                    |                            |
| Positive (enlarged font= Global Outlier) |               |                    |                            |

- As shown in Table 20, females in South Korea were more notably affected than males waiting for surgery or scan results, while males were more notably affected by:
  - Treatment for recurrence, and by
  - Dealing with the side effects of treatment.

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

| MOST DIFFICULT TIME                      | Males | Females | Notable Differences |
|--|-------|---------|---------------------|
| NOT AFFECTED                             | 1%    | 0%      |                     |
| During the process of diagnosis          | 64%   | 66%     |                     |
| Surveillance period                      | 29%   | 27%     |                     |
| Surgery and recovery afterwards          | 34%   | 36%     |                     |
| Follow up scans                          | 7%    | 3%      |                     |
| Waiting for surgery or scan results      | 33%   | 46%     | 13%                 |
| Diagnosis of recurrence                  | 26%   | 22%     |                     |
| Treatment for recurrence                 | 17%   | 12%     | 5%                  |
| Diagnosis of further disease progression | 21%   | 19%     |                     |
| Dealing with side effects of treatment   | 28%   | 22%     | 6%                  |
| Transition to palliative care            | 1%    | 0%      |                     |
| Long term adjustment, survivorship       | 15%   | 17%     |                     |
| LEGEND                                   |       |         |                     |
| Most negative                            |       |         |                     |
| Most positive                            |       |         |                     |

- Table 21 illustrates Global Outliers for patients' most difficult times in South Korea by gender.
- For example, male South Korean patients were considerably worse off during the surveillance period than male patients in other countries.

**Table 21**  
**Global Outliers for South Korea**  
**Most Difficult Times by Gender**

| MOST DIFFICULT TIME                     | Males | Females |
|---|-------|---------|
| Surveillance period                     | 29%   |         |
| During the process of diagnosis         |       | 66%     |
| Follow up scans                         |       | 3%      |
| LEGEND                                  |       |         |
| Negative Global Outlier for South Korea |       |         |
| Positive Global Outlier for South Korea |       |         |

## Communication and Support from Healthcare Professionals



- Of those patients in South Korea who experienced psychosocial issues 72% said they communicated the issues to a healthcare professional (a Global Outlier, compared to 50% globally) while 28% did not (a Global Outlier, compared to 50% globally).
- In South Korea:
  - 44% were very open and told the doctor everything in great detail,
  - 37% shared some of their issues, but not to the full extent (31% globally),
  - 10% 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
  - 9% had not had the opportunity to communicate their issues at all.
- Of patients in South Korea who chose to tell the doctor or everything in great detail about their psychosocial issues this was the case for:
  - 49% of males patients and 30% of female patients (42% globally),
  - 40% of patients<sup>17</sup> 30-45 yrs.,
  - 48% of those 46-65 yrs., and
  - 42% of those 66+ yrs. (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 6%.

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

- Patients in South Korea had the following types of healthcare coverage:
  - Government healthcare (93% compared to 73% globally),
  - Private insurance (57%, compared to 39% globally),
  - Self-coverage (25%, compared to 14% globally), and
  - Family coverage (10%, compared to 6% globally).
- As Table 22 shows, 14% of patients in South Korea had not experienced any barriers in receiving quality care (39% globally).
- They were affected most by a lack of affordability/cost of treatment.

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<sup>17</sup> Due to insufficient sample sizes, data was not reported for the under 30 age bracket.

- Patients in South Korea were considerably worse off than patients in other countries for:
  - Lack of affordability/cost of treatment,
  - Lack of access to up to date treatment/equipment,
  - Wait time to treatment longer than necessary, and for
  - Fear of discrimination.
  
- They were affected more notably than patients globally by:
  - Being affected overall by barriers to receiving quality care,
  - Lack of access to a treatment centre, and by
  - Lack of personal support.

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

| BARRIER TO RECEIVING QUALITY CARE                            | Global | South Korea | Notable Differences |
|--|--------|-------------|---------------------|
| NOT AFFECTED   | 39%    | 14%         | 25%                 |
| Lack of affordability, cost of treatment                     | 21%    | 54%         | 33%                 |
| Lack of access to treatment centre (travel)                  | 13%    | 18%         | 5%                  |
| Inability to understand the treatment                        | 6%     | 9%          |                     |
| Lack of access to up-to-date treatment/equipment             | 14%    | 23%         | 9%                  |
| Wait time to treatment was longer than necessary             | 14%    | 30%         | 16%                 |
| Lack of personal support                                     | 13%    | 18%         | 5%                  |
| No specialty doctor available locally                        | 9%     | 5%          |                     |
| Difficulty managing career/caregiver role while in treatment | 9%     | 12%         |                     |
| Fear of discrimination by my employer/ friends/ family       | 5%     | 14%         | 9%                  |
| No available treatments                                      | 5%     | 7%          |                     |
| LEGEND   |        |             |                     |
| Negative   |        |             |                     |
| Positive   |        |             |                     |

- According to Table 23, patients in the 66+ yr. age bracket in South Korea were affected overall by notably more barriers in receiving quality care than the other age groups, and most affected by the lack of affordability/cost of treatment.

**Table 23**  
**Notable Differences in South Korea for**  
**Barriers to Receiving Quality Care by Age<sup>18</sup>**

| BARRIER TO RECEIVING QUALITY CARE                            | 30-45 yrs. | 46-65 yrs. | 66+ yrs. |
|--|------------|------------|----------|
| NOT AFFECTED   | 10%        | 18%        | 8%       |
| Lack of affordability, cost of treatment                     | 50%        | 54%        | 64%      |
| Lack of access to treatment centre (travel)                  | 22%        | 11%        | 40%      |
| Inability to understand the treatment                        | 10%        | 5%         | 24%      |
| Lack of access to up-to-date treatment/equipment             | 15%        | 24%        | 36%      |
| Wait time to treatment was longer than necessary             | 38%        | 23%        | 36%      |
| Lack of personal support                                     | 15%        | 21%        | 16%      |
| No specialty doctor available locally                        | 6%         | 5%         | 4%       |
| Difficulty managing career/caregiver role while in treatment | 10%        | 11%        | 24%      |
| Fear of discrimination by my employer/ friends/ family       | 19%        | 11%        | 8%       |
| No available treatments                                      | 8%         | 7%         | 4%       |
| LEGEND   |            |            |          |
| Negative (white font = Global Outlier)                       |            |            |          |
| Positive (enlarged font= Global Outlier)                     |            |            |          |

- Table 24 shows Global Outliers for barriers to receiving quality care in South Korea by age.
- For example, South Korean patients aged 66+ yrs. were considerably worse off for a number of barriers to receiving quality care than patients of that age in other countries.
- Patients in this age bracket were impacted by the greatest number of physical conditions per patient compared to their peers in other countries.<sup>19</sup>

<sup>18</sup> Due to insufficient sample size, data is not reported for under 30 yrs.

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

**Table 24**  
**Global Outliers for South Korea**  
**Barriers to Receiving Quality Care by Age**

| BARRIER TO RECEIVING QUALITY CARE            | 30-45 yrs. | 46-65 yrs. | 66+ yrs. |
|--|------------|------------|----------|
| NOT AFFECTED                                 |            |            | 8%       |
| Wait time to treatment longer than necessary | 38%        |            | 36%      |
| Lack of affordability/cost of treatment      |            | 54%        | 64%      |
| Lack of up to date treatment/equipment       |            | 24%        | 36%      |
| Lack of access to treatment/travel           |            |            | 40%      |
| Inability to understand the treatment        |            |            | 24%      |
| Lack of personal support                     |            |            | 16%      |
| Difficulty managing career/caregiver role    |            |            | 24%      |
| LEGEND                                       |            |            |          |
| Negative Global Outlier for South Korea      |            |            |          |
| Positive Global Outlier for South Korea      |            |            |          |

- As Table 25 indicates, compared to female patients, male patients were more notably more affected by:
  - Lack of affordability/cost of treatment, and by
  - Lack of access to treatment/travel.
  
- Females were more notably affected by:
  - Inability to understand the treatment,
  - Lack of access to up to date treatment/equipment, and by
  - Difficulty managing their career/caregiver role.

**Table 25**  
**Notable Differences in South Korea for**  
**Barriers to Receiving Quality Care by Gender**

| BARRIER TO RECEIVING QUALITY CARE                            | Males | Females | Notable Differences |
|--|-------|---------|---------------------|
| NOT AFFECTED   | 13%   | 15%     |                     |
| Lack of affordability, cost of treatment                     | 56%   | 49%     | 7%                  |
| Lack of access to treatment centre (travel)                  | 22%   | 8%      | 14%                 |
| Inability to understand the treatment                        | 7%    | 12%     | 5%                  |
| Lack of access to up-to-date treatment/equipment             | 21%   | 29%     | 8%                  |
| Wait time to treatment was longer than necessary             | 31%   | 29%     |                     |
| Lack of personal support                                     | 18%   | 17%     |                     |
| No specialty doctor available locally                        | 4%    | 7%      |                     |
| Difficulty managing career/caregiver role while in treatment | 9%    | 20%     | 11%                 |
| Fear of discrimination by my employer/ friends/ family       | 14%   | 14%     |                     |
| No available treatments                                      | 6%    | 10%     |                     |
| LEGEND   |       |         |                     |
| Most negative  |       |         |                     |
| Most positive  |       |         |                     |

- Table 26 illustrates Global Outliers for barriers to receiving quality care in South Korea by gender.
- For example, males in South Korea experienced considerably fewer barriers than male patients in other countries with the lack of an available specialty doctor.

**Table 26**  
**Global Outliers for South Korea**  
**Barriers to Receiving Quality Care by Gender**

| BARRIER TO RECEIVING QUALITY CARE                | Males | Females |
|--|-------|---------|
| Lack of affordability/cost of treatment          | 56%   |         |
| Wait time to treatment longer than necessary     | 31%   | 29%     |
| No specialty doctor available locally            | 4%    |         |
| Fear of discrimination                           | 14%   |         |
| Lack of access to up to date treatment/equipment |       | 29%     |
| No available treatments                          |       | 10%     |
| LEGEND   |       |         |
| Negative Global Outlier for South Korea          |       |         |
| Positive Global Outlier for South Korea          |       |         |

- As shown in Table 27, patients with other sub-types experienced notably more barriers overall than patients with clear cell RCC.
- Patients with other sub-types were more notably affected by:
  - Lack of access to treatment centre/travel,
  - Lack of access to up to date treatment/equipment,
  - Wait times to treatment, and by
  - Lack of available treatments.
- Clear cell patients experienced notably more barriers than those with other sub-types for:
  - Inability to understand the treatment,
  - Lack of personal support,
  - Difficulty managing their career/caregiver role, and for
  - Fear of discrimination.

**Table 27**  
**Notable Differences in South Korea for**  
**Barriers to Receiving Quality Care by Sub-Type**

| BARRIER TO RECEIVING QUALITY CARE                            | Clear Cell | Other sub-types | Notable Differences |
|--|------------|-----------------|---------------------|
| NOT AFFECTED   | 16%        | 10%             | 6%                  |
| Lack of affordability, cost of treatment                     | 55%        | 54%             |                     |
| Lack of access to treatment centre (travel)                  | 16%        | 23%             | 7%                  |
| Inability to understand the treatment                        | 11%        | 2%              | 9%                  |
| Lack of access to up-to-date treatment/equipment             | 18%        | 35%             | 17%                 |
| Wait time to treatment was longer than necessary             | 27%        | 38%             | 11%                 |
| Lack of personal support                                     | 20%        | 15%             | 5%                  |
| No specialty doctor available locally                        | 3%         | 6%              |                     |
| Difficulty managing career/caregiver role while in treatment | 13%        | 6%              | 7%                  |
| Fear of discrimination by my employer/ friends/ family       | 14%        | 8%              | 6%                  |
| No available treatments                                      | 6%         | 13%             | 7%                  |
| LEGEND   |            |                 |                     |
| Most negative  |            |                 |                     |
| Most positive  |            |                 |                     |

- Table 28 illustrates Global Outliers for barriers to receiving quality care in South Korea by sub-type.
- For example, clear cell RCC patients in South Korea were affected considerably less than clear cell patients in other countries by the lack of an available specialty doctor.
- Clear cell RCC patients in South Korea were affected by among the greatest number of barriers to receiving quality care per patient compared to clear cell patients in other countries.<sup>20</sup>

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

**Table 28**  
**Global Outliers for South Korea**  
**Barriers to Receiving Quality Care by Sub-type**

| BARRIER TO RECEIVING QUALITY CARE         | Clear cell<br>RCC | Other<br>Sub-<br>types |
|---|-------------------|------------------------|
| Lack of affordability/cost of treatment   |                   | 54%                    |
| Lack of access to up to date treatment    |                   | 35%                    |
| Inability to understand the treatment     | 11%               |                        |
| Lack of personal support                  | 20%               |                        |
| No specialty doctor available locally     | 3%                |                        |
| Difficulty managing career/caregiver role | 13%               |                        |
| Fear of discrimination                    | 14%               |                        |
| LEGEND                                    |                   |                        |
| Negative Global Outlier for South Korea   |                   |                        |
| Positive Global Outlier for South Korea   |                   |                        |



## V. Opportunities to Improve Care

***There is an opportunity for IKCC and its Affiliate Organisations to improve survivorship of RCC patients everywhere by empowering patients through education to advocate for regular surveillance despite gender, age or stage. There is evidence to suggest that compared to global results, the South Korean healthcare system has been relatively proactive in the surveillance of its RCC patients, this presenting an opportunity to explore best practices.***

### **Surveillance**

- At the time of the survey, patients in South Korea were in the following stages of their RCC:
  - 17% were in Stage 1 or 2 (13% globally),
  - 6% in Stage 3,
  - 48% in Stage 4 (40% globally),
  - 10% had no evidence of the disease (19% globally),
  - 11% had been told they were cured, and
  - 2% had died.
  
- Their last follow up scan occurred:
  - Less than one year ago (92% compared to 85% globally),
  - 1-3 years ago (5%), and
  - More than 3 years ago (1%).
  
- Most recent follow up scans occurred more than three years ago<sup>21</sup> for:
  - 6% of those in Stage 1 or 2,
  - 0% in Stage 3 (6% globally),
  - 0% of those in Stage 4,
  - 0% of those who had no evidence of the disease or had been told they were cured (a Global Outlier, compared to 5% globally),
  
  - 0% of those aged 30-45 yrs.<sup>22</sup>,
  - 3% of those aged 46-65,
  - 0% of those aged 66+ yrs. (6% globally),
  
  - 2% of males,

<sup>21</sup> Due to insufficient data, results are not reported for those patients who had died.

<sup>22</sup> Due to insufficient data, results are not reported for under 30 yr. age brackets

- 0% of females (5% globally),
- 3% of those with no understanding of kidney cancer guidelines, and
- 2% of those with no understanding of the guidelines for kidney cancer follow up.

## VI. Shared decision making

***As shared decision making becomes increasingly recognized as a pillar of patient-centered healthcare, IKCC and its Affiliate Organisations have the opportunity to play a key role in South Korea 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.***

*27% of patients in South Korea had their treatment plans decided for them solely by their doctors. Compared to global results, this was more the case for those being treated at major cancer centres, and those who had no evidence of the disease, or who had been told they were cured.*

- 27% of patients in South Korea were not engaged at all in their treatment plans, in that their doctor had decided their treatment plans solely for them.
- Of those patients who were involved in their treatment decision:
  - 6% made the decision by themselves,
  - 46% made a joint decision with their doctors (51% globally), and
  - 20% were asked for input from their doctors (a Global Outlier, compared to 12% globally).
- The following helped South Korean patients with their treatment plans:
  - Partner/spouse (57%),
  - Parents (17%),
  - Children (23%),
  - Friends/other family members (30% a Global Outlier, compared to 20% globally),
  - Local family doctor (13% compared to 22% globally), and
  - A patient organisation (34% a Global Outlier, compared to 12% globally).
- 18% of patients made the decision by themselves, and for 8%, the decision rested on their personal financial situation (a Global Outlier compared to 4% globally).

- Of those patients in South Korea where their treatment plans were decided for them by their doctors:
  - 20% were being treated in community centres/local or general hospitals (34% globally),
  - 74% at major cancer centres<sup>23</sup>( 45% globally), and
  - 0% 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<sup>24</sup>:
  - 28% of those aged 30-45 yrs.,
  - 26% of those aged 46-65 yrs.,
  - 28% of those aged 66+ yrs,
  
  - 20% of those in Stage 1 or 2 (25% globally),
  - 0% in Stage 3 (20% globally),
  - 31% of those in Stage 4<sup>25</sup>,
  - 36% of those who had no evidence of the disease or who were told they were cured (a Global Outlier compared to 31% globally),
  
  - 26% of male patients,
  - 31% of female patients, and
  
  - 22% of those diagnosed 2016 and later.

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<sup>23</sup> Including major cancer centres with kidney cancer specialists (66%, a Global Outlier compared to 30% globally),

<sup>24</sup> Due to insufficient sample size, data is not reported for the under 30 age brackets.

<sup>25</sup> Due to insufficient sample sizes, data is not available for patients who had died.

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

## APPENDIX

### Methodology

#### Data Collection

The survey was mounted using the QuestionPro platform. It opened live August 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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